



MONASH University

**The COVID-19 Outbreak Public Evaluation (COPE) Initiative:
Assessment of Attitudes and Behaviours about Mitigation of SARS-CoV-2
Transmission and of Mental and Behavioural Health During the
Great Pandemic of Coronavirus Disease 2019**

Mark Éliás Czeisler

Artium Baccalaureus

A thesis submitted for the degree of Doctor of Philosophy

Turner Institute of Brain and Mental Health, School of Psychological Sciences

Faculty of Medicine, Nursing, and Health Sciences,

Monash University, Australia

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Czeisler MÉ, Marynak K, Clarke KEN, Salah Z, Shakya I, Thierry JM, Ali N, McMillan H, Wiley JF, Weaver MD, Czeisler CA, Rajaratnam SMW, Howard ME. Delay or Avoidance of Medical Care Because of COVID-19-Related Concerns - United States, June 2020. *MMWR Morb Mortal Wkly Rep.* 2020 Sep 11;69(36):1250-1257. digital object identifier (doi): 10.15585/mmwr.mm6936a4. PubMed reference number (PMID): 32915166; PubMed Central reference number (PMCID): PMC7499838.

Appendix 2

Published manuscript: Delay or avoidance of routine, urgent and emergency medical care due to concerns about COVID-19 in a region with low COVID-19 prevalence: Victoria, Australia.

Czeisler MÉ*, Kennedy JL*, Wiley JF, Facer-Childs ER, Robbins R, Barger LK, Czeisler CA, Rajaratnam SMW, Howard ME. Delay or avoidance of routine, urgent and emergency medical care due to concerns about COVID-19 in a region with low COVID-19 prevalence: Victoria, Australia. *Respirology.* 2021 Jul;26(7):707-712. doi: 10.1111/resp.14094. Epub 2021 Jun 3. PMID: 34081819.

* indicates equal contribution

Appendix 3

Published manuscript: Health Care Access and Use Among Adults with Diabetes During the COVID-19 Pandemic - United States, February-March 2021.

Czeisler MÉ*, Barrett CE*, Siegel KR, Weaver MD, Czeisler CA, Rajaratnam SMW, Howard ME, Bullard KM. Health Care Access and Use Among Adults with Diabetes During the COVID-19 Pandemic - United States, February-March 2021. *MMWR Morb Mortal Wkly Rep.* 2021 Nov 19;70(46):1597-1602. doi: 10.15585/mmwr.mm7046a2. PMID: 34793416; PMCID: PMC8601412.

* indicates equal contribution

Appendix 4

Published manuscript: Accommodating vaccine preferences among women of childbearing age.

Czeisler MÉ, Rajaratnam SMW, Howard ME, Czeisler CA. Accommodating vaccine preferences among women of childbearing age. *Am J Obstet Gynecol.* 2021 Dec;225(6):697-699. doi: 10.1016/j.ajog.2021.07.017. Epub 2021 Jul 31. PMID: 34343503; PMCID: PMC8372432.

Appendix 5

Submitted manuscript: Occupational burnout, associated demographic, sleep and employment factors, and adherence with mask usage and other recommended COVID-19 prevention behaviors

Czeisler MÉ, Wolkow AP, Czeisler CA, Howard ME, Rajaratnam SMW, Lane RI. Occupational burnout, associated demographic, sleep and employment factors, and adherence with mask usage and other recommended COVID-19 prevention behaviors. Submitted manuscript under review.

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2021 Global Partners in Disaster Behavioral Health Award from BOLANTE Threat Assessment & Disaster Behavioral Health Training and Consultation

Appendix 12

The COPE Initiative website

Abstract

Background

In March 2020, the World Health Organization declared the coronavirus disease 2019 (COVID-19) outbreak a pandemic. Absent widespread vaccination against COVID-19, nonpharmaceutical interventions (e.g., stay-at-home orders, lockdowns, masks) were applied on a scale unseen in a century, the efficacy of which depend upon community engagement. Surveillance of public support for and adherence with these measures was therefore critical.

Simultaneously, monitoring of anticipated mental health challenges related to the pandemic and its mitigation was also important. Finally, identifying disproportionately affected populations was needed to inform mental health response planning. The aims of this thesis were therefore to assess public attitudes, behaviours, and beliefs related to COVID-19 and its mitigation, and to evaluate mental and behavioural health during the pandemic.

Methods

To accomplish these aims, The COVID-19 Outbreak Public Evaluation (COPE) Initiative was launched as a multinational, interdisciplinary public health surveillance activity. Two datasets were generated.

1. Internet-based survey samples of adults in the United States (high COVID-19 prevalence) and Australia (low COVID-19 prevalence) were recruited by Qualtrics, a commercial survey company, using demographic quota sampling. Nine surveys (Australia [three], US [six]) were administered during intervals between April 2020 and March 2021.

2. Internet-based surveys of adult users of polysomnography-validated WHOOP wearable devices during June 2020. Surveys were linked with objective sleep-wake data.

The thesis is comprised of fifteen chapters, structured with an Introduction, Parts I and II to describe findings pertaining to each aim of The COPE Initiative, followed by a General Discussion.

Findings

Respondents generally reported high levels (60-80%) of support for nonpharmaceutical interventions and adherence with government and expert recommendations in regions independent of COVID-19 prevalence (Chapters Two, Three, Four), with lower levels among younger adults, men, and persons with lower COVID-19 risk perception. Two-thirds of US adult respondents indicated they would obtain vaccines as soon as possible (Chapter Five).

During the pandemic, prevalence estimates for anxiety or depression symptoms among US adults (~30% to 33%) were triple pre-pandemic estimates from longitudinal datasets using the same screening instrument (Chapters Four, Six, Seven) and substance use and suicidal ideation increased, with similarly high levels in Australia (Chapters Four, Ten). Young adults, unpaid caregivers, and people with disabilities disproportionately experienced these symptoms. Survivorship bias was present, whereby new anxiety or depression symptoms were significantly associated with loss-to-follow-up (Chapters Eight, Nine). Analysis of objective sleep-wake data indicated that sleep duration and consistency might be modifiable risks factors for adverse mental health (Chapter Eleven), while further characterisation of disproportionately affected populations (unpaid caregivers, Chapters Twelve, Thirteen) and people with disabilities (Chapter Fourteen) highlighted mental health disparities during the pandemic.

Discussion

Cumulative COVID-19 deaths exceeded 5.75 million in February 2022, positioning the pandemic among the deadliest in human history. Australia and regions with early implementation and enforcement of mitigation measures, which were initially strongly supported by the public, experienced lower COVID-19 mortality than the US and regions that acted later. Persistently high levels of adverse mental health symptoms were observed in Australia and the US. These findings provide insights for improving adherence with containment measures, and for preparing for mental health consequences of pandemics.

Declaration

This thesis contains no material that has been accepted for the award of any other degree or diploma at any university or equivalent institution. To the best of my knowledge, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

Name: Mark É Czeisler

Date: 23 July 2021

Publications, preprints, presentations, and peer reviewer activities during enrolment

Publications

Original research articles

Czeisler MÉ, Tynan MA, Howard ME, Honeycutt S, Fulmer EB, Kidder DP, Robbins R, Barger LK, Facer-Childs ER, Baldwin G, Rajaratnam SMW, Czeisler CA. Public Attitudes, Behaviors, and Beliefs Related to COVID-19, Stay-at-Home Orders, Nonessential Business Closures, and Public Health Guidance - United States, New York City, and Los Angeles, May 5-12, 2020. *MMWR Morb Mortal Wkly Rep.* 2020 Jun 19;69(24):751-758. doi: 10.15585/mmwr.mm6924e1. PMID: 32555138; PMCID: PMC7302477.

Czeisler MÉ, Lane RI, Petrosky E, Wiley JF, Christensen A, Njai R, Weaver MD, Robbins R, Facer-Childs ER, Barger LK, Czeisler CA, Howard ME, Rajaratnam SMW. Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic - United States, June 24-30, 2020. *MMWR Morb Mortal Wkly Rep.* 2020 Aug 14;69(32):1049-1057. doi: 10.15585/mmwr.mm6932a1. PMID: 32790653; PMCID: PMC7440121.

Czeisler MÉ, Marynak K, Clarke KEN, Salah Z, Shakya I, Thierry JM, Ali N, McMillan H, Wiley JF, Weaver MD, Czeisler CA, Rajaratnam SMW, Howard ME. Delay or Avoidance of Medical Care Because of COVID-19-Related Concerns - United States, June 2020. *MMWR Morb Mortal Wkly Rep.* 2020 Sep 11;69(36):1250-1257. doi: 10.15585/mmwr.mm6936a4. PMID: 32915166; PMCID: PMC7499838.

Czeisler MÉ, Garcia-Williams AG, Molinari NA, Gharpure R, Li Y, Barrett CE, Robbins R, Facer-Childs ER, Barger LK, Czeisler CA, Rajaratnam SMW, Howard ME. Demographic Characteristics, Experiences, and Beliefs Associated with Hand Hygiene Among Adults During the COVID-19 Pandemic - United States, June 24-30, 2020. *MMWR Morb Mortal Wkly Rep.* 2020 Oct 16;69(41):1485-1491. doi: 10.15585/mmwr.mm6941a3. PMID: 33056951; PMCID: PMC7561087.

Czeisler MÉ, Lane RI, Wiley JF, Czeisler CA, Howard ME, Rajaratnam SMW. Follow-up Survey of US Adult Reports of Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic, September 2020. *JAMA Netw Open.* 2021 Feb 1;4(2):e2037665. doi: 10.1001/jamanetworkopen.2020.37665. PMID: 33606030; PMCID: PMC7896196.

Czeisler MÉ, Howard ME, Robbins R, Barger LK, Facer-Childs ER, Rajaratnam SMW, Czeisler CA. Early public adherence with and support for stay-at-home COVID-19 mitigation strategies despite adverse life impact: a transnational cross-sectional survey study in the United States and

Australia. *BMC Public Health*. 2021 Mar 15;21(1):503. doi: 10.1186/s12889-021-10410-x. PMID: 33722226; PMCID: PMC7957462.

Czeisler MÉ, Wiley JF, Czeisler CA, Rajaratnam SMW, Howard ME. Uncovering survivorship bias in longitudinal mental health surveys during the COVID-19 pandemic. *Epidemiol Psychiatr Sci*. 2021 May 26;30:e45. doi: 10.1017/S204579602100038X. PMID: 34036933; PMCID: PMC8207539.

Czeisler MÉ*, Kennedy JL*, Wiley JF, Facer-Childs ER, Robbins R, Barger LK, Czeisler CA, Rajaratnam SMW, Howard ME. Delay or avoidance of routine, urgent and emergency medical care due to concerns about COVID-19 in a region with low COVID-19 prevalence: Victoria, Australia. *Respirology*. 2021 Jul;26(7):707-712. doi: 10.1111/resp.14094. Epub 2021 Jun 3. PMID: 34081819.

Czeisler MÉ*, Wiley JF*, Facer-Childs ER, Robbins R, Weaver MD, Barger LK, Czeisler CA, Howard ME, Rajaratnam SMW. Mental health, substance use, and suicidal ideation during a prolonged COVID-19-related lockdown in a region with low SARS-CoV-2 prevalence. *J Psychiatr Res*. 2021 Jun 4;140:533-544. doi: 10.1016/j.jpsychires.2021.05.080. Epub ahead of print. PMID: 34174556.

Czeisler MÉ, Rohan EA, Melillo S, Matjasko JL, DePadilla L, Patel CG, Weaver MD, Drane A, Winnay SS, Capodilupo ER, Robbins R, Wiley JF, Facer-Childs ER, Barger LK, Czeisler CA, Howard ME, Rajaratnam SMW. Mental Health Among Parents of Children Aged <18 Years and Unpaid Caregivers of Adults During the COVID-19 Pandemic - United States, December 2020 and February-March 2021. *MMWR Morb Mortal Wkly Rep*. 2021 Jun 18;70(24):879-887. doi: 10.15585/mmwr.mm7024a3. PMID: 34138835

Czeisler MÉ, Board A, Thierry JM, Czeisler CA, Rajaratnam SMW, Howard ME, Clarke KEN. Mental Health and Substance Use Among Adults with Disabilities During the COVID-19 Pandemic - United States, February-March 2021. *MMWR Morb Mortal Wkly Rep*. 2021 Aug 27;70(34):1142-1149. doi: 10.15585/mmwr.mm7034a3. PMID: 34437518; PMCID: PMC8389385.

Czeisler MÉ*, Barrett CE*, Siegel KR, Weaver MD, Czeisler CA, Rajaratnam SMW, Howard ME, Bullard KM. Health Care Access and Use Among Adults with Diabetes During the COVID-19 Pandemic - United States, February-March 2021. *MMWR Morb Mortal Wkly Rep*. 2021 Nov 19;70(46):1597-1602. doi: 10.15585/mmwr.mm7046a2. PMID: 34793416; PMCID: PMC8601412.

Czeisler MÉ, Drane A, Winnay SS, Capodilupo ER, Czeisler CA, Rajaratnam SM, Howard ME. Mental health, substance use, and suicidal ideation among unpaid caregivers of adults in the United States during the COVID-19 pandemic: Relationships to age, race/ethnicity, employment, and caregiver intensity. *J Affect Disord*. 2021 Dec 1;295:1259-1268. doi: 10.1016/j.jad.2021.08.130. Epub 2021 Sep 3. PMID: 34706440; PMCID: PMC8413485.

Reviews, editorials, and correspondences

Czeisler MÉ, Howard ME, Rajaratnam SMW. Mental Health During the COVID-19 Pandemic: Challenges, Populations at Risk, Implications, and Opportunities. *Am J Health Promot*. 2021 Feb;35(2):301-311. doi: 10.1177/0890117120983982b. PMID: 33554624.

Czeisler MÉ, Wiley JF, Czeisler CA, Rajaratnam SM, Howard ME. Tempering optimism from repeated longitudinal mental health surveys. *Lancet Psychiatry*. 2021 Apr;8(4):274-275. doi: 10.1016/S2215-0366(21)00045-6. PMID: 33743874.

Czeisler MÉ, Rajaratnam SMW, Howard ME, Czeisler CA. Accommodating vaccine preferences among women of childbearing age. *Am J Obstet Gynecol*. 2021 Dec;225(6):697-699. doi: 10.1016/j.ajog.2021.07.017. Epub 2021 Jul 31. PMID: 34343503; PMCID: PMC8372432.

Czeisler MÉ, Howard ME, Rajaratnam SMW. Direct and Indirect Mental Health Consequences of the COVID-19 Pandemic Parallel Prior Pandemics. *Am J Public Health*. 2021 Sep;111(9):1589-1592. doi: 10.2105/AJPH.2021.306460. Epub 2021 Aug 19. PMID: 34410828; PMCID: PMC8589065.

Non-peer-reviewed preprint reports (also under review)

Czeisler MÉ, Rajaratnam SMW, Howard ME, Czeisler CA. COVID-19 Vaccine Intentions in the United States—December 2020 to March 2021. *medRxiv* [Preprint]. 2021 May 17:2021.05.16.21257290. doi: 10.1101/2021.05.16.21257290.

Czeisler MÉ, Capodilupo ER, Weaver MD, Czeisler CA, Howard ME, Rajaratnam SMW. Prior sleep-wake behavior predicts mental health resilience among adults in the United States during the COVID-19 pandemic. *medRxiv* [Preprint]. 2021 Jun 22:2021.06.15.21258983. doi: 10.1101/2021.06.15.21258983.

Submitted manuscripts

Czeisler MÉ, Capodilupo ER, Weaver MD, Czeisler CA, Howard ME, Rajaratnam SMW. Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic among adult users of a wearable device in the United States. Original Investigation submitted for review.

Note: a prior version has been posted as a preprint (listed above).

Czeisler MÉ, Wolkow AP, Czeisler CA, Howard ME, Rajaratnam SMW, Lane RI. Occupational burnout, associated demographic, sleep and employment factors, and adherence with mask usage and other recommended COVID-19 prevention behaviors. Original Investigation submitted for review.

Czeisler MÉ, Lane RI, Weaver MD, Wiley JF, Robbins R, Barger LK, Facer-Childs ER, Rajaratnam SMW, Howard ME, Czeisler CA. Incident Anosmia and Adverse Mental Health Symptoms amid the COVID Pandemic. Original Investigation submitted for review.

Presentations

Czeisler MÉ. Assessment of Public Attitudes, Behaviors, and Impact Related to COVID-19 and its Mitigation. The Be Active Sleep Eat (BASE) Facility at Monash University held June 14, 2020, online via Zoom.

Lane RI, **Czeisler MÉ**, Christensen A. Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic — United States, June 24–30, 2020. American Psychiatric Association Council on Addiction Meeting held June 18, 2020, online via Zoom.

Lane RI, **Czeisler MÉ**. Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic — United States, June 24–30, 2020. Minnesota COVID-19 Opioid ECHO held October 6, 2020, online via Zoom.

Czeisler MÉ. Sleep, Behavior, and Mental Health Among US and Australian Adults Near the Onset of the COVID-19 Pandemic. 2020 Division of Sleep Medicine Poster Session at the Harvard Medical School Division of Sleep Medicine Sleep and Health Benefit Meeting held December 2020, online via Zoom.

Czeisler MÉ, Vinson S, Lane RI, Thompson K. General Session 1292—Applying a Racial Equity Lens to Mental Health During the COVID-19 Pandemic. 2021 American Psychiatric Association Annual Meeting held May 2021, online.

Czeisler MÉ. The COVID-19 Pandemic: Attitudes, Behaviors, and Health. Harvard Medical School Division of Sleep Medicine Scientific Staff Meeting held 25 January 2021, online via Zoom.

Czeisler MÉ, Follow-up Survey of US Adult Reports of Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic, September 2020, as part of the William James College Webinar Therapeutic Innovation in Substance Use Disorder Treatment and Recovery Session 1: Exploring the Data. Held February 2021, online via Zoom (<https://go.activecalendar.com/massdmh/site/learning/event/therapeutic-innovation-in-substance-use-disorder-treatment-and-recovery-webinar/>).

Czeisler MÉ, Mental health, substance use, and suicidal ideation during the COVID-19 pandemic—disproportionately affected populations. 10th Annual Virtual Ability Mental Health Symposium, “Mental Health in Trying Times.” Held April 2021, in Sojourner Auditorium, Virtual Ability Island In Second Life (<https://virtualability.org/mental-health-symposia/mental-health-symposium-2021/>).

Czeisler MÉ, The COPE Initiative. Monash University Sleep Theme Seminar: Professor Shantha Rajaratnam Group Update. Held April 2021, online via Zoom.

* indicates equal contribution.

Invited peer reviewer activities

BMC Public Health (2021 × 2)

BMJ Open (2020 × 1)

Drug and Alcohol Dependence (2021 × 1)

Frontiers in Psychology (2020 × 1)
International Journal of Behavioral Medicine (2020 × 1)
JAMA (2022 × 1)
JAMA Health Forum (2021 × 1)
JAMA Network Open (2021 × 2)
Journal of Intensive Care Medicine (2021 × 1)
Journal of Multidisciplinary Healthcare (2020 × 1)
Journal of Psychiatric Research (2021 × 1)
Journal of the American Dental Association (2021 × 1)
The Lancet Psychiatry (2021 × 1)
Nature and Science of Sleep (2021 × 1)
PLOS One (2021 × 1)
Public Health Reports (2021 × 1)
Science Advances (2021 × 1)
Translational Psychiatry (2021 × 2)

Impact of published research*

* All reported impact metrics were collected on 18 February 2022

Metric	Value	Notes
Scopus Citations (Citation Benchmarking)	<p>The Citation Count shows how many times this publication has been cited.</p> <p>(The citation benchmarking is based on SciVal's field-weighted version of the Outputs in Top Citation Percentiles metric. This metrics shows how citations received by this document compare with the average for documents in the same publication year, normalised by subject area. The 99th percentile is high and indicates a document in the top 1% globally.)</p>	<p>Text from:</p> <p>https://service.elsevier.com/app/answers/detail/a_id/12031/supporthub/scopus/</p>
Field-Weighted Citation Impact (F-WCI)	<p>Field-Weighted Citation Impact is the ratio of the total citations actually received by the denominator output, and the total citations that would be expected based on the average of the subject field.</p> <p>A Field-Weighted Citation Impact of:</p> <ul style="list-style-type: none"> • *Exactly 1* means that the output performs just as expected for the global average. • More *than 1* means that the output is more cited than expected according to the global average. For example, 1.48 means 48% more cited than expected. • Less than 1 means that the output is cited less than expected according to the global average. 	

Altmetric Attention Score (Journal rank [percentile]) (Overall rank [percentile]) Miscellaneous notes	The Altmetric Attention Score is a high-level measure of the quality and quantity of online attention that it has received.	https://www.altmetric.com/about-altmetrics/what-are-altmetrics/
Citations in policy documents	As detected by Altmetrics	
Narrative notes	Miscellaneous	

Czeisler MÉ, Tynan MA, Howard ME, Honeycutt S, Fulmer EB, Kidder DP, Robbins R, Barger LK, Facer-Childs ER, Baldwin G, Rajaratnam SMW, Czeisler CA. Public Attitudes, Behaviors, and Beliefs Related to COVID-19, Stay-at-Home Orders, Nonessential Business Closures, and Public Health Guidance - United States, New York City, and Los Angeles, May 5-12, 2020. *MMWR Morb Mortal Wkly Rep.* 2020 Jun 19;69(24):751-758. doi: 10.15585/mmwr.mm6924e1. PMID: 32555138; PMCID: PMC7302477.

Publication date: 19 June 2020

Metric	Value	Notes
Scopus Citations (Citation Benchmarking)	100 (98 th percentile)	
F-WCI	6.29	529% more cited than expected
Altmetric Score (Journal rank [percentile]) (Overall rank [percentile]) Miscellaneous notes	1364 184 of 3,426 outputs (94.63%) 6,069 of ~20 million outputs (99.97%)	
Citations in policy documents	1. Let's (Not) Get Together!: The Role of Social Norms in Social Distancing during COVID-19	Prepared by The Inter-American Development Bank
Narrative notes	<ul style="list-style-type: none"> Then-CDC Director Robert Redfield and CDC Deputy Director for Infectious Diseases Jay Butler discussed the findings from the MMWR in the first coronavirus press briefing in three months (12 June 2020) Then-Senator and Presidential candidate Joseph R. Biden Jr. referenced findings from the MMWR in a campaign speech that occurred about two weeks after the report was published 	https://www.cdc.gov/media/releases/2020/t0612-covid-19-update.html https://www.rev.com/blog/transcripts/joe-biden-speech-transcript-on-coronavirus-outbreak-june-30-in-delaware 45:10 mark

Czeisler MÉ, Lane RI, Petrosky E, Wiley JF, Christensen A, Njai R, Weaver MD, Robbins R, Facer-Childs ER, Barger LK, Czeisler CA, Howard ME, Rajaratnam SMW. Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic - United States, June 24-30, 2020. *MMWR Morb Mortal Wkly Rep*. 2020 Aug 14;69(32):1049-1057. doi: 10.15585/mmwr.mm6932a1. PMID: 32790653; PMCID: PMC7440121.

Publication date: 14 August 2020

Metric	Value	Notes
Scopus Citations (Citation Benchmarking)	698 (99 th percentile)	
F-WCI	118.32	11,732% more cited than expected
Altmetric Score (Journal rank [percentile]) (Overall rank [percentile]) Miscellaneous notes	7,820 18 of 3,426 outputs (99.47%) 262 of ~20 million outputs (99.999%) 3,121 news stories	
Citations in policy documents	<ol style="list-style-type: none"> 1. How Might State Responses to the Pandemic Affect the Safety Net? 2. How Might State Medicaid and Other Health Programs Be Affected in the Pandemic's Aftermath? 3. Serving Youth Remotely: Strategies for Practitioners 4. COVID-19 and Mental Health in Vulnerable Populations: A Narrative Review. Health, Nutrition and Population Discussion Paper 	<p>Prepared by The Urban Institute</p> <p>Prepared by The Urban Institute</p> <p>Prepared by The Urban Institute</p> <p>Prepared by the World Bank</p>
Narrative notes	<ul style="list-style-type: none"> • The findings were cited in a Presidential Executive Order (13954) providing USD\$425 million in funding for mental and behavioural health services during the pandemic • The Secretary of the Treasury (Treasury) cited the paper in its final rule to implement the Coronavirus State Fiscal Recovery Fund and the Coronavirus Local Fiscal Recovery Fund established 	<p>Federal Register /Vol. 85, No. 196 /Thursday, October 8, 2020 / Presidential Documents</p> <p>Federal Register / Vol. 86, No. 93 / Monday, May 17, 2021 / Rules and Regulations</p>

	<p>under the American Rescue Plan Act.</p> <ul style="list-style-type: none"> • The paper was cited in a Report to Congress to enhance suicide training and awareness nationally for Universal Prevention Act of 2020 • The National Academies of Sciences, Engineering, and Medicine cited the paper in their assessment of programs from the Comprehensive Addiction and Recovery Act • The data on suicidal ideation were cited in the US Surgeon General's Call to Action to implement the National Strategy for Suicide Prevention • The findings were cited in the Report of the Joint Economic Committee Congress of the United States on the 2020 Economic Report of the President • Professor Anne Case and Nobel laureate Professor Angus Deaton cited the paper in the paperback copy of their <i>New York Times</i> and <i>Wall Street Journal</i> Bestsellers and 2020 <i>New York Times</i> Notable Book: <i>Deaths of Despair and the Future of Capitalism</i> • The Organisation for Economic Co-operation and Development (OECD) cited the findings in its 	<p>116th Congress 2nd Session / House of Representatives / Report 116-542</p> <p>National Academies of Sciences, Engineering, and Medicine 2021. Progress of Four Programs from the Comprehensive Addiction and Recovery Act. Washington, DC: The National Academies Press. https://doi.org/10.17226/26060</p> <p>116th Congress 2nd Session / Senate / Report 116-335</p> <p>Case A & Deaton A. Preface to the Paperback. <i>Deaths of Despair and the Future of Capitalism</i>, Princeton: Princeton University Press, 2021, pp. ix-xiv. https://doi.org/10.1515/9780691217062-001</p> <p>OECD. A New Benchmark for Mental</p>
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	<p>book: <i>A New Benchmark for Mental Health Systems</i></p> <ul style="list-style-type: none"> The findings were cited in Supreme Court of the United States cases 20-37 and 20-38, which were about whether the US Department of Health and Human Services has the authority to approve state-imposed work requirements for some Medicaid recipients 	<p>Health Systems: Tackling the Social and Economic Costs of Mental Ill-Health, OECD Health Policy Studies, OECD Publishing, Paris, 2021. https://doi.org/10.1787/4ed890f6-en</p> <p>20-37 Xavier Becerra, Secretary of Health and Human Services, et al., Petitioners v. Charles Gresham, et al. https://www.supremecourt.gov/docket/docketfiles/html/public/20-37.html</p> <p>20-38 Arkansas, Petitioner v. Charles Gresham, et al. https://www.supremecourt.gov/docket/docketfiles/html/public/20-38.html</p>
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Czeisler MÉ, Marynak K, Clarke KEN, Salah Z, Shakya I, Thierry JM, Ali N, McMillan H, Wiley JF, Weaver MD, Czeisler CA, Rajaratnam SMW, Howard ME. Delay or Avoidance of Medical Care Because of COVID-19-Related Concerns - United States, June 2020. *MMWR Morb Mortal Wkly Rep*. 2020 Sep 11;69(36):1250-1257. doi: 10.15585/mmwr.mm6936a4. PMID: 32915166; PMCID: PMC7499838.

Publication date: 11 September 2020

Metric	Value	Notes
Scopus Citations (Citation Benchmarking)	258 (99 th percentile)	
F-WCI	43.52	4,252% more cited than expected
Altmetric Score (Journal rank [percentile]) (Overall rank [percentile])	2,474 106 of 3,426 outputs (96.91%)	

Miscellaneous notes	2,154 of ~20 million outputs (99.99%) 507 news stories	
Citations in policy documents	<ol style="list-style-type: none"> 1. Delayed and Forgone Health Care for Nonelderly Adults during the COVID-19 Pandemic 2. Strengthening population health surveillance: a tool for selecting indicators to signal and monitor the wider effects of the COVID-19 pandemic 	<p>Prepared by The Urban Institute</p> <p>Prepared by the World Health Organization</p>
Narrative notes	<ul style="list-style-type: none"> • The findings were by American Hospital Association chief executive Rick Pollack in a letter to the UnitedHealthcare chief executive officer (CEO) Brian Thompson outlining deep concerns about a policy announcement that would have allowed for the retroactive denial of coverage for emergency-level care in facilities... <p>Within a week, <i>The New York Times</i> reported that UnitedHealthcare announced that this policy would not go into effect until after the pandemic</p> <ul style="list-style-type: none"> • President & CEO of the Global Liver Institute Donna Cryer cited the findings in advocating US Congress to fund the mission against liver cancer • Senior Advisor to the COVID-19 Response Coordinator Andy Slavitt highlighted delay or avoidance of medical care in one of his Top 10 ways US President Joe R Biden could lead on health care 	<p>https://www.aha.org/lettercomment/2021-06-08-letter-unitedhealthcare-retroactive-denial-coverage-emergency-level-care</p> <p>https://www.nytimes.com/2021/06/10/health/united-health-insurance-emergency-care.html</p> <p>https://medicalresearch.com/hepatitis-liver-disease/global-liver-institute-urges-congress-to-fund-fight-against-liver-cancer-during-covid-19-epidemic/55595/</p> <p>https://www.usatoday.com/story/opinion/2020/11/16/covid-affordable-care-act-top-biden-health-care-list-column/6302515002/</p>

	<ul style="list-style-type: none"> New York State Governor Andrew Cuomo cited the paper in his annual State of the State of New York publication outlining priorities for 2021 	
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Czeisler MÉ, Lane RI, Wiley JF, Czeisler CA, Howard ME, Rajaratnam SMW. Follow-up Survey of US Adult Reports of Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic, September 2020. *JAMA Netw Open*. 2021 Feb 1;4(2):e2037665. doi: 10.1001/jamanetworkopen.2020.37665. PMID: 33606030; PMCID: PMC7896196.

Publication date: 19 February 2021

Metric	Value	Notes
Scopus Citations (Citation Benchmarking)	39 (99 th percentile)	
F-WCI	37.39	3,639% more cited than expected
Altmetric Score (Journal rank [percentile]) (Overall rank [percentile]) Miscellaneous notes	441 250 of 5,129 (95.12%) 41,941 of ~20 million outputs (99.79%)	
Narrative notes	<ul style="list-style-type: none"> The Letter was cited by CHESS Health as the company announced the addition of virtual recovery support meetings to its leading evidence-based Connections smartphone application as part of its comprehensive addiction technology and support services 	https://www.prweb.com/releases/chess_health_launches_virtual_recovery_support_meetings/prweb18012887.htm

Czeisler MÉ, Rohan EA, Melillo S, Matjasko JL, DePadilla L, Patel CG, Weaver MD, Drane A, Winnay SS, Capodilupo ER, Robbins R, Wiley JF, Facer-Childs ER, Barger LK, Czeisler CA, Howard ME, Rajaratnam SMW. Mental Health Among Parents of Children Aged <18 Years and Unpaid Caregivers of Adults During the COVID-19 Pandemic - United States, December 2020 and February-March 2021. *MMWR Morb Mortal Wkly Rep*. 2021 Jun 18;70(24):879-887. doi: 10.15585/mmwr.mm7024a3. PMID: 34138835.

Publication date: 18 June 2021

Metric	Value	Notes
Scopus Citations (Citation Benchmarking)	4 (98 th percentile)	

F-WCI	2.54	154% more cited than expected
Altmetric Score (Journal rank [percentile]) (Overall rank [percentile]) Miscellaneous notes	560 381 of 3,426 outputs (88.88%) 27,967 of ~20 million outputs (99.86%)	
Narrative notes	<ul style="list-style-type: none"> The findings were shared on NPR, both online and aired on the radio on <i>All Things Considered</i> 	https://www.npr.org/sections/health-shots/2021/06/17/1007579073/unpaid-caregivers-were-already-struggling-its-only-gotten-worse-during-the-pande

Overall, the 19 outputs of The COPE Initiative included in this thesis and its appendices have received 2,170 Google Scholar citations (mean = 114.2). The outputs have been cited in high-impact journals, including the *New England Journal of Medicine (NEJM)*, *The Lancet*, *Journal of the American Medical Association (JAMA)*, *Proceedings of the National Academy of Sciences of the United States of America (PNAS)*, *Nature*, *Nature Cancer*, *Nature Human Behaviour*, *The Lancet Psychiatry*, *The Lancet Global Health*, *The Lancet Planetary Health*, *JAMA Psychiatry*, *JAMA Pediatrics*, *JAMA Network Open*, *Annals of Internal Medicine*, *Morbidity and Mortality Weekly Report*, *Morbidity and Mortality Weekly Report Surveillance Summaries*, *Circulation*, and *World Psychiatry*, among others.

In addition, the 19 outputs of The COPE Initiative included in this thesis and its appendices in the Altmetric database have a cumulative score of 13,476 (mean = 709.3). The outputs were shared on Twitter by approximately 5,000 unique users across 102 countries, cited in 11 policy documents, and linked in approximately 4,100 news stories from 720 unique news outlets across 38 countries. News sources (number of mentions) included *Forbes* (77), *Yahoo!* (64), *Psychology Today* (52), *The New York Times* (33), *CNN News* (20), *The Washington Post* (19), *USA Today* (18), *NBC News* (16), *Health Affairs* (14), *Vox* (12), *Bloomberg* (10), *NPR* (9), *TODAY* (6), *Scientific American* (6), *LA Times* (6), *Kaiser*

Health News (6), *US News & World Report* (5), *World Economic Forum* (5), *Science Magazine* (5), *The Daily Mail* (5), and *TIME Magazine* (4), among others. The outputs were also linked in eight policy documents and on six Wikipedia pages.

In 2021, The COPE Initiative was the recipient of the first annual ***Global Partners in Disaster Behavioural Health Award***, which had been established to recognise an organisation or professional who has made significant contributions to the field of disaster behavioural health at an international level, at the Bolante Disaster Behavioral Health Conference (<https://www.monash.edu/turner-institute/news-and-events/latest-news/2021-articles/cope-initiative-receives-award-for-excellence-during-pandemic>).

Finally, since its creation in August 2020, The COPE Initiative website has had more than 8,000 page views from approximately 3,250 unique visitors from 62 countries across six continents. Countries with 10 or more visits include the US, Australia, Canada, the UK, India, Germany, China, the Netherlands, the Republic of the Philippines, France, Finland, Singapore, and Japan.

Thesis including published works declaration

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes ten original papers published in peer reviewed journals, three letters, editorials, or reviews published in peer reviewed journals, and two original investigations posted on a preprint server and submitted for publication. Four papers published in peer reviewed journals, and one submitted for review are also included as Appendices. The core themes of the thesis are (1) public attitudes, behaviours, and beliefs about the COVID-19 pandemic and its mitigation and (2) mental and behavioural health during the pandemic. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the student, working within the School of Psychological Sciences, under the joint supervision of Dr Mark E. Howard and Dr Shantha M.W. Rajaratnam.

The inclusion of co-authors reflects the fact that the work came from active collaboration between researchers and acknowledges input into team-based research. In the case of fourteen chapters and three appendices, my contribution to the work involved the following:

Thesis Chapter	Publication Title	Status	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
INTRODUCTION					
1	Direct and Indirect Mental Health Consequences of the COVID-19 Pandemic Parallel Prior Pandemics	Published	70% Concept, identifying primary sources, writing the first draft, revising manuscript	1) Howard ME (15%): Input to manuscript, supervision 2) Rajaratnam SMW (15%): Input to manuscript, supervision	No
PART I					
2	Public Attitudes, Behaviors, and Beliefs Related to COVID-19, Stay-at-Home Orders, Nonessential	Published	50% Concept, collecting data, analysing data, creating tables, writing the first	1) Tynan MA (10%): Concept, input to manuscript 2) Howard ME (10%): Concept, input to manuscript, supervision	No

Thesis Chapter	Publication Title	Status	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
	Business Closures, and Public Health Guidance - United States, New York City, and Los Angeles, May 5-12, 2020		draft, revising manuscript	3) Honeycutt S (1.43%): Input to manuscript 4) Fulmer EB (1.43%): Input to manuscript 5) Kidder DP (1.43%): Input to manuscript 6) Robbins R (1.43%): Input to manuscript 7) Barger LK (1.43%): Input to manuscript 8) Facer-Childs ER (1.43%): Input to manuscript 9) Baldwin G (1.42%): Input to manuscript 10) Rajaratnam SMW (10%): Concept, input to manuscript, supervision 11) Czeisler CA (10%): Concept, input to manuscript	
3	Demographic Characteristics, Experiences, and Beliefs Associated with Hand Hygiene Among Adults During the COVID-19 Pandemic - United States, June 24-30, 2020	Published	55% Concept, collecting data, analysing data, creating table, creating figures, writing the first draft, revising manuscript	1) Garcia-Williams, A (15%): Concept, input to manuscript 2) Molinari, N-A (5%): Input to manuscript, statistical guidance 3) Gharpure, R (1.43%): Input to manuscript 4) Li, Y (1.43%): Input to manuscript, statistical guidance 5) Barrett CE (1.43%): Input to manuscript 6) Robbins R (1.43%): Input to manuscript 7) Facer-Childs ER (1.43%):	No

Thesis Chapter	Publication Title	Status	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
				Input to manuscript 8) Barger LK (1.43%): Input to manuscript 9) Czeisler CA (1.42%): Input to manuscript 10) Rajaratnam SMW (5%): Concept, input to manuscript, supervision 11) Howard ME (10%): Concept, input to manuscript, supervision	
4	Early public adherence with and support for stay-at-home COVID-19 mitigation strategies despite adverse life impact: a transnational cross-sectional survey study in the United States and Australia	Published	50% Concept, collecting data, analysing data, creating tables, writing the first draft, revising manuscript	1) Howard ME (10%): Concept, input to manuscript, supervision 2) Robbins R (7.5%): Concept, input to manuscript, creation of figures 3) Barger LK (5%): Concept, input to manuscript 4) Facer-Childs ER (5%): Concept, input to manuscript 5) Rajaratnam SMW (10%): Concept, input to manuscript, supervision 6) Czeisler CA (12.5%): Concept, input to manuscript, supervision	No
5	COVID-19 Vaccine Intentions in the United States—December 2020 to March 2021	Under review (preprint posted)	70% Concept, collecting data, analysing data, creating tables, writing the first draft, revising manuscript	1) Rajaratnam SMW (7.5%): Concept, input to manuscript, supervision 2) Howard ME (7.5%): Concept, input to manuscript, supervision 3) Czeisler CA (15%): Concept, input to manuscript, supervision	No

Thesis Chapter	Publication Title	Status	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
PART II					
6	Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic - United States, June 24-30, 2020	Published	50% Concept, collecting data, analysing data, creating tables, writing the first draft, revising manuscript	1) Lane RI (15%): Concept, input to manuscript, supervision 2) Petrosky E (2.5%): Concept, input to manuscript 3) Wiley JF (2.5%): Statistical guidance, input to manuscript 4) Christensen A (2.5%): Concept, input to manuscript 5) Njai R (2.5%): Concept, input to manuscript 6) Weaver MD (2.5%): Concept, statistical guidance, input to manuscript 7) Robbins R (2.5%): Concept, input to manuscript 8) Facer-Childs ER (2.5%): Concept, input to manuscript 9) Barger LK (2.5%): Concept, input to manuscript 10) Czeisler CA (5%): Concept, input to manuscript, supervision 11) Howard ME (5%): Concept, input to manuscript, supervision 12) Rajaratnam SMW (5%): Concept, input to manuscript, supervision	No
7	Follow-up Survey of US Adult Reports of Mental Health,	Published	50% Concept, collecting data, analysing data,	1) Lane RI (12.5%): Concept, input to manuscript 2) Wiley JF (7.5%):	No

Thesis Chapter	Publication Title	Status	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
	Substance Use, and Suicidal Ideation During the COVID-19 Pandemic, September 2020		creating tables, writing the first draft, revising manuscript	Concept, statistical guidance, input to manuscript 3) Czeisler CA (10%): Concept, input to manuscript 4) Howard ME (10%): Concept, input to manuscript, supervision 5) Rajaratnam SMW (10%): Concept, input to manuscript, supervision	
8	Mental health, substance use, and suicidal ideation during a prolonged COVID-19–related lockdown in a region with low SARS-CoV-2 prevalence: Relationships with demographics, sleep, and behavioural changes and comparisons with acute-phase lockdowns	Published	50% Concept, collecting data, analysing data, creating tables, creating figures, creating appendix, writing the first draft (Introduction, Methods, Results), revising manuscript	1) Wiley JF* (18%): Concept, statistical guidance, writing the first draft (Discussion), revising manuscript, supervision 2) Facer-Childs ER (7%): Concept, creating Figure 1, outlining the first draft, input to manuscript 3) Robbins R (2%): Concept, input to manuscript 4) Weaver MD (2%): Concept, input to manuscript 5) Barger LK (2%): Concept, input to manuscript 6) Czeisler CA (2%): Concept, input to manuscript 7) Howard ME (2%): Concept, input to manuscript, supervision 8) Rajaratnam SMW (15%): Concept, statistical guidance, input to manuscript, supervision	No
9	Uncovering Survivorship Bias in Longitudinal Mental Health	Published	60% Concept, collecting data, analysing data,	1) Wiley JF (20%): Concept, statistical guidance, input to manuscript, supervision 2) Czeisler CA (5%):	No

Thesis Chapter	Publication Title	Status	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
	Surveys During the COVID-19 Pandemic		creating tables, creating figures, writing the first draft, revising manuscript	Input to manuscript, supervision 3) Rajaratnam SMW† (5%): Input to manuscript, supervision 4) Howard ME† (10%): Input to manuscript, supervision	
10	Tempering optimism from repeated longitudinal mental health surveys	Published	70% Concept, writing the first draft, revising manuscript	1) Wiley JF (7.5%): Input to manuscript 2) Czeisler CA (7.5%): Input to manuscript 3) Rajaratnam SMW† (7.5%): Input to manuscript, supervision 4) Howard ME† (7.5%): Input to manuscript, supervision	No
11	Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic among adult users of a wearable device in the United States.	Under review (preprint posted)	50% Concept, collecting data, analysing data, creating tables, creating figures, writing the first draft, revising manuscript	1) Capodilupo ER (20%): Concept, analysing data, creating tables, creating figures, input to manuscript 2) Weaver MD (10%): Concept, creating tables, creating figures, input to manuscript 3) Czeisler CA (5%): Concept, input to manuscript 4) Howard ME (5%): Concept, input to manuscript, supervision 5) Rajaratnam SMW (10%): Concept, creating tables, creating figures, input to manuscript, supervision	No
12	Mental Health, Substance Use, and Suicidal Ideation Among Unpaid Caregivers in the United States During the COVID-19	Published	50% Concept, collecting data, analysing data, creating tables, creating figures, writing the first draft,	1) Drane A (10%): Concept, input to manuscript 2) Winnay SS (10%): Concept, input to manuscript 3) Capodilupo ER (5%): Concept, input to manuscript	No

Thesis Chapter	Publication Title	Status	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
	Pandemic: Relationships to Age, Race/Ethnicity, Employment, and Caregiver Intensity		revising manuscript	4) Czeisler CA (5%): Concept, input to manuscript 5) Rajaratnam SMW (5%): Concept, input to manuscript, supervision 6) Howard ME (15%): Concept, input to manuscript, supervision	
13	Mental Health Among Parents of Children Aged <18 Years and Unpaid Caregivers of Adults During the COVID-19 Pandemic — United States, December 2020 and February–March 2021	Published	50% Concept, collecting data, analysing data, creating tables, writing the first draft, revising manuscript	1) Rohan EA (10%): Concept, writing the first draft, input to manuscript 2) Melillo S (2.5%): Concept, writing the first draft, input to manuscript 3) Matjasko JL (2.5%): Concept, writing the first draft, input to manuscript 4) DePadilla L (2.5%): Concept, writing the first draft, input to manuscript 5) Patel CG (2.5%): Concept, writing the first draft, input to manuscript 6) Weaver MD (2.5%): Statistical guidance, input to manuscript 7) Drane A (2.5%): Concept, input to manuscript 8) Winnay SS (2.5%): Concept, input to manuscript 9) Capodilupo ER (2.5%): Concept, input to manuscript 10) Robbins R (2.5%): Input to manuscript 11) Wiley JF (2.5%): Input to manuscript	No

Thesis Chapter	Publication Title	Status	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
				12) Facer-Childs ER (2.5%): Input to manuscript 13) Barger LK (2.5%): Input to manuscript 14) Czeisler CA (2.5%): Input to manuscript 15) Howard ME (2.5%): Input to manuscript, supervision 16) Rajaratnam SMW (5%): Input to manuscript, supervision	
14	Mental Health and Substance Use During the COVID-19 Pandemic Among Adults with Disabilities — United States, February–March 2021	Published	50% Concept, collecting data, analysing data, creating tables, writing the first draft, revising manuscript	1) Board A (12.5%): Concept, analysing data, writing the first draft, creating figures, input to manuscript 2) Thierry JM (10%): Concept, analysing data, writing the first draft, input to manuscript 3) Czeisler CA (5%): Input to manuscript 4) Rajaratnam SMW (5%): Input to manuscript, supervision 5) Howard ME (5%): Input to manuscript, supervision 6) Clarke KEN (12.5%): Concept, analysing data, writing the first draft, input to manuscript, supervision	No
APPENDICES					
Appendix 1	Delay or Avoidance of Medical Care Because of COVID-19–	Published	50% Concept, collecting data, analysing data,	1) Marynak K (10%): Concept, writing the first draft (Introduction, Discussion), revising manuscript	No

Thesis Chapter	Publication Title	Status	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
	Related Concerns — United States, June 2020		creating tables, creating figure, writing the first draft (Methods, Results), revising manuscript	2) Clarke KEN (5%): Concept, writing the first draft (Introduction, Discussion), revising manuscript 3) Salah Z (5%): Concept, statistical guidance, input to manuscript 4) Shakya I (2%): Concept, input to manuscript 5) Thierry JM (2%): Concept, input to manuscript 6) Ali N (2%): Concept, input to manuscript 7) McMillan H (2%): Concept, input to manuscript 8) Wiley JF (2%): Concept, statistical guidance, input to manuscript 9) Weaver MD (2%): Concept, statistical guidance, code review, input to manuscript 10) Czeisler CA (3%): Concept, input to manuscript 11) Rajaratnam SMW (5%): Concept, input to manuscript, supervision 12) Howard ME (10%): Concept, input to manuscript, supervision	
Appendix 2	Delay or avoidance of routine, urgent and emergency medical care due to concerns about COVID-19 in a region with Low	Published	50% Concept, collecting data, analysing data, creating table, writing the first draft (Methods,	1) Kennedy JL* (16%): Concept, writing the first draft (Introduction, Discussion), revising manuscript 2) Wiley JF (3%): Statistical guidance, input to manuscript	No

Thesis Chapter	Publication Title	Status	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
	COVID-19 Prevalence: Victoria, Australia		Results), revising manuscript	3) Facer-Childs ER (3%): Input to manuscript 4) Robbins R (3%): Input to manuscript 5) Barger LK (3%): Input to manuscript 6) Czeisler CA (3%): Input to manuscript 7) Rajaratnam SMW (3%): Input to manuscript, supervision 8) Howard ME (16%): Concept, input to manuscript, supervision	
Appendix 3	Health Care Access and Use Among Adults with Diabetes During the COVID-19 Pandemic - United States, February-March 2021	Published	50% Concept, collecting data, analysing data, creating tables, writing the first draft, revising manuscript	1) Barrett CE* (20%): Concept, analytic plan, creating tables, writing the first draft, revising manuscript 2) Siegel KR (5%): Concept, analytic plan, revising manuscript 3) Weaver MD (5%): Input to manuscript 4) Czeisler CA (5%): Input to manuscript 5) Rajaratnam SMW (5%): Input to manuscript, supervision 6) Howard ME (5%): Input to manuscript, supervision 7) Bullard KM (5%): Concept, analytic plan, revising manuscript, supervision	No
Appendix 4	Accommodating vaccine preferences among women of childbearing age	Published	70% Concept, writing the first draft, revising manuscript	1) Rajaratnam SMW (10%): Input to manuscript, supervision 2) Howard ME (10%): Input to manuscript, supervision	No

Thesis Chapter	Publication Title	Status	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
				3) Czeisler CA (10%): Input to manuscript, supervision	
Appendix 5	Occupational burnout, associated demographic, sleep and employment factors, and adherence with mask usage and other recommended COVID-19 prevention behaviors	Under review	50% Concept, collecting data, analysing data, creating tables, creating figure, writing the first draft, revising manuscript	1) Wolkow AP (15%): Concept, revising manuscript 2) Czeisler CA (5%): Concept, input to manuscript 3) Howard ME (10%): Concept, input to manuscript, supervision 4) Rajaratnam SMW (10%): Concept, input to manuscript, supervision 5) Lane RI (10%): Concept, input to manuscript, supervision	No

* indicates co-first authorship.

† indicates co-senior authorship.

A note for the examiners based on the MMWR author guide:

https://www.cdc.gov/mmwr/author_guide.html

“A hallmark of [Morbidity and Mortality Weekly Report] *MMWR* reports is simplicity. These reports are intended only to summarize the analysis and recommendations, not to provide every detail. The strict 10-reference rule is intended to limit the scope of the report.” This structure applied to the Original Investigations reported in Chapters Two, Three, Six, Thirteen, and Fourteen

I have not renumbered sections of submitted or published papers.

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the student's and co-authors' contributions to this work. In instances where I am not the responsible author, I have consulted with the responsible author to agree on the respective contributions of the authors.

Student: *Mark É Czeisler*

Date: 23 July 2021

Main Supervisor: *Mark E Howard*

Date: 23 July 2021

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One of the most meaningful experiences of my PhD was presenting as an invited speaker at the 10th Annual Mental Health Symposium of Virtual Ability (<https://virtualability.org/community/>), a diverse virtual community of people with disabilities (abilities). The presentation, which accommodated people with a variety of sensory disabilities, took place in Sojourner Auditorium on Virtual Ability Island in Second Life, and was given to a unique audience compared with my prior experiences—which have primarily been at academic conferences.

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“If opportunity doesn’t knock, build a door.”

—Milton Berle

Dedication

This thesis is dedicated to my great-grandfather and namesake Éliás Czeisler (1859—1917) of Mezőkövesd, Hungary, who passed away due to a pneumonia-like illness that is thought to be the same disease later recognised during the 1918 influenza pandemic; to my late grandparents Dr Tibor Czeisler (1910—2003) of Mezőkövesd, Hungary and Wanda V. nee Murzyn (1914—1971) of Krakow, Poland; to my surviving grandparents Mary L. Shanahan and James L. Shanahan; and to Chadwick A. Boseman (1976—2020), gone too soon.

CHAPTER 1: INTRODUCTION

1.1. PART I: NON-PHARMACEUTICAL INTERVENTIONS

1.1.1. Infectious Disease Outbreaks: Histories of the 1918 Influenza Pandemic and Other Outbreaks

The deadliest pandemic in recent history was the 1918 influenza pandemic, caused by influenza A virus subtype Hemagglutinin Type 1 and Neuraminidase Type 1 (A/H1N1) (**Morens & Fauci, 2007**). Though the origin of the pandemic strain remains unknown, the first documented case of the pandemic strain was recorded in the United States (US) in March of 1918 at the Fort Riley army base in Kansas (**J. M. Barry, 2004**). The virus quickly spread throughout the US and around the world, though public reports of the infectious disease were minimised to maintain morale during World War I (**Wever & van Bergen, 2014**). That is, except for the neutral Spain, where a free press enabled transparent reporting of the devastation caused by influenza, inadvertently leading to the unfortunate designation of the disease as the Spanish flu (**Martini et al., 2019**). Most people infected with the virus experienced typical influenza symptoms, including a sore throat, headache, and fever; however, a substantial fraction of people experienced a more severe course of illness, often including pneumonia, which was a common cause of death (**Morens & Fauci, 2007**).

The H1N1 virus was spread person-to-person through direct physical contact, touching contaminated surfaces, or encountering microdroplets expelled by people through exhalation, coughing, sneezing, or talking (**Opatowski et al., 2011**). With these various modes of transmission, the estimated basic reproductive number R_0 (pronounced “R-naught”) of the virus was approximately 1.8 (interquartile range [IQR] = 1.5 to 2.3), which indicates that in the absence of infection control measures, for each person who is infected with virus, on average, 1.8 additional persons would contract virus, leading to exponential growth (**Biggerstaff et al., 2014; Mahase, 2020**). Infection control measures (behavioural interventions, vaccines) and post-infection immunity

can reduce the effective reproduction number (R_e), which is the number of people expected to be infected by an individual at a specific point in time **(Mahase, 2020)**. In an effort to reduce to reduce R_e to below one, absent a protective vaccine or safe and efficacious treatment, governments and policymakers worldwide implemented nonpharmaceutical interventions (NPIs), such as isolation, quarantine, hand hygiene, use of disinfectants, and limitations on public gatherings **(Bootsma & Ferguson, 2007; Hatchett et al., 2007; Markel et al., 2007)**. In jurisdictions that had the benefit of geographic isolation, implementation of strict maritime quarantine for all travellers entering the region proved to be effective. In a comparison of mortality rate from pandemic influenza per 1,000 population among South Pacific jurisdictions, those that implemented strict maritime quarantine measures, including Australia (mortality rate = 2.4), Tasmania (mortality rate = 0.8), American Samoa (mortality rate = 0), experienced markedly lower mortality than those that did not implement such measures, such as New Zealand (mortality rate = 7.4), Guam (mortality rate = 45), Nauru (mortality rate = 160), Western Samoa (mortality rate = 220), and Tonga (mortality rate = 840) **(McLeod et al., 2008)**.

For many jurisdictions, including those in the US, maritime quarantine was challenging, and the most implemented NPIs were school closures and public gathering bans. During 8 September 1918 through 22 February 1919, there were 115,340 weekly excess pneumonia and influenza deaths (mortality rate = 5 per 1,000 population) across 43 US cities. Markel *et al.* found that cities that implemented NPIs (e.g., isolation and quarantine, school closures, public gathering bans) earlier experienced comparatively greater delays in reaching peak mortality (Spearman's $\rho = -0.74$, $P < 0.001$), lower peak mortality rates ($\rho = 0.31$, $P < 0.02$), lower total mortality ($\rho = 0.37$, $P < 0.008$) **(Markel et al., 2007)**. Moreover, cities that implemented NPIs for longer durations experienced lower total mortality ($\rho = -0.39$, $P < 0.005$). Hatchett *et al.* considered an expanded set of NPIs, including closures of theatres and churches, mask ordinances, business closures, and staggered

business hours to reduce congestion in stores and on transit systems, among others, in an analysis of 17 American cities, and similarly found that cities that had implemented NPIs at earlier phases relative to local community transmission of the virus experienced lower peak mortality rates (500 per 1,000 population) and cumulative death rates (200 per 1,000 population) while experiencing flattened epidemic curves (**Hatchett et al., 2007**). Additionally, an analysis of the timing of implementation of NPIs by 23 American cities by Bootsma & Ferguson found that time-limited interventions were associated with moderate reductions in mortality of 10% to 30%, with the efficacy hampered by delayed implementation and premature relaxation, while cities that rapidly implemented comprehensive NPIs experienced reductions in mortality of 30% to 50% (**Bootsma & Ferguson, 2007**).

A particularly stark contrast is painted between Philadelphia, Pennsylvania, and St. Louis, Missouri. The first cases of pandemic influenza were reported in these cities in 1918 on 17 September and 3 October, respectively. However, while officials in Philadelphia largely downplayed the significance of these cases and did not present a plan to contain the virus until 3 October, public health officials in St. Louis rapidly responded to the news and implemented a comprehensive plan of NPIs by 7 October. Over the subsequent three months, Philadelphia experienced peak and cumulative mortality rates per 1,000 population of 2.6 and 7.2, respectively, nearly 10-fold and more than 2-fold as high as those of St. Louis, which experienced peak and cumulative mortality rates of 0.3 and 3.5, respectively (**Hatchett et al., 2007**). One particularly consequential decision by Philadelphia was the allowance of the Liberty Loans Parade on 28 September, which was attended by more than 200,000 Philadelphians, and has been linked to more than 47,000 cases of influenza and 12,000 deaths from pneumonia or influenzas (**Collins et al., 2020**). Non-adherence with public health recommendations was not isolated to Philadelphia; across the country and around the world, dissenters emerged, including the Anti-Mask League of San Francisco, a group organised to protest

against mask ordinances (**Dolan, 2020**). Some cities made efforts to enforce NPI compliance, leading to fines for 25 men and warnings for 40 more in Philadelphia for spitting (**Philadelphia Evening Bulletin, 1918**) and to the sentencing of another 14 men in New York City for the use of unsanitary glassware (**The New York Times, 1918b**). Shortly after the US Public Health Service recommended the use of gauze masks or handkerchiefs to cover coughs and sneezes and warned that the colloquially-named “Spanish Flu” would otherwise become the “American Flu” (**US Public Health Services, 1918**), lawmakers in Chicago introduced legislature supporting the arrest of people who coughed or sneezed without using a handkerchief (**The New York Times, 1918a**). Reports on the efficacy of such enforcement efforts during the 1918 influenza pandemic were not available, though there were some notable gaffes in adherence with NPIs made by public figures, including the mayor of San Francisco and Commissioner of Health failing to wear masks at a parade and boxing match, respectively (**Tomes, 2010**).

Ultimately, without an understanding of the origin or pathology of the 1918 influenza, and between a delayed global response, non-adherence with or lack of NPIs, and without protective vaccinations or antibiotics against the infectious disease, during March 1918 through April 1920, over four waves of the 1918 influenza pandemic, approximately 500 million people—one-third of the global population at the time—had contracted the H1N1 virus, and approximately 50 to 100 million people died of influenza, with a fatality rate of approximately 10% to 20% (**Morens & Fauci, 2007; Taubenberger & Morens, 2006**).

Still, based on the efficacy of NPIs in the mitigation of the 1918 influenza pandemic, community mitigation strategies are widely considered the most effective way of containing infectious diseases. Such measures are particularly important when a pandemic is caused by a novel virus or pathogen

given that the human population has little or no immunity against it and proven safe and efficacious vaccines are not yet available.

Two milder influenza pandemics occurred during the 20th century (**Kilbourne, 2006**). First, the 1957-1958 influenza pandemic, caused by influenza A virus subtype Hemagglutinin Type 2 and Neuraminidase Type 2 (A/H2N2), originated in Guizhou, China, and spread to countries across the globe. The estimated R_0 of H2N2 was approximately 1.6 (IQR = 1.5 to 1.7) (**Biggerstaff et al., 2014**), and approximately 1.1 million people died during the second influenza pandemic of the 20th century, with an estimated mortality rate of approximately 0.2 per 1,000 population (**Viboud et al., 2016**). Second, the 1968 pandemic, caused by influenza A virus subtype Hemagglutinin Type 3 and Neuraminidase Type 2 (A/H3N2), is thought to have originated in Hong Kong, and similarly spread to countries across the globe. The estimated R_0 of H3N2 was approximately 1.8 (IQR = 1.6 to 1.9) (**Biggerstaff et al., 2014**), and approximately one million people died during the third influenza pandemic of the 20th century (**Centers for Disease Control and Prevention, 2019**). Both pandemics had lower mortality rates than the 1918 influenza pandemic, which—beyond differences in the virulence and transmissibility of the viruses—has been attributed to the introduction of antibiotics to manage bacterial infections, as well as improved sanitization and health care.

In the first two decades of the 21st century, there were four major outbreaks of infectious disease. First, severe acute respiratory syndrome coronavirus (SARS-CoV) crossed over from bats to humans via the intermediary host of palm civet cats in the southern province Guangdong, China, in November of 2002 (**L. F. Wang & Eaton, 2007**). SARS-CoV caused the 2003 outbreak of severe acute respiratory syndrome (SARS), during which more than 8,422 people were affected across 29 countries, and 916 people died before containment in July of 2003, with a mortality rate of 108.8 per 1,000 population (**Chan-Yeung & Xu, 2003**). In the wake of the 2003 SARS-CoV outbreak, the

use of nonpharmaceutical public health interventions was considered the most extensive of modern times **(Bell & World Health Organization Working Group on International and Community Transmission of SARS, 2004)**. Through active surveillance of hospitalised patients, heightened in-hospital infection control measures, aggressive contact tracing, and quarantine of persons believed to be exposed to SARS-CoV, Toronto effectively contained the largest SARS-CoV outbreak in North America **(Svoboda et al., 2004)**. In addition to quarantine and contact tracing, the use of face masks, frequent handwashing, and disinfecting living quarters were shown to be protective factors to control the SARS epidemic **(Lau et al., 2004)**. Many nations also instated travel advisories and other international border protection measures, including a combination of signage, videos, public health announcements, health alerts, symptom attestations, visual inspection to detect symptoms, and thermal scanning, though the efficacy of these measures remains unclear **(Bell & World Health Organization Working Group on International and Community Transmission of SARS, 2004)**. In recognition of the pandemic potential of coronaviruses, the 2003 outbreak prompted considerable research attention to SARS-CoV and other coronaviruses, including the development of diagnostic tests, animal models, antivirals, vaccines, and epidemiological and infection control measures **(V. C. C. Cheng et al., 2007)**.

Second, a 21st-century influenza pandemic emerged in 2009, as a new strain of the H1N1 influenza virus that caused the 1918 influenza pandemic led to an outbreak of severe influenza. The estimated R_0 of the 2009 H1N1 was 1.5 (IQR = 1.3 to 1.7) **(Biggerstaff et al., 2014)**, and during January 2009 through August 2010, approximately 500,000 laboratory-confirmed cases of the pandemic H1N1 virus, though a study has estimated that the actual number of cases including mild and asymptomatic carriers could range between 700 million and 1.4 billion people **(Kelly et al., 2011)**. With an estimated mortality rate between 10 and 30 per 1,000 population, the 2009 H1N1 virus was less lethal than previous pandemic influenza strains and led to approximately 18,000

laboratory-confirmed deaths (with estimated true mortality approximately 10-fold greater) **(Simonsen et al., 2013)**. With the high prevalence of subclinical and asymptomatic cases **(Pang et al., 2011)**, NPIs were widely implemented, including a mandatory 60-day quarantine enforced by the Chinese government during 10 May to 8 July 2009. This stringent mitigation policy had acute detrimental economic consequence, though a modelling analysis found that this reduced the prevalence of H1N1 by five-fold over the next several months **(X. Li et al., 2013)**.

Third, the Middle East respiratory syndrome coronavirus (MERS-CoV), crossed over from bats to humans via the intermediary host of dromedary camels in Saudi Arabia **(Zumla et al., 2015)**. The MERS coronavirus caused the 2012 outbreak of Middle East respiratory syndrome (MERS), during which approximately 2,500 people were affected and approximately 850 people died, with an estimated mortality rate between 300 and 400 per 1,000 population **(World Health Organization, 2015; Zumla et al., 2015)**. Nevertheless, the pandemic potential of SARS-CoV was relatively low. Pandemic potential requires the viral or pathogenic R_0 to be above one, and the estimated R_0 of pre-pandemic SARS-CoV was 0.8 (95% confidence interval = 0.5 to 1.1) **(Breban et al., 2013)**.

Fourth, the Ebola virus disease (EVD) caused the 2013 to 2016 Western African Ebola virus epidemic. The outbreak was largely localised to Guinea, Liberia, and Sierra Leone, with R_0 estimates between 1.5 and 2.5 across these regions **(Althaus, 2014)**. Overall, more than 11,000 deaths occurred among approximately 28,000 infected people, with a mortality rate of 400 per 1,000 population **(Malvy et al., 2019)**. As with previous infectious diseases, comprehensive NPIs proved effective in containment of the Ebola virus **(Caleo et al., 2018; Lindblade et al., 2015)**. Through August 2014, an estimated 38.3% (95% confidence interval = 17.4% to 76.4%) of Ebola infections were acquired in hospitals, 30.7% (95% confidence interval = 14.1% to 46.4%) in households, and 8.6% (95% confidence interval = 3.2% to 11.8%) while participating in funerals **(Merler et al.,**

2015). In remote rural areas of Liberia during August through December 2014, a combination of patient admission to Ebola treatment units and community engagement in physical distancing, washing hands, avoiding traditional burial practices, and sending patients for treatment outside the community led to a 94% decrease in Ebola transmission (and R_e value decreasing from 1.7 [95% confidence interval = 1.1 to 2.6] to 0.1 [95% confidence interval = 0.02 to 0.6]) (**Lindblade et al., 2015**). This was likely related to a 90% reduced risk of secondary infections for patients admitted to Ebola treatment units compared with those who died in the community.

With each of these outbreaks, NPIs were widely implemented to contain viral spread, during which time researchers designed and developed vaccinations that produce antibodies to protect against the virus and provide widespread immunity. Vaccinations, which are pharmaceutical interventions, were successfully designed for the H1N1 and Ebola virus diseases. For the H1N1 influenza virus, case-control studies support the safety and efficacy of monovalent 2009 H1N1 vaccines, though annual re-immunization is required for maximal protection (**Broadbent & Subbarao, 2011**). The first Ebola vaccine has also been successful, with preliminary data from compassionate use during an outbreak in the Democratic Republic of the Congo supportive of 97.5% efficacy; of approximately 94,000 individuals who were vaccinated, only 71 (~0.08%) contracted Ebola, and there were no fatalities, which strongly supports the efficacy of the vaccine considering the mortality rate of 400 per 1,000 population among unvaccinated persons (**World Health Organization, 2019**).

However, in contrast to the H1N1 influenza virus and Ebola virus, as of January 2020, there had never been a vaccine successfully developed for a coronavirus. Beyond the challenge of designing a safe and efficacious vaccine, the two major challenges with vaccines are timing and uptake. Vaccine candidates are conventionally evaluated for safety and immunogenicity in clinical trials and governed

by regulatory authorities, including the Food and Drug Administration (FDA) in the US, the European Medicines Agency (EMA) in the European Union (EU), and the Therapeutic Goods Agency (TGA) in Australia. Development and governance processes can take years, which is not conducive to mitigating the rapid transmission of some infectious diseases. For example, the first vaccine against Ebola virus, the Recombinant vesicular stomatitis virus–Zaire Ebola virus (rVSV-ZEBOV) vaccine, was approved in December 2019 **(Food and Drug Administration, 2020)**, more than three years after the conclusion of the 2013 to 2016 Ebola epidemic. Further, developed vaccines require widespread uptake to confer community immunity, and this depends on both the accessibility to the vaccine, as well as public willingness to take the vaccine.

In 2018, the centenary of the 1918 influenza pandemic, scientists and public health officials reflected on lessons from the pandemic and the global preparedness for the next pandemic threat **(Belser & Tumpey, 2018; Cinti, 2005; Greenberger, 2018; B. Jester et al., 2018; B. J. Jester et al., 2018; Tomes, 2010)**. The general sentiments from this literature were optimism based on advances in surveillance tools, communication platforms, medical care, antiviral medications, and vaccine development capabilities, coupled with forewarnings of remaining gaps—particularly with regards to limited capacity for testing and vaccine manufacturing. Moreover, as the first pandemic to occur in the era of mass society (marked by mass transportation, mass media, and mass consumption) and globalisation, the 1918 influenza pandemic demonstrated the simplicity with which viruses could spread, and difficulty of their control **(The Literary Digest, 1919)**. Indeed, some of the most effective infection control measures (bans on public gatherings, school closures, and strict quarantine and isolation) are the most challenging to implement in a globalised, mass society **(Tomes, 2010)**.

In summary, infectious diseases can be associated with astonishing global morbidity and mortality. With emerging infectious diseases, NPIs are the most effective initial measures to protect against community transmission, while the development and distribution of safe and effective vaccines may confer widespread immunity to ultimately end pandemic transmission. Yet, both NPIs and vaccines require public support and engagement to be maximally effective, making them difficult to implement effectively in mass society, and underscoring the values of (1) monitoring support for and adherence with these measures, and (2) clear and consistent public health communication.

1.1.2. SARS-CoV-2 and the Emergence of the COVID-19 Pandemic

Coronavirus disease 2019 (COVID-19) is a respiratory illness caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), a novel zoonotic coronavirus that emerged in humans starting in late 2019 (**Abebe et al., 2020; Singhal, 2020**). Following the presentation of severe pneumonia of unknown cause in December 2019 in Wuhan, capital city of Hubei province in China, contact tracing initially identified common exposure of the initial cases to the Huanan Seafood Wholesale Market, a live animal and seafood market in Wuhan, although the Director-General of the Chinese Center for Disease Control and Prevention Dr George Gao has more recently indicated that based on evidence of earlier infections, it is unlikely that the virus emerged from that seafood market (**Leucy, 2020**). Etiologic research was conducted using a surveillance system implemented following the 2003 SARS outbreak, which likely originated in a live animal market (**Webster, 2004**). On 31 December 2019, the Wuhan Municipal Health Commission notified the World Health Organization (WHO), and on 7 January 2020 the coronavirus eventually designated as SARS-CoV-2 was identified (**World Health Organization, 2020c**).

Though the novel SARS-CoV-2 was first identified in humans in Wuhan in late 2019, its mechanism of crossover to humans remains unknown and somewhat controversial. A

comprehensive study of the evolutionary divergence of SARS-CoV-2 from sarbecoviruses—the viral subgenus containing both SARS-CoV and SARS-CoV-2—estimated that SARS-CoV-2 has been circulating undetected in bats for decades, with the most plausible origin of the intermediate horseshoe bat (*Rhinolophus affinis*) (Boni et al., 2020). However, whether the crossover from animals to humans was directly from bats or through an intermediary host is unresolved. Pangolins were initially proposed as a potential intermediary host (Lam et al., 2020; K. Xiao et al., 2020), though neither pangolins nor bats were traded at the market during the years 2017 to 2019 (X. Xiao et al., 2021), and there has since been evidence that pangolins may have been infected directly, as humans were, rather than acting as a source of transmission to humans (Boni et al., 2020). Statements that SARS-CoV-2 was created at the Wuhan Institute of Virology by high-ranking US officials have been refuted by the WHO and expert virologists based on the genome (Burki, 2020), though many virologists now suggest that more recent evidence supporting the possibility of a laboratory accident should be investigated (Mallapaty et al., 2021). The precise origins of the virus therefore remain as of yet unknown.

Irrespective of the source of crossover from humans to animals, following the initial recognised cases of SARS-CoV-2 and COVID-19 in Wuhan, cases grew with an exponential trajectory, which indicated human-to-human transmission of SARS-CoV-2 was occurring (Huang et al., 2020).

The prognosis of COVID-19 varies significantly, with a high proportion of asymptomatic infections and a variety of symptoms ranging from mild symptoms to severe illness for those who do develop symptoms (He et al., 2021; Yanes-Lane et al., 2020). People with COVID-19 typically feel symptoms between two days and two weeks after exposure to the virus, and may experience a fever or chills, cough, headache, difficulty breathing, fatigue, achiness, sore throat, congestion, nausea or vomiting, diarrhoea, and, in most cases, an unusual and highly specific neurological

symptom of sudden-onset lost senses of smell or taste (**Moein et al., 2020; Spinato et al., 2020; Struyf et al., 2021**). People at elevated risk of severe COVID-19 morbidity and mortality include those of older age, those with one or multiple of the following underlying medical conditions (cancer, chronic kidney disease, chronic obstructive pulmonary disease, obesity [body mass index ≥ 30], serious heart conditions, sickle cell disease, and diabetes), and, in the US, people who are of Black race or Latinx ethnicity (**Centers for Disease Control and Prevention, 2020d; Wortham et al., 2020**).

1.1.3. Early Transmission Dynamics of SARS-CoV-2

Early community transmission of SARS-CoV-2 was likely accelerated by the Chunyun interval, which is a time of massive human migration within and outside of China that starts approximately 15 days before the Chinese Lunar New Year Holiday (25 January 2020) and lasts for approximately 40 days. The Ministry of Transport of the People's Republic of China had estimated that as many as three billion trips would occur during the 2020 Chunyun interval; before a restrictive travel ban was imposed on 23 January, 2020, approximately five of the 11 million people in Wuhan travelled outside the city, one-third of whom left Hubei province (**S. Chen, Yang, et al., 2020; S. Chen, Chen, et al., 2020**).

Evidence of widespread transmission of SARS-CoV-2 began to surface in China, with cases of COVID-19 in provinces outside of Hubei, and on 13 January 2020, the first case of COVID-19 outside of China was confirmed, as a patient was diagnosed with the disease in Thailand (**Okada et al., 2020**). Shortly thereafter, cases were identified across the globe, as by 25 January, patients with COVID-19 were reported in Japan, South Korea, the US, Taiwan, Hong Kong, Macau, Singapore, Vietnam, Nepal, France, Canada, Malaysia, and Australia. By 11 March 2020, Italy was an epicentre for the COVID-19 outbreak, and there were more than 115,000 confirmed cases of SARS-CoV-2 in

114 countries, with more than 4,000 deaths, which prompted the WHO to declare the infectious disease outbreak a pandemic (**World Health Organization, 2020d**).

Analysis of the early transmission dynamics based on the first 425 patients with COVID-19 found that 55% of cases with onset before 1 January 2020 were linked to the Huanan Seafood Wholesale Market, compared with 8.6% of subsequent cases (**Q. Li et al., 2020**). The mean incubation period was 5.2 days, and an estimated basic reproductive number R_0 of 2.2 (95% confidence interval = 1.4 to 3.9) or 2.7 (95% confidence interval = 2.5 to 2.9) (**Q. Li et al., 2020; J. T. Wu et al., 2020**). These R_0 estimates above two suggested that for each person infected with SARS-CoV-2, more than two additional persons would contract SARS-CoV-2, on average.

The most common mode of transmission of SARS-CoV-2 is from person-to-person, predominantly through respiratory droplets produced during exhalation, coughs, sneezes, speech, and song (**Centers for Disease Control and Prevention, 2020d, 2021b; Hamner et al., 2020; J. Liu et al., 2020; World Health Organization, 2020e, 2020i**). Given this mode of transmission, the potential for person-to-person transmission decreases with increases in interpersonal physical distance. Additionally, though not widely recognised initially by the medical community, governments, or public health agencies (**World Health Organization, 2020e**), there was early evidence of airborne transmission of the virus that contributed significantly to community spread during the pandemic (**Hamner et al., 2020; Morawska & Milton, 2020**). Along with comparatively large respiratory droplets released during exhalation, microdroplets small and light enough remain aloft in air. Microdroplets released by persons infected with SARS-CoV-2 would thereby have the potential to persons at greater distances, especially in indoor venues (**Lindsley et al., 2015; Xie et al., 2007; Yan et al., 2018**).

1.1.4. Nonpharmaceutical Interventions Employed to Contain COVID-19

In response to the rapidly developing pandemic spread of global proportions associated with widespread loss of life in early epicentres of COVID-19 including Wuhan, China, and Milan, Italy, governments and policymakers worldwide turned inward and implemented stringent mitigation policies to contain the spread of SARS-CoV-2. As with the 1918 influenza pandemic and previous pandemics with new infectious diseases, in the absence of vaccinations or widespread immunity, NPIs represented the most rapidly implementable and effective measures to reduce community transmission of SARS-CoV-2. Between curfews, stay-at-home orders, economic shutdowns, and lockdowns, by the first week of April, 2.6 to 3.9 billion people—between one-third and one-half of the global population—were under a government-imposed lockdown (**Asensio et al., 2020; Hiscott et al., 2020**). This figure included more than 90% of people in the US, where all states implemented at least some form of stay-at-home orders during the months of April and May (**Centers for Disease Control and Prevention, 2020c**). These measures were designed to limit movement outside of personal residences to essential activities only. Many jurisdictions also instituted gathering bans to limit the incidence of persons gathering and spreading the disease in social and employment settings (**Centers for Disease Control and Prevention, 2020c**).

To complement stay-at-home orders, public health officials advised that people maintain a physical distance of at least six feet or two metres between persons who did not live in the same residence, to cover coughs and sneezes, and to wash hands. The aetiology of the two-metre (approximately six-foot) physical distance recommendation is unclear, as for many years, the WHO recommended maintenance of a one-metre physical distanced based on work done in the 1930s by Williams Wells, who found that emitted droplets (e.g., from breathing, coughing, sneezing, or singing) were largely contained to a one metre radius of where they were expelled (**Wells, 1934**).

However, during the 2003 SARS epidemic, a study by Olsen *et al.* of a 120-person flight found that in some cases passengers seated more than three rows from infected persons contracted SARS, which could have been related to the close proximity of persons on the flight or to insufficient ventilation with recirculation of cabin air **(Olsen et al., 2003)**. More recently, in late March of 2020 and in response to the emerging COVID-19 pandemic, a fluid dynamics scientist at the Massachusetts Institute of Technology demonstrated that coughs and sneezes emitted droplets and aerosols capable of traveling up to nine metres (27 feet), suggesting that even two metres may not be protective in some cases **(Bourouiba, 2020)**. Nevertheless, public health messaging during the COVID-19 pandemic has consistently recommended a two-metre physical distance.

The recommendation to cover coughs and sneezes is based on the potential for coughs and sneezes to forcefully expel respiratory droplets that spread viral infections **(Dhand & Li, 2020)**. Evidence for public health recommendations to cover coughs and sneezes dates to the 1918 influenza pandemic, when US public health officials coined the slogan “Coughs and Sneezes Spread Diseases” to highlight their role in pandemic transmission of viral particles. Work in the 1940s found that a cough expel approximately 3,000 respiratory droplets, while sneezes may release approximately 40,000 respiratory droplets **(Duguid, 1945, 1946)**. There are limitations with this infection control method, including the variable size and spread of viral respiratory droplets, as well as the potential for people to incorrectly cover their coughs and sneezes, only to further spread the virus. Still, it is considered a key component of hygiene, and has been highlighted in the messaging surrounding the prevention of COVID-19 and other infectious diseases.

Hand hygiene, washing hands with soap and water for at least 20 seconds or using hand sanitizer with at least 60% alcohol when soap and water are not available, is considered a cornerstone of infection control **(Daniels & Rees, 1999; John, 2000; Laboratory Centre for Disease Control,**

Bureau of Infectious Diseases, Health Canada, 1998; Mathur, 2011; Shobowale et al., 2016).

The introduction of hand hygiene for infection control dates back to the mid-1800s, when the Hungarian physician Ignaz Semmelweis demonstrated that healthcare workers were transmitting hospital-acquired diseases between patients. Semmelweis made this breakthrough after observation of two obstetric clinics of the Vienna General Hospital with markedly different rates of maternal mortality (16% versus 7%). Semmelweis observed seeing that many doctors and medical students at the clinic with the 16% maternal mortality rate did not wash their hands between patient autopsies and entering the clinic, whereas none of the midwives in the second clinic participated in autopsies. More than one decade before Louis Pasteur substantiated the germ theory of disease, Semmelweis theorised that the higher maternal mortality in the clinic staffed by the medical students was due to poisoning from cadaverous particles on their hands. To test his theory, Semmelweis introduced a hand hygiene protocol using a chlorine bleaching agent (calcium hypochlorite) for medical students and doctors after patient autopsies and between patients, and found that the mortality rate dropped to below 3% (**Semmelweis, 1861**).

In addition to these central NPIs that have been commonly applied, public health officials have provided inconsistent messaging on the use of face masks to protect against transmission of SARS-CoV-2. In the early stages of the pandemic, due to a number of factors including shortages of medical masks and personal protective equipment, as well as uncertainty about the efficacy of face masks to protect against COVID-19, the WHO and many countries, including the US and Australia, did not recommend and in some cases discouraged universal masking (**60 Minutes, 2020; Feng et al., 2020; Prime Minister of Australia, 2020; World Health Organization, 2020g**). However, by 3 April 2020, the Centers for Disease Control and Prevention (CDC) reversed its positions on face masking for the general public (**Dwyer & Aubrey, 2020**), and thereafter the WHO revised its guidance on 5 June 2020 to recommend masks for the general public in regions with widespread

SARS-CoV-2 community transmission (**World Health Organization, 2020h**). Then, on 9 July 2020, the Australian Government indicated that masks could be recommended for the general public during SARS-CoV-2 waves (**Australian Government, 2020**). Mixed public health messaging on the use of face masks in the US (**Fazio, 2021; O. Rubin et al., 2020**), and the lack of mandates in some jurisdictions, may have hampered adherence with public health recommendations to use face masks when in public.

Beyond variation in the COVID-19 restriction implementations and recommendations, jurisdictions varied widely in the enforcement of these measures. Victoria, Australia was among the regions with the highest levels of COVID-19 restriction enforcement, which was carried out through spot checks by Victoria Police and use of emergency powers by the Department of Health Authorised Officers (**State Government of Victoria, 2021**). Victoria police could issue on-the-spot fines up to Australian Dollar (AUD)\$1,652 for adults and up to AUD\$9,913 for businesses, and the fines could escalate to up to AUD\$20,000 for individuals and AUD\$100,000 for corporations through the court system. Community members were also encouraged to raise concerns about compliance through a Police Assistance Line. Across the US, enforcement varied considerably (**Chesak, 2020**). States including Hawaii and Alaska, which are geographically advantaged in monitoring entry and exit points, had steep penalties for violating COVID-19 travel orders, for example. In Hawaii, violations were considered a criminal offense and could result in up to a year of imprisonment, a United States Dollar (USD)\$5,000 fine, or both, while in Alaska the fine could reach USD\$25,000. Most of the contiguous US, on the other hand, had more difficulty enforcing such restrictions, and relied heavily on the honour system. Business establishments were somewhat easier to monitor. Through October 2020, the US Department of Labor Occupational Safety and Health Administration had issued USD\$1.2 million in coronavirus violations across 85 business

establishments **(US Department of Labor, 2020)**, and that figure increased to USD\$3.9 million through the end of 2020 **(US Department of Labor, 2021)**.

1.1.5. Pharmaceutical Interventions Employed to Contain COVID-19

Prior to the COVID-19 pandemic, there had not yet been a successful vaccine to protect against a coronavirus, and a vaccine for an infectious disease had never been produced in fewer than 12 months. However, the genetic sequence of SARS-CoV-2 was published on 11 January 2020, which led to an enormous investment of resources toward the development of a vaccine against COVID-19, with some vaccine candidates entering clinical trials as early as March 2020 **(Le et al., 2020)**. Within months of the publication of the genetic sequence of the novel coronavirus, more than 100 vaccine candidates were under development **(World Health Organization, 2020b)**.

Beyond the intensive development and regulatory processes required for approval of a vaccine, manufacturing enough doses has been a challenge for many jurisdictions, especially considering the global scale of the disease and requirements for universal vaccination. In the US, the federal government initiated Operation Warp Speed, a partnership between the federal government and private sector partners to accelerate the development of a vaccine and prepare for its distribution **(The White House, 2020a)**. Through Operation Warp Speed, the US federal government invested more than USD\$12 billion on six different vaccine candidates, and established agreements with multiple companies, including Moderna, Sanofi, GlaxoSmithKline, and Johnson & Johnson, such that if a vaccine is approved by the FDA, there would be an advanced start on manufacturing. Meanwhile, in Australia, the federal government entered an AUD\$1.7 billion agreement with the University of Oxford/AstraZeneca and the University of Queensland/CSL to create millions of vaccine doses for the Australian population **(Australian Government Department of Health, 2020a)**.

In addition to barriers to access of a vaccine, to ensure maximal uptake of a vaccine, public health officials will also have to overcome vaccine hesitancy, which was growing before the pandemic (**Dubé et al., 2013, 2019; Facciola et al., 2019; Siddiqui et al., 2013**), and is expected to increase given the accelerated timeline of the development and approval processes of COVID-19 vaccine, as well as the politicization of the pandemic. Several factors contribute to vaccine hesitancy, including emotional, cultural, social, spiritual, political, and cognitive factors (**Dubé et al., 2013**). Though quantifying global vaccine-hesitancy is challenging, public health experts attribute lack of confidence in vaccines and the perception of vaccination as unsafe and unnecessary to decreasing vaccine coverage, which hampers the efficacy of one of the most effective public health measures to control infectious diseases. In Australia, there were considerations of a COVID-19 vaccine mandate, though these were dispelled following poor public reception (**Dalzell, 2020**).

With this context, in addition to the unprecedented development of a vaccine in under 12 months for a class of viruses against which an effective vaccine had never been created, both access and uptake of the vaccination were anticipated to present challenges to the efficacy of a vaccine to confer widespread immunogenicity against SARS-CoV-2 and eradicate the virus and associated disease.

1.1.6. Gaps in the Literature

With such intensive mitigation policies recommended worldwide for the first time in a century, there was an immediate need to assess the level of public support for and adherence with NPIs, including stay-at-home orders, nonessential business closures, avoiding gatherings, physical distancing, mask usage, and hand hygiene. This information could inform policymakers and public health officials in their evaluation of the efficacy of these measures and provide an understanding of which subgroups of the population to target health-promotion communication resources.

1.2. PART II: MENTAL HEALTH AND SUBSTANCE USE

1.2.1. Mental Health and Substance Use During Infectious Disease Outbreaks

The effects of infectious disease outbreaks on mental health and substance use can be indirect (i.e., adverse consequences of socio-economic and socio-behavioural disruptions) or direct (i.e., sequelae of infection with the pathogen). Near the onset of the COVID-19 pandemic, most forewarnings of mental health effects were predicated on concerns about indirect consequences of the pandemic. With governments and policymakers worldwide rapidly implementing stringent mitigation policies and recommending NPIs, many individuals were forced to confront profound changes to daily life and activities. The social impact of physical distancing and isolation, economic impact of nonessential business closures and travel bans, fear and anxiety associated with infection of oneself or loved ones, grief and bereavement from morbidity and mortality caused by the disease, and uncertainty about the duration of the pandemic and mitigation policies designed to contain the virus have all added stressors that led social and behavioural health experts to deliver warnings related to the potential mental health consequences of the pandemic and its mitigation.

Early during the COVID-19 pandemic, Brooks *et al.* conducted a rapid review of the evidence surrounding quarantine and self-isolation during prior infectious disease outbreaks. The authors found that stressors introduced by quarantine—including infection fears, frustration, boredom, inadequate information, financial loss, social isolation, loneliness, and stigma were associated with negative psychological effects, including post-traumatic stress disorder (PTSD) symptoms, confusion, and anger (S. K. Brooks et al., 2020).

A conceptual and methodological review of social isolation and mental health identified social network (quantity), social network (structure and quality), and appraisal of relationships (emotional and resources) as key domains that capture concepts related to social isolation and mental health (J.

Wang et al., 2017). The COVID-19 pandemic and its mitigation could have adverse impacts each of these domains, most saliently on social network quantity and quality by reducing the frequency and nature of contacts with persons during stay-at-home orders, and on the appraisal of relationships in terms of resources, whereby perceived access to resources from someone's social relationships would be reduced.

Similarly, a loneliness model described by Hawkley & Cacioppo proposes that loneliness (perceived social isolation) induces implicit hypervigilance for social threats in the environment (**Hawkley & Cacioppo, 2010**). This can lead individuals experiencing loneliness to view social interactions as more threatening, expect negative social exchanges, and more deeply remember negative social information. Pandemics can put strain on social relationships in the absence of unconscious surveillance for social threats associated with loneliness, increasing the potential for self-reinforcing loneliness loops that could contribute to adverse mental health symptoms and low self-esteem (**Cacioppo et al., 2006**).

Finally, for persons who contract the infectious disease or are quarantined for potential exposures, stigma can have adverse health and social impacts (**Stangl et al., 2019**). The Health Stigma and Discrimination Framework proposes that fear of infection, social and economic ramifications, social judgement, and stereotypes related to a health condition—which can be facilitated by cultural norms and health policy—drive health condition-related stigma. These drivers and facilitators, combined with intersecting stigmas (e.g., race, gender, sexual orientation) manifest as internalised, perceived, anticipated, and experienced stigma and discrimination. Stigma and discrimination can in turn reduce health care utilisation, test-seeking, treatment adherence, and resilience. Uncertainties about COVID-19 and its implications and communal fears of infection could exacerbate prejudices and the potential for stigmatisation.

These models and frameworks highlight the diverse mechanisms through which a pandemic or similarly traumatic event could increase adverse mental health. Goldmann & Galea characterised more broadly pre-, peri-, and post-disaster risk factors associated with post-disaster psychopathology for different types of traumatic events ranging from natural disasters such as Hurricane Katrina to the 11 September 2001 World Trade Center attack (**Goldmann & Galea, 2014**). For example, nearly 25% of New York residents reported increased substance use following the 11 September 2001 attacks (**Vlahov, Galea, Ahern, Resnick, Boscarino, et al., 2004; Vlahov, Galea, Ahern, Resnick, & Kilpatrick, 2004**). In the context of the COVID-19 pandemic, psychologists predicted substantial increases in anxiety and depression, substance use, loneliness, and domestic violence, as well as a potential child abuse epidemic (**Galea et al., 2020**).

In an analysis of 1509 Canadians quarantined during the 2003 SARS outbreak in Toronto, DiGiovanni *et al.* found that addressing concerns about the continuation of wages, salaries, and other forms of income, as well as supply of groceries and other essential services, was helpful for mental health and alleviating stress as people were entering quarantine (**DiGiovanni et al., 2004**). Similarly, a study of 129 quarantined persons in Toronto who completed an Internet-based survey exhibited a high prevalence of psychological distress, with 28.9% of respondents reporting symptoms of PTSD, and 31.2% of respondents reporting symptoms of depression (**Hawryluck et al., 2004**). Those who knew someone who had been diagnosed with SARS had higher odds of screening positive for symptoms of PTSD and depression. Moreover, those who contracted SARS also reported elevated levels of stress compared with those who did not contract SARS. Lee *et al.* found these higher stress levels reported among SARS survivors compared with controls, both during the outbreak (Perceived Stress Scale-10 scores = 19.8 and 17.9, respectively; $P < 0.01$) and one year later (19.9 and 17.3, respectively; $P < 0.01$), suggesting there may have been long-term psychological consequences for these patients (**Lee et al., 2007**).

Moreover, sudden increases in demand for social and behavioural health services can stress an under-resourced system, especially when systems are required to transform the delivery of services (e.g., from face-to-face to remote services to reduce transmission risk). For example, in Gyeonggi province, South Korea, 1221 people placed in quarantine during the MERS outbreak experienced psychological and emotional difficulties, 350 of whom required continuing services (**Yoon et al., 2016**). Of these 350 persons, just 124 (35%) received contact from service providers to deliver the required services.

Early evidence from the COVID-19 pandemic found health care workers in China who were exposed to COVID-19 had experienced elevated levels of adverse mental health symptoms, insomnia, and psychological distress during late January to early February 2020 (**J. Lai et al., 2020**). Among 1257 health care workers across 34 hospitals, symptoms of depression, anxiety, insomnia, and distress were reported by 50.4%, 44.6%, 34.0%, and 71.5% of respondents, respectively. Nurses, women, frontline health care workers, and those who worked at hospitals in Wuhan, China, reported worse mental health symptoms than other surveyed health care workers.

With a precedent for elevated levels of adverse mental health symptoms during infectious disease outbreaks and early evidence of impaired mental health among people in the initial epicentre of the pandemic, Holmes *et al.* issued a call to action for multidisciplinary research efforts to characterise the psychological, social, and neuroscientific impacts of the COVID-19 pandemic and its mitigation on the public (**Holmes et al., 2020**). The authors called attention to specific populations based on general disproportionate experience of adverse mental health symptoms and based on specific impacts anticipated for certain populations. Regarding the former, Holmes *et al.* noted the potential for disproportionate negative impacts for socially excluded groups, including persons experiencing incarceration, homelessness, financial insecurities, and inaccessibility of technologies as well as

people with existing mental health, substance use, or physical health conditions, who may be affected by relapse, disruptions to services, and social isolation. Regarding the latter, the authors suggested that mental health could be especially impacted among children, young people, and families related to school closures (with the potential for social network disruptions, potential exposure to substance misuse, domestic violence, child maltreatment), among older adults and people with disabilities, and among frontline healthcare workers affected by extended work hours, fear of personal infection or infection of household members, and moral injury.

Given the precedence for elevated adverse mental health symptom levels and substance use during previous respiratory infectious disease outbreaks, understanding the experience of adverse mental health and substance use among communities during the COVID-19 pandemic was of heightened importance. Moreover, with the potential for enhanced stress on the mental health care system, identifying populations disproportionately experiencing adverse mental health could help policymakers to optimise mental health and substance use resource allocation.

By April to early June of 2020, early signs of potential direct neuropsychiatric sequelae of SARS-CoV-2 infection had emerged, including anosmia, ageusia, headache (**Giacomelli et al., 2020**), and less commonly, stroke, impairment of consciousness, seizure, and encephalopathy (**Mao et al., 2020**). The Editorial following this paragraph, which was published in the *American Journal of Public Health*, was written to consider the direct and indirect mental health consequences of the COVID-19 pandemic in the context of mental health effects of prior pandemics.

1.2.2. CHAPTER ONE: Direct and Indirect Mental Health Consequences of the COVID-19 Pandemic Parallel Prior Pandemics

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Direct and Indirect Mental Health Consequences of the COVID-19 Pandemic Parallel Prior Pandemics

Mark É. Czeisler, AB, Mark E. Howard, PhD, MBBS, and Shantha M. W. Rajaratnam, PhD

ABOUT THE AUTHORS

Mark É. Czeisler, Mark E. Howard, and Shantha M. W. Rajaratnam are with the Turner Institute for Brain and Mental Health and School of Psychological Sciences, Monash University, and the Institute for Breathing and Sleep, Austin Health, both in Melbourne, Victoria, Australia.

A century ago, Karl Menninger, MD, documented adverse mental health consequences of the 1918 influenza pandemic,^{1–3} publishing a case series of patients with postinfluenza mental illness. He concluded, “There is also no doubt but that influenza was the direct cause of thousands and thousands of [psychiatric] cases”^{3(p244)} and cited evidence of mental illness during pandemics as early as 1385.³ In his classic textbook, William Osler, MD, wrote in 1899, “Among the most important of the nervous sequelae [of influenza] are depression of spirits, melancholia and . . . dementia.”^{4(p97)} As Julius Althaus, MD, wrote in 1892, “[there were] A good many people who, without being actually laid up with definite symptoms of grip [influenza], yet seemed to some extent to be under the influence of the poison, as shown by such symptoms as general languor and depression”; sometimes “such endurable despondency as to make the patient feel that death was preferable to the state in which he found himself, and suicide the only

means of relief,” and other times “other symptoms . . . causing the patients to make themselves drunk with alcohol or morphine, in order to find relief.”^{5(p24,25)}

Advances in psychiatry and data collection methodologies limit comparisons of mental health consequences of earlier pandemics and those observed during the COVID-19 pandemic, and pathogenic mechanisms of mental health conditions may vary. Nevertheless, these earlier descriptions have striking parallels with adverse mental health documented during recent epidemics.^{6,7} For example, patients hospitalized for SARS (severe acute respiratory syndrome) or MERS (Middle East respiratory syndrome) commonly experienced acute confusion, depressed mood, anxiety, impaired memory, and insomnia.⁶

DIRECT MENTAL HEALTH EFFECTS

Emerging evidence highlights the importance of monitoring and

addressing potential postacute neuropsychiatric sequelae of COVID-19. Analysis of 81 million electronic health records revealed that one third of COVID-19 survivors were diagnosed with neurologic or psychiatric conditions within six months.⁷ Patients with COVID-19 had an increased risk of such diagnoses compared with patients with other conditions (e.g., vs influenza, a 78% and 44% increased risk of first-time and any such diagnoses, respectively). Among patients with COVID-19, those admitted to intensive care had a 187% and 58% increased risk of first-time and any incident neurologic or psychiatric diagnosis. Heterogenous conditions observed (e.g., anxiety, ischemic stroke, intracranial hemorrhages, dementia, parkinsonism)⁷ may result from direct brain injury following viral infection, particularly given evidence of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) invasion of the central nervous system⁸ or from systemic factors, including inflammation, immune dysregulation, and adverse medical treatment responses.⁸ Even persons with mild COVID-19 and otherwise asymptomatic SARS-CoV-2 infection may experience psychiatric symptoms.⁷

INDIRECT MENTAL HEALTH EFFECTS

In addition to potential direct neuropsychiatric impacts of these viral infections, socioeconomic disruptions caused by pandemics and their mitigation can have indirect mental health consequences. Menninger asserted that the 1893 European financial panic was “indirectly [emphasis added] due to the depressing effect of . . . influenza, and the mutual loss of confidence and enthusiasm which it is well known to produce.”^{3(p243,244)} Measuring indirect

mental health effects of infectious disease outbreaks is particularly difficult, especially given differing sociopolitical contexts (e.g., World War I during the 1918 pandemic). However, evidence from the COVID-19 pandemic reveals considerably elevated levels of adverse mental health symptoms compared with prepandemic years, even in the absence of widespread SARS-CoV-2 transmission. As early as April 2020, anxiety and depression symptoms in the United States were two to four times as prevalent as in 2019—and similarly high in Australia despite exceptionally low COVID-19 prevalence.⁹

During the COVID-19 pandemic, governments have implemented stringent mitigation policies, including stay-at-home orders, gathering bans, economic shutdowns, school closures, and travel bans to reduce SARS-CoV-2 transmission. As unemployment, loneliness, and social isolation increased and financial security and social interaction decreased, factions of resistance emerged, perhaps because of adjustment disorders with disturbance of conduct, including norm-violating or inappropriate conduct (e.g., mask refusal), aggressive behavior (e.g., violent protests, purposefully exposing others to SARS-CoV-2), and other maladaptive reactions (e.g., substance use). US Army major George Soper, who discovered asymptomatic transmission of typhoid in the United States, commented on these social dynamics during the 1918 pandemic: “It does not lie in human nature for a man who thinks he has only a slight cold to shut himself up in rigid isolation as a means of protecting others.”^{10(p502)} That attitude is apparent today, as moral appeals for mutual protection from COVID-19 have often fallen on deaf ears amid socioeconomic disruption of uncertain duration.

People who embrace public health guidance may experience social isolation, concerns of COVID-19 morbidity and mortality, and grief and guilt associated with the isolated deaths of loved ones. Some may feel resentment toward what Paul Farmer, MD, PhD, designates containment nihilism, referring to approaches that abandon public health measures to contain SARS-CoV-2 and instead endorse enormous mortality to achieve population-level immunity. By June 2020, 40.9% of 5412 surveyed US adults reported adverse mental health symptoms or substance use, and suicidal ideation was twice as prevalent as in 2018.¹¹ Young adults, unpaid caregivers, Black persons, Latinx persons, essential workers, people with disabilities, and individuals with psychiatric or substance use conditions have disproportionately experienced adverse mental health symptoms. Anxiety and depression symptom levels among US adults continued to climb through February 2021,¹² likely representing direct and indirect effects of the COVID-19 pandemic complemented by seasonality. Provisional data indicate that US deaths classified as suicides declined by 2677 in 2020 versus 2019.¹³ However, unintentional injury deaths increased by 19 136 during the same interval, driven by a record increase in drug overdose deaths.¹³ Taken together, deaths of despair increased substantially in 2020.

RESPONDING TO MENTAL HEALTH NEEDS

Longstanding inadequate funding of mental and behavioral health services has left countries underprepared to respond to mental health needs during the COVID-19 pandemic. Despite an estimated \$1 trillion economic cost of anxiety and depression alone—and a

four-to-one benefit–cost ratio for investment in relevant treatment—mental health expenditure accounted for less than 2% of 2017 government health budgets.¹⁴ Addressing the chronic underinvestment in mental health infrastructure can reduce the impact of such unique challenges, with added benefits for population-level health and productivity. Fortunately, early indicators of mental health effects of the pandemic^{9,11} led the US president to sign Executive Order 13954, allocating \$425 million to address mental health, the opioid crisis, and suicide. Moreover, the US Congress has allocated \$1.15 billion to study postacute sequelae of COVID-19, including neuropsychiatric sequelae.

A comprehensive pandemic response will require recognition of both direct and indirect mental health consequences of the COVID-19 pandemic. Failure to recognize that COVID-19 is among the infectious diseases that may directly cause psychiatric conditions has led some policymakers to incorrectly conclude that adverse mental health consequences of the pandemic are driven solely by mitigation, creating a false choice between COVID-19 containment and preserving mental health. Similarly, failure to appreciate that fear, bereavement, and pandemic-associated life disruption can have adverse mental health consequences could lead policymakers to allocate mental health resources only to those who have had SARS-CoV-2 infection. Moreover, social determinants of health and the impacts of systemic and institutional racism and economic downturns compound pandemic-related stressors. Parallel stressors are, however, not unique to the COVID-19 pandemic; the 1918 influenza pandemic occurred during World War I alongside sociopolitical turmoil.

In describing the commonality of depression following influenza observed by internists and general practitioners in the wake of the 1918 influenza pandemic, Menninger states, “‘Since I had influenza’ is the touchstone of many a clinical history of depression.”^{2(p257)} Public health, societal, and medical efforts can help to reduce this experience with COVID-19. Public health prevention efforts should include promotion of COVID-19 prevention measures and coordination of COVID-19 vaccine distribution. Societal efforts should include integrated and sustained community-wide education campaigns and interventions to reduce social and health inequalities, both backed by strong legislative platforms. Medical efforts should prioritize expansion of mental health care access, as the already considerable percentage of US adults with unmet mental health care needs increased by 27% during the pandemic¹³ and many countries rely on out-of-pocket payment for mental health services.¹⁵ Increased, equitable access to tele-mental health services, digital mental health programs, and safe in-person services may mitigate the long-term consequences of neglecting this overlooked aspect of the pandemic.

Moreover, given evidence of neuropsychiatric consequences of SARS-CoV-2 infection,^{7,8} enhanced mental health monitoring of all individuals who contract SARS-CoV-2 may be warranted, with recognition that psychiatric symptoms experienced by patients with COVID-19 may reflect experiential aspects of COVID-19 (e.g., self-stigma) or indirect mental health effects of the pandemic, which are not mutually exclusive from potential direct brain effects of COVID-19. Given the potential for mental health challenges affecting

patients more broadly, integration of mental and behavioral health services into medical practices could help to better support community mental health needs.

With the global prevalence of laboratory-confirmed SARS-CoV-2 infections approaching 200 million in July 2021 and the true number of infections considerably larger, greatly enhanced research and clinical initiatives are needed to characterize and address the direct and indirect mental health consequences of the COVID-19 pandemic and to mitigate the detrimental impacts of mental health stigmatization. As Menninger warned in 1919,² failure to do so could further overwhelm underprepared US and global mental health care systems, the shortcomings of which were exposed beginning early during the current pandemic.¹⁵ **AJPH**

CORRESPONDENCE

Correspondence should be sent to Mark É. Czeisler, Harvard Medical School, 107 Ave Louis Pasteur, Box #236, Boston, MA 02115-5750 (e-mail: mark.czeisler@fulbrightmail.org). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

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CONFLICTS OF INTEREST

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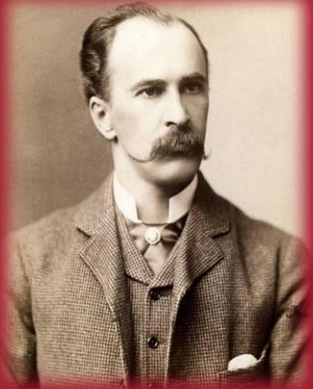
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Direct and Indirect Mental Health Consequences of the COVID-19 Pandemic Parallel Prior Pandemics

Prior Pandemics



“Among the most important of the **nervous sequelae** [of **influenza**] are depression of spirits, melancholia and . . . dementia.

Sir William Osler, 1899

The Principles and Practice of Medicine: Designed for the Use of Practitioners and Students of Medicine. 3rd ed. New York, NY: D. Appleton.

The 1893 European financial panic was “indirectly due to the depressing effect of . . . influenza, and the mutual loss of confidence and enthusiasm which it is well known to produce.”



Dr. Karl Menninger, 1919

DOI: <https://archive.org/details/journalofkansasm1919kans>

The COVID-19 Pandemic

3-4x

Population-level anxiety and depression symptom levels, as compared with 2019

Increased risk of first-time and any psychiatric or neurologic diagnoses among COVID-19 vs influenza survivors

78%

44%

Evidence of **central nervous system SARS-CoV-2 invasion, inflammation, immune dysregulation, and adverse medical treatment responses**

Evidence-Based Mental Health Promotion

Invest in mental health care and support systems



Promote social inclusion

Ensure freedom from discrimination and violence



Improve access to economic resources



Mark É Czeisler, Mark E Howard, Shantha MW Rajaratnam.
Direct and Indirect Mental Health Consequences of the COVID-19 Pandemic Parallel Prior Pandemics. *American Journal of Public Health*. 2021;111(9)
DOI: <https://doi.org/10.2105/AJPH.2021.306460>.

The COPE Initiative

In summary, descriptions of indirect and direct adverse mental health consequences of past pandemics dating back to 1385 parallel those of the COVID-19 pandemic. Differences in mental health research, data collection methodologies, and socio-political contexts limit direct comparisons between pandemics. Nonetheless, this historical perspective underscores that in addition to epidemiological and public health efforts to reduce SARS-CoV-2 transmission, monitoring population-level mental health and substance use is critical to support a comprehensive response to the global pandemic.

1.2.3. Gaps in the Literature

Mental health research and systematic data collection methodologies have advanced considerably since the 1918 influenza pandemic, which was the last time that population-level mitigation strategies were so widely implemented. Furthermore, much of the trauma-related literature documenting acute and chronic increases in adverse mental health symptoms were based on acute events (e.g., Hurricane Katrina, 9/11). While these events have had long-lasting structural and emotional implications, the immediacy and clear endpoint of the events themselves contrast the prolonged and uncertain nature of a pandemic, which leaves uncertainties about the short- and long-term impacts of exposure to trauma over a long interval of time. Additionally, in the context of infectious disease outbreaks, most studies had focused on disease survivors or in regions during a specific outbreak, rather than tracking the impact on the general population over time. Routine population-level mental health surveillance can therefore provide valuable information about disproportionately affected populations during the pandemic, which can both inform tailored intervention strategies during the COVID-19 pandemic and inform prevention strategies during future infectious disease outbreaks. Additional gaps in the mental health literature that merited investigation but were outside the scope of this thesis and therefore not explored in depth through

The COPE Initiative included comparisons between the experiences of individuals with mental health conditions that preceded the pandemic versus those with newly onset mental health conditions and whether their experiences with risk factors and treatments or access to care and medication differed; potential further stigmatisation or normalisation of mental health discussions; potential disruptions of and increased demand for access to mental health services; and potential novel prevention and intervention strategies to promote mental health and well-being, including community-based programs, telehealth, and other digital mental health platforms.

1.3. THE COVID-19 OUTBREAK PUBLIC EVALUATION (COPE) INITIATIVE

To gather evidence to address the research needs described in Sections 1.1.6. and 1.2.3., in March 2020, **The COVID-19 Outbreak Public Evaluation (COPE) Initiative** (www.thecopeinitiative.org) was launched as a transnational and multi-institutional collaborative public health surveillance activity. Two datasets were generated through The COPE Initiative.

The primary dataset presented was generated through Internet-based surveys administered through Qualtrics, LLC, a commercial survey company, using demographic quota sampling to match population estimates for sex, age, and race and ethnicity or ancestry, depending on the region. The first survey for The COPE Initiative was developed over a one-week interval (12 to 19 March 2020) by researchers at Monash University, Austin Health, Brigham and Women's Hospital, and Harvard Medical School. The initial intent was focused on mental and behavioural health in the wake of the potential life disruptions anticipated during the rapidly evolving pandemic outbreak. Validated and widely used survey instruments were administered where possible. Survey waves were administered to adults aged ≥ 18 years with residence in the US or Australia, countries that had prevalence estimates of COVID-19 cases and deaths on the high and low ends of the global spectrum, respectively (**Dong et al., 2020**). There are many differences between and regionally within these

countries, including differences that were longstanding cultural features and those related to the response to the COVID-19 pandemic. While acknowledging that these differences limit comparisons between the US and Australia, these primarily English-speaking countries with vastly different COVID-19 prevalence were chosen to provide insights as to whether adherence with mitigation measures or mental and behavioural health measures were related to the prevalence of SARS-CoV-2 and related factors (e.g., government policies and messaging about the pandemic).

In April 2020, following the release of a preprint report on public adherence with and support for COVID-19 prevention measures (now published in *BMC Public Health* and presented in **Chapter Four** of this thesis), the preprint was shared with public health officials serving on the COVID-19 Response Team for the US CDC. This led to the initiation of a collaboration with the CDC, wherein members on various task forces within the CDC COVID-19 Response (i.e., Monitoring and Evaluation Task Force, Community Interventions and Critical Populations Task Force, and Minority and Rural Health Task Force) provided subject matter expertise to support The COPE Initiative activities. CDC public health officials recommended and requested survey questions for each survey wave following the April 2020 wave. Given the need to understand population-level support for and adherence with COVID-19 prevention measures, and especially NPIs, many of the CDC requests were focused on these topics. This collaboration, which remains active as of the submission of this thesis, has led to the publication of seven COVID-19 papers authored by the founders of The COPE Initiative in the CDC's *Morbidity and Mortality Weekly Report (MMWR)*, “often called ‘the voice of CDC,’ and the agency’s primary vehicle for scientific publication of timely, reliable, authoritative, accurate, objective, and useful public health information and recommendations” (<https://www.cdc.gov/mmwr/publications/index.html>).

In a related project, to explore relationships between sleep and mental health using objective sleep-wake data, a second dataset was generated as part of the WHOOP COVID-19 Resilience Project. Internet-based surveys containing demographic questions and screening instruments for sleep and mental health were administered to adult users of WHOOP (WHOOP Inc., Boston, Massachusetts, USA, www.whoop.com), a sleep wearable device that has demonstrated good performance in detecting sleep vs wake when evaluated against polysomnography, the gold-standard technology for sleep measurement (Berryhill et al., 2020; Miller et al., 2020, 2021). Survey responses were linked with historical sleep-wake data dating back to January 2020 to enable analyses including pre-pandemic sleep-wake data. Relevant Methods are further detailed in the subsequent Chapters.

1.4. OVERVIEW OF THESIS STRUCTURE

The overall aims of this thesis are to assess (1) public attitudes, behaviours, and beliefs about the COVID-19 pandemic and its mitigation, and (2) mental and behavioural health during the pandemic. In addition to generating and disseminating data in a timely manner to help inform the public health response to the pandemic, a key theme of this body of work has been the identification of populations of interest (e.g., low levels of adherence with NPIs, vaccine hesitant, disproportionately affected by mental health and substance use) for tailored public health messaging, community health promotion, and support resources. The thesis comprises two Parts, each reporting on one of these aims, and Fifteen main chapters, the first of which is this Introduction. Chapters Two through Fourteen present original research, and Chapter Fifteen presents a General Discussion that integrates findings from these manuscripts and the overall thesis.

1.5. A NOTE ON THE USE OF LANGUAGE

As a system of communication, language has profound implications for shaping world views. Increased recognition of these implications including the perpetuation of inequities related to racism, sexism, ageism, ableism, classism, homophobia, religious prejudice, and other forms of oppression has prompted vigilance about terminology, usage, and word choice. For example, there has been a movement toward person-centred language, which puts people first in recognition that categorisations and identifiers do not define them (e.g., people with diabetes, rather than diabetics). Markers of progress on this front include evidence that four of five premier medical journals significantly increased the use of patient-centred language in titles and keywords, resulting in longer journal titles to accommodate the new approach **(G. M. Chen et al., 2019)**.

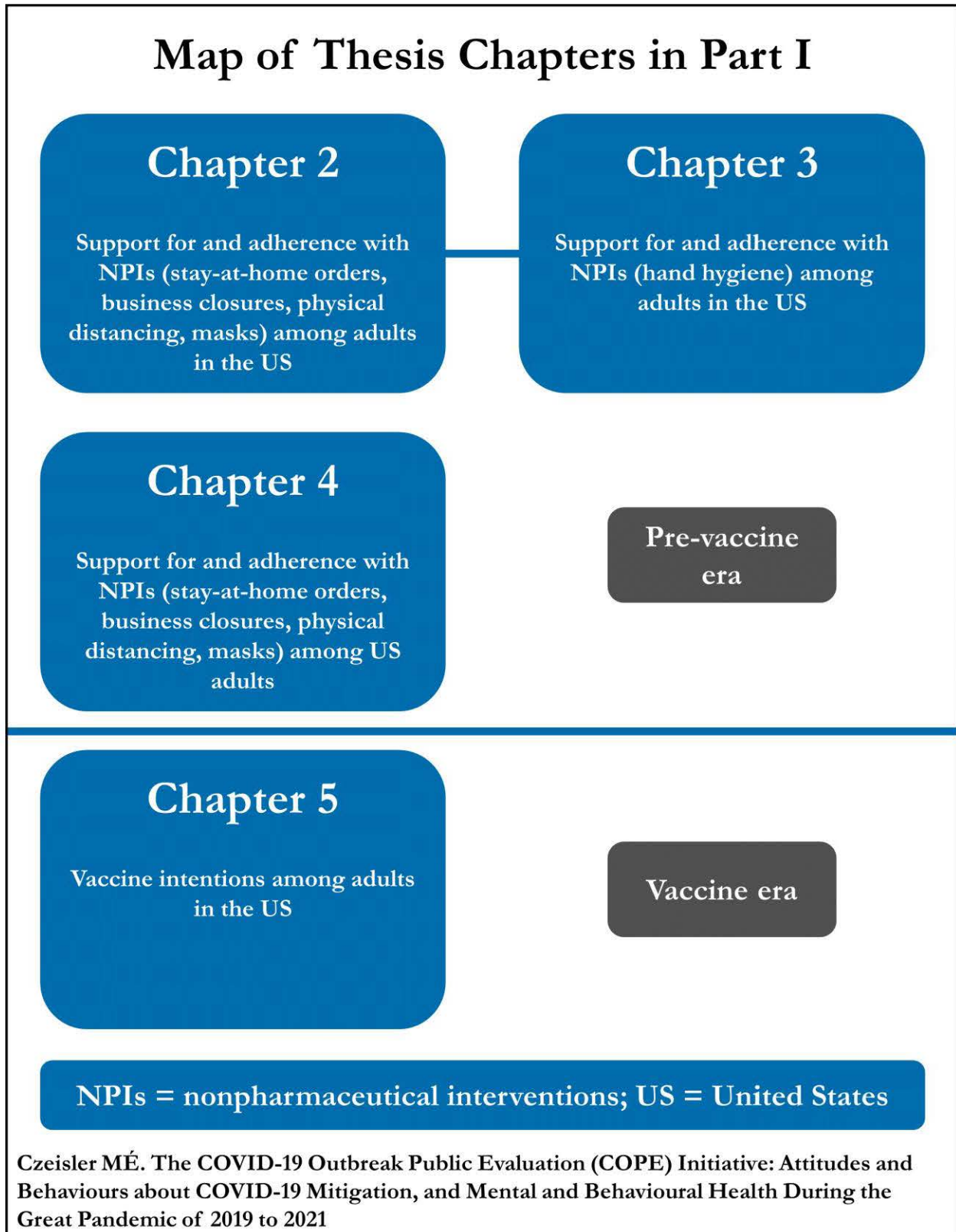
There are additional challenges, such as the reporting of race and ethnicity in the United States. Inconsistency of capitalisation across races and ethnicities, collective race and ethnicity terms as race/ethnicity (implying equivalence), and use of minority (overly vague, implying hierarchy among groups) can be insensitive, inaccurate, and impart bias on these social constructs **(Flanagin, Frey, Christiansen, & AMA Manual of Style Committee, 2021; Flanagin, Frey, Christiansen, & Bauchner, 2021)**. With respect to geographic origin and regionalisation considerations, a broad category such as Asian ethnicity can include regions with vastly different cultures, whether considering countries (e.g., Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Sri Lanka, Thailand, Vietnam) or regions (e.g., East Asia, South Asia, Southeast Asia) **(National Institute of Health, 2015)**. However, the US Census Bureau, used for survey weighting to improve demographic representativeness of The COPE Initiative samples, only used five broad categories for race (American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, or White), and only added a write-in option for 2020 **(US**

Census Bureau, 2021). Moreover, even with reasonable sample sizes on the order of 5,000 respondents per wave, accommodating nuanced individual identities in largescale public health surveillance such as The COPE Initiative is limited by the need for statistical power, which requires grouping with sufficiently populated categories.

Complicating matters further, members of some groups do not prefer language designed to be more sensitive and inclusive. For example, while inclusive communication principles would support using person-centred language (i.e., people with disabilities rather than disabled people), some members of the disability community identify as disabled people to demonstrate pride for this component of their identities or to affirm and validate their experiences (**Hall, 2020; Wong, 2019**). Ideally, individuals would be asked how they self-identify. Again, however, this was infeasible for The COPE Initiative during this public health emergency, which demanded swiftness of action.

Nevertheless, in this thesis, I have sought to employ best practices with preferred terminology and word choices, considering a health equity lens, inclusive communication principles, and guidance on the reporting of race and ethnicity in medical and science journals (**Centers for Disease Control and Prevention, 2021c, 2021d; Flanagan, Frey, Christiansen, & AMA Manual of Style Committee, 2021; Flanagan, Frey, Christiansen, & Bauchner, 2021**). There are, however, journal styles from publications included in this thesis, categorisations used by The COPE Initiative based on national datasets, as well as titles of papers that are cited, that include what could be considered oppressive language that might impart bias towards groups based on demographics or characteristics. Moreover, with language and society evolving, there might be terminology and word choices that are not currently perceived as oppressive or as imparting bias but are recognised as such in the future. By committing to continued review of commonly used words and improvement with increasingly fair, equitable, and consistent terminology, we will create a more just world.

Figure 1. Map of Thesis Chapters in Part I.



PART I: NONPHARMACEUTICAL INTERVENTIONS

CHAPTER 2: Public Attitudes, Behaviors, and Beliefs Related to COVID-19, Stay-at-Home Orders, Nonessential Business Closures, and Public Health Guidance - United States, New York City, and Los Angeles, May 5-12, 2020.

PREFACE TO CHAPTER 2

One of the first major COVID-19 prevention policies issued in the US was implemented on 2 February 2020, when the White House suspended entry into the US from China (**The White House, 2021a**). Within a couple of weeks, clusters of community transmission of SARS-CoV-2 in New York City had emerged; phylogenetic analysis revealed that most strains had been introduced from Europe and other parts of the US (**Gonzalez-Reiche et al., 2020**). In a 60 Minutes interview on 8 March, as daily infections began to rise, Dr Anthony Fauci—long-time Director of the National Institute of Allergy and Infectious Diseases—recommended that people in the US should not be wearing masks, indicating instead that such personal protective equipment should be reserved for healthcare providers and people with COVID-19 symptoms (**60 Minutes, 2020**). By 11 March, WHO Director-General Dr Tedros Adhanom Ghebreyesus declared that COVID-19 was a global pandemic (**World Health Organization, 2020d**). That same day, the White House announced additional travel restrictions from Europe (**The White House, 2021a**). Two days later, the White House declared the pandemic a national emergency (**The White House, 2020b**).

On 16 March, the White House announced that Social Distancing Guidelines would be in place for 15 days (**The White House, 2020d**). Three days later, California became the first state to issue a stay-at-home order (**California State Governor's Office, 2020; Moreland et al., 2020**), and all but six states went on to issue a stay-at-home order or advisory over the next month (**Moreland et al.,**

2020). Most stay-at-home orders included nonessential business closures, bar and restaurant closures, and restrictions on people from leaving their homes for anything other than essential activities, and to maintain a physical distance of at least six feet from other non-household members. During this interval, the CDC reversed its guidance on masks and recommended that people over two years old should wear masks that covered noses and mouths when in public areas to complement physical distancing, though US President Donald J. Trump emphasised that the guidance was voluntary and indicated that he would not be wearing a mask (Trump, 2020). On 24 April, Alaska became the first state to rescind or allow a stay-at-home order to expire (Moreland et al., 2020).

With evolving public health guidance on COVID-19 prevention behaviours designed to reduce community SARS-CoV-2 transmission within the US, understanding public attitudes, behaviours, and beliefs about these measures was critical. Importantly, in mid-May 2020, many state policymakers were faced with making decisions about whether to extend or rescind stay-at-home orders, particularly given record-breaking unemployment claims during the initial pandemic months.

The Original Investigation presented in Chapter Two (Czeisler, Tynan, et al., 2020), which was published in the *Morbidity and Mortality Weekly Report*, was prepared to provide public health officials and policymakers with information about public attitudes related to COVID-19. Findings are presented from The COPE Initiative public health surveillance conducted during 5 through 12 May 2020 from across the US (representing respondents from all 50 US states, plus Washington DC), and from subsamples in New York City, New York (a city with high COVID-19 prevalence at that time) and Los Angeles, California (a city with low COVID-19 prevalence at that time). Key outcome variables included support for stay-at-home orders and nonessential business closures, attitudes about and behavioural adherence with COVID-19 prevention measures (e.g., gathering bans, indoor

dining bans, physical distance recommendations), beliefs about the level of home-state restrictions, and whether respondents would feel safe if stay-at-home orders had been or were lifted at the time of the survey. These were chosen in collaboration with the CDC to capture public sentiment about and adherence with a spectrum of NPIs. The chapter concludes with a brief overview of findings from the Original Investigation.

CHAPTER TWO: Public Attitudes, Behaviors, and Beliefs Related to COVID-19, Stay-at-Home Orders, Nonessential Business Closures, and Public Health Guidance - United States, New York City, and Los Angeles, May 5-12, 2020

Czeisler MÉ, Tynan MA, Howard ME, Honeycutt S, Fulmer EB, Kidder DP, Robbins R, Barger LK, Facer-Childs ER, Baldwin G, Rajaratnam SMW, Czeisler CA. Public Attitudes, Behaviors, and Beliefs Related to COVID-19, Stay-at-Home Orders, Nonessential Business Closures, and Public Health Guidance - United States, New York City, and Los Angeles, May 5-12, 2020. *MMWR Morb Mortal Wkly Rep.* 2020 Jun 19;69(24):751-758. doi: 10.15585/mmwr.mm6924e1. PMID: 32555138; PMCID: PMC7302477.

Public Attitudes, Behaviors, and Beliefs Related to COVID-19, Stay-at-Home Orders, Nonessential Business Closures, and Public Health Guidance — United States, New York City, and Los Angeles, May 5–12, 2020

Mark É. Czeisler^{1,2}; Michael A. Tynan³; Mark E. Howard, MBBS, PhD^{1,2,4}; Sally Honeycutt, MPH³; Erika B. Fulmer, MHA³; Daniel P. Kidder, PhD³; Rebecca Robbins, PhD^{5,6}; Laura K. Barger, PhD^{5,6}; Elise R. Facer-Childs, PhD¹; Grant Baldwin, PhD³; Shantha M.W. Rajaratnam, PhD^{1,5,6}; Charles A. Czeisler, MD, PhD^{5,6}

SARS-CoV-2, the virus that causes coronavirus disease 2019 (COVID-19), is thought to be transmitted mainly by person-to-person contact (1). Implementation of nationwide public health orders to limit person-to-person interaction and of guidance on personal protective practices can slow transmission (2,3). Such strategies can include stay-at-home orders, business closures, prohibitions against mass gatherings, use of cloth face coverings, and maintenance of a physical distance between persons (2,3). To assess and understand public attitudes, behaviors, and beliefs related to this guidance and COVID-19, representative panel surveys were conducted among adults aged ≥18 years in New York City (NYC) and Los Angeles, and broadly across the United States during May 5–12, 2020. Most respondents in the three cohorts supported stay-at-home orders and nonessential business closures* (United States, 79.5%; New York City, 86.7%; and Los Angeles, 81.5%), reported always or often wearing cloth face coverings in public areas (United States, 74.1%, New York City, 89.6%; and Los Angeles 89.8%), and believed that their state's restrictions were the right balance or not restrictive enough (United States, 84.3%; New York City, 89.7%; and Los Angeles, 79.7%). Periodic assessments of public attitudes, behaviors, and beliefs can guide evidence-based public health decision-making and related prevention messaging about mitigation strategies needed as the COVID-19 pandemic evolves.

* Respondents were informed that, for the survey, stay-at-home orders mean that all nonessential services (e.g., dine-in restaurants, bars, social venues, gyms, fitness studios, and convention centers) are shut down. Essential services (e.g., groceries, pharmacies, gas stations, food banks, convenience stores, and delivery restaurants) remain open. Banks, local governments, and law enforcement agencies also remain open. Persons are still allowed to leave their homes but encouraged to observe social distancing guidelines. Public events and gatherings are not allowed.

During May 5–12, 2020, a total of 4,042 adults aged ≥18 years in the United States were invited to complete a web-based survey administered by Qualtrics, LLC.[†] Surveys were conducted among residents of NYC and Los Angeles to enable comparison of the two most populous cities in the United States with each other and with the nationwide cohort (4). The nationwide survey did not exclude respondents from NYC and Los Angeles, but no respondent was counted in more than one cohort. Invited participants were recruited using methods to create panels representative of the 2010 U.S. Census by age, gender, race, and ethnicity (5). Overall, 2,402 respondents completed surveys (response rate = 59.4%); of these, 2,221 (92.5%) (United States cohort = 1,676, NYC cohort = 286, and Los Angeles cohort = 259) passed quality screening procedures[§] (5); sample sizes provided a margin of error at 95% confidence levels of 2.4%, 5.7%, and 5.9%, respectively.

Questions about the effects of the COVID-19 pandemic focused on public attitudes, behaviors, and beliefs regarding stay-at-home orders, nonessential business closures, and public health guidance. Chi-squared statistics (threshold of $\alpha = 0.05$) were calculated to examine differences between the

[†] Eligibility for the nationwide U.S. cohort was determined on the basis of informed consent, age, and residence within the United States. Therefore, consented adult potential respondents residing in NYC and Los Angeles metro areas were eligible to complete surveys as part of the nationwide U.S. or NYC and Los Angeles cohorts.

[§] Qualtrics LLC data quality screening procedures included algorithmic and keystroke analysis for attention patterns, click-through behavior, duplicate responses, machine responses, and inattentiveness. Country-specific geolocation verification via IP address mapping was used to ensure respondents were from the United States. Respondents who failed an attention or speed check, along with any responses identified by the data scrubbing algorithms, were excluded from analysis.



survey cohorts and to examine potential associations between reported characteristics (gender, age, race, ethnicity, employment status, essential worker status, rural-urban residence, knowing someone with COVID-19, and knowing someone who had died from COVID-19). Jupyter Notebook (version 6.0.0; Project Jupyter) was used to conduct statistical analyses.

Among respondents in the U.S. cohort (1,676), 16.8% knew someone who had positive test results for COVID-19, compared with 42.0% of respondents in NYC and 10.8% in Los Angeles (Table 1); 5.9% of respondents in the U.S. survey

cohort knew someone who had died from COVID-19, compared with 23.1% in NYC and 7.3% in Los Angeles.

Broad support for recommended COVID-19 mitigation strategies was found nationwide (Table 2). Overall, 79.5% of respondents in the U.S. cohort supported government-issued stay-at-home orders and nonessential business closures, whereas 86.7% in NYC and 81.5% in Los Angeles supported these measures. Further, 67.3% of respondents in the United States, 76.6% in NYC, and 69.1% in Los Angeles agreed that nonessential workers should stay home. The majority of

Table 1 (2.1). Self-reported characteristics of invited participants and survey respondents

TABLE 1. Self-reported characteristics of invited participants and survey respondents — United States, New York City, and Los Angeles,* May 5–12, 2020

Characteristic	%†					
	United States		New York City		Los Angeles	
	Invited (N = 3,010)	Responded (N = 1,676)	Invited (N = 507)	Responded (N = 286)	Invited (N = 525)	Responded (N = 259)
Gender						
Female	55.9	56.1	52.9	55.2	52.4	52.9
Male	44.0	43.9	47.1	44.8	47.6	47.1
Other	0.1	0.0	0.0	0.0	0.0	0.0
Age group (yrs)						
18–24	11.4	3.9	11.2	4.2	11.0	5.8
25–34	14.8	8.5	18.5	11.5	18.1	10.4
35–44	17.6	15.0	15.6	14.0	17.5	12.4
45–54	17.6	19.0	15.0	13.6	16.4	18.5
55–64	18.0	23.4	19.3	26.9	17.1	22.0
≥65	20.6	30.2	20.3	29.7	19.8	30.9
Race						
White	78.4	84.7	72.6	82.5	74.3	80.7
Black or African American	9.2	5.0	11.2	4.5	9.1	4.6
Asian	5.7	6.2	6.1	7.3	5.7	7.3
Multiple race/Other‡	6.7	4.2	10.1	5.6	10.9	7.3
Ethnicity						
Hispanic or Latino	8.8	5.9	13.6	8.0	17.1	10.8
Not Hispanic or Latino	91.2	94.1	86.4	92.0	82.9	89.2
Rural-urban residence classification¶						
Rural	15.3	15.5	0.8	1.4	0.8	0.4
Urban	84.7	84.5	99.2	98.6	99.2	99.6
Employment status**						
Employed††	62.9	49.6	71.2	58.7	68.6	52.5
Essential	—	23.4	—	16.1	—	23.2
Nonessential	—	26.2	—	42.7	—	29.3
Retired	24.4	34.9	19.9	29.4	21.0	32.8
Unemployed	12.8	15.5	8.9	11.9	10.5	14.7
Know someone with positive test results for COVID-19	—	16.8	—	42.0	—	10.8
Know someone who died from COVID-19	—	5.9	—	23.1	—	7.3

Abbreviation: COVID-19 = coronavirus disease 2019.

* The U.S. survey group did not exclude respondents from New York City and Los Angeles.

† Totals might not all sum to 100 because of rounding.

‡ The multiple race/other category includes respondents who self-reported as a race with <2.5% of respondents in any cohort (e.g., American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or more than one race).

¶ Rural-urban classification was determined according to the Federal Office of Rural Health Policy definition of rurality. <https://www.hrsa.gov/rural-health/about-us/definition/datafiles.html>.

** Employment status as of December 2019.

†† Essential versus nonessential status was not assessed in relation to employment status among invited participants. Totals for this category do not all sum to 100 because of rounding.

Table 2 (2.2) Attitudes, behaviors, and beliefs related to COVID-19 non-pharmacologic mitigation measures

TABLE 2. Attitudes, behaviors, and beliefs related to COVID-19, stay-at-home orders, nonessential business closures, and public health guidance — United States (U.S.),* New York City (NYC), and Los Angeles (LA), May 5–12, 2020

	U.S. (N = 1,676)	NYC (N = 286)	LA (N = 259)	p-value [†] U.S. vs NYC	p-value [†] U.S. vs LA	p-value [†] NYC vs LA
Attitudes, behaviors, and beliefs						
Attitudes, no. of respondents (%)						
Support stay-at-home order and nonessential business closures						
Yes	1,332 (79.5)	248 (86.7)	211 (81.5)	<0.05 [§]	0.5097	0.1187
No	344 (20.5)	38 (13.3)	48 (18.5)			
Nonessential workers should stay home						
Agree	1,128 (67.3)	219 (76.6)	179 (69.1)	<0.05 [§]	0.6722	<0.05 [§]
Neither agree nor disagree	283 (16.9)	41 (14.3)	38 (14.7)			
Disagree	265 (15.8)	26 (9.1)	42 (16.2)			
Persons should always keep ≥6-ft of physical distance						
Agree	1,470 (87.7)	262 (91.6)	234 (90.3)	0.1242	0.4707	0.6377
Neither agree nor disagree	127 (7.6)	17 (5.9)	15 (5.8)			
Disagree	79 (4.7)	7 (2.4)	10 (3.9)			
Groups of 10 or more persons should not be allowed						
Agree	1,381 (82.4)	247 (86.4)	226 (87.3)	0.1245	0.1374	0.8130
Neither agree nor disagree	156 (9.3)	25 (8.7)	19 (7.3)			
Disagree	139 (8.3)	14 (4.9)	14 (5.4)			
Dining inside restaurants should not be allowed						
Agree	1,117 (66.6)	233 (81.5)	186 (71.8)	<0.05 [§]	0.1769	<0.05 [§]
Neither agree nor disagree	244 (14.6)	28 (9.8)	36 (13.9)			
Disagree	315 (18.8)	25 (8.7)	37 (14.3)			
Behaviors, no. of respondents (%)						
In self-isolation[¶]						
Yes	1,296 (77.3)	242 (84.6)	215 (83.0)	<0.05 [§]	<0.05 [§]	0.6954
No	380 (22.7)	44 (15.4)	44 (17.0)			
Keep ≥6 ft apart from others						
Always	975 (58.2)	191 (66.8)	172 (66.4)	0.0653	0.1576	0.8331
Often	357 (21.3)	54 (18.9)	42 (16.2)			
Sometimes	138 (8.2)	16 (5.6)	17 (6.6)			
Rarely	69 (4.1)	10 (3.5)	10 (3.9)			
Never	137 (8.2)	15 (5.2)	18 (6.9)			
Avoid groups of 10 or more persons						
Always	1,259 (75.1)	222 (77.6)	196 (75.7)	0.7621	0.9568	0.8975
Often	181 (10.8)	32 (11.2)	29 (11.2)			
Sometimes	59 (3.5)	9 (3.1)	7 (2.7)			
Rarely	39 (2.3)	5 (1.7)	5 (1.9)			
Never	138 (8.2)	18 (6.3)	22 (8.5)			
Been to a public area in the previous week						
Yes	1,533 (91.5)	260 (90.9)	235 (90.7)	0.8436	0.7851	0.9381
No	143 (8.5)	26 (9.1)	24 (9.3)			
Wear cloth face covering when in public^{**}						
Always	925 (60.3)	208 (80.0)	183 (77.9)	<0.05 [§]	<0.05 [§]	0.7659
Often	212 (13.8)	25 (9.6)	28 (11.9)			
Sometimes	134 (8.7)	14 (5.4)	16 (6.8)			
Rarely	63 (4.1)	5 (1.9)	3 (1.3)			
Never	199 (13.0)	8 (3.1)	5 (2.1)			
Beliefs, no. of respondents (%)						
Believe community mitigation strategies are						
Not restrictive enough	302 (18.0)	49 (17.4)	42 (16.3)	0.0500	0.1699	<0.05 [§]
The right balance	1,112 (66.3)	204 (72.3)	163 (63.4)			
Too restrictive	262 (15.6)	29 (10.3)	52 (20.2)			
Would feel safe if community mitigation strategies were lifted nationwide at the time of survey						
Yes	431 (25.7)	53 (18.5)	69 (26.6)	<0.05 [§]	0.8102	0.0304
No	1,245 (74.3)	233 (81.5)	190 (73.4)			
No, but would like restrictions lifted and accept risks	287 (17.1)	36 (12.6)	33 (12.7)			

Abbreviation: COVID-19 = coronavirus disease 2019.

* The U.S. survey group did not exclude respondents from New York City and Los Angeles.

† Calculated with Chi-squared test of independence.

§ P-value is statistically significant (p<0.05).

¶ For this survey, self-isolating means having no contact with others outside of the respondent's household unless required for essential services.

** Of respondents who reported having been in a public area in the preceding week.

respondents in NYC and Los Angeles and broadly across the United States agreed with public health guidelines, including recommendations for maintaining 6 feet of distance between persons (>87% in each area) and limiting gatherings to fewer than 10 persons (>82% in each area). At the time of the survey, most also agreed that dining inside restaurants should not be allowed, with agreement higher in NYC (81.5%) than in Los Angeles (71.8%) and in the United States overall (66.6%).

Widespread adherence to recommended COVID-19 mitigation strategies was reported in all three cohorts. Overall, 77.3% of adults nationwide reported self-isolating,[‡] with 84.6% reporting this behavior in NYC and 83.0% in Los Angeles. Most respondents (79.5%) in the United States also reported the behavior of always or often keeping ≥6 feet apart from others, with higher percentages reporting this behavior in NYC (85.7%) and Los Angeles (82.6%). Always or often avoiding groups of 10 or more persons was reported by >85% of adults in the three cohorts. Approximately 90% of respondents reported having been in a public area during the preceding week; among those, 74.1% nationwide reported always or often wearing cloth face coverings when in public, with higher percentages reporting this behavior in NYC (89.6%) and Los Angeles (89.8%).

Overall, 84.3% of adults in the U.S. survey cohort believed their state's COVID-19 community mitigation strategies were the right balance or not restrictive enough, compared with 89.7% in NYC and 79.7% in Los Angeles. As well, 74.3% of respondents in the United States reported they would not feel safe if these restrictions were lifted nationwide at the time the survey was conducted, compared with 81.5% in NYC and 73.4% in Los Angeles. In addition, among those who reported that they would not feel safe, some indicated that they would nonetheless want community mitigation strategies lifted and would accept associated risks (17.1%, 12.6%, and 12.7%, respectively).

Reported prevalence of self-isolation and feeling safe if community mitigation strategies were lifted differed significantly by age, employment status, and essential worker status among adults in the U.S. survey cohort (Table 3). The percentage of respondents who reported that they were in self-isolation was highest among persons aged 18–24 years (92.3%) and lowest among those aged 45–54 years (71.5%). The percentage who reported that they would feel safe if community mitigation strategies were lifted was approximately twice as high among persons aged 18–24 as it was among those aged ≥65 years (43.1% versus 19.2%). Respondents who reported that they

Summary

What is already known about this topic?

Stay-at-home orders and recommended personal protective practices were disseminated to mitigate the spread of COVID-19 in the United States.

What is added by this report?

During May 5–12, 2020, a survey among adults in New York City and Los Angeles and broadly across the United States found widespread support of stay-at-home orders and nonessential business closures and high degree of adherence to COVID-19 mitigation guidelines. Most respondents reported that they would feel unsafe if restrictions were lifted at the time of the survey.

What are the implications for public health practice?

Routine assessment of public priorities can guide public health decisions requiring collective action. Current levels of public support for restrictions and adherence to mitigation strategies can inform decisions about reopening and balancing duration and intensity of restrictions.

were essential workers** accounted for 47.2% of employed respondents in the U.S. cohort and were significantly less likely than were nonessential workers to report self-isolating (63.1% versus 80.6%). Essential workers were also significantly more likely than were nonessential workers to report that they would feel safe if COVID-19 community mitigation strategies were lifted (37.7% versus 23.7%).

Reported prevalences of always or often wearing a cloth face covering in public and maintaining ≥6 feet of physical distance also varied significantly across respondent demographics and characteristics. Respondents who were male, employed, or essential workers were significantly more likely to report having been in public areas in the past week. Among respondents who had been in public areas during the preceding week, significantly higher percentages of women, adults aged ≥65 years, retired persons, and those living in urban areas reported wearing cloth face coverings. A significantly higher percentage of adults aged ≥65 years and nonessential workers reported maintaining 6 feet of physical distance between themselves and others and abiding by the recommendation to avoid gatherings of 10 or more persons than did others. Adherence to recommendations to maintain 6 feet of physical distance and limit gatherings to fewer than 10 persons also differed significantly by employment status and race, respectively, with employed persons less likely than were retired persons to have maintained 6 feet of distance and black persons less likely than were white or Asian persons to have limited gatherings to fewer than 10 persons.

[‡] For this survey, self-isolating means having no contact with others outside of the respondent's household unless required for essential services.

** The definition of essential workers was largely determined on a state-by-state basis.

Table 3 (2.3) Attitudes, behaviors, and beliefs related to COVID-19 stay-at-home orders, nonessential business closures, and public health guidance by respondent characteristics — United States, May 5–12, 2020

TABLE 3. Attitudes, behaviors, and beliefs related to COVID-19, stay-at-home orders, nonessential business closures, and public health guidance, by respondent characteristics* — United States, May 5–12, 2020

By gender, age group, and ethnicity, %										
Attitudes, behaviors and, beliefs	Gender		Age group (yrs)						Ethnicity	
	Male	Female	18–24	25–34	35–44	45–54	55–64	≥65	Hispanic	Non-Hispanic
Attitudes										
Support stay-at-home orders and nonessential business closures										
Yes	76.3	81.9	84.6	85.2	83.7	75.2	76.0	80.4	83.8	79.2
p-value [†]	0.0521				0.1803				1.0	
Nonessential workers should stay home										
Agree	64.9	69.2	55.4	76.8	72.2	62.7	62.0	70.8	72.7	67.0
Disagree	17.8	14.2	13.8	7.7	11.5	20.7	19.6	14.4	11.1	16.1
p-value [†]	0.9043				<0.05 [§]				1.0	
Persons should always keep ≥6-ft of physical distance										
Agree	86.5	88.6	73.8	82.4	86.9	85.0	91.1	90.5	77.8	88.3
Disagree	4.8	4.7	4.6	5.6	2.8	7.2	4.8	3.8	6.1	4.6
p-value [†]	1.0				<0.05 [§]				<0.05 [§]	
Groups of 10 or more persons should not be allowed										
Agree	80.4	84.0	70.8	80.3	83.7	76.8	82.9	87.0	80.8	82.5
Disagree	9.9	7.0	10.8	8.5	6.0	11.9	9.2	6.1	5.1	8.5
p-value [†]	0.7238							<0.05 [§]		1.0
Dining inside restaurants should not be allowed										
Agree	62.2	70.1	67.7	72.5	68.3	60.8	65.6	68.6	66.7	66.6
Disagree	21.8	16.5	9.2	12.0	15.9	23.8	23.2	16.8	14.1	19.1
p-value [†]	<0.05 [§]				<0.05 [§]				1.0	
Behaviors										
In self-isolation										
Yes	75.8	78.5	92.3	81.7	77.8	71.5	72.7	81.2	87.9	76.7
p-value [†]	1.0				<0.05 [§]				0.1246	
Keep ≥6 ft apart from others										
Always	54.6	61.0	29.2	56.3	60.3	55.2	56.4	64.6	54.5	58.4
Often	22.6	20.3	30.8	23.2	18.3	21.6	23.5	19.2	18.2	21.5
Sometimes	9.0	7.7	26.2	7.0	9.1	9.1	7.7	5.7	14.1	7.9
Rarely	5.0	3.4	9.2	5.6	2.8	4.4	4.6	3.2	7.1	3.9
Never	8.8	7.7	4.6	7.7	9.5	9.7	7.9	7.3	6.1	8.3
p-value [†]	0.7508				<0.05 [§]				0.8299	
Avoid groups of 10 or more persons										
Always	72.5	77.2	52.3	68.3	74.2	73.4	73.7	82.6	63.6	75.8
Often	12.2	9.7	15.4	18.3	11.9	8.8	12.0	7.9	14.1	10.6
Sometimes	3.9	3.2	15.4	2.1	4.4	4.4	3.1	1.8	6.1	3.4
Rarely	2.4	2.2	15.4	2.8	0.4	2.2	2.0	1.8	6.1	2.1
Never	8.8	7.8	1.5	8.5	9.1	11.3	9.2	5.9	10.1	8.1
p-value [†]	1.0				<0.05 [§]				0.1843	
Been to a public area in the preceding week										
Yes	94.7	88.9	96.9	88.0	92.5	90.6	94.4	89.5	90.9	91.5
p-value [†]	<0.05 [§]				0.3145				1.0	
Wear cloth face covering when in public [¶]										
Always	54.6	65.1	44.4	59.2	57.9	56.1	55.1	71.1	57.8	60.5
Often	14.9	12.9	15.9	16.0	12.9	13.1	17.6	10.8	13.3	13.9
Sometimes	10.1	7.6	15.9	8.8	8.6	8.7	10.3	6.6	13.3	8.5
Rarely	4.6	3.7	12.7	4.0	4.7	4.5	3.5	2.9	4.4	4.1
Never	15.8	10.6	11.1	12.0	15.9	17.6	13.5	8.6	11.1	13.1
p-value [†]	<0.05 [§]				<0.05 [§]				1.0	
Beliefs										
State restrictions are										
The right balance	64.5	67.8	61.5	57.0	65.1	63.3	67.3	71.3	60.6	66.7
Not restrictive enough	18.0	18.1	21.5	31.7	19.0	16.9	16.1	15.4	26.3	17.5
p-value [†]	1.0							<0.05 [§]		0.7720
Would feel safe if restrictions were lifted nationwide at the time the survey was conducted										
Yes	28.8	23.3	43.1	26.8	27.4	30.1	26.3	19.2	25.3	25.7
p-value [†]	0.1019				<0.05 [§]				1.0	

See table footnotes on page 7.

TABLE 3. (Continued) Attitudes, behaviors, and beliefs related to COVID-19, stay-at-home orders, nonessential business closures, and public health guidance, by respondent characteristics* — United States, May 5–12, 2020

By race, employment status, and essential worker status, %									
Attitudes, behaviors, and beliefs	Race**				Employment status			Essential worker††	
	White	Black	Asian	Multiple race/Other	Unemployed	Retired	Employed	Yes	No
Attitudes									
Support stay-at-home orders and nonessential business closures									
Yes	77.9	89.2	90.4	84.3	81.9	80.0	78.4	75.6	80.9
p-value†		<0.05§				1.0		0.6953	
Nonessential workers should stay home									
Agree	66.4	63.9	78.8	72.9	68.3	69.9	65.1	58.3	71.3
Disagree	16.8	16.9	4.8	11.4	13.9	14.9	17.1	19.6	14.8
p-value†		0.4225				1.0		<0.05§	
Persons should always keep ≥6-ft of physical distance									
Agree	88.2	81.9	89.4	81.4	83.0	92.5	85.8	81.7	89.5
Disagree	4.9	6.0	1.9	4.3	8.1	2.1	5.5	7.1	4.1
p-value†		1.0				<0.05§		<0.05§	
Groups of 10 or more persons should not be allowed									
Agree	82.0	84.3	89.4	78.6	79.5	87.5	79.7	74.8	84.1
Disagree	8.9	7.2	1.9	7.1	9.7	5.8	9.6	10.7	8.7
p-value†		1.0				<0.05§		<0.05§	
Dining inside restaurants should not be allowed									
Agree	65.8	75.9	72.1	64.3	66.0	69.6	64.8	59.5	69.5
Disagree	20.5	7.2	6.7	15.7	19.3	16.9	20.0	22.4	17.8
p-value†		<0.05§				1.0		0.0899	
Behaviors									
In self-isolation									
Yes	77.2	78.3	73.1	84.3	81.1	82.7	72.4	63.1	80.6
p-value†		1.0				<0.05§		<0.05§	
Keep ≥6 ft apart from others									
Always	58.2	48.2	67.3	55.7	58.3	65.8	52.8	44.8	59.9
Often	21.6	20.5	17.3	21.4	21.6	19.0	22.8	26.0	20.0
Sometimes	8.0	14.5	4.8	11.4	5.8	5.5	10.9	13.0	9.1
Rarely	3.9	9.6	1.0	5.7	5.4	2.9	4.6	6.6	2.7
Never	8.2	7.2	9.6	5.7	8.9	6.8	8.9	9.7	8.2
p-value†		0.5507				<0.05§		<0.05§	
Avoid groups of 10 or more persons									
Always	76.2	56.6	77.9	71.4	73.0	81.2	71.5	65.6	76.8
Often	10.8	15.7	6.7	11.4	10.8	8.2	12.6	16.0	9.6
Sometimes	3.0	12.0	1.9	5.7	4.2	2.2	4.2	5.6	3.0
Rarely	2.0	8.4	1.9	2.9	2.3	2.1	2.5	4.1	1.1
Never	8.0	7.2	11.5	8.6	9.7	6.3	9.1	8.7	9.6
p-value†		<0.05§				0.1179		<0.05§	
Been to a public area in the preceding week									
Yes	91.8	91.6	87.5	91.4	88.4	89.1	94.1	97.5	91.1
p-value†		1.0				<0.05§		<0.05§	
Wear cloth face covering when in public¶									
Always	60.1	55.3	71.4	54.7	58.5	70.4	54.2	49.3	58.8
Often	13.7	19.7	9.9	14.1	10.0	11.1	16.7	20.4	13.3
Sometimes	8.4	13.2	8.8	10.9	10.5	5.6	10.3	9.7	11.0
Rarely	3.8	7.9	3.3	7.8	2.2	3.1	5.4	6.5	4.3
Never	14.0	3.9	6.6	12.5	18.8	9.8	13.4	14.1	12.8
p-value†		0.3708				<0.05§		0.1843	
Beliefs									
State restrictions are									
Not restrictive enough	66.7	65.1	67.3	60.0	67.6	68.7	64.3	64.9	63.8
The right balance	16.7	28.9	22.1	25.7	18.5	17.4	18.3	14.5	21.6
p-value†				0.0523			1.0		0.0563
Would feel safe if restrictions were lifted nationwide at the time the survey was conducted									
Yes	25.8	37.3	15.4	25.7	22.4	20.7	30.3	37.7	23.7
p-value†		0.0765				<0.05§		<0.05§	

See table footnotes on page 7.

TABLE 3. (Continued) Attitudes, behaviors, and beliefs related to COVID-19, stay-at-home orders, nonessential business closures, and public health guidance, by respondent characteristics* — United States, May 5–12, 2020

* Nationwide cohort (n = 1,676) only unless otherwise specified. The six respondent characteristic categories shown in the table (gender, age, ethnicity, race, employment status, and essential worker status) account for 32 of 34 significant associations among the 108 potential interactions evaluated. Responses and p-values values for significant associations with characteristics not presented in the table that are associated with the attitudes, behaviors, and beliefs include the following: Use of cloth face coverings when in public × Rural-urban classification, (p-value = 0.0324); Rural: Always = 51.4%, Often = 15.5%, Sometimes = 10.2%, Rarely = 7.8%, Never = 15.1%; Urban: Always = 62.0%, Often = 13.5%, Sometimes = 8.5%, Rarely = 3.4%, Never = 12.6%; attitude that dining inside restaurants should not be allowed × Know someone with COVID-19 (p-value = 0.0243), Know someone: Agree = 75.1%, Disagree = 12.5%; Do not know someone: Agree = 64.9%, Disagree = 20.1%.

† Calculated with Chi-squared test of independence.

‡ P-value is statistically significant.

¶ Of respondents who reported having been in a public area in the preceding week.

** The multiple race/other category includes respondents who self-reported as a race with <2.5% of respondents in any cohort (e.g., American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or more than one race).

†† Of 832 employed respondents in the U.S. cohort.

Discussion

There was broad support for stay-at-home orders, nonessential business closures, and adherence to public health recommendations to mitigate the spread of COVID-19 in early- to mid-May 2020. Most adults reported they would not feel safe if government-ordered community mitigation strategies such as stay-at-home orders and nonessential business closures were lifted nationwide at the time the survey was conducted, although a minority of these adults who did not feel safe wanted these restrictions lifted despite the risks.

There was a significant association between age and feeling safe without community mitigation strategies, with younger adults feeling safer than those aged ≥65 years, which might relate to perceived risk for infection and severe disease. As of May 16, adults aged ≥65 years accounted for approximately 80% of reported COVID-19–associated deaths, compared with those aged 15–24 years, who accounted for 0.1% of such deaths (6). Identifying variations in public attitudes, behaviors, and beliefs by respondent characteristics can inform tailored messaging and targeted nonpharmacological interventions that might help to reduce the spread of COVID-19.

Other variations in attitudes, behaviors, and beliefs by respondent characteristics have implications for implementation of COVID-19 mitigation strategies and related prevention messaging. For example, a lower percentage of respondents in the U.S. survey cohort reported wearing cloth face coverings and self-isolating than did those in NYC and Los Angeles. However, although use of cloth face coverings in NYC and Los Angeles were similar, NYC experienced substantially higher COVID-19-related mortality during the initial months of the pandemic than did Los Angeles (4). Nationwide, higher percentages of respondents from urban areas reported use of cloth face coverings than did rural area respondents. Because outbreaks have been reported in rural communities and among certain populations since March 2020 (7,8), these data suggest a need for additional and culturally effective messaging around the benefits of cloth face coverings targeting these areas.

Essential workers also reported lower adherence to recommendations for self-isolation, 6 feet of physical distancing, and limiting gatherings to fewer than 10 persons. These behaviors might be related to job requirements and other factors that could limit the ability to effectively adhere to these recommendations. Nevertheless, the high rate of person-to-person contact associated with these behaviors increases the risk for widespread transmission of SARS-CoV-2 and underscores the potential value of tailored and targeted public health interventions.

The findings in this report are subject to at least four limitations. First, behaviors and adherence to recommendations were self-reported; therefore, responses might be subject to recall, response, and social desirability biases. Second, responses were cross-sectional, precluding inferences about causality. Third, respondents were not necessarily representative among all groups; notably a lower percentage of African Americans responded than is representative of the U.S. population. In addition, participation might have been higher among persons who knew someone who had tested positive or had died from COVID-19, which could have affected support for and adherence to mitigation efforts. Finally, given that the web-based survey does not recruit participants using population-based probability sampling and respondents might not be fully representative of the U.S. population, findings might have limited generalizability. However, this survey did apply screening procedures to address issues related to web-based panel quality.

Widespread support for community mitigation strategies and commitment to COVID-19 public health recommendations indicate that protecting health and controlling disease are public priorities amid this pandemic, despite daily-life disruption and adverse economic impacts (5,9). These findings of high public support might inform reopening policies and the timelines and restriction levels of these mitigation strategies as understanding of public support for and adherence to these policies evolves. Absent a vaccine, controlling COVID-19 depends on community mitigation strategies that require public support to be effective. As the pandemic progresses and mitigation strategies evolve, understanding

public attitudes, behaviors, and beliefs is critical. Adherence to recommendations to wear cloth face coverings and physical distancing guidelines are of public health importance. Strong public support for these behaviors suggests an opportunity to normalize safe practices and promote continued use of these and other recommended personal protective behaviors to minimize further spread of COVID-19 as jurisdictions reopen. These findings and periodic assessments of public attitudes, behaviors, and beliefs can also inform future planning if subsequent outbreak waves occur, and if additional periods of expanded mitigation efforts are necessary to prevent the spread of COVID-19 and save lives.

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Corresponding author: Michael A. Tynan, mtynan@cdc.gov, 404-498-1202.

¹Monash University, Melbourne, Australia; ²Austin Health, Melbourne, Australia; ³CDC COVID-19 Response Team; ⁴University of Melbourne, Melbourne, Australia; ⁵Brigham and Women's Hospital, Boston, Massachusetts; ⁶Harvard Medical School, Boston, Massachusetts.

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U.S. adults reported widespread support of public health measures to slow the spread of COVID-19*



Agree people should
always keep at least
6-feet apart



Agree groups of 10 or
more people should not
be allowed



Support stay-at-home
orders and nonessential
business closures

SUMMARY OF FINDINGS

The Original Investigation presented in Chapter Two revealed broad support for and adherence with COVID-19 prevention behaviours in early- to mid-May, including stay-at-home orders, nonessential business closures, mask usage in public areas, avoidance of social gatherings, and maintenance of a physical distance from other persons. As noted in the Limitations section of the Original Investigation, Internet-based surveys might be subject to biases that could limit the generalisability of findings (**Hays et al., 2015**). However, widespread support was found at that time across the US, and in both New York City and Los Angeles, suggesting that these findings were not solely reflective of high COVID-19 prevalence. Moreover, the prevalence estimate for frequent mask usage (74.1%) was within three percentage points and the 95% confidence interval of an estimate from a concurrent CDC study (76.4% [95% confidence interval = 72.0 to 80.8]), which also found that the prevalence of mask usage had increased by approximately 15% compared with early April 2020 (**Fisher, Barile, et al., 2020**).

Interestingly, the percentage of adults who reported they would feel safe if COVID-19 prevention behaviours were lifted was approximately twice as high among persons aged 18 to 24 years (43.1%) as it was among those aged 65 years or older, which may have reflected the manifold increased risk of COVID-19 morbidity and mortality among older adults (**Gold et al., 2020; Stokes et al., 2020; Wortham et al., 2020**). Age-related differences in risk perception and subsequent adherence with COVID-19 prevention behaviours may have contributed to shifting age distributions of SARS-CoV-2 infections over the course of the pandemic in the US (**Boehmer et al., 2020; Monod et al., 2021; Salvatore et al., 2020**).

Though not reported in this Chapter, political partisanship has been inextricably linked with adherence with NPIs. Political sensitivity by the CDC's *MMWR* dissuaded publication of analyses of

associations between political partisanship and early levels of support with NPIs, which applies to both Chapter Two and Chapter Three, though robust relationships between partisanship and engagement with COVID-19 prevention behaviours have been documented throughout the pandemic. Indeed, governor partisanship was a stronger predictor of state-wide indoor mask mandates than SARS-CoV-2 infections and COVID-19 case counts (**Adolph et al., 2021**). At an individual level, states with higher percentages of Republican/leaning Republican individuals displayed smaller reductions in mobility (**Hsiehchen et al., 2020**) and US counties that voted for Donald Trump (Republican) over Hillary Clinton (Democrat) in the 2016 presidential election exhibited 14% less physical distancing between March and May 2020 (**Gollwitzer et al., 2020**). Partisanship was more predictive of adherence with physical distancing than counties' COVID-19 cases, population density, median income, and racial and age demographics; these counties in turn had higher SARS-CoV-2 infection and COVID-19 fatality growth rates during this interval (**Gollwitzer et al., 2020**). This relationship has extended to COVID-19 vaccine intentions and obtainment, which are further described in **Chapter Five**.

Findings from this paper were used by the CDC to create a visual abstract highlighting the support for and adherence with NPIs across the US, and were cited in a CDC media telebriefing to encouraged continued community engagement with these measures (**Centers for Disease Control and Prevention, 2020e**). Absent from this Original Investigation was an analysis of behavioural adherence with hand hygiene, which is an essential piece of the multicomponent bundle of NPIs recommended to protect against COVID-19. Chapter Three presents findings from an Original Investigation of hand hygiene among US adults during June 2020.

CHAPTER 3: Demographic Characteristics, Experiences, and Beliefs Associated with Hand Hygiene Among Adults During the COVID-19 Pandemic - United States, June 24-30, 2020

PREFACE TO CHAPTER 3

The Original Investigation in Chapter Three (**Czeisler, Garcia-Williams, et al., 2020**), which was published in the *Morbidity and Mortality Weekly Report*, was written to address a knowledge gap regarding behavioural adherence with hand hygiene (i.e., handwashing with soap and water or using hand sanitizer containing $\geq 60\%$ alcohol) following contact with high-touch public surfaces (e.g., shopping carts, gas pumps, and automatic teller machines [also known as ATMs]) during the COVID-19 pandemic. These outcome variables were chosen in collaboration with the CDC's Domestic Water, Sanitation, and Hygiene (WASH) Epidemiology Team. Both handwashing and hand sanitising were assessed, given that handwashing is the primary recommendation for hand hygiene by the CDC, though alcohol-based hand sanitisers are advised when soap and water are not readily available (which is often the case in public settings) (**Centers for Disease Control and Prevention, 2020h**).

Hand hygiene represents a unique COVID-19 prevention behaviour, because in contrast to avoiding gatherings, physical distancing, and wearing masks, hand hygiene had been common practice prior to the COVID-19 pandemic—and therefore perhaps more stable than other behaviours. On the other hand, various evidence-based and non-evidence-based cleaning and disinfecting practices were initiated in efforts to prevent COVID-19 exposure (**Gharpure, Hunter, et al., 2020; Gharpure, Miller, et al., 2020**). While assessment of changes to hand hygiene practices was not possible in this cross-sectional analysis, the overarching purpose of this paper was to identify demographic characteristics, SARS-CoV-2 experiences, and beliefs associated with hand

hygiene among US adults to inform CDC health promotion messaging campaigns. Findings are presented from The COPE Initiative public health surveillance conducted during 24 through 30 June 2020 from across the US. This chapter concludes with a brief overview of findings from the Original Investigation.

CHAPTER THREE: Demographic Characteristics, Experiences, and Beliefs Associated with Hand Hygiene Among Adults During the COVID-19 Pandemic - United States, June 24-30, 2020

Czeisler MÉ, Garcia-Williams AG, Molinari NA, Gharpure R, Li Y, Barrett CE, Robbins R, Facer-Childs ER, Barger LK, Czeisler CA, Rajaratnam SMW, Howard ME. Demographic Characteristics, Experiences, and Beliefs Associated with Hand Hygiene Among Adults During the COVID-19 Pandemic - United States, June 24-30, 2020. *MMWR Morb Mortal Wkly Rep.* 2020 Oct 16;69(41):1485-1491. doi: 10.15585/mmwr.mm6941a3. PMID: 33056951; PMCID: PMC7561087.

Demographic Characteristics, Experiences, and Beliefs Associated with Hand Hygiene Among Adults During the COVID-19 Pandemic — United States, June 24–30, 2020

Mark É. Czeisler^{1,2,3}; Amanda G. Garcia-Williams, PhD⁴; Noelle-Angelique Molinari, PhD⁴; Radhika Gharpure, DVM⁴; Yiman Li, MPH⁵; Catherine E. Barrett, PhD⁴; Rebecca Robbins, PhD^{3,6}; Elise R. Facer-Childs, PhD¹; Laura K. Barger, PhD^{3,6}; Charles A. Czeisler, PhD, MD^{1,3,6}; Shantha M.W. Rajaratnam, PhD^{1,2,3,6}; Mark E. Howard, MBBS, PhD^{1,2,7}

Frequent hand hygiene, including handwashing with soap and water or using a hand sanitizer containing $\geq 60\%$ alcohol when soap and water are not readily available, is one of several critical prevention measures recommended to reduce the spread of SARS-CoV-2, the virus that causes coronavirus disease 2019 (COVID-19).^{*} Previous studies identified demographic factors associated with handwashing among U.S. adults during the COVID-19 pandemic (1,2); however, demographic factors associated with hand sanitizing and experiences and beliefs associated with hand hygiene have not been well characterized. To evaluate these factors, an Internet-based survey was conducted among U.S. adults aged ≥ 18 years during June 24–30, 2020. Overall, 85.2% of respondents reported always or often engaging in hand hygiene following contact with high-touch public surfaces such as shopping carts, gas pumps, and automatic teller machines (ATMs).[†] Respondents who were male (versus female) and of younger age reported lower handwashing and hand sanitizing rates, as did respondents who reported lower concern about their own infection with SARS-CoV-2[§] and respondents without personal experience with COVID-19. Focused health promotion efforts to increase hand hygiene adherence should include increasing visibility and accessibility of handwashing and hand sanitizing materials in public settings, along with targeted communication to males and younger adults with focused messages that address COVID-19 risk perception.

During June 24–30, among 9,896 eligible U.S. adults,[¶] 5,412 (54.7%) completed Internet-based surveys administered by Qualtrics, LLC, as part of The COVID-19 Outbreak Public Evaluation (COPE) Initiative.^{**} The Monash University Human Research Ethics Committee of Monash University (Melbourne, Australia) reviewed and approved the study protocol on human subjects research. This activity was also reviewed by CDC and was conducted consistent with applicable federal law and CDC policy.^{††} Respondents were informed of study purposes and provided electronic consent before commencement, and investigators received anonymized responses. The 5,412 participants who completed surveys

[¶] Eligibility to complete a survey during June 24–30, 2020, was determined following electronic contact of potential participants with criteria of age ≥ 18 years and residence within the United States. Age and residence were assessed using screening questions without indication of eligibility criteria before commencement of the earliest survey (recontacted respondents: April 2–8, 2020; first-time respondents: June 24–30, 2020). Residence was reassessed among recontacted respondents during June 24–30, and one respondent whose primary residence had changed to outside of the United States was excluded from the analysis. Country-specific geolocation verification via IP address mapping was used to ensure respondents were from the United States. Informed consent was obtained electronically during June 24–30, 2020, before enrollment into the study as a participant. All surveys underwent Qualtrics, LLC data quality screening procedures including algorithmic and keystroke analysis for attention patterns, click-through behavior, duplicate responses, machine responses, and inattentiveness. Respondents who failed an attention or speed check, along with any responses identified that failed data quality screening procedures, were excluded from the analysis (6.6%).

^{**} The COVID-19 Outbreak Public Evaluation (COPE) Initiative (<http://www.thecopeinitiative.org/>) is designed to assess public attitudes, behaviors, and beliefs related to COVID-19 pandemic and to evaluate the mental and physical health consequences of the pandemic. The COPE Initiative surveys included in this analysis were administered by Qualtrics, LLC (<https://www.qualtrics.com/>), a commercial survey company with a network of participant pools comprising hundreds of suppliers and with varying recruitment methodologies that include digital advertisements and promotions, word-of-mouth and membership referrals, social networks, television and radio advertisements, and offline mail-based approaches. This analysis focused on questions about hand hygiene behavior during the COVID-19 pandemic.

^{††} 45 C.F.R. part 46, 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d); 5 U.S.C. Sect. 552a; 44 U.S.C. Sect. 3501 et seq.

^{*} <https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/prevention.html>.

[†] Respondents were provided with the following examples as high-touch public surfaces: shopping carts, gas pumps, and ATMs.

[§] For this question, respondents were asked to rate on a scale from “Not at all” to “Extremely” the extent to which they were concerned about the following statement regarding COVID-19 and infection control measures: “My own risk of infection with COVID-19.”

during June included 3,683 (68.1%) first-time respondents and 1,729 (31.9%) respondents who were recontacted after having been recruited to participate in The COPE Initiative during April 2–8, 2020.^{§§} Complete data for explanatory variables included in the analysis were obtained from 5,000 (92.4%) respondents. Among these respondents, 4,817 (96.3%) reported having been in public during the previous week and were included in this analysis (3,243 [67.3%] first-time respondents and 1,574 [32.7%] recontacted respondents). Quota sampling and survey weighting were employed to improve sample representativeness of the adult U.S. population by gender, age, and race/ethnicity. Hand hygiene frequency was assessed on a five-item Likert scale from “Never” to “Always” using the following questions: “In the last week, how frequently did you use hand sanitizer after touching high-touch surfaces in public?” and “In the last week, how frequently did you wash your hands with soap and water after touching high-touch surfaces in public?” Bivariate chi-squared analyses identified covariates associated with frequency of hand hygiene.

With handwashing and hand sanitizing frequency as dependent variables for separate models, adjusted odds ratios (aORs) and 95% confidence intervals (CIs) for hand hygiene frequency were estimated using weighted ordered logistic regressions with the following explanatory variables: gender, age, race/ethnicity, 2019 household income, U.S. Census region,^{¶¶} rural/urban residence,^{***} whether respondents knew someone who had positive test results for SARS-CoV-2 or who was hospitalized for or died from COVID-19, and concern for personal risk for infection with SARS-CoV-2 (from “Not at all” to “Extremely”). Statistical analyses were conducted in R (version 4.0.2; The R Foundation) with the R survey package (version 3.29).

Among 4,817 U.S. adults, 85.2% reported frequent (always or often) use of at least one form of hand hygiene after contact with high-touch public surfaces, including handwashing (78.5%) and hand sanitizing (70.7%) (Table). Frequent handwashing and hand sanitizing were least prevalent among adults aged 18–24 years (64.6% and 59.8%, respectively, with 72.4% reporting at least one form of hand hygiene); frequency increased with age and was highest among persons aged ≥65 years (83.3% and 73.3%, respectively, with 89.4% reporting at least one form of hand hygiene). Frequent hand sanitizing was more prevalent among respondents with a 2019 household income ≥\$100,000 (72.6%) compared with those with a household income <\$25,000 (62.5%). Regarding concern for personal risk for SARS-CoV-2 infection, frequent handwashing and hand sanitizing were least prevalent among

those not at all concerned (68.0% and 54.0%, respectively, with 72.1% reporting at least one form of hand hygiene); prevalence increased with level of concern and was most prevalent among those extremely concerned (89.5% and 83.1%, respectively, with 93.7% reporting at least one form of hand hygiene).

The aORs and 95% CIs reflect significant differences in odds of more frequent handwashing associated with gender, age, race/ethnicity, whether the respondent knew someone who had received a positive SARS-CoV-2 test result, and concern for personal risk for SARS-CoV-2 infection (Figure 1). Odds of more frequent handwashing were lower for males than for females (aOR = 0.65; 95% CI = 0.57–0.74) and higher among older than among younger respondents (e.g., aOR = 2.36; 95% CI = 1.85–3.01 for persons aged 45–64 years compared with those aged 18–24 years). Odds of more frequent handwashing were 66% higher among non-Hispanic Asian respondents than among non-Hispanic White (White) respondents (aOR = 1.66; 95% CI = 1.34–2.06) and were 30% higher among those who knew someone who received a positive SARS-CoV-2 test result than among those who did not (aOR = 1.30; 95% CI = 1.10–1.53). Compared with those who were not at all concerned about SARS-CoV-2 infection, those who were moderately, very, and extremely concerned had 35% (aOR = 1.35; 95% CI = 1.07–1.72), 77% (aOR = 1.77; 95% CI = 1.36–2.31), and 209% higher odds (aOR = 3.09; 95% CI = 2.38–4.01), respectively, of more frequent handwashing.

Adjusted odds of more frequent hand sanitizing were similar to those observed for more frequent handwashing (Figure 2), with the following exceptions: those with higher 2019 household income (\$25,000–\$49,999) had 30% higher odds of more frequent hand sanitizing (aOR = 1.30, 95% CI = 1.04–1.64) than did those with household income <\$25,000, and those who knew someone hospitalized for or who died from COVID-19 had 28% higher odds of more frequent hand sanitizing (aOR = 1.28; 95% CI = 1.04–1.59) than did those who did not know someone who had been hospitalized or died from COVID-19.

Discussion

Approximately 85% of 4,817 U.S. adults frequently engaged in either handwashing or using hand sanitizer after contact with high-touch public surfaces, including only 72.4% of those aged 18–24 years. These findings highlight the need for continued health communication and outreach promoting hand hygiene. Respondents who were male and of younger age reported less frequent handwashing and hand sanitizing. These findings are consistent with those from previous pandemics (3) and earlier in the COVID-19 pandemic (1), when males and younger adults engaged in less frequent handwashing than did females

^{§§} <https://www.medrxiv.org/content/10.1101/2020.04.22.20076141v1>.

^{¶¶} https://www2.census.gov/geo/pdfs/maps-data/maps/reference/us_regdiv.pdf.

^{***} <https://www.hrsa.gov/rural-health/about-us/definition/datafiles.html>.

Table 4 (3.1). Prevalence of frequent hand hygiene after contact with high-touch public surfaces among adults, by select respondent characteristics — United States, June 24–30, 2020

TABLE. Prevalence of frequent hand hygiene* after contact with high-touch public surfaces among adults, by select respondent characteristics — United States, June 24–30, 2020

United States, June 24–30, 2020

	All respondents	Often or always wash hands		Often or always use hand sanitizer	
Characteristic	Weighted no. (%) [†]	Weighted no. (%) [†]	P-value [§]	Weighted no. (%) [†]	P-value [§]
Overall	4,817 (100)	3,781 (78.5)	—	3,407 (70.7)	—
Demographic characteristic					
Sex					
Female	2,448 (50.8)	1,971 (80.5)	<0.001	1,800 (73.5)	<0.001
Male	2,369 (49.2)	1,810 (76.4)		1,608 (67.9)	
Age group, yrs					
18–24	629 (13.1)	406 (64.6)	<0.001	376 (59.8)	<0.001
25–44	1,685 (35.0)	1,295 (76.8)		1,210 (71.8)	
45–64	1,672 (34.7)	1,388 (83.0)		1,212 (72.5)	
≥65	830 (17.2)	692 (83.3)		609 (73.3)	
Race/Ethnicity					
White, non-Hispanic	3,068 (63.7)	2,461 (80.2)	<0.001	2,208 (72.0)	<0.001
Black, non-Hispanic	587 (12.2)	427 (72.7)		385 (65.6)	
Asian, non-Hispanic	230 (4.8)	198 (86.2)		182 (79.0)	
Other or multiple race or races, non-Hispanic [¶]	145 (3.0)	104 (71.9)		95 (65.9)	
Hispanic, any race or races	787 (16.3)	590 (75.0)		537 (68.2)	
2019 household income, USD					
<\$25,000	639 (13.3)	471 (73.6)	<0.001	400 (62.5)	<0.001
\$25,000–\$49,999	992 (20.6)	765 (77.1)		707 (71.3)	
\$50,000–\$99,999	1,670 (34.7)	1,343 (80.4)		1,200 (71.9)	
≥\$100,000	1,515 (31.5)	1,202 (79.4)		1,100 (72.6)	
U.S. Census region**					
Northeast	1,073 (22.3)	862 (80.3)	0.941	747 (69.6)	0.044
Midwest	913 (19.0)	710 (77.7)		646 (70.7)	
South	1,674 (34.7)	1,300 (77.7)		1,217 (72.7)	
West	1,157 (24.0)	909 (78.6)		797 (68.9)	
Rural/Urban residence ^{††}					
Rural	544 (11.3)	423 (77.8)	0.003	396 (72.7)	0.211
Urban	4,273 (88.7)	3,358 (78.6)		3,012 (70.5)	
COVID-19 experiences and beliefs					
Knew someone who had test results positive for SARS-CoV-2					
Yes	970 (20.1)	837 (86.4)	<0.001	771 (79.5)	<0.001
No	3,847 (79.9)	2,944 (76.5)		2,636 (68.5)	
Knew someone who was hospitalized for severe illness or died from COVID-19					
Yes	624 (12.9)	518 (83.0)	0.002	495 (79.4)	<0.001
No	4,193 (87.1)	3,263 (77.8)		2,912 (69.4)	
Level of concern of own risk of SARS-CoV-2 infection ^{§§}					
Not at all	576 (12.0)	392 (68.0)	<0.001	311 (54.0)	<0.001
Slightly	1,093 (22.7)	810 (74.1)		727 (66.5)	
Moderately	1,411 (29.3)	1,086 (77.0)		966 (68.5)	
Very	783 (16.2)	639 (81.6)		610 (77.9)	
Extremely	954 (19.8)	854 (89.5)		793 (83.1)	

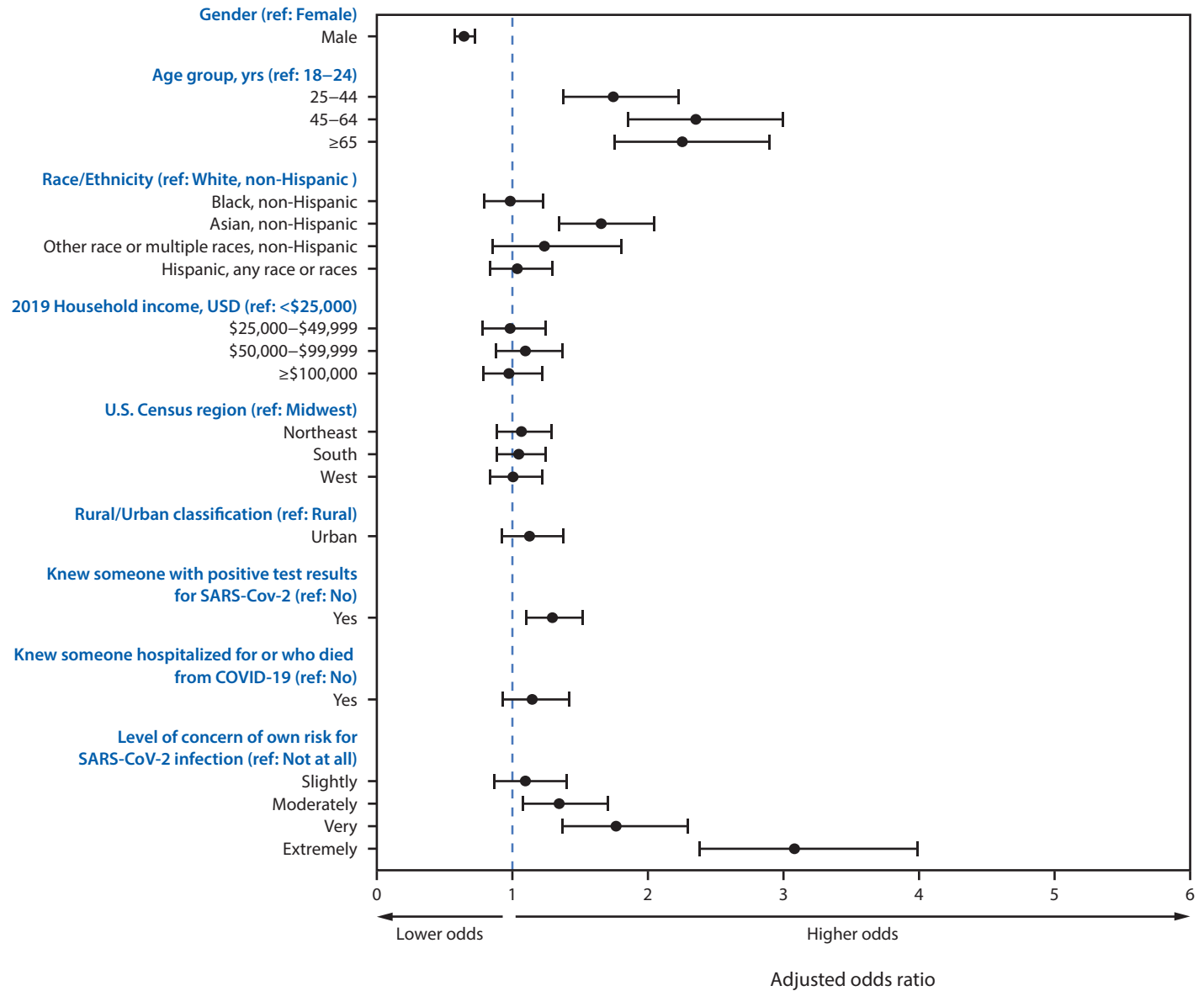
Abbreviations: COVID-19 = coronavirus disease 2019; USD = U.S. dollars.

* Frequency of hand hygiene was assessed on a 5-point Likert scale from “Never” to “Always” using the following questions: “In the last week, how frequently did you use hand sanitizer after touching high-touch surfaces in public?” and “In the last week, how frequently did you wash hands with soap and water after touching high-touch surfaces in public.” For this table, answers of “Often” or “Always” were considered frequent.

[†] Quota sampling and survey weighting were employed to improve representativeness of the cross-sectional June cohort of the United States population by gender, age, and race/ethnicity according to the 2010 U.S. Census.[§] Bivariate chi-squared test was used to test for differences in observed and expected frequencies among groups by characteristic for each type of hand hygiene on the full 5-item Likert scale from “Never” to “Always.” Statistical significance for bivariate analyses was evaluated as $p < 0.05$.[¶] The non-Hispanic, other race or multiple races category includes respondents who identified as not Hispanic and as more than one race or as American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or Other.^{**} Region classification was determined using the U.S. Census Bureau’s Census Regions and Divisions of the United States. https://www2.census.gov/geo/pdfs/maps-data/maps/reference/us_regdiv.pdf.^{††} Rural/urban residence was classified as urban or rural based on self-reported ZIP codes according to the Federal Office of Rural Health Policy definition of rurality. <https://www.hrsa.gov/rural-health/about-us/definition/datafiles.html>.^{§§} For this question, respondents were asked to rate on a scale from “Not at all” to “Extremely” the extent to which they were concerned about the following statement regarding COVID-19 and infection control measures: “My own risk of infection with COVID-19.”

Figure 2 (3.1). Adjusted odds ratios for washing hands after contact with high-touch public surfaces, by select respondent characteristics — United States, June 24–30, 2020

FIGURE 1. Adjusted odds ratios^{*,†} for washing hands after contact with high-touch public surfaces,[§] by select respondent characteristics^{¶,**,††,§§} — United States, June 24–30, 2020



Abbreviations: COVID-19 = coronavirus disease 2019; ref = referent; USD = U.S. dollars.

* Adjusted odds ratios were estimated using an ordered logit model of handwashing on the variables listed in the column with a proportional odds assumption.

† 95% confidence intervals indicated with error bars.

§ Frequency of handwashing was assessed on a 5-point Likert scale from “Never” to “Always” using the following question: “In the last week, how frequently did you wash your hands with soap and water after touching high-touch surfaces in public?”

¶ The non-Hispanic, other race, or multiple races category includes respondents who identified as not Hispanic and as more than one race or as American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or Other.

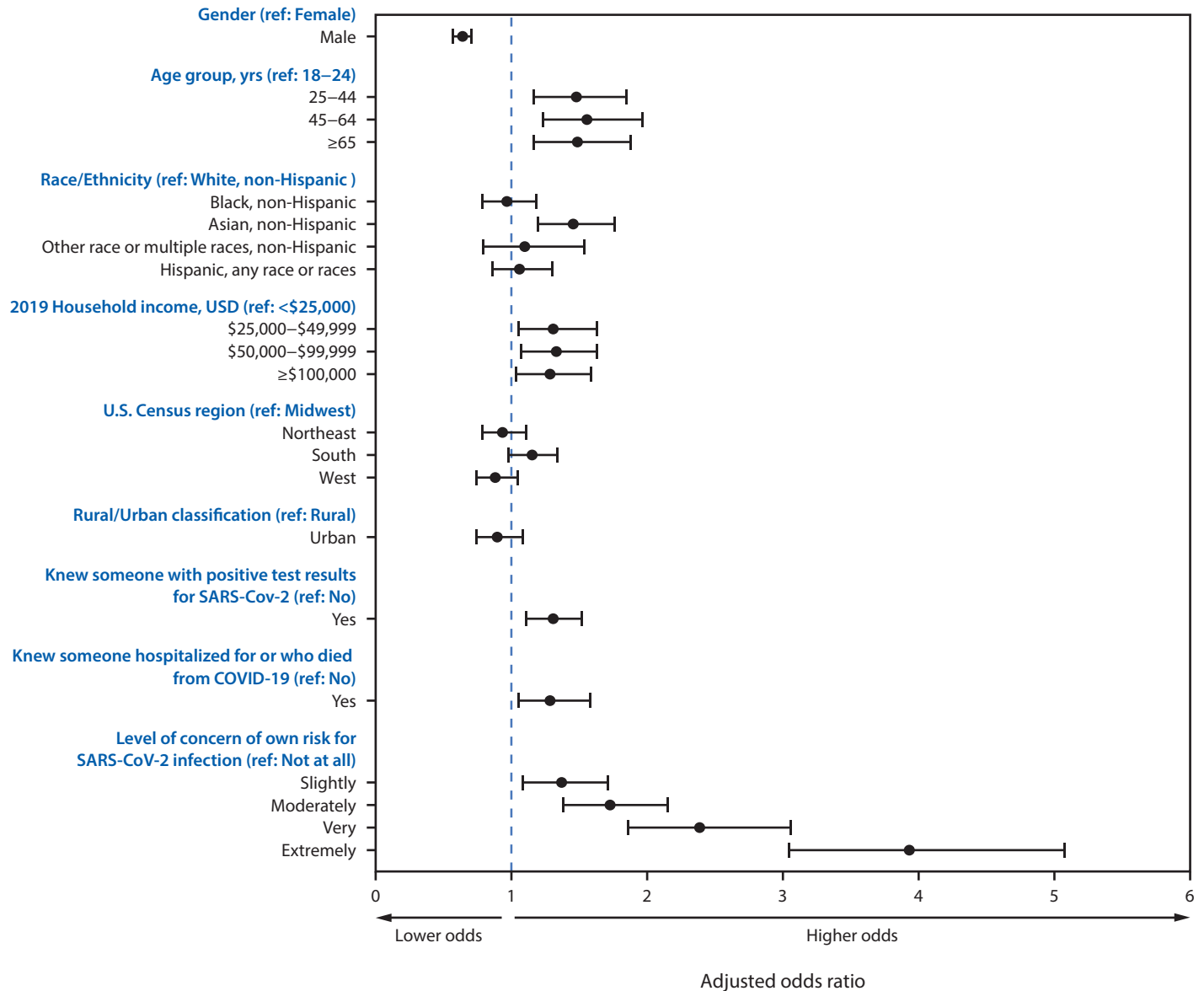
** Region classification was determined using the U.S. Census Bureau’s Census Regions and Divisions of the United States. https://www2.census.gov/geo/pdfs/maps-data/maps/reference/us_regdiv.pdf.

†† Rural/urban residence was classified as urban or rural based on self-reported ZIP codes according to the Federal Office of Rural Health Policy definition of rurality. <https://www.hrsa.gov/rural-health/about-us/definition/datafiles.html>.

§§ For this question, respondents were asked to rate on a scale from “Not at all” to “Extremely” the extent to which they were concerned about the following statement regarding COVID-19 and infection control measures: “My own risk of infection with COVID-19.”

FIGURE 3 (3.2) Adjusted odds ratios for use of hand sanitizer after contact with high-touch public surfaces, by select respondent characteristics — United States, June 24–30, 2020

FIGURE 2. Adjusted odds ratios^{*,†} for use of hand sanitizer after contact with high-touch public surfaces,[§] by select respondent characteristics^{¶,**,††,§§} — United States, June 24–30, 2020



Abbreviations: COVID-19 = coronavirus disease 2019; ref = referent; USD = U.S. dollars.

* Adjusted odds ratios were estimated using an ordered logit model of using hand sanitizer on the variables listed in the column with a proportional odds assumption.

† 95% confidence intervals indicated with error bars.

§ Frequency of hand sanitizing was assessed on a 5-point Likert scale from “Never” to “Always” using the following question: “In the last week, how frequently did you use hand sanitizer after touching high-touch surfaces in public after touching high-touch surfaces in public?”

¶ The non-Hispanic, other race, or multiple races category includes respondents who identified as not Hispanic and as more than one race or as American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or Other.

** Region classification was determined using the U.S. Census Bureau’s Census Regions and Divisions of the United States. https://www2.census.gov/geo/pdfs/maps-data/maps/reference/us_regdiv.pdf.

†† Rural/urban residence was classified as urban or rural based on self-reported ZIP codes according to the Federal Office of Rural Health Policy definition of rurality. <https://www.hrsa.gov/rural-health/about-us/definition/datafiles.html>.

§§ For this question, respondents were asked to rate on a scale from “Not at all” to “Extremely” the extent to which they were concerned about the following statement regarding COVID-19 and infection control measures: “My own risk of infection with COVID-19.”

and older adults (2,3). During the COVID-19 pandemic, one study found that Hispanic adults reported more frequent handwashing than did White adults (1); however, the current study did not find a difference in handwashing between Hispanic and White adults after adjusting for concern for SARS-CoV-2 infection.

Respondents with lower income reported less frequent hand sanitizing. This could reflect lack of access to hand sanitizer; higher income and access to handwashing infrastructure have been previously found to be associated with adherence to hand hygiene (4). Difficulty obtaining hand sanitizer has been documented during the COVID-19 pandemic (5), and purchasing hand sanitizer might be prohibitive for persons with low income, particularly given recent reported increases in cost.^{†††} Strategies to increase hand sanitizing among lower-income populations could apply innovative approaches with regard to the location of signage and contactless dispensers (e.g., the center of a lobby or market or next to or built into gas filling stations) to make hand sanitizer and handwashing materials visible and readily available in public settings and address disparities in access.

Increased concern for personal risk for SARS-CoV-2 infection and personal experience with COVID-19 were both positively associated with handwashing and hand sanitizing. During previous respiratory pandemics, general concern, perceived susceptibility, and perceived severity of illness were found to be positively associated with engagement in hygiene-related prevention behaviors (3). During this pandemic, higher perceived risk has been associated with increased handwashing (6). In addition to hand hygiene, risk perceptions have been associated with engaging in other protective behaviors such as physical distancing,^{§§§} avoiding handshakes and crowds (7), and wearing cloth face masks (8). Perceived risk for COVID-19 in the United States, when assessed during March–April 2020, was moderately high (6); however, some evidence indicates U.S. adults underestimate their risk of becoming ill with COVID-19 (7). Differences in risk perceptions might partially explain why men and younger adults reported less frequent practicing of hand hygiene compared with women and older adults. Although differences in risk perceptions by gender and age were not assessed in this study, research conducted during the COVID-19 pandemic has found that younger persons (7,9) and men (6) had lower COVID-19 risk perceptions compared with older adults and women. For both populations, efforts are needed to further characterize COVID-19 risk perceptions and their relationships to hand hygiene, and

to identify how health communication efforts can address risk perceptions in promotion of preventive behaviors. This is particularly important given that only 72.1% of those who were not at all concerned about their risk for SARS-CoV-2 infection frequently engaged in either handwashing or using hand sanitizer after contact with high-touch public surfaces, compared with 93.7% of those who were extremely concerned.

The findings in this report are subject to at least five limitations. First, self-reported data are subject to recall, response, and social desirability biases, and self-reported hand hygiene behavior might be overreported. Survey weighting might not have eliminated nonresponse bias. Second, estimation assumed proportional odds (i.e., that odds are constant across response levels), an assumption that is often violated (10); weighted ordered logistic regressions were used for ease of interpretation given that the estimates did not differ substantially from models that did not assume proportional odds. Third, although quota sampling methods and survey weighting were employed to improve sample representativeness of 2010 U.S. Census adult population estimates for age, gender, and race/ethnicity, the Internet-based survey sample might not be fully representative of the 2020 U.S. population for income, educational attainment, and access to technology. Fourth, hand hygiene was self-reported by respondents after contact with high-touch public surfaces; future studies could evaluate hand hygiene within households, workplaces, and other environments. Similarly, although respondents included in this analysis had been in public during the preceding week, adherence to hand hygiene did not account for the number of times respondents contacted high-touch public surfaces, or the number of hand hygiene methods used following contact with such surfaces. Finally, respondents were not asked whether they had access to soap and water or hand sanitizer, which could influence hand hygiene behaviors.

Hand hygiene is part of a multicomponent public health approach, which also includes wearing face masks and maintaining a physical distance of ≥ 6 feet from others, among additional prevention measures, to prevent and control COVID-19 in community settings. Public health promotional outreach about hand hygiene is needed, given that these findings indicate that hand hygiene adherence could be improved, especially among certain groups. Hand-hygiene–related health promotion strategies should be tailored toward men and young adults. To motivate hand hygiene behavior, health promotion messaging could focus on addressing risk perceptions of COVID-19, which might have shared benefits to promote engagement in additional COVID-19 prevention measures. Finally, increasing visibility and accessibility of handwashing and hand sanitizing signage and materials in public settings could encourage and facilitate hand hygiene to prevent the spread of COVID-19.

^{†††} <https://www.npr.org/sections/coronavirus-live-updates/2020/03/25/821513190/stop-price-gouging-33-attorneys-general-tell-amazon-walmart-others>.

^{§§§} <https://psyarxiv.com/dz428/>.

Summary

What is already known about this topic?

Hand hygiene, including handwashing with soap and water and using hand sanitizer containing $\geq 60\%$ alcohol, is one measure recommended to prevent COVID-19 and other infectious diseases.

What is added by this report?

In an Internet-based survey, approximately 85% of 4,817 U.S. adults reported frequent hand hygiene after contact with public surfaces. Males, young adults, respondents with lower concern about risk for SARS-CoV-2 infection, and respondents without personal COVID-19 experience reported less frequent hand hygiene.

What are the implications for public health practice?

COVID-19 messages should continue promoting hand hygiene, particularly among men and young adults. Messages addressing COVID-19 risk perceptions and making handwashing accessible and hand sanitizer available by facilities in public settings should be considered to encourage and facilitate hand hygiene.

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Corresponding author: Mark É. Czeisler, mark.czeisler@fulbrightmail.org.

¹Turner Institute for Brain and Mental Health, Monash University, Melbourne, Australia; ²Austin Health, Melbourne, Australia; ³Brigham and Women's Hospital, Boston, Massachusetts; ⁴CDC COVID-19 Response Team; ⁵Division of Foodborne, Waterborne and Environmental Diseases, National Center for Emerging and Zoonotic Infectious Diseases, CDC; ⁶Harvard Medical School, Boston, Massachusetts; ⁷University of Melbourne, Melbourne, Australia.

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SUMMARY OF FINDINGS

The Original Investigation presented in Chapter Three revealed that 85% of surveyed US adults reported always or often practicing hand hygiene after contact with high-touch public surfaces. Weighted multivariable ordered logistic regression models revealed that less frequent hand hygiene was associated with male gender, younger age, lower concern about risk for SARS-CoV-2 infection, and no personal experience with COVID-19 (i.e., not having known someone who had been infected with SARS-CoV-2 or who had been hospitalised for or died from COVID-19).

Importantly, the analysis also revealed a difference in the associations between income and handwashing versus hand sanitising, whereby the lowest category of household income (i.e., less than USD\$25,000 annually) was associated with less frequent use of hand sanitizer, but not less frequent handwashing. Given reports of price gouging for hand sanitizer and other similar supplies early during the COVID-19 pandemic in the US (**Selyukh, 2020**), it is conceivable that this may reflect differences in access to resources to support hand sanitizer, which is especially important when soap and running water are inaccessible (i.e., in many public spaces).

Implications of the findings reported in this Original Investigation for public health practice included the identification of men and young adults as important groups for tailored COVID-19 health promotion messaging, and the potential value of addressing COVID-19 risk perceptions. Messaging regarding multiple dimensions of COVID-19 prevention measures could be beneficial for men, young adults, and individuals living in rural areas. Indeed, as reported in **Chapter Two**, these groups reported less frequently wearing masks in public and less support for COVID-19 prevention strategies compared with women, older adults, and people living in urban areas, respectively (**Czeisler, Tynan, et al., 2020**).

Moreover, the association of low household income and less frequent hand sanitizer usage highlighted the need to ensure accessibility of hand hygiene resources in public settings to encourage and facilitate hand hygiene. The paper was published on Global Handwashing Day in 2020 (15 October), and the findings were used for hand hygiene promotion via Twitter posts from the CDC, with retweets by the Federal Emergency Management Agency and Department of Health & Human Services. The publication is also featured on the CDC's websites for Healthy Water (<https://www.cdc.gov/healthywater/publications-data-stats.html>) and Water, Sanitation & Environmentally-related Hygiene (https://www.cdc.gov/healthywater/hygiene/hygiene_publications.html). In terms of infection control, a study found that WHO-recommended hand rubs demonstrated efficient SARS-CoV-2 inactivation (**Kratzel et al., 2020**). The inclusion of hand hygiene in multicomponent bundles of interventions limits evidence of the estimated unique impact of hand hygiene on SARS-CoV-2 transmission. However, in terms of hand hygiene promotion, a study demonstrated that between a simple exchange message, a gain message, a social norm appeal, and a guilt appeal, the simple exchange message produced significantly higher intentions than the other message types (**Matkovic et al., 2021**), which could further improve the effectiveness of tailored messaging from the Original Investigation in Chapter Three.

CHAPTER 4: Early public adherence with and support for stay-at-home COVID-19 mitigation strategies despite adverse life impact: a transnational cross-sectional survey study in the United States and Australia

PREFACE TO CHAPTER 4

The Original Investigation in Chapter Four (**Czeisler, Howard, et al., 2021**), which was posted as a preprint on *medRxiv* (**Czeisler, Howard, et al., 2020**) and later published in *BMC Public Health*, was conducted to extend the surveillance reported in Chapters Two and Three, both by including comparator groups with considerably different COVID-19 prevalence (US and Australia) and US cities (New York City and Los Angeles), and by evaluating mental and behavioural health during the initial stages of widespread stringent COVID-19 mitigation policies. Key outcome variables for the first aim included self-reported quarantine or self-isolation and beliefs that governments should impose stay-at-home orders to contain COVID-19. Additional variables included concerns about personal SARS-CoV-2 infection and COVID-19 mortality risk, as well as concerns of personal financial loss or an economic recession.

Key outcome variables for the second aim included symptoms of anxiety, depression, and insomnia, as well as perceived lifestyle improvements or disruptions (social life, family life, work/studies, productivity, sleep patterns, physical activity, sexual activity) and behavioural measures (time on screens, time outdoors, virtual versus face-to-face interactions). Perceived lifestyle improvements or disruptions chosen based on pre-pandemic associations between substantial functional impairment and mental health found using the Sheehan Disability Scale (SDS) (**Leon et al., 1997**). However, the SDS is unidirectional (impairment), whereas some changes during the pandemic could conceivably improve some functions for some persons. We therefore created a scale

with both improvement and disruption. In addition, measures of changes in screen time and time outdoors were included given pre-pandemic positive associations between screen time and disrupted sleep and circadian rhythms and adverse psychological outcomes (**A.-M. Chang et al., 2015; Oswald et al., 2020**), and between time outdoors and positive psychological outcomes (**Oswald et al., 2020**). Findings are presented from The COPE Initiative public health surveillance conducted during 2 through 8 April 2020 from across the US and Australia, with additional samples collected from adult residents of New York City and Los Angeles. The chapter concludes with a brief overview of findings from the Original Investigation.

CHAPTER FOUR: Early public adherence with and support for stay-at-home COVID-19 mitigation strategies despite adverse life impact: a transnational cross-sectional survey study in the United States and Australia



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RESEARCH ARTICLE

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Early public adherence with and support for stay-at-home COVID-19 mitigation strategies despite adverse life impact: a transnational cross-sectional survey study in the United States and Australia

Mark É. Czeisler^{1,2,3*} , Mark E. Howard^{1,2,4} , Rebecca Robbins^{5,6} , Laura K. Barger^{1,5,6} , Elise R. Facer-Childs¹ ,
Shantha M. W. Rajaratnam^{1,2,5,6†}  and Charles A. Czeisler^{1,5,6†} 

Abstract

Background: Governments worldwide recommended unprecedented measures to contain the coronavirus disease 2019 (COVID-19) pandemic, caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). As pressure mounted to scale back measures, understanding public priorities was critical. We assessed initial public adherence with and support for stay-at-home orders in nations and cities with different SARS-CoV-2 infection and COVID-19 death rates.

Methods: Cross-sectional surveys were administered to representative samples of adults aged ≥ 18 years from regions with different SARS-CoV-2 prevalences from April 2–8, 2020. Regions included two nations [the United States (US—high prevalence) and Australia (AU—low prevalence)] and two US cities [New York City (NY—high prevalence) and Los Angeles (LA—low prevalence)]. Regional SARS-CoV-2 and COVID-19 prevalence (cumulative SARS-CoV-2 infections, COVID-19 deaths) as of April 8, 2020: US (363,321, 10,845), AU (5956, 45), NY (81,803, 4571), LA (7530, 198). Of 8718 eligible potential respondents, 5573 (response rate, 63.9%) completed surveys. Median age was 47 years (range, 18–89); 3039 (54.5%) were female.

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* Correspondence: mark.czeisler@fulbrightmail.org

†Shantha M. W. Rajaratnam and Charles A. Czeisler contributed equally to this work.

¹Turner Institute for Brain and Mental Health, Monash University, Melbourne, VIC 3800, Australia

²Institute for Breathing and Sleep, Austin Health, Melbourne, VIC 3084, Australia

Full list of author information is available at the end of the article



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Results: Of 5573 total respondents, 4560 (81.8%) reported adherence with recommended quarantine or stay-at-home policies (range of samples, 75.5–88.2%). Additionally, 29.1% of respondents screened positive for anxiety or depression symptoms (range of samples, 28.6–32.0%), with higher prevalences among those of younger age, female gender, and those in quarantine or staying at home most of the time versus those who did not report these behaviours. Despite elevated prevalences of adverse mental health symptoms and significant life disruptions, 5022 respondents (90.1%) supported government-imposed stay-at-home orders (range of samples, 88.9–93.1%). Of these, 90.8% believed orders should last at least three more weeks or until public health or government officials recommended, with support spanning the political spectrum.

Conclusions: Public adherence with COVID-19 mitigation policies was highly prevalent, in both highly-affected (US, NY) and minimally-affected regions (AU, LA). Despite disruption of respondents' lives, the vast majority supported continuation of extended stay-at-home orders. Despite common support, these two countries diverged in stringent mitigation implementation, which may have contributed to subsequent outcomes. These results reveal the importance of surveillance of public support for and adherence with such policies during the COVID-19 pandemic and for future infectious disease outbreaks.

Keywords: COVID-19, Coronavirus, SARS-CoV-2, Pandemic, Stay-at-home orders, Mitigation strategies, Mental health, Insomnia, Public health policy, Qualtrics

Background

As of 7 March 2021, there have been 116 million confirmed cases of the novel severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) worldwide, which have contributed to nearly 2.6 million deaths from coronavirus disease 2019 (COVID-19) [1]. In March 2020, during the initial phase of the COVID-19 pandemic and absent widespread testing, safe and efficacious treatments or protective vaccines, isolation and quarantine were recommended worldwide for the first time in a century. SARS-CoV-2 prevalence and associated public health policies have varied across jurisdictions and changed over time, largely without systematic assessment of public responses to the crisis or the mitigation strategies. To provide policymakers with public priorities and perspectives, we conducted a transnational cross-sectional study to assess public adherence with and support for government-imposed stay-at-home orders among individuals from regions with varying SARS-CoV-2 prevalence, including two nations [the United States (US—high SARS-CoV-2 prevalence) and Australia (AU—low SARS-CoV-2 prevalence)] and two cities [New York City (NY—high SARS-CoV-2 prevalence) and Los Angeles (LA—low SARS-CoV-2 prevalence)]. The aims of this analysis were to assess the following in the initial stages of the pandemic: public adherence with and support for stringent COVID-19 mitigation policies, including stay-at-home orders; public concerns and experiences related to the pandemic and its mitigation; and mental health, including symptoms of anxiety, depression, and insomnia. We also sought to identify characteristics associated with non-support for and non-adherence with mitigation strategies and with adverse mental health symptoms during the COVID-19 pandemic.

Methods

Study design and recruitment

To evaluate public adherence with and support for recommended COVID-19 mitigation strategies, we collected cross-sectional surveys of nationally representative samples of respondents using demographic quota sampling [2]. Surveys were administered to online respondent panels by Qualtrics, LLC (Provo, Utah, and Seattle, Washington, US), a commercial survey company with a network of participants consisting of hundreds of suppliers. Recruitment methodologies include digital advertisements and promotions, word of mouth, membership referrals, social networks, TV & radio advertisements, and offline approaches.

Between April 2–8, 2020 (a one-week interval), respondents were recruited from regions with markedly different infection and death rates from COVID-19 (Table 1), including nationwide samples in the US (high SARS-CoV-2 prevalence) and AU (low SARS-CoV-2 prevalence), and citywide samples in the NY (high SARS-CoV-2 prevalence) and LA (low SARS-CoV-2 prevalence) metropolitan areas. Data reported from the US sample exclude respondents from the separate NY and LA samples, unless otherwise noted.

Study approval and informed consent

The study protocol was approved by the Monash University Human Research Ethics Committee (#24036) and conducted in accordance with ethical guidelines. This activity was also reviewed by the United States Centers for Disease Control and Prevention (CDC), which affirmed that the activity was conducted consistent with applicable federal law and CDC policies for the protection of human participants from research risks: 45 Code of Federal Regulations (CFR) part 46, 21 CFR part 56; 42

Table 5 (4.1). Prevalence of SARS-CoV-2 cases and COVID-19 deaths**Table 1** Prevalence of SARS-CoV-2 cases and COVID-19 deaths

	Overall (N = 5573)	US (N = 3010)	NY (N = 507)	LA (N = 525)	AU (N = 1531)
SARS-CoV-2 infections and deaths due to COVID-19					
Cumulative confirmed SARS-CoV-2 cases					
Study midpoint (April 5, 2020)	279,443	273,808	67,552	5940	5635
Range (April 2—April 8, 2020)	192,278–369,277	187,302–363,321	51,810–81,803	4045–7530	4976–5956
Cumulative COVID-19 deaths					
Study midpoint (April 5, 2020)	7054	7020	2472	132	34
Range (April 2—April 8, 2020)	3867–10,890	3846–10,845	1562–4571	78–198	21–45

Country-level cumulative cases and deaths for US and AU were retrieved from World Health Organization COVID-19 Situational Reports [3–5]. City-level cumulative cases and deaths for NY and LA were retrieved from The New York Times Coronavirus (Covid-19) Data in the United States project, based on reports from state and local health agencies [6]. Given that cases and deaths from NY and LA were also counted in the US, the Overall column reports cases and deaths from the US and AU, retrieved from the WHO COVID-19 Situation Reports

United States Code (USC) Section 241(d); 5 USC Section 552a; 44 USC Section 3501 et seq. Respondents were informed of the study purposes and provided informed electronic consent prior to commencement. Investigators received anonymised responses.

Population

Target numbers of respondent-completed surveys follow: US (3000), NY (500), LA (500), AU (1500). These sample sizes were selected to obtain samples with margins of error at 95% confidence levels of ± 1.8 , ± 4.4 , ± 4.4 , and $\pm 2.5\%$, respectively. To be eligible to participate, respondents were required to have provided informed electronic consent and to have reported being aged ≥ 18 years with current residence in the specified regions. Demographic sampling quotas were implemented for age, gender, and either race and ethnicity (US, NY, LA) or ancestry (AU), based on 2010 US and 2016 Australian census national population estimates. Potential respondents likely to qualify based on demographic characteristics listed in their Qualtrics panellist profile were targeted during recruitment; demographic questions (gender, age, race, ethnicity, and ancestry) were included in the survey to confirm eligibility. Potential respondents received invitations and could opt to participate by activating a survey link directing them to the participant information and consent page preceding the survey. Ineligible respondents who did not meet inclusion criteria (eg, aged < 18 years, not a resident of a targeted region) or exceeded pre-set quotas (ie, maximum demographic characteristic quota already met) were disempanelled.

Survey instruments

The surveys contained 86 [US, NY, LA] or 85 [adapted for AU] items, with each item requiring a response, and was designed to take approximately 15 min to complete.

Respondents were required to self-report demographic characteristics and respond to questions about COVID-19 and mitigation strategies, including adherence, priorities, sources of concern, and comparisons of current lifestyle versus lifestyle between October and December 2019 (ie, before COVID-19 and COVID-19 mitigation strategies). Additional health-related questions were asked independent of COVID-19. When possible, brief validated instruments were used, including the Short-Form Sleep Condition Indicator (SCI-02) for insomnia symptom assessment, Patient Health Questionnaire-4 (PHQ-4) for anxiety and depression symptom assessment, the Perceived Stress Scale-4 (PSS-4) for perceived stress assessment, and the Mini Z for burnout symptom assessment [7–10]. When required, validated instruments were adapted, including the Horne and Östberg Morningness-Eveningness Questionnaire (MEQ) for chronotype assessment, the μ short Munich ChronoType Questionnaire (μ MCTQ) for chronotype and sleep behaviour assessment, Obstructive Sleep Apnoea 50 (OSA50) for obstructive sleep apnoea risk assessment, single-item physical activity measure, and Hurt-Insult-Threaten-Scream (HITS) screening tool for domestic violence [11–16].

Quality screening

To verify response quality, Qualtrics conducted standardised quality screening and data cleaning procedures. Techniques included algorithmic analysis for attention patterns, click-through behaviour, duplicate responses, keystroke analysis, machine responses, and inattentiveness. Country-specific geolocation verification via IP address mapping was used to ensure respondents were from the country specified in their response. Respondents who failed an attention or speed check, along with any responses identified by the data scrubbing algorithms, were excluded from the final sample.

Statistical analysis

Descriptive summary data are reported overall and by each sample. Multivariable Poisson regression models with robust standard errors were used to estimate adjusted prevalence ratios (aPRs) and 95% confidence intervals (CIs) for mitigation behaviours adjusted for the following explanatory variables: gender, age, political ideology, and nation (US or Australia) or city (New York or Los Angeles). For the multivariable analysis, respondents who reported a gender other than Male or Female (ie, “Other,” $n = 4$ [2 in the US sample, 2 in the Australian sample]) were excluded due to small cell sizes. The nation or city variable was used to account for differences in these sample populations, including SARS-CoV-2 and COVID-19 prevalence, mitigation policies, and other cultural or regional differences. In the cities model, combined race/ethnicity was also included as an explanatory variable. Employment status and marital status were excluded from the models to avoid collinearity with age. Separate models were run with dependent variables of having not self-reported quarantine or spending most of the time at home and having not supported stay-at-home orders as dependent variables. Additional models were run to estimate aPRs and 95% CIs for anxiety or depressive disorder symptoms and for insomnia symptoms with the same explanatory variables, plus a variable indicating whether respondents self-reported having been in quarantine or spending most of time at home. Python (version 3.7.8; Python Software Foundation) and the Python statsmodels package were used to conduct all analyses. Statistical significance was determined as $p < 0.05$.

Results

Between April 2 and April 8, 2020, of 8717 eligible invited adults, 5573 (63.9%) completed surveys (Fig. 1). The regional number of respondents, response rates, and 95% confidence level margins of error follow: US: $n = 3010$, response rate = 64.1%, margin of error = $\pm 1.8\%$; NY: 507, response rate = 53.2%, margin of error = $\pm 4.4\%$; LA: 525, response rate = 58.6%, margin of error = $\pm 4.3\%$; AU: 1531, response rate = 70.6%, margin of error = $\pm 2.5\%$. Overall, 3039 (54.5%) respondents were female; the median age of participants was 47 years (range, 18–89). Respondent demographic characteristics of categories with and without pre-specified quotas are reported in Tables 2 and 3, respectively. The state- and territory-level geographic distributions of respondents' residency for each nationwide sample are reported in Additional file 1 online. Respondents' personal experiences with COVID-19 and knowledge of others' experiences with COVID-19 (Table 4) were consistent with the samples having recruited respondents with residence in regions with markedly different regional SARS-CoV-2 infection and COVID-19 death rates. NY had the highest percentage of respondents who reported knowing someone who had tested positive for SARS-CoV-2 (27.0% vs. 5.6–11.0% for the rest of the samples), or who had been hospitalised for (14.6% vs. 2.4–6.5% for the rest of the samples) or died from (9.5% vs. 0.7–2.9% for the rest of the samples) COVID-19.

Respondents' COVID-19-mitigation adherence, public priorities, life impact, and mental health symptoms are illustrated in Figs. 2, 3, 4. Altogether, 4560 respondents

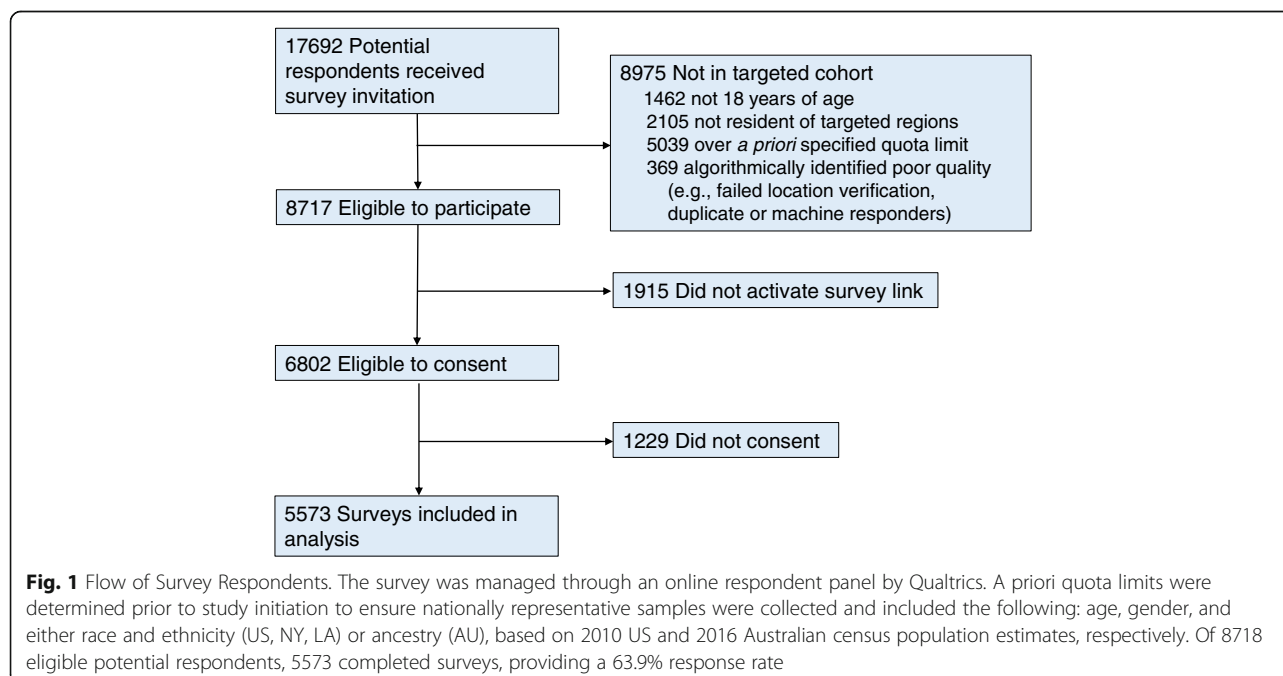


Figure 4 (4.1) Flow of Survey Respondents

Table 6 (4.2) Self-reported respondent characteristics with pre-specified quotas**Table 2** Self-reported respondent characteristics with pre-specified quotas

Characteristic	Overall (N = 5573)		US ^a (N = 3010)		NY (N = 507)		LA (N = 525)		AU (N = 1531)	
Age (years)										
Mean (SD)	47.1	(17.3)	47.4	(16.9)	46.7	(18.0)	45.5	(17.0)	45.6	(17.3)
Median	47		48		45		45		44.5	
Range	18–89		18–89		18–86		18–87		18–89	
Gender—No. (%)										
Female	3039	(54.5)	1683	(55.9)	239	(47.1)	275	(52.4)	842	(55.0)
Male	2530	(45.4)	1325	(44.0)	268	(52.9)	250	(47.6)	687	(44.9)
Other	4	(0.1)	2	(0.1)	0	(0.0)	0	(0.0)	2	(0.1)
Race ^b (All US, N = 4042)—No. (%)										
White	3196	(79.1)	2423	(80.5)	373	(73.6)	400	(76.2)		
Black or African American	428	(10.6)	313	(10.4)	63	(12.4)	52	(9.9)		
Asian	256	(6.3)	192	(6.4)	32	(6.3)	32	(6.1)		
American Indian or Alaskan Native	80	(2.0)	60	(2.0)	9	(1.8)	11	(2.1)		
Native Hawaiian or Pacific Islander	22	(0.5)	17	(0.6)	3	(0.6)	2	(0.4)		
Other	182	(4.5)	104	(3.5)	38	(7.5)	40	(7.6)		
Ethnicity (All US, N = 4042)—No. (%)										
Hispanic or Latino	424	(10.5)	265	(8.8)	69	(13.6)	90	(17.1)		
Not Hispanic or Latino	3618	(89.5)	2745	(91.2)	438	(86.4)	435	(82.9)		
Ancestry ^c (AU, N = 1531)—No. (%)										
Australian									556	(36.3)
English									501	(32.7)
Other European (Irish, Scottish, German, Italian, Greek, Dutch)									346	(22.6)
Scottish									95	(6.2)
Chinese									90	(5.9)
Indian									45	(2.9)
Indigenous—Aboriginal Australians and Torres Strait Islanders									16	(1.0)
Other									455	(29.8)

Self-reported characteristics of categories with pre-specified quota limits overall and in regional samples collected in the US, NY, LA, and AU. For age, mean (standard deviation), median, and range are shown per sample. For all other characteristics, the number and percentage of respondents are reported by cohort. Race and ethnicity (US, NY, LA) or ancestry (AU) were reported in based on questions culturally adapted to match the characteristic data collected in the 2010 United States and 2016 Australian Census, respectively

^aRespondents in the US sample do not include those who were separately recruited for the NY or LA samples, but include respondents from these cities

^bFor the US sample, respondents had the option to select more than one racial affiliation

^cFor the AU sample, respondents had the option to select up to two ancestral affiliations

The 'Other' category includes Filipino, Vietnamese, Lebanese, Hmong, Kurdish, Maori, and Australian South Sea Islander

(81.8%) reported having been in quarantine or spending the majority of time at home (range of samples, 75.5–88.2%) (Fig. 2, Table 5). Moreover, 5022 (90.1%) believed a government-imposed stay-at-home order was warranted (range of samples, 88.9–93.1%). Of these, 90.8% believed the order should have lasted at least 3 weeks (9.1%), a month or longer (43.8%), or until public health (31.1%) or government officials (6.8%) determined it was safe to lift the restrictions. Of 5304 respondents (95.2%) who made predictions, the average predicted date by which COVID-19 would no longer affect their daily lives was between mid-June 2020 and mid-August 2020, though there

was high variability in predictions (Table 5). Strong support for government-imposed stay-at-home orders spanned the political spectrum.

In the nations model for non-adherence with mitigation policies, respondents of female versus male gender and aged 18–24 years versus ≥65 years significantly less commonly reported neither being in quarantine nor spending the majority of time at home (Table 6). Compared to those with centrist liberal ideology, liberal respondents less commonly reported non-adherence, while very conservative respondents more commonly reported this behaviour. Respondents

Table 7 (4.3) Self-reported respondent characteristics without pre-specified quotas**Table 3** Self-reported respondent characteristics without pre-specified quotas

Characteristic	Overall		US ^a		NY		LA		AU	
	(N = 5573)		(N = 3010)		(N = 507)		(N = 525)		(N = 1531)	
Highest degree or level of education completed—No. (%)										
Less than high school	107	(1.9)	61	(2.0)	4	(0.8)	5	(1.0)	37	(2.4)
High school or equivalent	1257	(22.6)	524	(17.4)	81	(16.0)	61	(11.6)	591	(38.6)
Some college	1444	(25.9)	910	(30.2)	121	(23.9)	157	(29.9)	256	(16.7)
Bachelor's degree (4-year) or equivalent	1806	(32.4)	927	(30.8)	159	(31.4)	212	(40.4)	508	(33.2)
Doctoral or professional degree	917	(16.5)	567	(18.8)	137	(27.0)	88	(16.8)	125	(8.2)
Prefer not to say	42	(0.8)	21	(0.7)	5	(1.0)	2	(0.4)	14	(0.9)
Marital status—No. (%)										
Married	2724	(48.9)	1567	(52.1)	231	(45.6)	226	(43.0)	700	(45.7)
Living with partner	533	(9.6)	241	(8.0)	43	(8.5)	51	(9.7)	198	(12.9)
Separated	92	(1.7)	32	(1.1)	7	(1.4)	2	(0.4)	51	(3.3)
Divorced	490	(8.8)	291	(9.7)	40	(7.9)	46	(8.8)	113	(7.4)
Widowed	178	(3.2)	109	(3.6)	12	(2.4)	21	(4.0)	36	(2.4)
Never married	1490	(26.7)	739	(24.6)	165	(32.5)	169	(32.2)	417	(27.2)
Prefer not to say	66	(1.2)	31	(1.0)	9	(1.8)	10	(1.9)	16	(1.0)
2019 household income (USD)—No. (%)										
Less than \$25,000	940	(16.9)	454	(15.1)	57	(11.2)	67	(12.8)	362	(23.6)
\$25,000 to \$49,999	1296	(23.3)	641	(21.3)	88	(17.4)	88	(16.8)	479	(31.3)
\$50,000 to \$99,999	1723	(30.9)	989	(32.9)	139	(27.4)	164	(31.2)	431	(28.2)
\$100,000 to \$199,999	1054	(18.9)	657	(21.8)	151	(29.8)	134	(25.5)	112	(7.3)
\$200,000 or more	229	(4.1)	132	(4.4)	41	(8.1)	42	(8.0)	14	(0.9)
Prefer not to say	331	(5.9)	137	(4.6)	31	(6.1)	30	(5.7)	133	(8.7)
2019 employment status—No. (%)										
Employed full-time	2245	(40.3)	1284	(42.7)	246	(48.5)	217	(41.3)	498	(32.5)
Employed part-time	760	(13.6)	338	(11.2)	63	(12.4)	61	(11.6)	298	(19.5)
Self-employed	361	(6.5)	189	(6.3)	30	(5.9)	52	(9.9)	90	(5.9)
Student	337	(6.0)	147	(4.9)	30	(5.9)	36	(6.9)	124	(8.1)
Retired	1268	(22.8)	734	(24.4)	101	(19.9)	110	(21.0)	323	(21.1)
Unemployed	714	(12.8)	384	(12.8)	45	(8.9)	55	(10.5)	230	(15.0)
Political ideology—No. (%)										
Very liberal	701	(12.6)	410	(13.6)	97	(19.1)	94	(17.9)	100	(6.5)
Slightly liberal	1121	(20.1)	586	(19.5)	107	(21.1)	129	(24.6)	299	(19.5)
Neither liberal nor conservative	1465	(26.3)	727	(24.2)	122	(24.1)	126	(24.0)	490	(32.0)
Slightly conservative	1097	(19.7)	621	(20.6)	80	(15.8)	84	(16.0)	312	(20.4)
Very conservative	701	(12.6)	484	(16.1)	60	(11.8)	58	(11.0)	99	(6.5)
Apolitical and/or prefer not to say	488	(8.8)	182	(6.0)	41	(8.1)	34	(6.5)	231	(15.1)

Self-reported characteristics of categories without pre-specified quota limits overall and in regional samples collected in the US, NY, LA, and AU. As in Table 2, the number and percentage of respondents are reported by cohort

^aRespondents in the US sample do not include those who were separately recruited for the NY or LA samples, but include respondents from these cities

from the US also less commonly reported non-adherence than those from Australia. In the cities model, the gender difference was also observed. No other characteristics were associated with significant differences.

In the nations model, the gender effect was similar for non-support for stay-at-home orders, with female significantly less commonly having reported not supporting such measures (aPR = 0.67, 95% CI = 0.57–0.80, $p < 0.001$) (Table 6). However, the age effect was reversed, with all

Table 8 (4.4) Experiences with COVID-19 overall and by region**Table 4** Experiences with COVID-19 overall and by region

	Overall		US ^a		NY		LA		AU	
	(N = 5573)		(N = 3010)		(N = 507)		(N = 525)		(N = 1531)	
Experience with COVID-19										
Tested for SARS-CoV-2—No. (%)	119	(2.1)	56	(1.9)	18	(3.6)	11	(2.1)	34	(2.2)
Positive	10	(0.2)	5	(0.2)	4	(0.8)	0	(0.0)	1	(0.1)
Negative	88	(1.6)	36	(1.2)	13	(2.6)	11	(2.1)	28	(1.8)
Awaiting results	21	(0.4)	15	(0.5)	1	(0.2)	0	(0.0)	5	(0.3)
Not tested	5454	(97.9)	2954	(98.1)	489	(96.4)	514	(97.9)	1497	(97.8)
Hospitalized for COVID-19—No. (%)	38	(0.7)	20	(0.7)	7	(1.4)	6	(1.1)	5	(0.3)
Not hospitalized	5535	(99.3)	2990	(99.3)	500	(98.6)	519	(98.9)	1526	(99.7)
Know someone...—No. (%)										
confirmed positive with SARS-CoV-2	602	(10.8)	331	(11.0)	137	(27.0)	49	(9.3)	85	(5.6)
Colleague(s)	141	(2.5)	74	(2.5)	40	(7.9)	4	(0.8)	23	(1.5)
Family Member(s)	120	(2.2)	71	(2.4)	30	(5.9)	7	(1.3)	12	(0.8)
Friend(s)	315	(5.7)	165	(5.5)	83	(16.4)	30	(5.7)	37	(2.4)
Significant other(s)	28	(0.5)	18	(0.6)	4	(0.8)	0	(0.0)	6	(0.4)
Other	75	(1.3)	42	(1.4)	11	(2.2)	9	(1.7)	13	(0.8)
No	4971	(89.2)	2679	(89.0)	370	(73.0)	476	(90.7)	1446	(94.4)
hospitalized due to COVID-19	336	(6.0)	192	(6.4)	74	(14.6)	34	(6.5)	36	(2.4)
Colleague(s)	68	(1.2)	39	(1.3)	16	(3.2)	4	(0.8)	9	(0.6)
Family Member(s)	80	(1.4)	51	(1.7)	14	(2.8)	7	(1.3)	8	(0.5)
Friend(s)	168	(3.0)	85	(2.8)	42	(8.3)	20	(3.8)	21	(1.4)
Significant other(s)	15	(0.3)	8	(0.3)	3	(0.6)	2	(0.4)	2	(0.1)
Other	42	(0.8)	28	(0.9)	5	(1.0)	6	(1.1)	3	(0.2)
No	5237	(94.0)	2818	(93.6)	433	(85.4)	491	(93.5)	1495	(97.6)
who died due to COVID-19	158	(2.8)	86	(2.9)	48	(9.5)	13	(2.5)	11	(0.7)
Colleague(s)	27	(0.5)	13	(0.4)	9	(1.8)	1	(0.2)	4	(0.3)
Family Member(s)	15	(0.3)	7	(0.2)	6	(1.2)	1	(0.2)	1	(0.1)
Friend(s)	81	(1.5)	44	(1.5)	26	(5.1)	6	(1.1)	5	(0.3)
Significant other(s)	12	(0.2)	9	(0.3)	1	(0.2)	0	(0.0)	2	(0.1)
Other	39	(0.7)	22	(0.7)	11	(2.2)	5	(1.0)	1	(0.1)
No	5415	(97.2)	2924	(97.1)	459	(90.5)	512	(97.5)	1520	(99.3)

Survey responses are reported using descriptive statistics as indicated, including number of respondents (No.), percentage of respondents (%), mean, and standard deviation (sd). For cases in which subgroups are stratified, the percentage of the total sample is reported

^aRespondents in the US sample do not include those who were separately recruited for the NY or LA samples, but include respondents from these cities

younger age groups more commonly reporting non-support for stay-at-home orders than those aged ≥ 65 years (eg, 18–24 years, 1.83, 1.30–2.56, $p < 0.001$). In the city samples, many of the aPRs are of similar magnitude and direction to the nation samples, though statistical significance was not reached. However, in contrast to the nationwide samples, in the cities model, both slightly and very conservative respondents had more than 2-fold increased prevalence of non-support than those with centred political ideology. Statistically significant differences in non-support for stay-at-home orders were not observed regionally.

Broad support for stringent mitigation policies was reported despite elevated prevalences of adverse mental health symptoms compared with pre-pandemic estimates using similar screening instruments. Overall, 1303 respondents (23.4%, range of samples, 22.1–25.4%) screened positive for symptoms of an anxiety disorder and 1172 (21.0%, range of samples, 20.0–22.7%) screened positive for symptoms of a depressive disorder, with 1622 participants (29.1%, range of samples, 28.6–32.0%) having screened positive for symptoms of at least one of these adverse mental health conditions (Table 7). Moreover, 1029 respondents (18.5%, range of samples, 15.2–20.0%) screened positive for insomnia symptoms.

Figure 5 (4.2) Public COVID-19 Mitigation Adherence, Concerns, Policy Support, and Experience

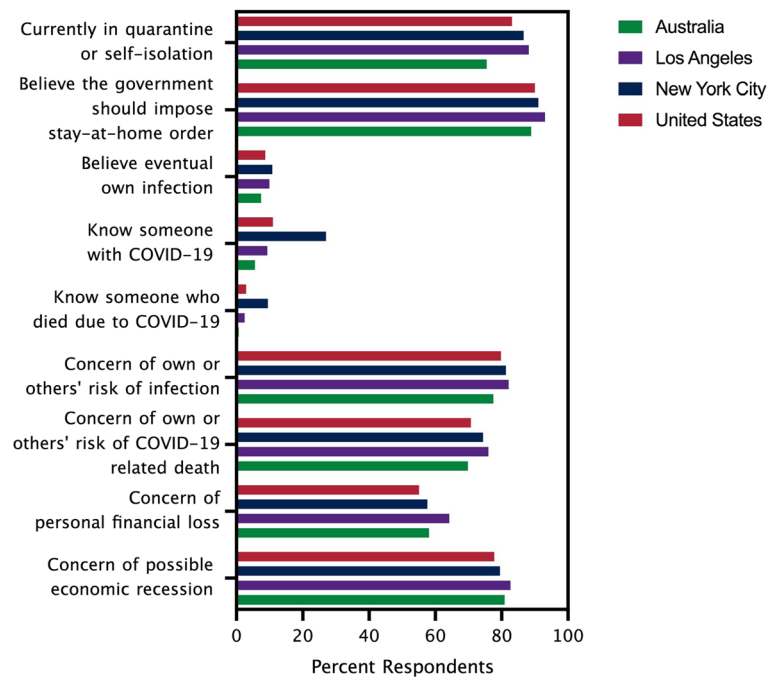


Fig. 2 Public COVID-19 Mitigation Adherence, Concerns, Policy Support, and Experience. Percentage of respondents by region who reported: adherence with recommended mitigation strategies; support for a government-mandated stay-at-home order; perceived risk of eventual infection with SARS-CoV-2; personal experience with COVID-19 (ie, knowing someone who was infected with SARS-CoV-2 or who died from COVID-19); and moderate to extreme concerns regarding: one's own or others' risk of infection with SARS-CoV-2 or risk for death from COVID-19, personal financial loss, and possible economic recession

Figure 6 (4.3) Life Disruption Due to COVID-19 and Mitigation Strategies

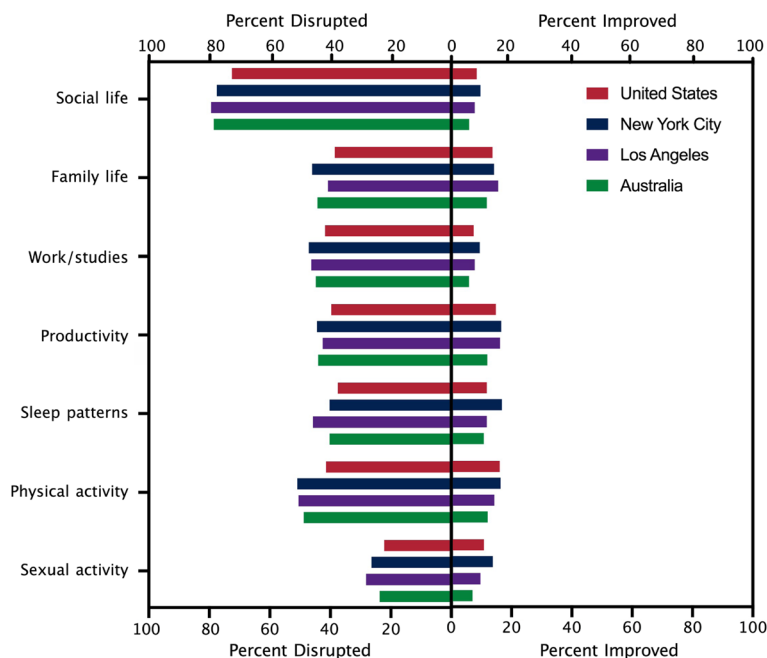
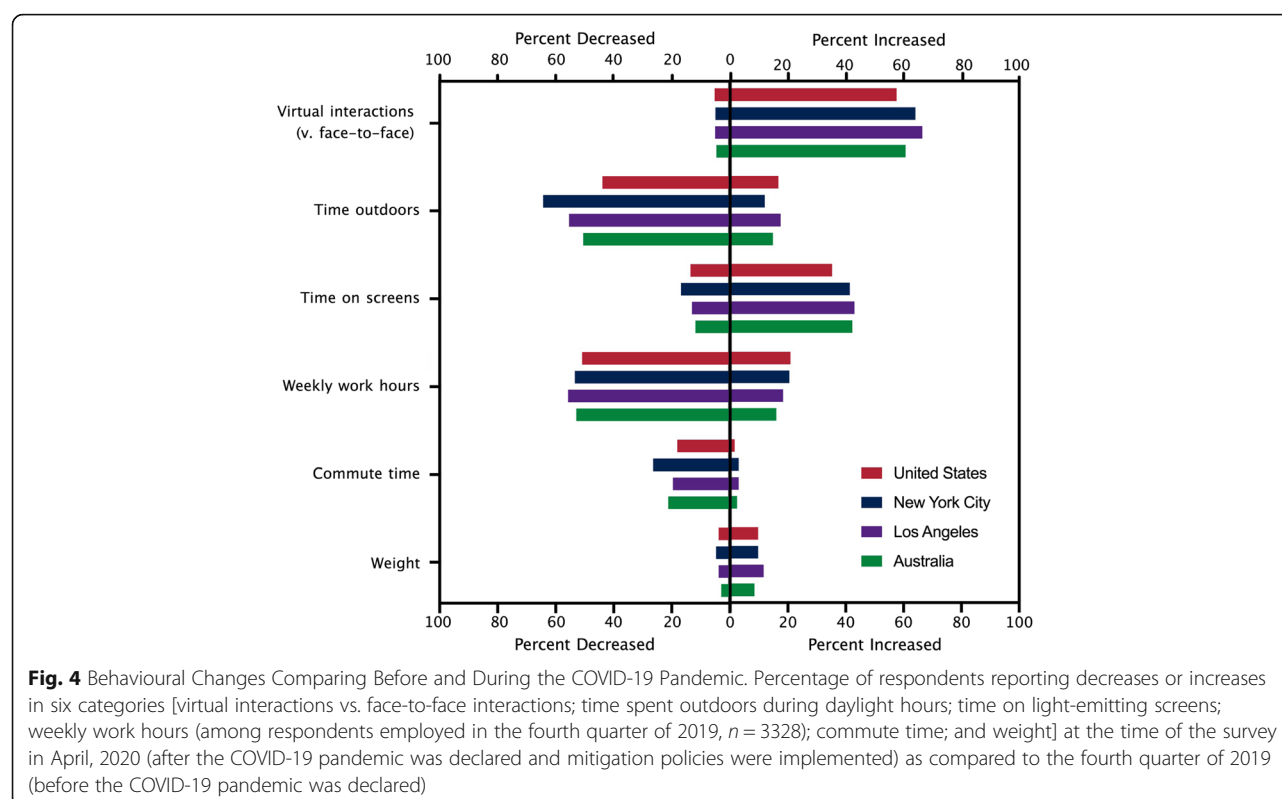


Fig. 3 Life Disruption Due to COVID-19 and Mitigation Strategies. Impact by region of COVID-19 and mitigation strategies on social life, family life, work and/or study, productivity, sleep patterns, physical activity, and sexual activity; percentage of respondents reporting that the indicated behavioural category was moderately to extremely disrupted or improved is shown

Figure 7 (4.4). Behavioural Changes Comparing Before and During the COVID-19 Pandemic



Multivariable analysis of adverse mental health symptoms in the nation and cities models revealed that symptoms of anxiety or depressive disorders were more common among adults of female versus male gender (eg, cities model, aPR = 1.49, 95% CI = 1.23–1.81) and younger versus older age (eg, 18–24 versus ≥ 65 years, cities model, 3.28, 2.20–4.90), with all $p \leq 0.001$ (Table 8). There were also differences by adherence with COVID-19 mitigation measures. In the nations model, symptoms of anxiety or depressive disorders were more common among those who reported being in quarantine or voluntarily spending the majority of time at home (1.77, 1.52–2.05 and 1.32, 1.14–1.53, respectively, both $p < 0.001$) versus those doing neither of these. The magnitudes of both aPRs were similar in the cities model, though adjusted prevalence of those spending the majority of time at home was not statistically significant. Very liberal respondents more commonly experienced anxiety or depressive disorder symptoms in both models. Insomnia symptoms were also more common among female versus male respondents (eg, cities model, 1.81, 1.35–2.42, $p < 0.001$), while the only difference by age group was observed among those aged 45–65 versus ≥ 65 years in the nations model (1.25, 1.04–1.49, $p = 0.015$). In the nations model but not the cities model, insomnia symptoms were more common among those who

reported being in quarantine or voluntarily spending the majority of time at home (1.36, 1.13–1.65, $p = 0.001$ and 1.22, 1.02–1.46, $p = 0.027$, respectively) versus those doing neither of these. Statistically significant differences were not observed for adverse mental health symptoms regionally.

In addition to symptoms of anxiety, depression, and insomnia, many respondents reported COVID-19-specific concerns, as 4431 respondents (79.5%, range of samples, 77.5–82.1%) reported moderate to extreme concern about their own (61.9%) or others' (75.5%) infection with SARS-CoV-2, and 3974 (71.3%, range of samples, 69.8–76.0%) reported similar concerns about their own (43.4%) or others' (68.7%) death due to COVID-19 (Fig. 2). Access to testing (59.3%), medical care for COVID-19 (64.5%), medical care for pre-existing conditions due to hospital overload (59.2%), social or physical isolation (58.1%), and sense of purpose (49.8%) were also sources of moderate to extreme concern. Overall, 1217 respondents (21.8%) identified as high risk for severe COVID-19 infection. Across regions, nearly half (42.0–45.3%) reported spending considerable time (average, 23.2 h per week) consuming information (media, government reports, health officials, family) about COVID-19. Moreover, widespread concerns included the possibility of

Table 9 (4.5) Adherence with, support for, and predictions about mitigation strategies**Table 5** Adherence with, support for, and predictions about mitigation strategies

	Overall		US ^a		NY		LA		AU	
	(N = 5573)		(N = 3010)		(N = 507)		(N = 525)		(N = 1531)	
Adherence with COVID-19 Mitigation Strategies										
Neither in quarantine nor spending the majority of time at home	1013	(18.2)	508	(16.9)	68	(13.4)	62	(11.8)	375	(24.5)
In quarantine or self-isolation	4560	(81.8)	2502	(83.1)	439	(86.6)	463	(88.2)	1156	(75.5)
Quarantine ^b	1946	(34.9)	1151	(38.2)	214	(42.2)	224	(42.7)	357	(23.3)
Spending most of the time at home	2614	(46.9)	1351	(44.9)	225	(44.4)	239	(45.5)	799	(52.2)
Predictions for When COVID-19 Will Stop Affecting Daily Life										
Respondents offering predictions ^c —No. (%)	5304	(95.2)	2878	(95.6)	480	(94.7)	501	(95.4)	1445	(94.4)
Number of days from survey completion date—mean (sd)	92.5	99.37	76.4	84.12	79.4	77.02	78.6	77.45	134.0	125.51
Calendar Date	7/5/2020		6/16/2020		6/22/2020		6/21/2020		8/15/2020	
Public Priorities for COVID-19 Mitigation Strategies										
Government should impose stay-at-home order ^d —No. (%)										
No	551	(9.9)	300	(10.0)	45	(8.9)	36	(6.9)	170	(11.1)
Yes	5022	(90.1)	2710	(90.0)	462	(91.1)	489	(93.1)	1361	(88.9)
for 1 week	89	(1.6)	56	(1.9)	6	(1.2)	8	(1.5)	19	(1.2)
for 2 weeks	373	(6.7)	215	(7.1)	46	(9.1)	25	(4.8)	87	(5.7)
for 3 weeks	457	(8.2)	271	(9.0)	51	(10.1)	49	(9.3)	86	(5.6)
for at least 1 month	2201	(39.5)	1298	(43.1)	190	(37.5)	254	(48.4)	459	(30.0)
until health officials say it is safe	1562	(28.0)	737	(24.5)	133	(26.2)	127	(24.2)	565	(36.9)
until government officials say it is safe	340	(6.1)	133	(4.4)	36	(7.1)	26	(5.0)	145	(9.5)
By political affiliation										
Very liberal	701	(12.6)	410	(13.6)	97	(19.1)	94	(17.9)	100	(6.5)
No	51	(0.9)	30	(1.0)	4	(0.8)	2	(0.4)	15	(1.0)
Yes	650	(11.7)	380	(12.6)	93	(18.3)	92	(17.5)	85	(5.6)
Somewhat liberal	1121	(20.1)	586	(19.5)	107	(21.1)	129	(24.6)	299	(19.5)
No	64	(1.1)	28	(0.9)	4	(0.8)	6	(1.1)	26	(1.7)
Yes	1057	(19.0)	558	(18.5)	103	(20.3)	123	(23.4)	273	(17.8)
Neither liberal nor conservative	1465	(26.3)	727	(24.2)	122	(24.1)	126	(24.0)	490	(32.0)
No	161	(2.9)	81	(2.7)	9	(1.8)	9	(1.7)	62	(4.0)
Yes	1304	(23.4)	646	(21.5)	113	(22.3)	117	(22.3)	428	(28.0)
Somewhat conservative	1097	(19.7)	621	(20.6)	80	(15.8)	84	(16.0)	312	(20.4)
No	117	(2.1)	59	(2.0)	12	(2.4)	12	(2.3)	34	(2.2)
Yes	980	(17.6)	562	(18.7)	68	(13.4)	72	(13.7)	278	(18.2)
Very conservative	701	(12.6)	484	(16.1)	60	(11.8)	58	(11.0)	99	(6.5)
No	97	(1.7)	70	(2.3)	11	(2.2)	6	(1.1)	10	(0.7)
Yes	604	(10.8)	414	(13.8)	49	(9.7)	52	(9.9)	89	(5.8)
Apolitical/prefer not to say	488	(8.8)	182	(6.0)	41	(8.1)	34	(6.5)	231	(15.1)
No	61	(1.1)	32	(1.1)	5	(1.0)	1	(0.2)	23	(1.5)
Yes	427	(7.7)	150	(5.0)	36	(7.1)	33	(6.3)	208	(13.6)

Survey responses are reported using descriptive statistics as indicated, including number of respondents (No.), percentage of respondents (%), mean, and standard deviation (sd)

^aRespondents in the US sample do not include those who were separately recruited for the NY or LA samples, but include respondents from these cities

^bQuarantine was defined as “not attending public places, including work, supermarkets or pharmacies, school or childcare, places of worship, etc. Individuals in quarantine do not have visitors and only live with people who usually live in your home. They stay at home or accommodation unless medical care is required.”

^cPredictions in the year 2030 or beyond were excluded. There were six such predictions: (US, 8/6/2064, 2/1/2071), (LA, 1/1/2030, 1/1/2032, 12/31/2050), (AU, 8/10/2066)

^dStay-at-home was defined as “all non-essential services, such as dine-in restaurants, bars, social venues, gyms, fitness studios, and convention centers, are shut down. Essential services, such as groceries, pharmacies, gas stations, food banks, convenience stores, and delivery restaurants, remain open. Banks, local governments that provide services, and law enforcement agencies also remain open”

Table 10 (4.6) Characteristics associated with non-adherence with and non-support for COVID-19 mitigation measures**Table 6** Characteristics associated with non-adherence with and non-support for COVID-19 mitigation measures

Non-adherence: aPRs for neither being in quarantine nor spending most of the time at home						
	Nations US and Australia <i>n</i> = 4537			Cities New York and Los Angeles <i>n</i> = 1032		
	aPR	95% CI	<i>P</i>	aPR	95% CI	<i>P</i>
Gender ^a (reference: Male)						
Female	0.81	(0.72, 0.91)	0.001	0.67	(0.48, 0.93)	0.016
Age group, years (reference: ≥65)						
18–24	0.59	(0.46, 0.76)	< 0.001	0.65	(0.29, 1.44)	0.29
25–44	0.88	(0.74, 1.04)	0.13	1.29	(0.76, 2.17)	0.34
45–64	1.07	(0.91, 1.25)	0.40	1.50	(0.91, 2.46)	0.11
Political ideology (reference: Centre)						
Very Liberal	0.64	(0.50, 0.82)	< 0.001	1.05	(0.64, 1.71)	0.85
Slightly Liberal	0.64	(0.53, 0.78)	< 0.001	0.76	(0.45, 1.27)	0.29
Slightly Conservative	0.89	(0.76, 1.05)	0.18	0.95	(0.57, 1.59)	0.85
Very Conservative	0.93	(0.76, 1.13)	0.44	1.15	(0.68, 1.94)	0.59
Apolitical and/or prefer not to say	1.22	(1.00, 1.48)	0.049	1.35	(0.74, 2.46)	0.33
Region ^b (reference: Australia and LA, respectively)						
US and NY, respectively	0.72	(0.63, 0.81)	< 0.001	1.12	(0.81, 1.54)	0.50
Non-Support: aPRs for not supporting stay-at-home orders						
	Nations US and Australia <i>n</i> = 4537			Cities New York and Los Angeles <i>n</i> = 1032		
	aPR	95% CI	<i>P</i>	aPR	95% CI	<i>P</i>
Gender ^a (reference: Male)						
Female	0.67	(0.57, 0.80)	< 0.001	0.78	(0.51, 1.19)	0.25
Age group, years (reference: ≥65)						
18–24	1.83	(1.30, 2.56)	< 0.001	1.44	(0.58, 3.56)	0.43
25–44	1.71	(1.29, 2.27)	< 0.001	1.42	(0.74, 2.73)	0.29
45–64	1.73	(1.31, 2.29)	< 0.001	1.53	(0.81, 2.86)	0.19
Political ideology (reference: Centre)						
Very Liberal	0.77	(0.56, 1.07)	0.12	0.44	(0.18, 1.07)	0.070
Slightly Liberal	0.53	(0.39, 0.72)	< 0.001	0.66	(0.31, 1.41)	0.29
Slightly Conservative	0.90	(0.70, 1.15)	0.40	2.14	(1.20, 3.83)	0.010
Very Conservative	1.24	(0.96, 1.60)	0.11	2.04	(1.09, 3.82)	0.027
Apolitical and/or prefer not to say	1.13	(0.84, 1.53)	0.41	0.96	(0.40, 2.29)	0.92
Region ^b (reference: Australia and LA, respectively)						
US and NY, respectively	0.90	(0.75, 1.09)	0.28	1.27	(0.84, 1.93)	0.25

^aFor the multivariable analysis, respondents who reported a gender other than Male or Female (i.e., "Other," *n* = 4 [2 in the US sample, 2 in the Australian sample]) were excluded due to small cell sizes

^bRegional reference groups were chosen to represent estimated prevalence ratios for dependent variables in high versus low SARS-CoV-2 prevalence regions

an economic recession and open-endedness of COVID-19 mitigation measures (79.2 and 72.2%, respectively) (Fig. 2).

Consistent across regions, respondents reported that COVID-19 and mitigation strategies have caused moderate to extreme disruption of social life (75.3%), family life (41.0%), work/studies (43.5%), productivity

(41.6%), physical activity (45.1%), sexual activity (23.6%), and sleep patterns (39.3%) (Fig. 3). Overall, 1999 respondents (35.9%) reported exercising less frequently, and 409 (7.4%) reported concerning weight gain (Fig. 4). Daily outdoor light exposure was reduced by 1 h or more in 2279 respondents (40.9%). The estimated percentage of virtual interactions

Table 11 (4.7) Prevalences of adverse mental health symptoms**Table 7** Prevalences of adverse mental health symptoms

Adverse mental health symptoms	Overall (N = 5573)		US (N = 3010)		NY (N = 507)		LA (N = 525)		AU (N = 1531)	
Anxiety Symptoms ^a										
Mean GAD-2 Score (SD)	1.59	1.810	1.60	1.847	1.64	1.799	1.61	1.745	1.57	1.759
No. with positive screens (%)	1303	(23.4)	712	(23.7)	129	(25.4)	124	(23.6)	338	(22.1)
Depression Symptoms ^b										
Mean PHQ-2 Score (SD)	1.39	1.750	1.33	1.749	1.43	1.651	1.49	1.780	1.49	1.780
No. with positive screens (%)	1172	(21.0)	617	(20.5)	115	(22.7)	105	(20.0)	335	(21.9)
Anxiety or Depression Symptoms										
No. with positive screens (%)	1622	(29.1)	872	(29.0)	162	(32.0)	150	(28.6)	438	(28.6)
Insomnia Symptoms ^c										
Mean SCI-02 Score (SD)	5.32	2.559	5.32	2.562	5.49	2.446	5.34	2.590	5.24	2.573
No. with positive screens (%)	1029	(18.5)	549	(18.2)	77	(15.2)	97	(18.5)	306	(20.0)

Survey responses are reported using descriptive statistics as indicated, including number of respondents (No.), percentage of respondents (%), mean, and standard deviation (sd)

^aSymptoms of an anxiety disorder were assessed using the Generalized Anxiety Disorder 2-item (GAD-2) subscale of the Patient Health Questionnaire 4-item (PHQ-4). Respondents who scored ≥ 3 out of 6 on the GAD-2 were considered symptomatic

^bSymptoms of a depressive disorder were assessed using the Patient Health Questionnaire 2-item (PHQ-2) subscale of the PHQ-4. Respondents who scored ≥ 3 out of 6 on the PHQ-2 were considered symptomatic

^cSymptoms of insomnia were assessed using the Sleep Condition Indicator 2-item (SCI-02). Respondents who scored ≤ 2 out of 8 on the SCI-02 were considered symptomatic

(versus face-to-face) increased from 14.6 to 66.1%, and 1786 respondents (32.0%) reported more than 1 h increase in daily screen time.

Discussion

Resounding adherence with and support for strict COVID-19 mitigation measures was demonstrated in representative samples from the United States and Australia, despite the broad disruption these mitigation measures had on their social lives and daily routines, and their concerns about the economic consequences of such measures. Although 91.4% of respondents reported they believed they would never be infected with SARS-CoV-2 (range of samples, 89.2–92.6%), controlling COVID-19 was a top public priority at the outset of the pandemic. Contrary to negative public attitudes about and low adherence with recommended mitigation during the last pandemic [17, 18] declared by the World Health Organization for novel influenza A (H1N1) in 2009 [19], the initial public response to the COVID-19 pandemic represented a hitherto unprecedented level of adherence with public health emergency measures that has had and will continue to have a profound impact on economics and public life.

These results demonstrate an enhanced public adherence with stay-at-home orders in the US compared to reported adherence during the weeks before such orders were initially widely implemented [20]. Recently published data from a convenience sample suggest that one month later (May 2020), nearly half of adults in the

UK were intentionally non-adherent with government-imposed mitigation measures [21]. Differences in the survey sampling methodology, the questions used to assess adherence with mitigation policies, recruitment timeframe, and study populations make it difficult to make direct comparisons of these results, however, which are not consistent with our findings in May 2020 among US adults, who reported sustained adherence to and support for stay-at-home orders and nonessential business closures [22]. Our findings represent one of the earliest assessments of mental health and life impact of the COVID-19 pandemic and its mitigation, having been administered in early April 2020, near the onset of initial stay-at-home orders in the US and Australia. They reveal that the adverse life impact and mental health symptoms observed throughout the pandemic—including significant disruption of daily life and two- to three-fold increased prevalences of anxiety and depressive disorder symptoms compared with pre-pandemic estimates [23–31]—were evident within a month after the pandemic was declared by the WHO, in regions and countries with both high and low prevalences of COVID-19. These broad impacts of the COVID-19 pandemic and its mitigation are similar to those observed during previous infectious disease outbreaks [32–34]. These findings may also provide insight into behavioural countermeasures related to sleep, exercise, and diet that may reduce adverse health consequences of COVID-19 mitigation measures.

Strengths of this study include rapid and largescale assessment of public adherence, priorities, and life impacts

Table 12 (4.8) Characteristics associated with adverse mental health symptoms**Table 8** Characteristics associated with adverse mental health symptoms**For symptoms of an anxiety or depressive disorder**

	Nations (US and Australia [<i>n</i> = 4537])			Cities (New York and Los Angeles [<i>n</i> = 1032])		
	aPR	95% CI	<i>P</i>	aPR	95% CI	<i>P</i>
Gender ^a (reference: Male)						
Female	1.48	(1.34, 1.63)	< 0.001	1.49	(1.23, 1.81)	< 0.001
Age group, years (reference: ≥65)						
18–24	2.21	(1.85, 2.64)	< 0.001	3.28	(2.20, 4.90)	< 0.001
25–44	2.02	(1.72, 2.38)	< 0.001	2.78	(1.93, 3.99)	< 0.001
45–64	1.33	(1.12, 1.58)	0.001	2.07	(1.43, 2.98)	< 0.001
Political ideology (reference: Centre)						
Very Liberal	1.28	(1.12, 1.46)	< 0.001	1.38	(1.07, 1.80)	0.014
Slightly Liberal	1.00	(0.88, 1.14)	0.99	1.13	(0.86, 1.48)	0.38
Slightly Conservative	0.89	(0.77, 1.02)	0.099	1.15	(0.84, 1.58)	0.38
Very Conservative	0.94	(0.80, 1.10)	0.44	1.02	(0.71, 1.48)	0.90
Apolitical and/or prefer not to say	0.91	(0.77, 1.08)	0.28	1.12	(0.79, 1.58)	0.53
Region ^b (reference: Australia and LA, respectively)						
US and NY, respectively	0.97	(0.88, 1.07)	0.49	1.13	(0.95, 1.35)	0.18
Self-reported quarantine or spending the majority of time at home (reference: No)						
Yes, Spending the majority of time at home	1.32	(1.14, 1.53)	< 0.001	1.22	(0.86, 1.74)	0.27
Yes, Quarantine	1.77	(1.52, 2.05)	< 0.001	1.52	(1.07, 2.15)	0.018

For symptoms of insomnia

	Nations (US and Australia [<i>n</i> = 4537])			Cities (New York and Los Angeles [<i>n</i> = 1032])		
	aPR	95% CI	<i>P</i>	aPR	95% CI	<i>P</i>
Gender ^a (reference: Male)						
Female	1.66	(1.46, 1.90)	< 0.001	1.81	(1.35, 2.42)	< 0.001
Age group, years (reference: ≥65)						
18–24	1.00	(0.79, 1.27)	0.98	0.73	(0.41, 1.31)	0.29
25–44	1.01	(0.84, 1.22)	0.92	1.02	(0.69, 1.52)	0.92
45–64	1.25	(1.04, 1.49)	0.015	1.09	(0.74, 1.59)	0.66
Political ideology (reference: Centre)						
Very Liberal	0.96	(0.78, 1.19)	0.71	1.16	(0.78, 1.73)	0.47
Slightly Liberal	0.95	(0.80, 1.13)	0.60	0.95	(0.64, 1.41)	0.79
Slightly Conservative	0.78	(0.65, 0.94)	0.011	1.02	(0.66, 1.59)	0.93
Very Conservative	0.98	(0.80, 1.20)	0.84	0.96	(0.58, 1.59)	0.87
Apolitical and/or prefer not to say	1.03	(0.83, 1.27)	0.82	0.86	(0.47, 1.59)	0.64
Region ^b (reference: Australia and LA, respectively)						
US and NY, respectively	0.88	(0.77, 1.00)	0.058	0.83	(0.63, 1.08)	0.170
Self-reported quarantine or spending the majority of time at home (reference: No)						
Yes, Spending the majority of time at home	1.22	(1.02, 1.46)	0.027	1.04	(0.65, 1.67)	0.86
Yes, Quarantine	1.36	(1.13, 1.65)	0.001	1.31	(0.82, 2.10)	0.26

^aFor the multivariable analysis, respondents who reported a gender other than Male or Female (ie, "Other", *n* = 4 [2 in the US sample, 2 in the Australian sample]) were excluded due to small cell sizes

^bRegional reference groups were chosen to represent estimated prevalence ratios for dependent variables in high versus low SARS-CoV-2 prevalence regions

related to COVID-19 and its mitigation in representative samples from developed nations and cities with high and low SARS-CoV-2 prevalences near the onset of the pandemic and widespread stay-at-home orders, enabling comparisons across jurisdictions at a simultaneous time-point using consistent questions. Limitations include self-report measures of behaviours, which are subject to recall, response, and social desirability biases. Survey samples also have potential non-response and self-selection biases among respondents, and while quota sampling was used to improve sample representativeness in each region, Internet-based samples may not fully represent the 2020 US and Australian populations. However, the high response rate (63.9%) and consistency of responses across cities and countries despite vastly different rates of SARS-CoV-2 infection, governments, and mitigation strategies support the robustness of our findings.

As controversies over the legality [35] and balance between duration and nature of mitigation strategies and related consequences mounted following their implementation in the second quarter of 2020, with the prospect of repeated and protracted stay-at-home orders being recommended over the next 2 years [36], rigorous assessment of public priorities, adherence, and life impact will be paramount. Over the past year, Australia capitalized on the broad support for stringent mitigation measures documented herein, implementing widescale testing, contact tracing, and, in some cases, strict mitigation measures (eg, mandatory mask usage in public, physical distancing, and quarantining as necessary to contain regional outbreaks). In contrast, the United States did not capitalize on this broad initial support for stringent mitigation measures, which were effective in reducing community mobility [37] and slowing community transmission of SARS-CoV-2 [38]. Jurisdictions across the US opted instead to lift restrictions, which was associated with increased mobility [39], before testing for SARS-CoV-2 infection was readily available and widespread community transmission of COVID-19 was contained. These are among policies that a recent *Lancet Commission* deemed to have substantially contributed to excess preventable COVID-19 deaths in the US compared with other high-income countries [40]. Notably, as of December 27, 2020, the cumulative COVID-19 death rate in Australia was 3.6 deaths per 100,000 population, with 0 new deaths in the prior week, and the COVID-19 death rate in the United States was 99.1 deaths per 100,000 population, with 16,864 new deaths in the prior week (5.1 deaths per 100,000 population) [41]. The weekly death rate in the US in the last full week of December was more than 40% greater than the cumulative per capita death rate during the entire pandemic in Australia.

Conclusions

In early April 2020, within 1 month of the declaration of the COVID-19 pandemic, US and Australian adults reported widespread adherence with stringent mitigation policies, and strongly supported continued government-imposed stay-at-home orders for as long as necessary to contain the COVID-19 pandemic, despite the considerable sacrifices that these measures required, and the potentially significant economic consequences. Markedly elevated prevalences of adverse mental health symptoms compared to pre-pandemic estimates were found in both nations and cities, and an extensive degree of life disruption attributed to COVID-19 was documented. These data highlight that respondents of younger age, female gender, and those in quarantine or spending most of the time at home more commonly experienced anxiety and depression symptoms than persons of other demographic groups, regardless of whether they were in regions with high or low SARS-CoV-2 prevalence. Timely dissemination of routine surveillance of public attitudes, behaviours, and beliefs regarding mitigation measures that require public support and adherence is important to inform strategies to improve adherence. They further underscore the importance of assessment of the potential life and mental health impacts of the pandemic and its mitigation, and may be used to inform policymakers during both the current and future infectious disease outbreaks.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12889-021-10410-x>.

Additional file 1. Respondent 2019 Place of Residency in Nationwide Samples. Description of data: Respondents reported their primary place of residence between October and December 2019. For the nationwide US sample, the distribution of respondents among the fifty states and Washington District of Columbia are reported in comparison to population estimates from the US Census Bureau as of July 2019 [42]. For the nationwide AU sample, the distribution of respondents among the six states and two internal territories are reported in comparison to population estimates from the AU Bureau of Statistics as of September 2019 [43]. In total, 44/4541 respondents (0.97%) lived outside of the US or AU between October and December 2019 and were currently residing in these regions. These data support the nationwide samples as geographically representative by state or territory.

Abbreviations

AU: Australia; COVID-19: Coronavirus disease 2019; GAD-2: 2-item Generalized Anxiety Disorder; HITS: Hurt-Insult-Threaten-Scream; H1N1: Novel influenza A; LA: Los Angeles metropolitan area; MEQ: Morningness-Eveningness Questionnaire; No.: Number; NY: New York City metropolitan area; OSA50: Obstructive Sleep Apnoea 50; PHQ-2: 2-item Patient Health Questionnaire; PHQ-4: 4-item Patient Health Questionnaire; PSS-4: 4-item Perceived Stress Scale; SCI-02: Short-Form Sleep Condition Indicator; sd: Standard deviation; μ MCTQ: μ short Munich ChronoType Questionnaire; US: United States of America

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Authors' contributions

MÉC had full access to all data in the study and takes responsibility for the integrity of the data and accuracy of data analyses. MÉC, MEH, SMWR, and CAC contributed to the study concept and design. MÉC, MEH, RR, LKB, ERF-C, SMWR, and CAC contributed to the development of the survey instrument. MÉC acquired and analysed the survey data. MÉC, SMWR, and CAC were all substantially involved in writing the first draft of the manuscript. MÉC and RR created the figures and tables. MEH, SMWR, and CAC had supervisory roles. All authors contributed critical revision of the manuscript for important intellectual content and approved the final manuscript. All authors have agreed both to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

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Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author upon reasonable request.

Ethics approval and consent to participate

The study protocol was approved by the Monash University Human Research Ethics Committee (#24036) and conducted in accordance with ethical guidelines. This activity was also reviewed by the United States Centers for Disease Control and Prevention (CDC), which affirmed that the activity was conducted consistent with applicable federal law and CDC policies for the protection of human participants from research risks: 45 Code of Federal Regulations (CFR) part 46, 21 CFR part 56; 42 United States Code (USC) Section 241(d); 5 USC Section 552a; 44 USC Section 3501 et seq. Respondents were informed of the study purposes and provided informed consent electronically prior to commencement. Investigators received anonymised responses.

Consent for publication

Not applicable.

Competing interests

CAC reports grants from Cephalon Inc., Jazz Pharmaceuticals Plc., Inc., Philips Respironics, Inc., Regeneron Pharmaceuticals, and Sanofi S.A.; and personal fees from Institute of Digital Media and Child Development, Klarman Family Foundation, Teva Pharma Australia, and Vanda Pharmaceuticals. In addition, CAC holds an equity interest in Vanda Pharmaceuticals, Inc. CAC receives royalties from Philips Respironics, Inc. for the Actiwatch-2 and Actiwatch-Spectrum devices. Interests for CAC were reviewed and managed by Brigham and Women's Hospital and Mass General Brigham in accordance with their conflict of interest policies. MÉC, MEH, RR, LKB, ERF-C, and SMWR declare no potential conflicts of interest.

Author details

¹Turner Institute for Brain and Mental Health, Monash University, Melbourne, VIC 3800, Australia. ²Institute for Breathing and Sleep, Austin Health, Melbourne, VIC 3084, Australia. ³Department of Psychiatry, Brigham and Women's Hospital, Boston, MA 02115, USA. ⁴Department of Medicine, University of Melbourne, Melbourne, VIC 3010, Australia. ⁵Division of Sleep and Circadian Disorders, Departments of Medicine and Neurology, Brigham and Women's Hospital, Boston, MA 02115, USA. ⁶Division of Sleep Medicine, Harvard Medical School, Boston, MA 02115, USA.

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SUMMARY OF FINDINGS

The Original Investigation presented in Chapter Four revealed that early during the COVID-19 pandemic, both in regions with low and high COVID-19 prevalence, there was widespread public support for and adherence with stringent mitigation policies despite the considerable life disruption. The survey was administered within a few weeks of the declaration of COVID-19 as a pandemic by the WHO (**World Health Organization, 2020d**), which was followed by the implementation of widespread stay-at-home orders for the first time in a century. Despite resounding adherence with and support for stringent mitigation policies in all surveyed regions, the continuance of such stringent policies differed considerably between the US and Australia. US states had largely lifted stay-at-home orders by the end of May 2020 (**Moreland et al., 2020**), whereas in Australia, the city of Melbourne, Victoria maintained one of the longest global lockdowns, which lasted 111 days into October 2020 (**Oxner, 2020; Victoria Department of Health and Human Services, n.d.**) despite a relatively low SARS-CoV-2 prevalence compared with the US over that interval (**Dong et al., 2020**).

The Original Investigation was also one of the earliest assessments of mental health in the US and Australia during the COVID-19 pandemic. Overall, 29.1% of respondents screened positive for symptoms of anxiety or depression, with the range of samples from 28.6% in Australia to 32.0% in New York City. Although The COPE Initiative was launched in response to the pandemic and therefore did not have pre-pandemic mental health data, the early-pandemic prevalence estimates for anxiety and depression we reported were very similar to prevalence estimates derived from data collected during a contemporaneous, nearly overlapping interval early in the COVID-19 pandemic in the US, in a different study that included comparisons with data that had been collected before the pandemic began (**Ettman et al., 2020**). Based on that comparison, Ettman *et al.* reported that

the prevalence of adverse mental health symptoms was several-fold higher in the initial weeks of the COVID-19 pandemic compared with data gathered in prior years immediately before the pandemic.

The findings are also in alignment with a study of 1,013 US adults conducted during 9 through 10 April 2020 by Killgore *et al.* (**Killgore et al., 2021**), among whom 32.2% screened positive for depression symptoms via the PHQ-9 (**Kroenke et al., 2001, p.**), 17.6% screened positive for evidence of suicidal ideation via the PHQ-9 Item 9 or Beck Depression Inventory-II Item 9 (**Grothe et al., 2005**), and 25.1% screened positive for clinically significant insomnia via the Insomnia Severity Index (**Bastien et al., 2001**). The study also reported positive associations of depression symptoms and both social isolation and alcohol use, and negative associations with spending time outside in the sunshine and social support.

Interestingly, in the Original Investigation in Chapter Four, respondents residing in regions with high COVID-19 prevalence (i.e., the US and New York City) did not have a higher prevalence of symptoms of anxiety or depression compared with respondents residing in regions with low COVID-19 prevalence at that time (i.e., Australia and Los Angeles, respectively). However, spending the majority of time at home or being in quarantine were associated with anxiety or depression and insomnia symptoms, consistent with literature from prior infectious disease outbreaks (**S. K. Brooks et al., 2020; Hawryluck et al., 2004; Robertson et al., 2004**). Moreover, younger age was associated with a higher prevalence of adverse mental health symptoms, which was an early indicator of unanticipated age differences in mental health during the pandemic (**Vahia et al., 2020**). These early indicators of population-level increases in the prevalence of adverse mental health symptoms raised questions about the extent to which symptom levels would remain elevated over time, and about the long-term health consequences associated with a potentially prolonged pandemic.

CHAPTER 5: COVID-19 Vaccine Intentions in the United States—December 2020 to March 2021

PREFACE TO CHAPTER 5

While NPIs provide immediate and non-specific measures to reduce community transmission of infectious diseases, safe and effective pharmaceutical interventions (i.e., vaccines) designed specifically to induce population-level immunity against pathogens or viruses have greater potential to (1) prevent infection through vaccine-induced immunity and (2) protect against severe illness when there are breakthrough infections. Therefore, understanding willingness to obtain COVID-19 vaccines during this time interval was of critical importance, as identifying groups that were disproportionately vaccine hesitant could inform tailored vaccine education programs to enhance national and global vaccine uptake and accelerate the timeline of reaching population-level immunity.

The Original Investigation in Chapter Five (**Czeisler, Rajaratnam, Howard, et al., 2021**), which was posted as a preprint on *medRxiv* and is currently submitted for peer review, was conducted to address knowledge gaps in public vaccine intentions. Specifically, through assessment of public vaccine intentions in 6 through 27 December 2020 and 16 February through 8 March 2021, we sought to evaluate (1) groups that remained disproportionately vaccine hesitant, and identify common reasons for hesitancy, (2) vaccine intentions among pregnant persons, who were excluded from the initial largescale clinical trials, (3) intentions to vaccinate children among parents and caregivers, and (4) potential acceptance of COVID-19 vaccine boosters designed to combat coronavirus variants. The chapter concludes with a brief overview of findings from the Original Investigation.

CHAPTER FIVE: Vaccine Intentions in the United States—December 2020 to March 2021

Czeisler MÉ, Rajaratnam SMW, Howard ME, Czeisler CA. COVID-19 Vaccine Intentions in the United States—December 2020 to March 2021. medRxiv [Preprint]. 2021 May 16: 2021.05.16.21257290. doi: 10.1101/2021.05.16.21257290.

Title

COVID-19 Vaccine Intentions in the United States—December 2020 to March 2021

Authors

Mark É Czeisler, AB,¹⁻³ Shantha MW Rajaratnam, PhD,^{1,2,4,5} Mark E Howard, MBBS, PhD,^{1,2,6} Charles A Czeisler, PhD, MD^{1,4,5}

1. Turner Institute for Brain and Mental Health, Monash University, Melbourne, Victoria, Australia
2. Institute for Breathing and Sleep, Austin Health, Melbourne, Victoria, Australia
3. Department of Psychiatry, Brigham & Women's Hospital, Boston, Massachusetts, United States
4. Division of Sleep and Circadian Disorders, Departments of Medicine and Neurology, Brigham & Women's Hospital, Boston, Massachusetts, United States
5. Division of Sleep Medicine, Harvard Medical School, Boston, Massachusetts, United States
6. Division of Medicine, University of Melbourne, Melbourne, Victoria, Australia

Corresponding Author

Mark É. Czeisler, AB, Australian-American Fulbright Scholar and PhD Candidate
Turner Institute for Brain and Mental Health, Monash University
Level 5, 18 Innovation Walk, Clayton Campus, Clayton, 3800, Victoria, Australia
Telephone: +1 (617) 571-7887; Email: mark.czeisler@fulbrightmail.org

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Key Points

Question

What are COVID-19 vaccines intentions, for adults and for children under their care?

Findings

Two-thirds of 5256 US adults surveyed in early 2021 indicated they would obtain a COVID-19 vaccine as soon as possible. Intentions for children and booster vaccines largely matched personal vaccine intentions. Refusal was more common among adults who were younger, female, Black, very politically conservative, less educated, less adherent with COVID-19 prevention behaviors (eg, wearing masks), had more medical mistrust, or had not received influenza vaccines in 2020.

Meaning

Tailored vaccine promotion efforts and vaccine programs may improve vaccine uptake and contribute to US immunity against COVID-19.

Abstract

Importance

SARS-CoV-2 containment is estimated to require attainment of high (>80%) post-infection and post-vaccination population immunity.

Objective

To assess COVID-19 vaccine intentions among US adults and their children, and reasons for vaccine hesitancy among potential refusers.

Design

Internet-based surveys were administered cross-sectionally to US adults during December 2020 and February to March 2021 (March-2021).

Setting

Surveys were administered through Qualtrics using demographic quota sampling.

Participants

A large, demographically diverse sample of 10,444 US adults (response rate, 63.9%).

Main Outcomes and Measures

COVID-19 vaccine uptake, intentions, and reasons for potential refusal. Adults living with or caring for children aged 2 to 18 years were asked about their intent to have their children vaccinated. Multivariable weighted logistic regression models were used to estimate adjusted odds ratios for vaccine refusal.

Results

Of 5256 March-2021 respondents, 3467 (66.0%) reported they would definitely or most likely obtain a COVID-19 vaccine as soon as possible (ASAP Obtainers), and an additional 478 (9.1%) reported they were waiting for more safety and efficacy data before obtaining the vaccine. Intentions for children and willingness to receive a booster shot largely matched personal COVID-19 vaccination intentions. Vaccine refusal (ie, neither ASAP Obtainers nor waiting for more safety and efficacy data) was most strongly associated with not having obtained an influenza vaccine in 2020 (adjusted odds ratio, 4.11 [95% CI, 3.05-5.54]), less frequent mask usage (eg, rarely or never versus always or often, 3.92 [2.52-6.10]) or social gathering avoidance (eg, rarely or never versus always or often, 2.65 [1.95-3.60]), younger age (eg, aged 18-24 versus over 65 years, 3.88 [2.02-7.46]), and more conservative political ideology (eg, very conservative versus very liberal, 3.58 [2.16-5.94]); all $P < .001$.

Conclusions and Relevance

Three-quarters of March-2021 respondents in our large, demographically diverse sample of US adults reported they would likely obtain a COVID-19 vaccine, and 60% of adults living with or caring for children plan to have them vaccinated as soon as possible. With an estimated 27% of the US population having been infected with SARS-CoV-2, once vaccines are available to children and they have been vaccinated, combined post-infection and post-vaccination immunity will approach 80% of the US population in 2021, even without further infections.

Main Text

Introduction

As of mid-May 2021, the US Food & Drug Administration (FDA) has granted Emergency Use Authorization for 3 coronavirus disease 2019 (COVID-19) vaccines (Pfizer-BioNTech, Moderna, and Janssen),¹ and nearly 60% of US adults have been fully (120 million) or partially (35 million) vaccinated.² Consistent with vaccine prioritization,³ ~85% of adults aged 65-plus years have received vaccines.² Early indicators demonstrate high efficacy of these vaccines in reducing severe acute respiratory coronavirus syndrome 2 (SARS-CoV-2) transmission and severe COVID-19 outcomes.⁴⁻¹⁴ These represent remarkable public health and scientific achievements. Yet, several obstacles remain to containing COVID-19 in the US and globally.

First, until recently, the rate-limiting steps in the US have been vaccine supplies and delivery capacity. Only now that supply is plentiful has vaccine hesitancy started to present as a barrier to vaccination *en masse*. Prior studies provided information for tailored educational programs to enhance informed COVID-19 vaccine decision-making.¹⁵⁻²³ Understanding groups that remain disproportionately vaccine hesitant, and common reasons for hesitancy, are critical to promote vaccination.

Second, initial COVID-19 vaccine clinical trials excluded individuals aged under 16 years and pregnant persons. Encouragingly, recent studies have led to Emergency Use Authorization of the Pfizer-BioNTech COVID-19 vaccine for children aged 12-15 years,^{24,25} with studies of additional age groups underway. Moreover, COVID-19 mRNA vaccines are safe and effective in pregnant people^{26,27} and confer immunity to

neonates,²⁸ which is particularly important given substantially elevated risk of adverse maternal and neonatal health outcomes from SARS-CoV-2 infection.²⁹⁻³³

Third, vaccine-evasive coronavirus variants could threaten post-vaccination immunity. Fortunately, the developed vaccines are effective against most common variants,^{10,34} though more evasive variants have started to appear,³⁵ some of which may require modified COVID-19 vaccine boosters.^{36,37} Understanding COVID-19 booster vaccine intentions is therefore important.

We therefore assessed COVID-19 vaccine uptake, intentions, and reasons for hesitancy in a large, diverse sample of US adults, including pregnant people. We examined child vaccine intentions among parents and caregivers, and willingness to receive variant-protective COVID-19 booster vaccines.

Methods

Setting and Participants

From December 6-27, 2020 (December-2020) and February 16 to March 8, 2021 (March-2021), anonymous, Internet-based surveys were administered to non-overlapping 18-plus year-old US residents for The COVID-19 Outbreak Public Evaluation (COPE) Initiative (www.thecopeinitiative.org). Surveys were administered to panels maintained by Qualtrics. Nonprobability demographic quota sampling and survey weighting were employed to match national US adult population 2019 American Community Survey estimates for sex, age, and race/ethnicity. Weighted values are reported unless specified.

Survey Instrument

The December-2020 and March-2021 survey instruments comprised 136 and 160 items, respectively, and included questions about demographics, pandemic-related attitudes and behaviors, and mental health. Respondents were not informed of survey topics prior to commencement.

Key Definitions

Vaccine Intentions

COVID-19 vaccination intentions were assessed using the question, “If an FDA-approved vaccine to protect against COVID-19 were widely accessible, would you get one as soon as possible?” Respondents answered using a five-item Likert scale: “No, definitely not,” “Unlikely,” “Maybe/Not sure,” “Most likely,” or “Yes, definitely”. March-2021 respondents could also answer that they had been vaccinated against COVID-19. Respondents who selected “No, definitely not,” “Unlikely,” or “Maybe/Not sure” selected among 8 reasons for not obtaining a vaccine as soon as possible (ASAP), with multiple selections allowed: waiting for more safety and efficacy data, low COVID-19 risk perception, beliefs the vaccine would not protect against COVID-19, the approval process was rushed, or that all vaccines are dangerous, concern of a hidden purpose, religious refusal, and other. March-2021 respondents who reported living with or caring for persons aged 2 to 18 years were asked about COVID-19 vaccination intentions for their children. All March-2021 respondents were asked about potential COVID-19 booster intentions.

Characteristics

Demographic characteristics assessed included sex, age, race/ethnicity, education attainment, pregnancy, parental or unpaid caregiver roles, and political ideology. Medical mistrust was assessed using the Medical Mistrust Index (MMI),³⁸ with responses categorized into 4 levels (0-6, 7-13, 14-17, and 18-21). Higher scores reflect more mistrust. Respondents reported whether they had received an influenza vaccine last year or ever tested SARS-CoV-2-positive, and past-week frequency of mask usage in public and avoidance of 10-plus-person gatherings using 5-item Likert scales: never, rarely, sometimes, often, and always.³⁹

Statistical Analysis

Intentions to receive COVID-19 vaccines in December-2020 and March-2021 were grouped as Decliners (“No, definitely not” or “Unlikely”), Undecideds (“Maybe/Not sure”), or ASAP Obtainers (“Most likely” or “Yes, definitely,” plus March-2021 respondents who had already been vaccinated). A category of Overall Obtainers was created as ASAP Obtainers, plus respondents waiting for more safety and efficacy data (a subset of Decliners and Undecideds). Chi-square tests with design effect correction factors were used to test for differences between March-2021 subgroups (eg, male versus female respondents), and between the December-2020 and March-2021 samples within subgroups (eg, non-overlapping female respondents over time). Bonferroni adjustments of 9 and 33, respectively, were applied to account for multiple comparisons.

Weighted logistic regression models were used to estimate unadjusted and adjusted odds ratios (aORs) and 95% confidence intervals (CIs) for vaccine Refusal (ie, Decliners, minus those waiting for safety and efficacy data) among March-2021

respondents. Multivariable models included sex, age group, race/ethnicity, education attainment, parental or unpaid caregiving roles, political ideology, and health insurance as covariates. To avoid collinearity, separate models were run for frequency of mask usage and avoiding gatherings, MMI score, and past-year influenza vaccination. Among female respondents of childbearing age, a regression was run based on pregnancy status. To account for 11 comparisons, point estimates are reported with 95% CIs that were estimated at the 99.545% confidence level and Bonferroni-adjusted ($n=11$) P .

Among vaccine Decliners and Undecideds, crosstabs of select characteristics and reasons for hesitancy were calculated. Intentions for vaccinating children among March-2021 respondents living with or caring for children, and acceptance of potential vaccine booster doses among all March-2021 respondents, were described based on personal vaccine intentions. To identify factors associated with indecision versus complete Refusal, weighted logistic regression models were used to estimate ORs and aORs for indecision (ie, responding Maybe versus Unlikely or Definitely not, or selecting that they were waiting for more safety and efficacy data versus other reasons). Multivariable models included all demographics listed in the primary regression models. To account for 7 comparisons, point estimates are reported with 95% CIs that were estimated at the 99.286% confidence level and Bonferroni-adjusted ($n=7$) P .

Data were cleaned in Python version 3.7.8 (Python Software Foundation). Calculations were made in R version 4.0.2 (The R Project for Statistical Computing) using the R survey package version 3.29. Statistical significance was set at 2-sided $P<.05$. Detailed methods are in the Supplement.

Study Review

Respondents provided informed electronic consent. The Monash University Human Research Ethics Committee (Melbourne, Australia) reviewed and approved the protocol. Given exclusive recruitment of US residents in 2021, the Mass General Brigham Institutional Review Board (Boston, Massachusetts) also reviewed the protocol prior to the March-2021 wave and determined that this public health surveillance activity did not require institutional review board review. This study followed the American Association for Public Opinion Research guidelines.

Results

Overall, 10,469 of 16,384 (response rate, 63.9%) invited eligible adults completed surveys. Of these, 10,444 (99.8%) reported sex, age, race, and ethnicity used for survey weighting and were included in this analysis (eFigure 1). Of analyzed respondents, 5188 completed December-2020 surveys, and 5256 completed March-2021 surveys (Table 1).

Of December-2020 respondents, 909 (17.5%) respondents were Decliners, 976 (18.8%) were Undecideds, and 3303 (63.7%) were ASAP Obtainers (Table 1). Of 5256 March-2021 respondents, 1053 (20.0%) were Decliners, 736 (14.0%) were Undecideds, and 3467 (66.0%) were ASAP Obtainers. The percentage of Overall Obtainers was lower in March-2021 as compared to December-2020 (3944 of 5256 [75.0%], 4087 of 5188 [78.8%], respectively, $P=.009$). Within demographic subgroups across waves, the prevalence of Overall Obtainers was lower in March-2021 as compared to December-2020 among male respondents (2099 of 2628 [79.9%], 2222 of 2594 [85.7%], $P=.001$), adults aged 18 to 24 years (422 of 626 [67.4%], 507 of 618 [82.0%], $P=.005$), and White

respondents (2365 of 3151 [75.1%], 2491 of 3110 [80.1%], $P<.001$). Between all subgroups in Table 1, the prevalence of Overall Obtainers differed significantly. In general, the prevalence was higher among respondents who were male versus female, older versus younger, Asian or Hispanic compared with Black, liberal versus conservative, and, among female respondents of childbearing age, those who were pregnant versus those who were not. The prevalence of Overall Obtainers was also higher among respondents who wore masks in public or avoided social gatherings more frequently, had received or planned to receive the influenza vaccine, and had lower levels of medical mistrust.

Multivariable analysis of March-2021 respondents revealed that odds of vaccine Refusal were highest among adults who had not received an influenza vaccine (aOR, 4.11 [95% CI, 3.05-5.54], $P<.001$) (Figure 1, eTable 1). Refusal was also positively associated with less frequent mask usage (eg, rarely or never versus always or often, .92 [2.52-6.10], $P<.001$) or gathering avoidance (eg, rarely or never versus always or often, 2.65 [1.95-3.60], $P<.001$), younger age (eg, aged 18-24 versus 65-plus years, 3.88 [2.02-7.46], $P<.001$), more conservative political ideology (eg, very conservative versus very liberal, 3.58 [2.16-5.94], $P<.001$), lower education attainment (eg, high school diploma or less versus more than bachelor's degree, 3.43 [2.11-5.59], $P<.001$), higher levels of medical mistrust (MMI scores 18-21 versus 0-6, 2.11 [1.10-4.07], $P<.001$), female versus sex (1.51 [1.16-1.96], $P<.001$), and Black (1.60 [1.10-2.33], $P=.004$) or other (1.99 [1.15-3.42], $P=.004$) versus White race/ethnicity. Conversely, lower odds of vaccine refusal were observed for respondents who were of Asian versus

White race/ethnicity (.42 [.20-.90], $P=.013$), and among multigenerational caregivers versus non-caregivers (.51 [.35-.74], $P<.001$). Unadjusted ORs are in eTable 2.

Among 1789 March-2021 Undecideds or Decliners, common reasons for potentially not being ASAP Obtainers were concern that the vaccine may be risky due to rushed approval (41.8%), plans to wait 6-12 months for safety and efficacy data (26.7%), concern of a hidden purpose (25.0%), and belief that the vaccine would not offer protection from COVID-19 (24.3%) or low COVID-19 risk perception (18.0%) (Table 2). Comparing March-2021 ($n=1789$) versus December-2021 ($n=1885$) respondents who were Undecideds or Decliners, the percentage who were planning to wait for more data decreased over time (478 [26.7%], 784 [41.6%], respectively, $P<.001$), as did the percentage who reported concerns that the approval process had been rushed (746 [41.7%], 919 [48.7%], $P=.004$). The percentage who were concerned of a hidden purpose was increased over time (446 [24.9%], 358 [19.0%], $P=.008$).

Of March-2021 Undecideds or Decliners, aORs for being an Undecided rather than a Decliner were higher among individuals aged 18-24 versus 65-plus years (aOR, 2.30 [95% CI, 1.08-4.90], $P=.021$), multigenerational caregivers versus non-caregivers (1.58 [1.01-2.47], $P=.042$), and those with more centrist versus very conservative political ideology (Figure 2A, eTable 3). Lower aORs for being an Undecided were found for individuals with a high school diploma or less versus more than a bachelor's degree (.42 [.22-.81], $P=.003$). Regarding waiting for more safety and efficacy data, aORs were significantly lower for adults aged 25-44 versus 65-plus years (.41 [.19-.89], $P=.013$) (Figure 2B, eTable 5). No other significant demographic associations were found. Unadjusted ORs are in eTables 4 and 6.

Among 2160 March-2021 respondents living with or caring for children aged 2-18 years, intentions to vaccinate those children were similar to those for adults (1305 [60.4%] ASAP Obtainers 463 [18.1%] Undecideds, 463 [21.4%] Decliners) (Figure 3A). Of 1305 ASAP Obtainers for their children aged 2-18 years, 1221 (93.5%) were ASAP Obtainers for themselves, while only 39 (3.0%) were Decliners for themselves. Conversely, of 463 Decliners for their children aged 2-18 years, only 119 (25.7%) were ASAP Obtainers for themselves, while 261 (56.5%) were Decliners for themselves. Similar relationships with personal vaccine intentions were found for booster vaccine intentions. Of 3074 March-2021 ASAP booster Obtainers, 2928 (95.2%) were ASAP Obtainers of the original COVID-19 vaccine, while Decliners accounted for just 49 (1.6%) of these ASAP booster Obtainers (Figure 3B).

Discussion

Nearly two-thirds of 5256 US adults surveyed during mid-February to early March 2021 reported they had obtained or would definitely or most likely obtain an FDA-approved COVID-19 vaccine as soon as possible, with up to three-quarters likely obtainers when including individuals waiting for more safety and efficacy data. Given that approximately 60% of the US adult population has received at least one dose of the COVID-19 vaccine as of May 15, 2021,² these data suggest that less than one-quarter of the remaining unvaccinated US adults planned to obtain vaccines ASAP, and less than one-half planned to ever be vaccinated against COVID-19. Vaccine Refusal was highest among adults who were younger, female, Black or other (versus White) race/ethnicity, very conservative politically, those with lower education attainment, more medical mistrust, lesser COVID-19 prevention behavior adherence, and those who had

not received influenza vaccines. As the US vaccine rollout faces the barriers of vaccine hesitancy in the majority of the remaining unvaccinated US adults, vaccine promotion activities tailored for these groups may improve uptake.

Nearly 70% of March-2021 pregnant females of childbearing age were ASAP obtainers. Early COVID-19 vaccine safety and efficacy among pregnant persons are encouraging.^{28,29} Higher risk of adverse clinical outcomes among pregnant persons and their neonates among individuals with SARS-CoV-2 infection,^{29,30,33} including a 22-fold increased risk of maternal mortality,⁴⁰ underscores the importance of ensuring vaccination access for this willing, at-risk population. Parental decisions about obtaining COVID-19 vaccines for their children largely matched their personal intentions, revealing that groups identified as potential vaccine refusers will likely do the same for their children. Our findings indicate that parents and caregivers intend to use the vaccine distribution infrastructure to vaccinate children under their care once emergency use authorizations are revised to expand the range of approved ages. This is particularly encouraging given that young adults and children facilitate SARS-CoV-2 transmission⁴¹⁻⁴⁴ and have sustained regional outbreaks.⁴⁵⁻⁴⁸

According to Sanche *et al.* in the CDC's *Emerging Infectious Diseases*, with an estimated R_0 of 5.7, SARS-CoV-2 containment requires approximately 82% of the population to obtain post-vaccination or post-infection immunity.⁴⁹ In Israel, which was among the world leaders in vaccination rate through mid-May 2021, COVID-19 deaths declined from 70 deaths per day in January 2021 to 0.⁵⁰ New SARS-CoV-2 infections and COVID-19 deaths have also dropped considerably in the US, where more than half of US adults have received at least one COVID-19 vaccine dose. Given that the CDC

estimates that at least 27% of US adults had been infected with SARS-CoV-2 as of December 2020,^{51,52} and considerably more since then, even if only 33% of these were vaccine refusers, combined post-vaccination and post-infection immunity among US adults should approach 76%. Thus, if half of the 9% of individuals waiting for more safety and efficacy data were to obtain the vaccine, approximately 80% of US adults would have some SARS-CoV-2 immunity. Moreover, as SARS-CoV-2 infection is particularly prevalent among those who were non-adherent with CDC COVID-19 prevention guidance,^{53,54} this group of mostly vaccine Refusers likely has more post-infection immunity. Achieving population-level immunity, however, depends on vaccination or infection of children. Fortunately, 60% of surveyed parents or caregivers for children reported being ASAP Obtainers for their children.

To achieve high levels of immunity, engaging the Undecideds (15% of March-2021 respondents) will be critical. Young age, more centrist political ideology, and multigenerational caregiver status were associated with being Undecided, and may represent high-yield demographics to incentivize uptake. Interestingly, only one-quarter of young adult Undecideds indicated that they were waiting for more vaccine safety and efficacy data, suggesting that alternative incentives should be reviewed based on prior immunization programs⁵⁵⁻⁵⁹ and investigated during the current rollout^{60,61} (eg, monetary incentives,⁶² vaccine mandates for return to campus, employer or workplace vaccination programs, or easing restrictions for vaccinated persons, such as those reported in recent CDC guidance⁶³ and the European Union's international travel ban for those fully vaccinated⁶⁴). Concurrently, ensuring equitable access to vaccines may reduce

disparities—particularly regarding internet connectivity and technology usability and literacy.⁶⁵

Monitoring and responding to SARS-CoV-2 variants will be essential. Development of vaccine boosters to combat vaccine-evasive variants is underway. Our results suggest that acceptance of COVID-19 vaccine boosters will largely reflect overall COVID-19 vaccination trends. To avoid further COVID-19 health disparities, improving vaccine uptake among groups with high levels of vaccine refusal will prove important. Furthermore, the race against variants will occur globally.^{66,67} The US is among the high-income countries with abundant vaccine supply, while many low- and middle-income countries have struggled to initiate vaccination campaigns.^{68,69}

Strengths of this study include assessment of COVID-19 vaccine and booster intentions in large, demographically diverse samples of US adults at multiple timepoints, and inclusion of diverse characteristics. Limitations include self-reported metrics that may not correlate with future behavior and Internet-based survey methods that may not fully represent the US population. However, our data for the prevalence of COVID-19 vaccine recipients as of mid-February to early March 2021 were consistent with nationwide surveillance data,⁷⁰ and 88.7% of respondents who had received 1 dose in a 2-dose regimen indicated that they planned to complete the series, consistent with CDC surveillance data (88.0%).⁷¹

Projections of US population immunity are contingent on assumptions.^{72,73} First, post-vaccination population immunity requires efficacy against infection above 80%,⁷⁴ well below current estimates.⁶ Second, evidence from other coronaviruses^{75,76} and preliminary reports of SARS-CoV-2 re-infection⁷⁷⁻⁷⁹ or breakthrough infections among

fully vaccinated individuals⁸⁰⁻⁸³ suggest both vaccination- and infection-derived immunity may be transient, requiring re-vaccination. Third, current FDA-approved vaccines are not authorized for children aged under 12 years. Fourth, most current vaccines require multiple doses for maximal efficacy, presenting a barrier to distribution.⁸⁴ However, nearly 90% of people in 2-dose COVID-19 vaccine regimens received both doses, and more than 95% of completers did so within the recommended interval between the first and second doses.⁷¹ Finally, considerable regional differences in vaccination rates will affect local transmission of the SARS-CoV-2 viral infections.

Our findings reveal that vaccine hesitancy is unlikely to prevent the US from achieving high levels of immunity against COVID-19 in 2021, and that intentions for vaccination of children and obtaining boosters largely match personal vaccine intentions. Vaccine education campaigns tailored for Undecideds, coupled with robust vaccine distribution programs, could enhance vaccine obtainment and assist in controlling the COVID-19 pandemic in the US.

Author Contributions: Mr Czeisler had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Concept and design: All authors.

Acquisition, analysis, or interpretation of data: All authors.

Drafting of the manuscript: Czeisler, Czeisler.

Critical revision of the manuscript for important intellectual content: All authors.

Statistical analysis: Mr Czeisler.

Obtained funding: All authors.

Supervision: Howard, Rajaratnam.

Conflict of Interest Disclosures: Mr Czeisler reported personal fees from Vanda Pharmaceuticals Inc. Dr Rajaratnam reported receiving grants and personal fees from Cooperative Research Centre for Alertness, Safety and Productivity, receiving grants and institutional consultancy fees from Teva Pharma Australia, and institutional consultancy fees from Vanda Pharmaceuticals, Circadian Therapeutics, BHP Billiton, and Herbert Smith Freehills. Dr Czeisler reported receiving grants and personal fees from Teva Pharma Australia, receiving grants from the National Institute of Occupational Safety and Health R01-OH-011773, receiving personal fees from and equity interest in Vanda Pharmaceuticals Inc, educational and research support from Philips Respironics Inc, an endowed professorship provided to Harvard Medical School from Cephalon, Inc,

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Table 5 (5.1). COVID-19 vaccine intentions among US adults-December 2020 and March 2021

Table 1. COVID-19 vaccine intentions among US adults—December 2020 and March 2021

	All respondents	COVID-19 vaccine intentions				Chi-square test for differences in Overall obtainers	
		Unlikely or Definitely not	Maybe or Not sure	Most likely or definitely	Overall Obtainers	By wave	By subgroup in Mar 2021
Characteristic	No. %	No. %	No. %	No. %	No. %	P	P
Total Dec 2020	5188 (100)	909 (17.5)	976 (18.8)	3303 (63.7)	4087 (78.8)	.009	-
Total Mar 2021	5256 (100)	1053 (20.0)	736 (14.0)	3467 (66.0)	3944 (75.0)		
Demographic characteristics							
Sex							
Female—Dec 2020	2594 (50.0)	627 (24.2)	612 (23.6)	1355 (52.2)	1865 (71.9)	>.99	<.001
Female—Mar 2021	2628 (50.0)	647 (24.6)	414 (15.7)	1568 (59.7)	1846 (70.2)		
Male—Dec 2020	2594 (50.0)	282 (10.9)	364 (14.0)	1948 (75.1)	2222 (85.7)	.001	
Male—Mar 2021	2628 (50.0)	406 (15.5)	323 (12.3)	1899 (72.3)	2099 (79.9)		
Age group, years							
18-24—Dec 2020	618 (11.9)	85 (13.8)	119 (19.2)	414 (67.0)	507 (82.0)	.005	<.001
18-24—Mar 2021	626 (11.9)	121 (19.4)	145 (23.2)	360 (57.4)	422 (67.4)		
25-44—Dec 2020	1782 (34.4)	310 (17.4)	325 (18.2)	1148 (64.4)	1351 (75.8)	.34	
25-44—Mar 2021	1806 (34.4)	386 (21.4)	270 (14.9)	1149 (63.7)	1302 (72.1)		
45-64—Dec 2020	1692 (32.6)	378 (22.3)	347 (20.5)	967 (57.1)	1277 (75.5)	>.99	
45-64—Mar 2021	1714 (32.6)	380 (22.2)	252 (14.7)	1082 (63.1)	1249 (72.9)		
≥65—Dec 2020	1096 (21.1)	136 (12.4)	186 (16.9)	775 (70.6)	952 (86.8)	>.99	
≥65—Mar 2021	1111 (21.1)	166 (14.9)	69 (6.2)	876 (78.9)	972 (87.5)		
Pregnancy status among women of childbearing age							
Yes—Dec 2020	205 (4.0)	20 (9.8)	46 (22.3)	139 (67.8)	167 (81.6)	>.99	<.001
Yes—Mar 2021	252 (4.8)	28 (11.1)	49 (19.6)	174 (69.2)	196 (78.0)		
No—Dec 2020	1187 (22.9)	346 (29.1)	294 (24.7)	548 (46.1)	772 (65.0)	>.99	
No—Mar 2021	1109 (21.1)	344 (31.0)	217 (19.6)	548 (49.4)	676 (60.9)		
Race/ethnicity							
White, non-Hispanic—Dec 2020	3110 (60.0)	534 (17.2)	498 (16.0)	2078 (66.8)	2491 (80.1)	<.001	<.001
White, non-Hispanic—Mar 2021	3151 (60.0)	662 (21.0)	410 (13.0)	2080 (66.0)	2365 (75.1)		
Black, non-Hispanic—Dec 2020	642 (12.4)	158 (24.6)	206 (32.1)	278 (43.3)	407 (63.4)	>.99	
Black, non-Hispanic—Mar 2021	650 (12.4)	149 (23.0)	120 (18.4)	381 (58.6)	443 (68.2)		
Asian, non-Hispanic—Dec 2020	291 (5.6)	24 (8.3)	75 (25.7)	192 (66.0)	245 (84.0)	>.99	
Asian, non-Hispanic—Mar 2021	295 (5.6)	23 (7.9)	45 (15.3)	226 (76.7)	260 (88.1)		
Other, non-Hispanic—Dec 2020	189 (3.6)	37 (19.9)	46 (24.6)	105 (55.5)	135 (71.7)	>.99	
Other, non-Hispanic—Mar 2021	191 (3.6)	54 (28.4)	35 (18.4)	102 (53.2)	117 (61.1)		
Hispanic, any race(s)—Dec 2020	956 (18.4)	156 (16.3)	151 (15.8)	650 (67.9)	809 (84.6)	>.99	
Hispanic, any race(s)—Mar 2021	968 (18.4)	164 (17.0)	126 (13.0)	678 (70.0)	759 (78.4)		
Political ideology							
Very liberal—Dec 2020	924 (17.8)	78 (8.4)	113 (12.2)	733 (79.4)	808 (87.5)	>.99	<.001
Very liberal—Mar 2021	833 (15.9)	99 (11.9)	54 (6.5)	680 (81.6)	712 (85.5)		
Slightly liberal—Dec 2020	833 (16.1)	100 (12.0)	132 (15.8)	602 (72.2)	727 (87.2)	>.99	
Slightly liberal—Mar 2021	824 (15.7)	75 (9.1)	83 (10.0)	666 (80.8)	718 (87.2)		
Center—Dec 2020	1438 (27.7)	254 (17.7)	390 (27.1)	794 (55.2)	1058 (73.6)	.66	
Center—Mar 2021	1484 (28.2)	325 (21.9)	301 (20.3)	858 (57.8)	1016 (68.4)		
Slightly conservative—Dec 2020	871 (16.8)	169 (19.4)	162 (18.6)	540 (62.0)	696 (79.9)	>.99	
Slightly conservative—Mar 2021	892 (17.0)	154 (17.3)	123 (13.8)	615 (68.9)	707 (79.2)		
Very conservative—Dec 2020	916 (17.7)	239 (26.1)	132 (14.5)	544 (59.4)	667 (72.8)	>.99	
Very conservative—Mar 2021	870 (16.6)	274 (31.5)	93 (10.7)	502 (57.7)	599 (68.9)		

Apolitical or unknown—Dec 2020	206 (4.0)	69 (33.5)	47 (22.9)	90 (43.7)	131 (63.6)	>.99	
Apolitical or unknown—Mar 2021	352 (6.7)	125 (35.4)	82 (23.3)	146 (41.3)	192 (54.5)		
Past-week mask usage when in public							
Always or Often—Dec 2020	4256 (82.0)	678 (15.9)	736 (17.3)	2842 (66.8)	3497 (82.2)	.57	<.001
Always or Often—Mar 2021	3975 (75.6)	644 (16.2)	529 (13.3)	2802 (70.5)	3168 (79.7)		
Sometimes—Dec 2020	365 (7.0)	75 (20.6)	106 (29.0)	184 (50.4)	234 (64.1)	>.99	
Sometimes—Mar 2021	436 (8.3)	112 (25.7)	76 (17.5)	248 (56.9)	280 (64.3)		
Rarely or Never—Dec 2020	323 (6.2)	107 (33.0)	79 (24.4)	138 (42.6)	178 (55.0)	>.99	
Rarely or Never—Mar 2021	582 (11.1)	238 (40.9)	89 (15.3)	255 (43.8)	287 (49.3)		
Not in public—Dec 2020	245 (4.7)	49 (20.0)	56 (22.7)	140 (57.2)	179 (73.1)	>.99	
Not in public—Mar 2021	263 (5.0)	59 (22.5)	42 (15.8)	162 (61.7)	209 (79.5)		
Past-week avoidance of gatherings of 10 or more persons							
Always or Often—Dec 2020	3695 (71.2)	526 (14.2)	623 (16.9)	2545 (68.9)	3097 (83.8)	.66	<.001
Always or Often—Mar 2021	3226 (61.4)	480 (14.9)	414 (12.8)	2333 (72.3)	2626 (81.4)		
Sometimes—Dec 2020	565 (10.9)	80 (14.2)	157 (27.8)	327 (57.9)	409 (72.5)	>.99	
Sometimes—Mar 2021	608 (11.6)	73 (12.1)	117 (19.2)	418 (68.7)	474 (78.0)		
Rarely or Never—Dec 2020	928 (17.9)	302 (32.6)	196 (21.1)	430 (46.4)	580 (62.5)	>.99	
Rarely or Never—Mar 2021	1422 (27.1)	500 (35.2)	206 (14.5)	716 (50.4)	845 (59.4)		
Received or plan to obtain influenza vaccine last year							
No—Dec 2020	1879 (36.2)	687 (36.6)	514 (27.3)	678 (36.1)	1101 (58.6)	>.99	<.001
No—Mar 2021	2367 (45.0)	826 (34.9)	473 (20.0)	1068 (45.1)	1373 (58.0)		
Yes—Dec 2020	3309 (63.8)	222 (6.7)	462 (14.0)	2625 (79.3)	2986 (90.2)	>.99	
Yes—Mar 2021	2889 (55.0)	227 (7.9)	263 (9.1)	2399 (83.0)	2571 (89.0)		
Medical Mistrust Index (MMI) score							
0-6—Dec 2020	463 (8.9)	58 (12.4)	46 (10.0)	359 (77.5)	393 (84.8)	.73	<.001
0-6—Mar 2021	522 (10.1)	92 (17.6)	49 (9.4)	381 (73.0)	403 (77.2)		
7-13—Dec 2020	2567 (48.8)	377 (14.7)	542 (21.1)	1649 (64.2)	2067 (80.5)	>.99	
7-13—Mar 2021	2654 (50.5)	434 (16.3)	389 (14.7)	1831 (69.0)	2098 (79.1)		
14-17—Dec 2020	1536 (29.6)	333 (21.7)	319 (20.8)	884 (57.5)	1163 (75.7)	>.99	
14-17—Mar 2021	1453 (28.0)	317 (21.8)	229 (15.7)	907 (62.5)	1038 (71.5)		
18-21—Dec 2020	622 (11.8)	142 (22.8)	68 (11.0)	412 (66.2)	464 (74.7)	.13	
18-21—Mar 2021	628 (11.9)	211 (33.6)	69 (11.0)	348 (55.4)	405 (64.5)		

Figure 8 (5.1). Adjusted odds ratios for COVID-19 vaccine refusal among US adults—March 2021

Figure 1. Adjusted odds ratios for COVID-19 vaccine refusal among US adults—March 2021

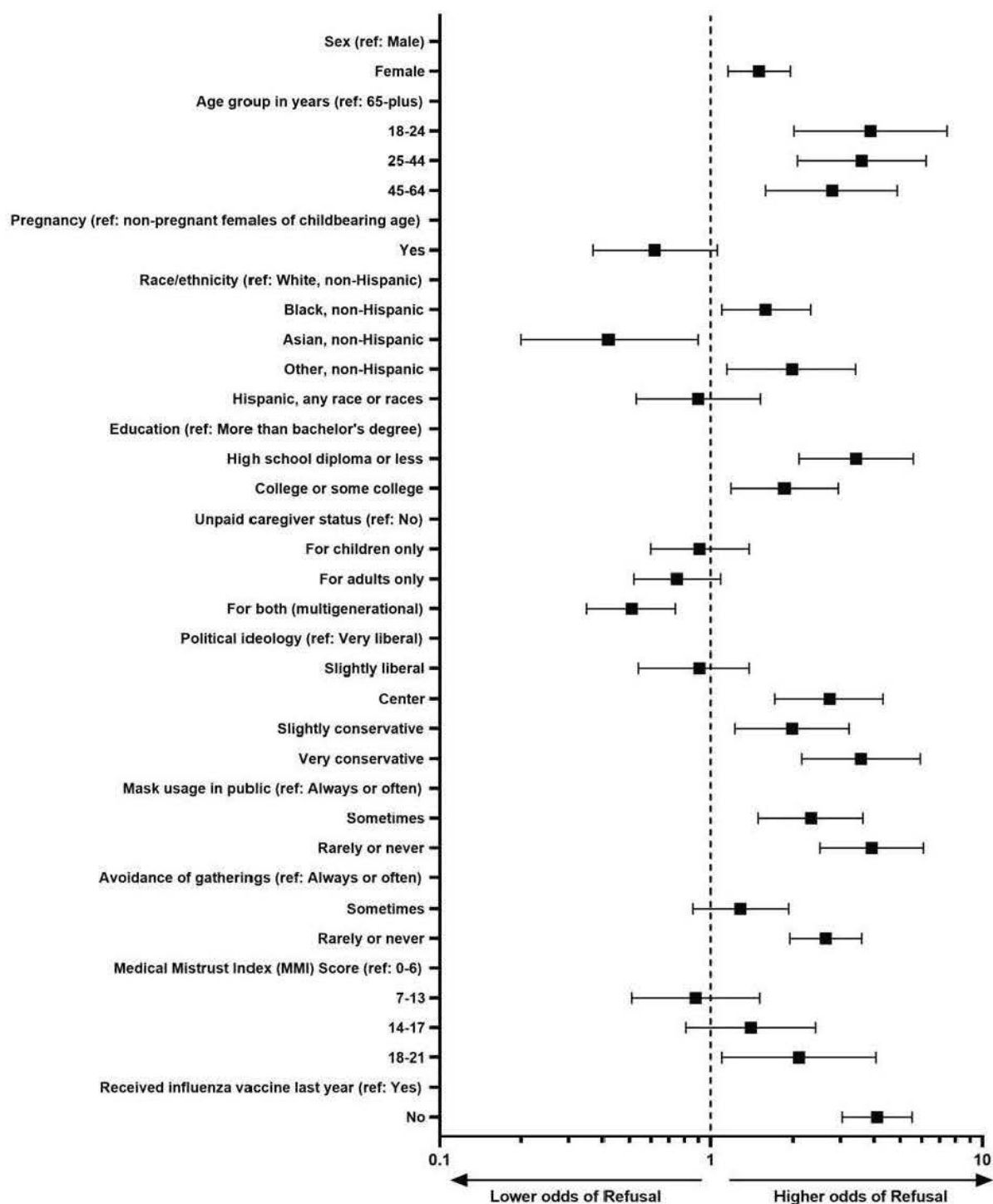


Table 6 (5.2) . Reasons for potential COVID-19 vaccine refusal among US adults--December 2020 and March 2021

Table 2. Reasons for potential COVID-19 vaccine refusal among US adults—December 2020 and March 2021

	Potential vaccine refusers	Plan to wait 6-12 months	COVID-19 vaccine will not offer protection	Not at risk for severe COVID-19	Approval process was rushed	All vaccines are dangerous	Concern of hidden purpose
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
Total—Dec 20	1885 (100)	784 (41.6)	389 (20.6)	287 (15.2)	919 (48.7)	277 (14.7)	358 (19.0)
Total—Mar 21	1789 (100)	478 (26.7)	433 (24.2)	322 (18.0)	746 (41.7)	255 (14.3)	446 (24.9)
Chi-Square test P		<.001	.25	.49	.004	>.99	.008
March-2021 respondents							
COVID-19 vaccine response							
Maybe/Not sure	736 (41.1)	295 (40.1)	113 (15.3)	127 (17.3)	310 (42.1)	72 (9.8)	101 (13.7)
Unlikely	340 (19.0)	103 (30.1)	74 (21.9)	58 (16.9)	137 (40.2)	39 (11.6)	86 (25.1)
Definitely not	713 (39.8)	80 (11.2)	246 (34.5)	137 (19.2)	299 (42.0)	144 (20.2)	259 (36.4)
Sex							
Female	1060 (59.3)	278 (26.2)	250 (23.6)	141 (13.3)	458 (43.2)	126 (11.8)	257 (24.3)
Male	729 (40.7)	200 (27.4)	183 (25.0)	181 (24.8)	288 (39.4)	130 (17.8)	188 (25.8)
Age group, years							
18-24	267 (14.9)	63 (23.5)	82 (30.7)	71 (26.6)	111 (41.5)	39 (14.8)	67 (25.0)
25-44	656 (36.7)	152 (23.2)	177 (26.9)	115 (17.5)	255 (38.9)	108 (16.4)	165 (25.2)
45-64	632 (35.3)	167 (26.4)	147 (23.2)	117 (18.5)	291 (46.0)	86 (13.6)	142 (22.5)
≥65	235 (13.1)	96 (40.8)	28 (11.8)	20 (8.3)	89 (37.9)	22 (9.4)	72 (30.5)
Pregnancy							
Yes	77 (4.3)	22 (28.3)	22 (28.2)	9 (11.2)	27 (35.3)	14 (17.9)	6 (8.2)
No	561 (31.3)	127 (22.7)	158 (28.2)	88 (15.7)	237 (42.2)	72 (12.8)	137 (24.5)
Race/ethnicity							
White, non-Hispanic	1071 (59.9)	286 (26.7)	258 (24.1)	209 (19.5)	487 (45.4)	154 (14.4)	259 (24.2)
Black, non-Hispanic	269 (15.0)	63 (23.2)	71 (26.3)	36 (13.3)	81 (30.0)	41 (15.1)	60 (22.4)
Asian, non-Hispanic	69 (3.8)	34 (48.9)	9 (13.7)	13 (19.6)	30 (43.7)	6 (8.6)	9 (13.1)
Other, non-Hispanic	90 (5.0)	15 (16.9)	22 (24.6)	19 (20.9)	44 (49.6)	16 (18.3)	32 (35.3)
Hispanic, any race(s)	290 (16.2)	81 (27.8)	73 (25.0)	45 (15.5)	104 (35.7)	38 (13.1)	86 (29.5)
Political ideology							
Very liberal	153 (8.6)	32 (21.1)	39 (25.3)	20 (12.9)	48 (31.1)	25 (16.1)	34 (22.4)
Slightly liberal	158 (8.8)	52 (32.9)	38 (24.2)	30 (18.9)	68 (43.2)	16 (9.8)	18 (11.7)
Center	627 (35.0)	158 (25.2)	144 (23.0)	117 (18.7)	258 (41.1)	84 (13.5)	177 (28.3)
Slightly conservative	277 (15.5)	92 (33.2)	55 (19.7)	50 (18.1)	130 (46.8)	45 (16.4)	56 (20.3)
Very conservative	368 (20.6)	97 (26.4)	99 (27.0)	77 (20.9)	170 (46.3)	53 (14.3)	115 (31.2)
Apolitical or prefer not to say	207 (11.6)	46 (22.4)	58 (27.8)	28 (13.6)	72 (35.0)	32 (15.7)	45 (21.6)
Mask-wearing in public							
Always or Often	1174 (65.6)	367 (31.2)	241 (20.6)	191 (16.3)	544 (46.4)	142 (12.1)	288 (24.5)
Sometimes	188 (10.5)	33 (17.3)	65 (34.6)	42 (22.1)	71 (37.6)	44 (23.4)	55 (29.0)
Rarely or Never	327 (18.3)	32 (9.7)	109 (33.4)	76 (23.3)	89 (27.2)	59 (17.9)	92 (28.0)
Not in public place last week	101 (5.6)	47 (46.6)	17 (17.0)	13 (12.8)	42 (41.6)	10 (10.2)	12 (11.7)
Avoidance of gatherings							
Always or Often	893 (49.9)	293 (32.8)	207 (23.1)	134 (15.0)	410 (45.8)	96 (10.7)	195 (21.8)
Sometimes	190 (10.6)	56 (29.7)	34 (17.8)	44 (22.9)	70 (36.8)	24 (12.9)	39 (20.5)
Rarely or Never	706 (39.4)	128 (18.2)	192 (27.3)	145 (20.5)	266 (37.7)	135 (19.2)	212 (30.0)
Medical Mistrust Index							
0-6	141 (7.9)	22 (15.6)	29 (20.3)	27 (19.1)	48 (34.2)	11 (8.0)	43 (30.3)
7-13	823 (46.0)	267 (32.5)	186 (22.5)	130 (15.8)	321 (39.1)	80 (9.7)	138 (16.8)
14-17	545 (30.5)	131 (24.1)	121 (22.2)	101 (18.6)	249 (45.7)	88 (16.0)	140 (25.7)

	18-21	280 (15.6)	57 (20.4)	98 (35.0)	63 (22.6)	127 (45.4)	76 (27.3)	125 (44.5)
Plan or received influenza vaccine this year								
	Yes	490 (27.4)	173 (35.2)	87 (17.7)	62 (12.7)	230 (47.0)	47 (9.6)	114 (23.2)
	No or Not Sure	1299 (72.6)	305 (23.5)	346 (26.6)	259 (20.0)	515 (39.7)	208 (16.0)	332 (25.6)

Figure 9 (5.2). Adjusted odds ratios for responding Maybe or waiting for more safety and efficacy data before obtaining a COVID-19 vaccine among US adult vaccine Refusers —March 2021

Figure 2. Adjusted odds ratios for responding Maybe or waiting for more safety and efficacy data before obtaining a COVID-19 vaccine among US adult vaccine Refusers —March 2021

Figure 2A. aORs for Maybe obtaining a COVID-19 vaccine ASAP

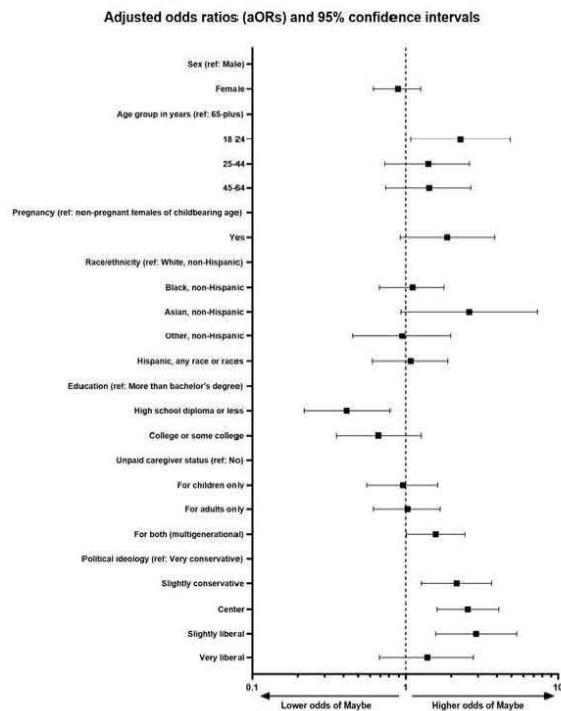


Figure 2B. aORs for waiting for more safety and efficacy data before obtaining a COVID-19 vaccine

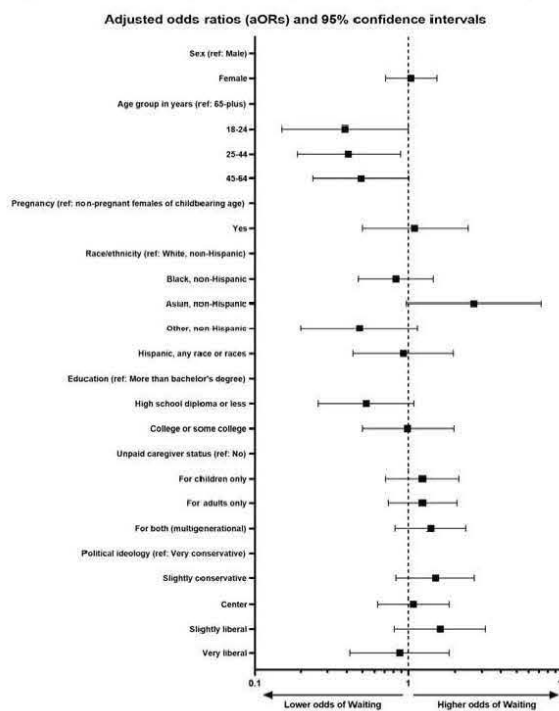


Figure 10 (5.3). Intentions for obtaining COVID-19 vaccines for children and potential vaccine boosters to protect against variants—March 2021

Figure 3. Intentions for obtaining COVID-19 vaccines for children and potential vaccine boosters to protect against variants—March 2021

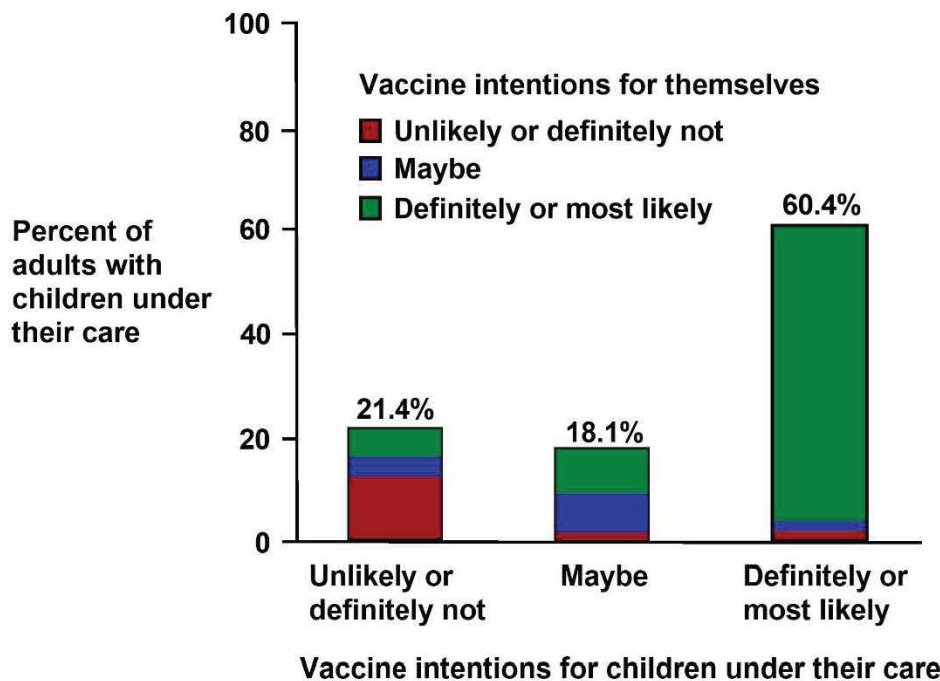
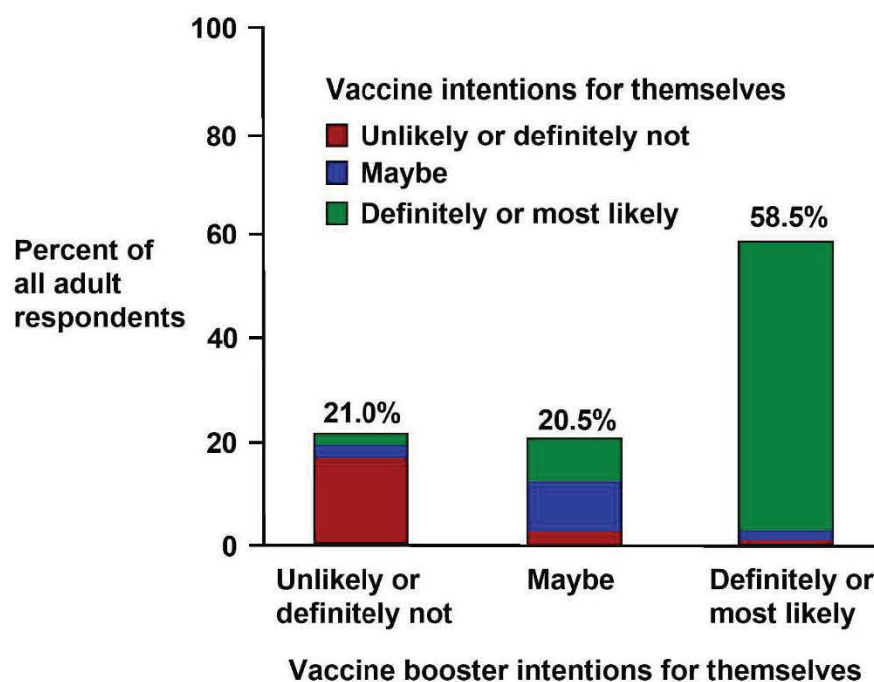


Figure 3A. Intentions for obtaining COVID-19 vaccines for children among parents or caregivers

Figure 3B. Intentions for obtaining COVID-19 vaccine booster among US adults



SUMMARY OF FINDINGS

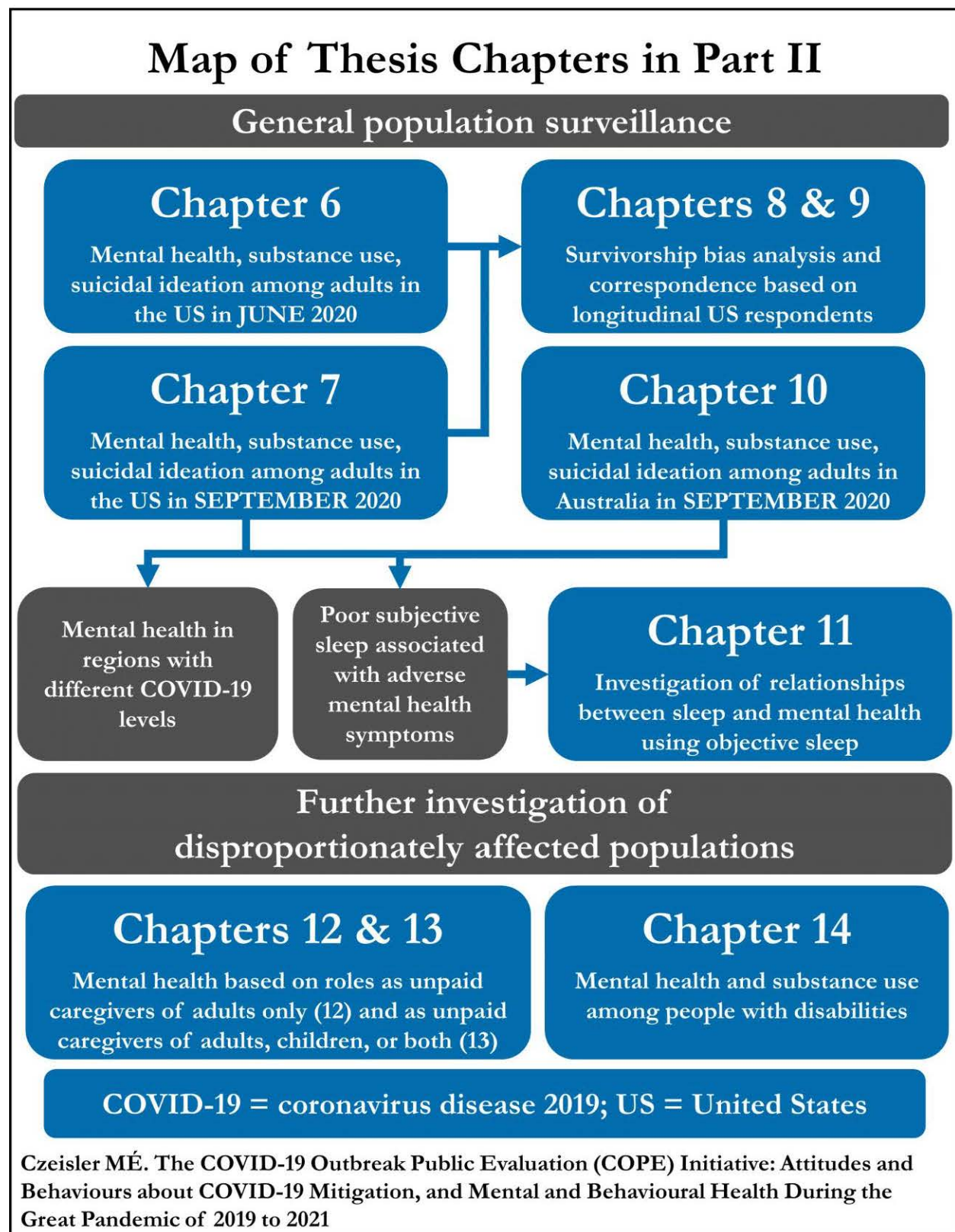
The Original Investigation presented in Chapter Five was conducted to provide insights to COVID-19 vaccine intentions among US adults during the initial months of the vaccine rollout. Overall, nearly two-thirds of 5,256 respondents in February-to-March of 2021 reported that they had obtained a COVID-19 vaccine or that they would definitely or most likely receive one as soon as it were available to them. An additional 9% of respondents reported that they were awaiting further safety and efficacy data before deciding. Factors most strongly associated with vaccine refusal included not having obtained an influenza vaccine in 2020 (adjusted odds ratio = 4.1 [95% confidence interval = 3.1 to 5.5]), less frequent mask usage (rarely or never versus always or often, adjusted odds ratio = 3.9 [95% confidence interval = 2.5 to 6.1]), younger age (aged 18 to 24 versus 65-or-more years, adjusted odds ratio = 3.9 [95% confidence interval = 2.0 to 7.5]) and more conservative political ideology (very conservative versus very liberal, adjusted odds ratio = 3.6 [95% confidence interval = 2.2 to 5.9]).

Key secondary findings included that pregnant people were largely willing to obtain COVID-19 vaccines (70% of pregnant persons in February to March 2021 would most likely obtain a vaccine as soon as possible), and that peoples' intentions for vaccinating their children and for obtaining potential COVID-19 vaccine boosters largely matched their own intentions for completing the initial COVID-19 vaccine regimens. Jurisdictions have attempted various incentives to improve vaccine coverage. US state incentives include USD\$100 savings bonds in West Virginia, free beer in New Jersey and Connecticut, lottery-based incentives topping out at USD\$5 million in New York and USD\$1 million in Ohio, while Krispy Kreme offered donuts nationwide (Volpp & Cannuscio, 2021). Beyond ethical considerations, there is limited evidence that these interventions have been effective. For example, Ohio observed no difference in national versus state vaccine levels in the

three weeks following the announcement of the USD\$1 million lottery-based incentive **(Walkey et al., 2021)**. Limited efficacy of interventions is consistent with pre-pandemic evidence **(Nyhan et al., 2014)**, and a randomised control trial found that recent misinformation caused a decline in intent to obtain COVID-19 vaccines in both the US and the United Kingdom (UK) **(Loomba et al., 2021)**. Qualitative, interview-based studies might provide insights for strategies to improve vaccine intentions, which would complement largescale surveillance efforts, and might be better equipped to assess prevalence estimates for vaccine intentions and high-level reasons for non-obtainment. For example, qualitative studies could elucidate concrete types of safety data that would be acceptable before vaccination, as the inability to determine whether these individuals are legitimately considering vaccination within a meaningful timeframe is a limitation of largescale surveys.

Behaviourally informed strategies to improve coverage include making the vaccines free (which has been done in most places), public endorsements from trusted voices, and transforming individual vaccine decisions into public acts **(Volpp et al., 2021)**, with increased observability of vaccine status **(Wood & Schulman, 2021a)**. Another aspect of the national US COVID-19 vaccination campaign is accessibility of COVID-19 vaccines, as barriers related to access to and usability of technology prevented some groups from obtaining vaccines as soon as possible **(Press et al., 2021)**. Finally, obtaining population-level immunity will depend on global vaccine coverage, where significant progress has yet to be made **(Burki, 2021; Katz et al., 2021; Ritchie et al., 2020; Stephenson, 2021)**.

Figure 11. Map of Thesis Chapters in Part I.



PART II: MENTAL AND BEHAVIOURAL HEALTH

CHAPTER 6: Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic — United States, June 24–30, 2020

PREFACE TO CHAPTER 6

Shortly after recognising the increasing potential scale of the COVID-19 pandemic, and the possibility of both stringent COVID-19 prevention policies and widespread mortality, mental health experts issued warnings about the potential mental health impacts (**S. K. Brooks et al., 2020; Galea et al., 2020**) and issued a multidisciplinary call for action for mental health science (**Holmes et al., 2020**). The call stated that an immediate priority was collecting high-quality data on mental health during the COVID-19 pandemic, both across the whole population and disproportionately affected subpopulations. Specifically, Holmes *et al.* stated that immediate priorities including monitoring and reporting levels of anxiety, depression, self-harm, suicide, and other mental health conditions, both across the general population and in disproportionately affected populations (**Holmes et al., 2020**).

The Original Investigation in Chapter Six (**Czeisler, Lane, et al., 2020**), which was published in the *Morbidity and Mortality Weekly Report*, responded to this call to action with data on mental health and substance use among US adults during late June 2020. Specifically, through assessment of anxiety or depression symptoms, COVID-19 trauma- and stressor-related disorder (TSRD) symptoms, new or increased substance use, and suicidal ideation, we sought to (1) generate prevalence estimates for adverse mental health symptom levels across the US population and (2) identify populations with disproportionately high levels of adverse mental health symptoms.

The potential for increased prevalences of these conditions was predicted based on their strong associations with social isolation and loneliness (**Elovainio et al., 2017; Matthews et al., 2019**),

which had already started to present at the beginning of the pandemic (**Holmes et al., 2020**).

COVID-19 TSRD symptoms (**Haseltine, 2020**) were screened for given that symptoms from pandemic-related trauma and stress might represent a spectrum of related disorders. According to the Diagnostic And Statistical Manual Of Mental Disorders, Fifth Edition (DSM-5) (**American Psychiatric Association, 2013**), TSRD symptoms largely overlap with symptoms of PTSD, acute stress disorder (ASD), and adjustment disorders (ADs), among others. TSRDs could sufficiently characterise observed symptoms without specifying a specific disorder, which could depend on information that would be difficult to systematically assess in population-level surveillance.

Recognising that The COPE Initiative lacked pre-pandemic mental health data, we used validated and widely used instruments to compare anxiety or depression symptoms and suicidal ideation prevalence estimates with recent prior years based on data collected from other population-level surveys. The chapter concludes with a brief overview of findings from the Original Investigation.

CHAPTER SIX: Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic - United States, June 24-30, 2020

Czeisler MÉ, Lane RI, Petrosky E, Wiley JF, Christensen A, Njai R, Weaver MD, Robbins R, Facer-Childs ER, Barger LK, Czeisler CA, Howard ME, Rajaratnam SMW. Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic - United States, June 24-30, 2020. *MMWR Morb Mortal Wkly Rep.* 2020 Aug 14;69(32):1049-1057. doi: 10.15585/mmwr.mm6932a1. PMID: 32790653; PMCID: PMC7440121.

Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic — United States, June 24–30, 2020

Mark É. Czeisler^{1,2}; Rashon I. Lane MA³; Emiko Petrosky, MD³; Joshua F. Wiley, PhD¹; Aleta Christensen, MPH³; Rashid Njai, PhD³; Matthew D. Weaver, PhD^{1,4,5}; Rebecca Robbins, PhD^{4,5}; Elise R. Facer-Childs, PhD¹; Laura K. Barger, PhD^{4,5}; Charles A. Czeisler, MD, PhD^{1,4,5}; Mark E. Howard, MBBS, PhD^{1,2,6}; Shantha M.W. Rajaratnam, PhD^{1,4,5}

The coronavirus disease 2019 (COVID-19) pandemic has been associated with mental health challenges related to the morbidity and mortality caused by the disease and to mitigation activities, including the impact of physical distancing and stay-at-home orders.* Symptoms of anxiety disorder and depressive disorder increased considerably in the United States during April–June of 2020, compared with the same period in 2019 (1,2). To assess mental health, substance use, and suicidal ideation during the pandemic, representative panel surveys were conducted among adults aged ≥18 years across the United States during June 24–30, 2020. Overall, 40.9% of respondents reported at least one adverse mental or behavioral health condition, including symptoms of anxiety disorder or depressive disorder (30.9%), symptoms of a trauma- and stressor-related disorder (TSRD) related to the pandemic[†] (26.3%), and having started or increased substance use to cope with stress or emotions related to COVID-19 (13.3%). The percentage of respondents who reported having seriously considered suicide in the 30 days before completing the survey (10.7%) was significantly higher among respondents aged 18–24 years (25.5%), minority racial/ethnic groups (Hispanic respondents [18.6%], non-Hispanic black [black] respondents [15.1%]), self-reported unpaid caregivers for adults[§] (30.7%), and essential workers[¶] (21.7%).

* <https://www.medrxiv.org/content/10.1101/2020.04.22.20076141v1>.

[†] Disorders classified as TSRDs in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM–5) include posttraumatic stress disorder (PTSD), acute stress disorder (ASD), and adjustment disorders (ADs), among others.

[§] Unpaid adult caregiver status was self-reported. The definition of an unpaid caregiver for adults was a person who had provided unpaid care to a relative or friend aged ≥18 years to help them take care of themselves at any time in the last 3 months. Examples provided included helping with personal needs, household chores, health care tasks, managing a person's finances, taking them to a doctor's appointment, arranging for outside services, and visiting regularly to see how they are doing.

[¶] Essential worker status was self-reported. The comparison was between employed respondents (n = 3,431) who identified as essential versus nonessential. For this analysis, students who were not separately employed as essential workers were considered nonessential workers.

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Community-level intervention and prevention efforts, including health communication strategies, designed to reach these groups could help address various mental health conditions associated with the COVID-19 pandemic.

During June 24–30, 2020, a total of 5,412 (54.7%) of 9,896 eligible invited adults** completed web-based surveys†† administered by Qualtrics.§§ The Monash University Human Research Ethics Committee of Monash University (Melbourne, Australia) reviewed and approved the study protocol on human

** A minimum age of 18 years and residence within the United States as of April 2–8, 2020, were required for eligibility for the longitudinal cohort to complete a survey during June 24–30, 2020. Residence was reassessed during June 24–30, 2020, and one respondent who had moved from the United States was excluded from the analysis. A minimum age of 18 years and residence within the United States were required for eligibility for newly recruited respondents included in the cross-sectional analysis. For both the longitudinal cohort and newly recruited respondents, respondents were required to provide informed consent before enrollment into the study. All surveys underwent data quality screening procedures including algorithmic and keystroke analysis for attention patterns, click-through behavior, duplicate responses, machine responses, and inattentiveness. Country-specific geolocation verification via IP address mapping was used to ensure respondents were from the United States. Respondents who failed an attention or speed check, along with any responses identified by the data-scrubbing algorithms, were excluded from analysis.

†† The surveys contained 101 items for first-time respondents and 86 items for respondents who also participated in later surveys, with the 15 additional items for first-time respondents consisting of questions on demographics. The survey instruments included a combination of individual questions, validated questionnaires, and COVID-19-specific questionnaires, which were used to assess respondent attitudes, behaviors, and beliefs related to COVID-19 and its mitigation, as well as the social and behavioral health impacts of the COVID-19 pandemic.

§§ <https://www.qualtrics.com/>.

subjects research. Respondents were informed of the study purposes and provided electronic consent before commencement, and investigators received anonymized responses. Participants included 3,683 (68.1%) first-time respondents and 1,729 (31.9%) respondents who had completed a related survey during April 2–8, May 5–12, 2020, or both intervals; 1,497 (27.7%) respondents participated during all three intervals (2,3). Quota sampling and survey weighting were employed to improve cohort representativeness of the U.S. population by gender, age, and race/ethnicity.¶¶ Symptoms of anxiety disorder and depressive disorder were assessed using the four-item Patient Health Questionnaire*** (4), and symptoms of a COVID-19–related TSRD were assessed using the six-item Impact of Event Scale††† (5). Respondents also reported

¶¶ Survey weighting was implemented according to the 2010 U.S. Census with respondents who reported gender, age, and race/ethnicity. Respondents who reported a gender of “Other,” or who did not report race/ethnicity were assigned a weight of one.

*** Symptoms of anxiety disorder and depressive disorder were assessed via the four-item Patient Health Questionnaire (PHQ-4). Those who scored ≥ 3 out of 6 on the Generalized Anxiety Disorder (GAD-2) and Patient Health Questionnaire (PHQ-2) subscales were considered symptomatic for these respective disorders. This instrument was included in the April, May, and June surveys.

††† Symptoms of a TSRD attributed to the COVID-19 pandemic were assessed via the six-item Impact of Event Scale (IES-6) to screen for overlapping symptoms of PTSD, ASD, and ADs. For this survey, the COVID-19 pandemic was specified as the traumatic exposure to record peri- and posttraumatic symptoms associated with the range of stressors introduced by the COVID-19 pandemic. Those who scored ≥ 1.75 out of 4 were considered symptomatic. This instrument was included in the May and June surveys only.

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whether they had started or increased substance use to cope with stress or emotions related to COVID-19 or seriously considered suicide in the 30 days preceding the survey.^{§§§}

Analyses were stratified by gender, age, race/ethnicity, employment status, essential worker status, unpaid adult caregiver status, rural-urban residence classification,^{¶¶¶} whether the respondent knew someone who had positive test results for SARS-CoV-2, the virus that causes COVID-19, or who had died from COVID-19, and whether the respondent was receiving treatment for diagnosed anxiety, depression, or post-traumatic stress disorder (PTSD) at the time of the survey. Comparisons within subgroups were evaluated using Poisson regressions with robust standard errors to calculate prevalence ratios, 95% confidence intervals (CIs), and p-values to evaluate statistical significance ($\alpha = 0.005$ to account for multiple comparisons). Among the 1,497 respondents who completed all three surveys, longitudinal analyses of the odds of incidence^{****} of symptoms of adverse mental or behavioral health conditions by essential worker and unpaid adult caregiver status were conducted on unweighted responses using logistic regressions to calculate unadjusted and adjusted^{††††} odds ratios (ORs), 95% CI, and p-values ($\alpha = 0.05$). The statsmodels package in Python (version 3.7.8; Python Software Foundation) was used to conduct all analyses.

Overall, 40.9% of 5,470 respondents who completed surveys during June reported an adverse mental or behavioral health condition, including those who reported symptoms of anxiety disorder or depressive disorder (30.9%), those with TSRD symptoms related to COVID-19 (26.3%), those who reported having

started or increased substance use to cope with stress or emotions related to COVID-19 (13.3%), and those who reported having seriously considered suicide in the preceding 30 days (10.7%) (Table 1). At least one adverse mental or behavioral health symptom was reported by more than one half of respondents who were aged 18–24 years (74.9%) and 25–44 years (51.9%), of Hispanic ethnicity (52.1%), and who held less than a high school diploma (66.2%), as well as those who were essential workers (54.0%), unpaid caregivers for adults (66.6%), and who reported treatment for diagnosed anxiety (72.7%), depression (68.8%), or PTSD (88.0%) at the time of the survey.

Prevalences of symptoms of adverse mental or behavioral health conditions varied significantly among subgroups (Table 2). Suicidal ideation was more prevalent among males than among females. Symptoms of anxiety disorder or depressive disorder, COVID-19–related TSRD, initiation of or increase in substance use to cope with COVID-19–associated stress, and serious suicidal ideation in the previous 30 days were most commonly reported by persons aged 18–24 years; prevalence decreased progressively with age. Hispanic respondents reported higher prevalences of symptoms of anxiety disorder or depressive disorder, COVID-19–related TSRD, increased substance use, and suicidal ideation than did non-Hispanic whites (whites) or non-Hispanic Asian (Asian) respondents. Black respondents reported increased substance use and past 30-day serious consideration of suicide in the previous 30 days more commonly than did white and Asian respondents. Respondents who reported treatment for diagnosed anxiety, depression, or PTSD at the time of the survey reported higher prevalences of symptoms of adverse mental and behavioral health conditions compared with those who did not. Symptoms of a COVID-19–related TSRD, increased substance use, and suicidal ideation were more prevalent among employed than unemployed respondents, and among essential workers than nonessential workers. Adverse conditions also were more prevalent among unpaid caregivers for adults than among those who were not, with particularly large differences in increased substance use (32.9% versus 6.3%) and suicidal ideation (30.7% versus 3.6%) in this group.

Longitudinal analysis of responses of 1,497 persons who completed all three surveys revealed that unpaid caregivers for adults had a significantly higher odds of incidence of adverse mental health conditions compared with others (Table 3). Among those who did not report having started or increased substance use to cope with stress or emotions related to COVID-19 in May, unpaid caregivers for adults had 3.33 times the odds of reporting this behavior in June (adjusted OR 95% CI = 1.75–6.31; $p < 0.001$). Similarly, among those who did not report having seriously considered suicide in the previous 30 days in May, unpaid caregivers for adults had 3.03 times the odds of reporting suicidal ideation in June (adjusted OR 95% CI = 1.20–7.63; $p = 0.019$).

^{§§§} For this survey, substance use was defined as use of “alcohol, legal or illegal drugs, or prescriptions drugs that are taken in a way not recommended by your doctor.” Questions regarding substance use and suicidal ideation were included in the May and June surveys only. Participants were informed that responses were deidentified and that direct support could not be provided to those who reported substance use behavior or suicidal ideation. Regarding substance use, respondents were provided the following: “This survey is anonymous so we cannot provide direct support. If you would like crisis support please contact the Substance Abuse and Mental Health Services Administration National Helpline, 1-800-662-HELP (4357), (also known as the Treatment Referral Routing Service) or TTY: 1-800-487-4889. This is a confidential, free, 24-hour-a-day, 365-day-a-year, information service, in English and Spanish, for persons and family members facing mental and/or substance use disorders.” Regarding suicidal ideation, respondents were provided the following: “This survey is anonymous so we cannot provide direct support. If you would like crisis support please contact the National Suicide Prevention Lifeline, 1-800-273-TALK (8255, or chat line) for help for themselves or others.”

^{¶¶¶} Rural-urban classification was determined by using self-reported ZIP codes according to the Federal Office of Rural Health Policy definition of rurality. <https://www.hrsa.gov/rural-health/about-us/definition/datafiles.html>.

^{****} Odds of incidence was defined as the odds of the presence of an adverse mental or behavioral health outcome reported during a later survey after previously having reported the absence of that outcome (e.g., having reported symptoms of anxiety disorder during June 24–30, 2020, after not having reported symptoms of anxiety disorder during April 2–8, 2020).

^{††††} Adjusted for gender, employment status, and essential worker status or unpaid adult caregiver status.

Table 15 (6.1) Respondent characteristics and prevalence of adverse mental health outcomes, increased substance use to cope with stress or emotions related to COVID-19 pandemic, and suicidal ideation — United States, June 24–30, 2020

TABLE 1. Respondent characteristics and prevalence of adverse mental health outcomes, increased substance use to cope with stress or emotions related to COVID-19 pandemic, and suicidal ideation — United States, June 24–30, 2020

Characteristic	All respondents who completed surveys during June 24–30, 2020 weighted* no. (%)	Weighted %*						
		Conditions				Started or increased substance use to cope with pandemic-related stress or emotions¶	Seriously considered suicide in past 30 days	≥1 adverse mental or behavioral health symptom
		Anxiety disorder†	Depressive disorder†	Anxiety or depressive disorder†	COVID-19– related TSRD§			
All respondents	5,470 (100)	25.5	24.3	30.9	26.3	13.3	10.7	40.9
Gender								
Female	2,784 (50.9)	26.3	23.9	31.5	24.7	12.2	8.9	41.4
Male	2,676 (48.9)	24.7	24.8	30.4	27.9	14.4	12.6	40.5
Other	10 (0.2)	20.0	30.0	30.0	30.0	10.0	0.0	30.0
Age group (yrs)								
18–24	731 (13.4)	49.1	52.3	62.9	46.0	24.7	25.5	74.9
25–44	1,911 (34.9)	35.3	32.5	40.4	36.0	19.5	16.0	51.9
45–64	1,895 (34.6)	16.1	14.4	20.3	17.2	7.7	3.8	29.5
≥65	933 (17.1)	6.2	5.8	8.1	9.2	3.0	2.0	15.1
Race/Ethnicity								
White, non-Hispanic	3,453 (63.1)	24.0	22.9	29.2	23.3	10.6	7.9	37.8
Black, non-Hispanic	663 (12.1)	23.4	24.6	30.2	30.4	18.4	15.1	44.2
Asian, non-Hispanic	256 (4.7)	14.1	14.2	18.0	22.1	6.7	6.6	31.9
Other race or multiple races, non-Hispanic**	164 (3.0)	27.8	29.3	33.2	28.3	11.0	9.8	43.8
Hispanic, any race(s)	885 (16.2)	35.5	31.3	40.8	35.1	21.9	18.6	52.1
Unknown	50 (0.9)	38.0	34.0	44.0	34.0	18.0	26.0	48.0
2019 Household income (USD)								
<25,000	741 (13.6)	30.6	30.8	36.6	29.9	12.5	9.9	45.4
25,000–49,999	1,123 (20.5)	26.0	25.6	33.2	27.2	13.5	10.1	43.9
50,999–99,999	1,775 (32.5)	27.1	24.8	31.6	26.4	12.6	11.4	40.3
100,999–199,999	1,301 (23.8)	23.1	20.8	27.7	24.2	15.5	11.7	37.8
≥200,000	282 (5.2)	17.4	17.0	20.6	23.1	14.8	11.6	35.1
Unknown	247 (4.5)	19.6	23.1	27.2	24.9	6.2	3.9	41.5
Education								
Less than high school diploma	78 (1.4)	44.5	51.4	57.5	44.5	22.1	30.0	66.2
High school diploma	943 (17.2)	31.5	32.8	38.4	32.1	15.3	13.1	48.0
Some college	1,455 (26.6)	25.2	23.4	31.7	22.8	10.9	8.6	39.9
Bachelor's degree	1,888 (34.5)	24.7	22.5	28.7	26.4	14.2	10.7	40.6
Professional degree	1,074 (19.6)	20.9	19.5	25.4	24.5	12.6	10.0	35.2
Unknown	33 (0.6)	25.2	23.2	28.2	23.2	10.5	5.5	28.2
Employment status††								
Employed	3,431 (62.7)	30.1	29.1	36.4	32.1	17.9	15.0	47.8
Essential	1,785 (32.6)	35.5	33.6	42.4	38.5	24.7	21.7	54.0
Nonessential	1,646 (30.1)	24.1	24.1	29.9	25.2	10.5	7.8	41.0
Unemployed	761 (13.9)	32.0	29.4	37.8	25.0	7.7	4.7	45.9
Retired	1,278 (23.4)	9.6	8.7	12.1	11.3	4.2	2.5	19.6
Unpaid adult caregiver status§§								
Yes	1,435 (26.2)	47.6	45.2	56.1	48.4	32.9	30.7	66.6
No	4,035 (73.8)	17.7	16.9	22.0	18.4	6.3	3.6	31.8
Region¶¶								
Northeast	1,193 (21.8)	23.9	23.9	29.9	22.8	12.8	10.2	37.1
Midwest	1,015 (18.6)	22.7	21.1	27.5	24.4	9.0	7.5	36.1
South	1,921 (35.1)	27.9	26.5	33.4	29.1	15.4	12.5	44.4
West	1,340 (24.5)	25.8	24.2	30.9	26.7	14.0	10.9	43
Rural-urban classification***								
Rural	599 (10.9)	26.0	22.5	29.3	25.4	11.5	10.2	38.3
Urban	4,871 (89.1)	25.5	24.6	31.1	26.4	13.5	10.7	41.2

See table footnotes on the next page.

Table 15 (6.1) (Continued) Respondent characteristics and prevalence of adverse mental health outcomes, increased substance use to cope with stress or emotions related to COVID-19 pandemic, and suicidal ideation — United States, June 24–30, 2020

TABLE 1. (Continued) Respondent characteristics and prevalence of adverse mental health outcomes, increased substance use to cope with stress or emotions related to COVID-19 pandemic, and suicidal ideation — United States, June 24–30, 2020

Weighted %*								
Characteristic	All respondents who completed surveys during June 24–30, 2020 weighted* no. (%)	Conditions			Started or increased substance use to cope with pandemic-related stress or emotions [¶]	Seriously considered suicide in past 30 days	≥1 adverse mental or behavioral health symptom	
		Anxiety disorder [†]	Depressive disorder [†]	Anxiety or depressive disorder [†]				COVID-19–related TSRD [§]
Know someone who had positive test results for SARS-CoV-2								
Yes	1,109 (20.3)	23.8	21.9	29.6	21.5	12.9	7.5	39.2
No	4,361 (79.7)	26.0	25.0	31.3	27.5	13.4	11.5	41.3
Knew someone who died from COVID-19								
Yes	428 (7.8)	25.8	20.6	30.6	28.1	11.3	7.6	40.1
No	5,042 (92.2)	25.5	24.7	31.0	26.1	13.4	10.9	41
Receiving treatment for previously diagnosed condition								
Anxiety								
Yes	536 (9.8)	59.6	52.0	66.0	51.9	26.6	23.6	72.7
No	4,934 (90.2)	21.8	21.3	27.1	23.5	11.8	9.3	37.5
Depression								
Yes	540 (9.9)	52.5	50.6	60.8	45.5	25.2	22.1	68.8
No	4,930 (90.1)	22.6	21.5	27.7	24.2	12.0	9.4	37.9
Posttraumatic stress disorder								
Yes	251 (4.6)	72.3	69.1	78.7	69.4	43.8	44.8	88
No	5,219 (95.4)	23.3	22.2	28.6	24.2	11.8	9.0	38.7

Abbreviations: COVID-19 = coronavirus disease 2019; TSRD = trauma- or stress-related disorder.

* Survey weighting was employed to improve the cross-sectional June cohort representativeness of the U.S. population by gender, age, and race/ethnicity according to the 2010 U.S. Census with respondents in which gender, age, and race/ethnicity were reported. Respondents who reported a gender of "Other" or who did not report race/ethnicity were assigned a weight of one.

[†] Symptoms of anxiety disorder and depressive disorder were assessed via the four-item Patient Health Questionnaire (PHQ-4). Those who scored ≥3 out of 6 on the Generalized Anxiety Disorder (GAD-2) and Patient Health Questionnaire (PHQ-2) subscales were considered symptomatic for each disorder, respectively.

[§] Disorders classified as TSRDs in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) include posttraumatic stress disorder (PTSD), acute stress disorder (ASD), and adjustment disorders (ADs), among others. Symptoms of a TSRD precipitated by the COVID-19 pandemic were assessed via the six-item Impact of Event Scale (IES-6) to screen for overlapping symptoms of PTSD, ASD, and ADs. For this survey, the COVID-19 pandemic was specified as the traumatic exposure to record peri- and posttraumatic symptoms associated with the range of stressors introduced by the COVID-19 pandemic. Those who scored ≥1.75 out of 4 were considered symptomatic.

[¶] 104 respondents selected "Prefer not to answer."

** The Other race or multiple races, non-Hispanic category includes respondents who identified as not being Hispanic and as more than one race or as American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or "Other."

^{††} Essential worker status was self-reported. The comparison was between employed respondents (n = 3,431) who identified as essential vs. nonessential. For this analysis, students who were not separately employed as essential workers were considered nonessential workers.

^{§§} Unpaid adult caregiver status was self-reported. The definition of an unpaid caregiver for adults was a person who had provided unpaid care to a relative or friend aged ≥18 years to help them take care of themselves at any time in the last three months. Examples provided included helping with personal needs, household chores, health care tasks, managing a person's finances, taking them to a doctor's appointment, arranging for outside services, and visiting regularly to see how they are doing.

^{¶¶} Region classification was determined by using the U.S. Census Bureau's Census Regions and Divisions of the United States. https://www2.census.gov/geo/pdfs/maps-data/maps/reference/us_regdiv.pdf.

*** Rural-urban classification was determined by using self-reported ZIP codes according to the Federal Office of Rural Health Policy definition of rurality. <https://www.hrsa.gov/rural-health/about-us/definition/datafiles.html>.

Discussion

Elevated levels of adverse mental health conditions, substance use, and suicidal ideation were reported by adults in the United States in June 2020. The prevalence of symptoms of anxiety disorder was approximately three times those reported in the second quarter of 2019 (25.5% versus 8.1%), and prevalence of depressive disorder was approximately four times that reported in the second quarter of 2019 (24.3% versus 6.5%) (2). However, given the methodological differences and potential unknown biases in survey designs, this analysis might not be directly comparable with data reported on anxiety and depression disorders in 2019 (2). Approximately one quarter of respondents

reported symptoms of a TSRD related to the pandemic, and approximately one in 10 reported that they started or increased substance use because of COVID-19. Suicidal ideation was also elevated; approximately twice as many respondents reported serious consideration of suicide in the previous 30 days than did adults in the United States in 2018, referring to the previous 12 months (10.7% versus 4.3%) (6).

Mental health conditions are disproportionately affecting specific populations, especially young adults, Hispanic persons, black persons, essential workers, unpaid caregivers for adults, and those receiving treatment for preexisting psychiatric conditions. Unpaid caregivers for adults, many of whom are currently providing critical aid to persons at increased risk

Table 16 (6.2). Comparison of symptoms of adverse mental health outcomes among all respondents who completed surveys (N = 5,470), by respondent characteristic* — United States, June 24–30, 2020

TABLE 2. Comparison of symptoms of adverse mental health outcomes among all respondents who completed surveys (N = 5,470), by respondent characteristic* — United States, June 24–30, 2020

Characteristic	Prevalence ratio [¶] (95% CI [¶])			
	Symptoms of anxiety disorder or depressive disorder [†]	Symptoms of a TSRD related to COVID-19 [§]	Started or increased substance use to cope with stress or emotions related to COVID-19	Serious consideration of suicide in past 30 days
Gender				
Female vs. male	1.04 (0.96–1.12)	0.88 (0.81–0.97)	0.85 (0.75–0.98)	0.70 (0.60–0.82)**
Age group (yrs)				
18–24 vs. 25–44	1.56 (1.44–1.68)**	1.28 (1.16–1.41)**	1.31 (1.12–1.53)**	1.59 (1.35–1.87)**
18–24 vs. 45–64	3.10 (2.79–3.44)**	2.67 (2.35–3.03)**	3.35 (2.75–4.10)**	6.66 (5.15–8.61)**
18–24 vs. ≥65	7.73 (6.19–9.66)**	5.01 (4.04–6.22)**	8.77 (5.95–12.93)**	12.51 (7.88–19.86)**
25–44 vs. 45–64	1.99 (1.79–2.21)**	2.09 (1.86–2.35)**	2.56 (2.14–3.07)**	4.18 (3.26–5.36)**
25–44 vs. ≥65	4.96 (3.97–6.20)**	3.93 (3.18–4.85)**	6.70 (4.59–9.78)**	7.86 (4.98–12.41)**
45–64 vs. ≥65	2.49 (1.98–3.15)**	1.88 (1.50–2.35)**	2.62 (1.76–3.9)**	1.88 (1.14–3.10)
Race/Ethnicity^{††}				
Hispanic vs. non-Hispanic black	1.35 (1.18–1.56)**	1.15 (1.00–1.33)	1.19 (0.97–1.46)	1.23 (0.98–1.55)
Hispanic vs. non-Hispanic Asian	2.27 (1.73–2.98)**	1.59 (1.24–2.04)**	3.29 (2.05–5.28)**	2.82 (1.74–4.57)**
Hispanic vs. non-Hispanic other race or multiple races	1.23 (0.98–1.55)	1.24 (0.96–1.61)	1.99 (1.27–3.13)**	1.89 (1.16–3.06)
Hispanic vs. non-Hispanic white	1.40 (1.27–1.54)**	1.50 (1.35–1.68)**	2.09 (1.79–2.45)**	2.35 (1.96–2.80)**
Non-Hispanic black vs. non-Hispanic Asian	1.68 (1.26–2.23)**	1.38 (1.07–1.78)	2.75 (1.70–4.47)**	2.29 (1.39–3.76)**
Non-Hispanic black vs. non-Hispanic other race or multiple races	0.91 (0.71–1.16)	1.08 (0.82–1.41)	1.67 (1.05–2.65)	1.53 (0.93–2.52)
Non-Hispanic black vs. non-Hispanic white	1.03 (0.91–1.17)	1.30 (1.14–1.48)**	1.75 (1.45–2.11)**	1.90 (1.54–2.36)**
Non-Hispanic Asian vs. non-Hispanic other race or multiple races	0.54 (0.39–0.76)**	0.78 (0.56–1.09)	0.61 (0.32–1.14)	0.67 (0.35–1.29)
Non-Hispanic Asian vs. non-Hispanic white	0.62 (0.47–0.80)**	0.95 (0.74–1.20)	0.64 (0.40–1.02)	0.83 (0.52–1.34)
Non-Hispanic other race or multiple races vs. non-Hispanic white	1.14 (0.91–1.42)	1.21 (0.94–1.56)	1.05 (0.67–1.64)	1.24 (0.77–2)

See table footnotes on the next page.

for severe illness from COVID-19, had a higher incidence of adverse mental and behavioral health conditions compared with others. Although unpaid caregivers of children were not evaluated in this study, approximately 39% of unpaid caregivers for adults shared a household with children (compared with 27% of other respondents). Caregiver workload, especially in multigenerational caregivers, should be considered for future assessment of mental health, given the findings of this report and hardships potentially faced by caregivers.

The findings in this report are subject to at least four limitations. First, a diagnostic evaluation for anxiety disorder or depressive disorder was not conducted; however, clinically validated screening instruments were used to assess symptoms. Second, the trauma- and stressor-related symptoms assessed were common to multiple TSRDs, precluding distinction among them; however, the findings highlight the importance of including COVID-19–specific trauma measures to gain insights into peri- and posttraumatic impacts of the COVID-19 pandemic (7). Third, substance use behavior was self-reported; therefore, responses might be subject to recall, response, and social desirability biases. Finally, given that the web-based survey might not be fully representative of the United States population, findings might have limited

generalizability. However, standardized quality and data inclusion screening procedures, including algorithmic analysis of click-through behavior, removal of duplicate responses and scrubbing methods for web-based panel quality were applied. Further the prevalence of symptoms of anxiety disorder and depressive disorder were largely consistent with findings from the Household Pulse Survey during June (1).

Markedly elevated prevalences of reported adverse mental and behavioral health conditions associated with the COVID-19 pandemic highlight the broad impact of the pandemic and the need to prevent and treat these conditions. Identification of populations at increased risk for psychological distress and unhealthy coping can inform policies to address health inequity, including increasing access to resources for clinical diagnoses and treatment options. Expanded use of telehealth, an effective means of delivering treatment for mental health conditions, including depression, substance use disorder, and suicidal ideation (8), might reduce COVID-19-related mental health consequences. Future studies should identify drivers of adverse mental and behavioral health during the COVID-19 pandemic and whether factors such as social isolation, absence of school structure, unemployment and other financial worries, and various forms of violence (e.g., physical,

Table 16 (6.2) (Continued). Comparison of symptoms of adverse mental health outcomes among all respondents who completed (N = 5,470), by respondent characteristic* — United States, June 24–30, 2020

TABLE 2. (Continued) Comparison of symptoms of adverse mental health outcomes among all respondents who completed surveys (N = 5,470), by respondent characteristic* — United States, June 24–30, 2020

Characteristic	Prevalence ratio [¶] (95% CI [¶])			
	Symptoms of anxiety disorder or depressive disorder [†]	Symptoms of a TSRD related to COVID-19 [§]	Started or increased substance use to cope with stress or emotions related to COVID-19	Serious consideration of suicide in past 30 days
Employment status				
Employed vs. unemployed	0.96 (0.87–1.07)	1.28 (1.12–1.46)**	2.30 (1.78–2.98)**	3.21 (2.31–4.47)**
Employed vs. retired	3.01 (2.58–3.51)**	2.84 (2.42–3.34)**	4.30 (3.28–5.63)**	5.97 (4.20–8.47)**
Unemployed vs. retired	3.12 (2.63–3.71)**	2.21 (1.82–2.69)**	1.87 (1.30–2.67)**	1.86 (1.16–2.96)
Essential vs. nonessential worker^{§§}	1.42 (1.30–1.56)**	1.52 (1.38–1.69)**	2.36 (2.00–2.77)**	2.76 (2.29–3.33)**
Unpaid caregiver for adults vs. not^{¶¶}	2.55 (2.37–2.75)**	2.63 (2.42–2.86)**	5.28 (4.59–6.07)**	8.64 (7.23–10.33)**
Rural vs. urban residence^{***}	0.94 (0.82–1.07)	0.96 (0.83–1.11)	0.84 (0.67–1.06)	0.95 (0.74–1.22)
Knows someone with positive SARS-CoV-2 test result vs. not	0.95 (0.86–1.05)	0.78 (0.69–0.88)**	0.96 (0.81–1.14)	0.65 (0.52–0.81)**
Knew someone who died from COVID-19 vs. not	0.99 (0.85–1.15)	1.08 (0.92–1.26)	0.84 (0.64–1.11)	0.69 (0.49–0.97)
Receiving treatment for anxiety vs. not	2.43 (2.26–2.63)**	2.21 (2.01–2.43)**	2.27 (1.94–2.66)**	2.54 (2.13–3.03)**
Receiving treatment for depression vs. not	2.20 (2.03–2.39)**	1.88 (1.70–2.09)**	2.13 (1.81–2.51)**	2.35 (1.96–2.82)**
Receiving treatment for PTSD vs. not	2.75 (2.55–2.97)**	2.87 (2.61–3.16)**	3.78 (3.23–4.42)**	4.95 (4.21–5.83)**

Abbreviations: CI = confidence interval; COVID-19 = coronavirus disease 2019; PTSD = posttraumatic stress disorder; TSRD = trauma- or stress-related disorder.

* Number of respondents for characteristics: gender (female = 2,784, male = 2,676), age group in years (18–24 = 731; 25–44 = 1,911; 45–64 = 1,895; ≥65 = 933), race/ethnicity (non-Hispanic white = 3453, non-Hispanic black = 663, non-Hispanic Asian = 256, non-Hispanic other race or multiple races = 164, Hispanic = 885).

[†] Symptoms of anxiety disorder and depressive disorder were assessed via the four-item Patient Health Questionnaire (PHQ-4). Those who scored ≥3 out of 6 on the Generalized Anxiety Disorder (GAD-2) and Patient Health Questionnaire (PHQ-2) subscales were considered to have symptoms of these disorders.

[§] Disorders classified as TSRDs in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) include PTSD, acute stress disorder (ASD), and adjustment disorders (ADs), among others. Symptoms of a TSRD precipitated by the COVID-19 pandemic were assessed via the six-item Impact of Event Scale (IES-6) to screen for overlapping symptoms of PTSD, ASD, and ADs. For this survey, the COVID-19 pandemic was specified as the traumatic exposure to record peri- and posttraumatic symptoms associated with the range of stressors introduced by the COVID-19 pandemic. Persons who scored ≥1.75 out of 4 were considered to be symptomatic.

[¶] Comparisons within subgroups were evaluated on weighted responses via Poisson regressions used to calculate a prevalence ratio, 95% CI, and p-value (not shown). Statistical significance was evaluated at a threshold of $\alpha = 0.005$ to account for multiple comparisons. In the calculation of prevalence ratios for started or increased substance use, respondents who selected "Prefer not to answer" (n = 104) were excluded.

** P-value is statistically significant ($p < 0.005$).

^{††} Respondents identified as a single race unless otherwise specified. The non-Hispanic, other race or multiple races category includes respondents who identified as not Hispanic and as more than one race or as American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or 'Other'.

^{§§} Essential worker status was self-reported. The comparison was between employed respondents (n = 3,431) who identified as essential vs. nonessential. For this analysis, students who were not separately employed as essential workers were considered nonessential workers.

^{¶¶} Unpaid adult caregiver status was self-reported. The definition of an unpaid caregiver for adults was having provided unpaid care to a relative or friend aged ≥18 years to help them take care of themselves at any time in the last three months. Examples provided included helping with personal needs, household chores, health care tasks, managing a person's finances, taking them to a doctor's appointment, arranging for outside services, and visiting regularly to see how they are doing.

^{***} Rural-urban classification was determined by using self-reported ZIP codes according to the Federal Office of Rural Health Policy definition of rurality. <https://www.hrsa.gov/rural-health/about-us/definition/datafiles.html>.

emotional, mental, or sexual abuse) serve as additional stressors. Community-level intervention and prevention efforts should include strengthening economic supports to reduce financial strain, addressing stress from experienced racial discrimination, promoting social connectedness, and supporting persons at risk for suicide (9). Communication strategies should focus on promotion of health services^{§§§§,¶¶¶¶,*****} and culturally and

linguistically tailored prevention messaging regarding practices to improve emotional well-being. Development and implementation of COVID-19–specific screening instruments for early identification of COVID-19–related TSRD symptoms would allow for early clinical interventions that might prevent progression from acute to chronic TSRDs. To reduce potential harms of increased substance use related to COVID-19, resources, including social support, comprehensive treatment options, and harm reduction services, are essential and should remain accessible. Periodic assessment of mental health, substance use, and suicidal ideation should evaluate the prevalence of psychological distress over time. Addressing mental health disparities and preparing support systems to mitigate mental health consequences as the pandemic evolves will continue to be needed urgently.

^{§§§§} Disaster Distress Helpline (<https://www.samhsa.gov/disaster-preparedness>): 1-800-985-5990 (press 2 for Spanish), or text TalkWithUs for English or Hablanos for Spanish to 66746. Spanish speakers from Puerto Rico can text Hablanos to 1-787-339-2663.

^{¶¶¶¶} Substance Abuse and Mental Health Services Administration National Helpline (also known as the Treatment Referral Routing Service) for persons and families facing mental disorders, substance use disorders, or both: <https://www.samhsa.gov/find-help/national-helpline>, 1-800-662-HELP, or TTY 1-800-487-4889.

^{*****} National Suicide Prevention Lifeline (<https://suicidepreventionlifeline.org/>): 1-800-273-TALK for English, 1-888-628-9454 for Spanish, or Lifeline Crisis Chat (<https://suicidepreventionlifeline.org/chat/>).

Table 17 (6.3). Odds of incidence of symptoms of adverse mental health, substance use to cope with stress or emotions related to COVID-19 pandemic, and suicidal ideation in the third survey wave, by essential worker status and unpaid adult caregiver status

TABLE 3. Odds of incidence* of symptoms of adverse mental health, substance use to cope with stress or emotions related to COVID-19 pandemic, and suicidal ideation in the third survey wave, by essential worker status and unpaid adult caregiver status among respondents who completed monthly surveys from April through June (N = 1,497) — United States, April 2–8, May 5–12, and June 24–30, 2020

Symptom or behavior	Essential worker [†] vs. all other employment statuses (nonessential worker, unemployed, retired)				Unpaid caregiver for adults [§] vs. not unpaid caregiver			
	Unadjusted		Adjusted [¶]		Unadjusted		Adjusted ^{**}	
	OR (95% CI) ^{††}	p-value ^{††}	OR (95% CI) ^{††}	p-value ^{††}	OR (95% CI) ^{††}	p-value ^{††}	OR (95% CI) ^{††}	p-value ^{††}
Symptoms of anxiety disorder ^{§§}	1.92 (1.29–2.87)	0.001	1.63 (0.99–2.69)	0.056	1.97 (1.25–3.11)	0.004	1.81 (1.14–2.87)	0.012
Symptoms of depressive disorder ^{§§}	1.49 (1.00–2.22)	0.052	1.13 (0.70–1.82)	0.606	2.29 (1.50–3.50)	<0.001	2.22 (1.45–3.41)	<0.001
Symptoms of anxiety disorder or depressive disorder ^{§§}	1.67 (1.14–2.46)	0.008	1.26 (0.79–2.00)	0.326	1.84 (1.19–2.85)	0.006	1.73 (1.11–2.70)	0.015
Symptoms of a TSRD related to COVID-19 ^{¶¶}	1.55 (0.86–2.81)	0.146	1.27 (0.63–2.56)	0.512	1.88 (0.99–3.56)	0.054	1.79 (0.94–3.42)	0.076
Started or increased substance use to cope with stress or emotions related to COVID-19	2.36 (1.26–4.42)	0.007	2.04 (0.92–4.48)	0.078	3.51 (1.86–6.61)	<0.001	3.33 (1.75–6.31)	<0.001
Serious consideration of suicide in previous 30 days	0.93 (0.31–2.78)	0.895	0.53 (0.16–1.70)	0.285	3.00 (1.20–7.52)	0.019	3.03 (1.20–7.63)	0.019

Abbreviations: CI = confidence interval, COVID-19 = coronavirus disease 2019, OR = odds ratio, TSRD = trauma- and stressor-related disorder.

* For outcomes assessed via the four-item Patient Health Questionnaire (PHQ-4), odds of incidence were marked by the presence of symptoms during May 5–12 or June 24–30, 2020, after the absence of symptoms during April 2–8, 2020. Respondent pools for prospective analysis of odds of incidence (did not screen positive for symptoms during April 2–8): anxiety disorder (n = 1,236), depressive disorder (n = 1,301) and anxiety disorder or depressive disorder (n = 1,190). For symptoms of a TSRD precipitated by COVID-19, started or increased substance use to cope with stress or emotions related to COVID-19, and serious suicidal ideation in the previous 30 days, odds of incidence were marked by the presence of an outcome during June 24–30, 2020, after the absence of that outcome during May 5–12, 2020. Respondent pools for prospective analysis of odds of incidence (did not report symptoms or behavior during May 5–12): symptoms of a TSRD (n = 1,206), started or increased substance use (n = 1,408), and suicidal ideation (n = 1,456).

[†] Essential worker status was self-reported. For Table 3, essential worker status was determined by identification as an essential worker during the June 24–30 survey. Essential workers were compared with all other respondents, not just employed respondents (i.e., essential workers vs. all other employment statuses [nonessential worker, unemployed, and retired], not essential vs. nonessential workers).

[§] Unpaid adult caregiver status was self-reported. The definition of an unpaid caregiver for adults was having provided unpaid care to a relative or friend 18 years or older to help them take care of themselves at any time in the last three months. Examples provided included helping with personal needs, household chores, health care tasks, managing a person's finances, taking them to a doctor's appointment, arranging for outside services, and visiting regularly to see how they are doing.

[¶] Adjusted for gender, employment status, and unpaid adult caregiver status.

^{**} Adjusted for gender, employment status, and essential worker status.

^{††} Respondents who completed surveys from all three waves (April, May, June) were eligible to be included in an unweighted longitudinal analysis. Comparisons within subgroups were evaluated via logit-linked Binomial regressions used to calculate unadjusted and adjusted odds ratios, 95% confidence intervals, and p-values. Statistical significance was evaluated at a threshold of $\alpha = 0.05$. In the calculation of odds ratios for started or increased substance use, respondents who selected "Prefer not to answer" (n = 11) were excluded.

^{§§} Symptoms of anxiety disorder and depressive disorder were assessed via the PHQ-4. Those who scored ≥ 3 out of 6 on the two-item Generalized Anxiety Disorder (GAD-2) and two-item Patient Health Questionnaire (PHQ-2) subscales were considered symptomatic for each disorder, respectively.

^{¶¶} Disorders classified as TSRDs in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) include posttraumatic stress disorder (PTSD), acute stress disorder (ASD), and adjustment disorders (ADs), among others. Symptoms of a TSRD precipitated by the COVID-19 pandemic were assessed via the six-item Impact of Event Scale (IES-6) to screen for overlapping symptoms of PTSD, ASD, and ADs. For this survey, the COVID-19 pandemic was specified as the traumatic exposure to record peri- and posttraumatic symptoms associated with the range of potential stressors introduced by the COVID-19 pandemic. Those who scored ≥ 1.75 out of 4 were considered symptomatic.

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Corresponding author: Rashon Lane for the CDC COVID-19 Response Team, Rlane@cdc.gov.

¹Turner Institute for Brain and Mental Health, Monash University, Melbourne, Australia; ²Austin Health, Melbourne, Australia; ³CDC COVID-19 Response Team; ⁴Brigham and Women's Hospital, Boston, Massachusetts; ⁵Harvard Medical School, Boston, Massachusetts; ⁶University of Melbourne, Melbourne, Australia.

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Summary

What is already known about this topic?

Communities have faced mental health challenges related to COVID-19–associated morbidity, mortality, and mitigation activities.

What is added by this report?

During June 24–30, 2020, U.S. adults reported considerably elevated adverse mental health conditions associated with COVID-19. Younger adults, racial/ethnic minorities, essential workers, and unpaid adult caregivers reported having experienced disproportionately worse mental health outcomes, increased substance use, and elevated suicidal ideation.

What are the implications for public health practice?

The public health response to the COVID-19 pandemic should increase intervention and prevention efforts to address associated mental health conditions. Community-level efforts, including health communication strategies, should prioritize young adults, racial/ethnic minorities, essential workers, and unpaid adult caregivers.

administration of the survey in June. No other potential conflicts of interest were disclosed.

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During late June, 40% of U.S. adults reported struggling with mental health or substance use*

ANXIETY/DEPRESSION SYMPTOMS



STARTED OR INCREASED SUBSTANCE USE



TRAUMA/STRESSOR-RELATED DISORDER SYMPTOMS



SERIOUSLY CONSIDERED SUICIDE†



*Based on a survey of U.S. adults aged ≥18 years during June 24-30, 2020

†In the 30 days prior to survey

For stress and coping strategies: bit.ly/dailylifecoping

Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic — United States, June 24–30, 2020

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SUMMARY OF FINDINGS

The Original Investigation presented in Chapter Six, which was the first largescale, national population assessment of mental health among US adults published during the COVID-19 pandemic, revealed that 41% of 5,470 surveyed US adults reported adverse mental health symptoms or substance use. The prevalence estimates for symptoms of anxiety (25.5%) and symptoms of depression (24.3%) were three and four times higher, respectively, than those reported in the second quarter of 2019, based on the 2019 National Health Interview Survey (NHIS) **(Department of Health and Human Services, 2020)**. Additionally, the prevalence of suicidal ideation was also elevated, with approximately twice as many respondents having reported serious consideration of suicide in the previous 30 days compared with US adults in 2018, referring to the previous 12 months based on the 2018 National Survey on Drug Use and Health (NSDUH) (10.7% versus 4.3%) **(Substance Abuse and Mental Health Services Administration, 2019)**. As noted in the report, methodological differences and potential unknown biases might limit the accuracy of comparisons between these prevalence estimates. However, subsequent publications using the same measures have found similar prevalence estimates for anxiety and depression symptoms **(Ettman et al., 2020; McKnight-Eily et al., 2021; Vahratian et al., 2021)**, new or increased substance use **(McKnight-Eily et al., 2021)**, and suicidal ideation **(McKnight-Eily et al., 2021)**.

The findings in this Original Investigation also revealed considerable demographic differences in the prevalence of adverse mental health symptoms, with particularly disproportionate levels by age, race and ethnicity, essential worker status, unpaid caregiver status, and whether adults had pre-existing psychiatric diagnoses. While some of these groups have experienced elevated levels of adverse mental health symptoms prior to the pandemic (e.g., essential workers, people with pre-existing psychiatric conditions), longitudinal analyses on a subset of respondents who had completed

multiple waves of The COPE Initiative surveys revealed that unpaid caregivers of adults had three times the odds of new substance use and new suicidal ideation in June 2020 after not having reported these experiences in May 2020. Though other populations received more attention in warnings about disproportionate impacts of the pandemic (**S. K. Brooks et al., 2020; Galea et al., 2020; Holmes et al., 2020**), unpaid caregivers had nearly 10 times the prevalence of suicidal ideation compared with non-caregivers (30.7% versus 3.6%, respectively). The magnitude of differences in mental health by age were also surprising. Despite lower risk of COVID-19 morbidity and mortality (**Gold et al., 2020; Wortham et al., 2020**), and contrary to the hypothesis that older adults would be disproportionately affected (**Holmes et al., 2020**), approximately 75% of adults aged 18-24 years experienced adverse mental health symptoms or substance use in June 2020, compared with 15% of adults aged ≥ 65 years (**Czeisler, Lane, et al., 2020**). The finding of enhanced mental health resilience among older adults during the pandemic compared with younger adults, which countered the expectations of some gerontologists (**Vahia et al., 2020**), has been consistently reproduced in subsequent publications (**Czeisler, Lane, et al., 2021; Ettman et al., 2020; Holman et al., 2020; McKnight-Eily et al., 2021; Vahratian et al., 2021**). Though these population-level differences may mask deterioration among some subgroups (e.g., older adults with dementia or other chronic health conditions), Vahia *et al.* hypothesised that the observed mental health resilience may reflect a combination of internal factors (e.g., an attenuated biological stress response, enhance cognitive capacity, personality traits) and external resources (e.g., social status, financial stability) (**Laird et al., 2019; Vahia et al., 2020**).

Encouragingly, the data from the Original Investigation presented in Chapter Six prompted policies in the US, including enhanced resource allocations and mental health service planning during the pandemic. Specifically, the high prevalence of adverse mental health symptoms and substance use were quoted in the following: Presidential Executive Order 13954 allocating USD\$425

million for mental and behavioural health services during the pandemic and establishing a federal Coronavirus Mental Health Working Group **(The White House, 2020e)**; Senate Bill No. 855 expanding coverage for mental health and substance use **(California Legislative Information, 2020)**; and a letter from the President of the National Safety Council to President Trump and President Joseph R. Biden advocating for a comprehensive, national plan to address opioid misuse in the US **(Martin, 2020)**.

The findings also raised the question of whether the acutely elevated levels of adverse mental health symptoms would be transient and self-resolving as people adapted to profound life changes beginning in March 2020, or whether they would remain elevated? The answer to that question could affect mental health response planning and resource allocation **(Gordon & Borja, 2020)**, and inform the underlying mechanisms of these adverse mental health symptoms.

CHAPTER 7: Follow-up Survey of US Adult Reports of Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic, September 2020

PREFACE TO CHAPTER 7

To begin to investigate the question posed at the end of [Chapter Six](#) as to whether the estimated prevalence of adverse mental health symptoms and substance use among US adults would be self-resolving with time, there was a continued need for mental health surveillance. Some postulated that the prevalence would rapidly attenuate given such observations following recent public health emergencies in the US, such as Hurricane Katrina and the September 11 attacks on the World Trade Center (**The National Academies of Sciences Engineering and Medicine, 2020**). However, unlike these events, which were relatively immediate and concentrated traumas, the COVID-19 pandemic represented a sustained exposure, and mental health responses may have been further exacerbated by cascading collective traumas in the US, including a housing crisis, an economic recession, race-related social unrest, weather-related disasters, and political tension (**Silver et al., 2021**).

The Original Investigation in Chapter Seven (**Czeisler, Lane, et al., 2021**), which was published in *JAMA Network Open*, presents data collected during 28 August to 6 September 2020—approximately six months after the declaration of the COVID-19 pandemic by the WHO and five months after the initial wave of data collection assessing mental health from The COPE Initiative ([Chapter Four](#)). The dataset included a combination of recontacted and first-time respondents for The COPE Initiative, with approximately 22% recontacted after April 2020, 31% recontacted after June 2020, and 47% contacted for the first time. The mental health and substance use measures were the same as those presented in [Chapter Six](#) (i.e., anxiety or depression symptoms, COVID-19

TSRD symptoms, new or increased substance use, and suicidal ideation). The chapter concludes with a brief overview of findings from the Original Investigation.

CHAPTER SEVEN: Follow-up Survey of US Adult Reports of Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic, September 2020

Czeisler MÉ, Lane RI, Wiley JF, Czeisler CA, Howard ME, Rajaratnam SMW. Follow-up Survey of US Adult Reports of Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic, September 2020. *JAMA Netw Open*. 2021 Feb 1;4(2):e2037665. doi: 10.1001/jamanetworkopen.2020.37665. PMID: 33606030; PMCID: PMC7896196.



Research Letter | Psychiatry

Follow-up Survey of US Adult Reports of Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic, September 2020

Mark É. Czeisler, AB; Rashon I. Lane, MA; Joshua F. Wiley, PhD; Charles A. Czeisler, PhD, MD; Mark E. Howard, MBBS, PhD; Shantha M. W. Rajaratnam, PhD

Introduction

Adverse mental health symptoms among US adults were more prevalent during the early phase (April-June 2020) of the coronavirus disease 2019 (COVID-19) pandemic compared with prepandemic estimates (eg, 3-fold increased prevalences of anxiety and depression symptoms, 2-fold increased prevalence of suicidal ideation).^{1,2} In June 2020, 2238 (40.9%) of 5470 US adults reported adverse mental or behavioral health symptoms. During this time, the prevalence of symptoms was lower in adults aged 65 years or older (141 of 933 [15.1%]) than in young adults aged 18 to 24 years (547 of 731 [74.9%]; $P < .001$).¹ Given suggestions that acute increases in the prevalence of adverse mental health symptoms may represent a transient response to mass trauma,³ we sought to determine whether these patterns persisted in September 2020 and to examine disproportionately affected demographic groups.

+ Supplemental content

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Methods

In this survey study from August 28 to September 6, 2020, US adults aged 18 years or older completed 139-item internet-based surveys through Qualtrics for The COVID-19 Outbreak Public Evaluation (COPE) Initiative. Surveys were administered to an online respondent panel maintained by Qualtrics, a commercial survey company with networks of participant pools. Respondents reported demographic characteristics and completed questions assessing attitudes, behaviors, and beliefs about COVID-19, mitigation measures, and mental and behavioral health. When possible, brief, validated instruments were used or adapted.

Demographic quota sampling and survey weighting were used to make the sample representative of the US population by age, sex, and race/ethnicity, and weighted values are presented. Participants reported symptoms of anxiety and depression, COVID-19–related trauma- and stressor-related disorders, starting or increasing substance use to cope with pandemic-related stress, or having seriously considered suicide within 30 days. The Monash University Human Research Ethics Committee approved the study protocol, and participants provided informed consent electronically. The article followed the American Association for Public Opinion Research (AAPOR) reporting guideline.

Multivariable Poisson regressions with robust standard errors were used to estimate adjusted prevalence ratios (aPRs) and 95% CIs for any adverse mental or behavioral health symptom with the following factors: sex, age, sexual orientation, race/ethnicity, Census region, urban/rural residence, and unpaid caregiver status. Separate models were run for the following collinear factors: disability status, insomnia symptoms, prior psychiatric diagnosis (anxiety, depression, posttraumatic stress disorder, or a substance use disorder), and age-excluded employment status. Age was not adjusted for in the model that included employment status to avoid collinearity between these variables. Continuity-corrected McNemar tests were used to assess longitudinal differences in adverse mental health symptom prevalences among respondents who completed surveys in June 2020 and September 2020. All calculations were performed in Python version 3.7.8 (Python Software Foundation) and R version 4.0.2 (The R Project for Statistical Computing) using the R survey package version 3.29. P values were 2-sided, and statistical significance was set at $P < .05$. Detailed methods¹

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Table 18 (7.1). Prevalence of Adverse Mental and Behavioral Health Symptoms, by Respondent Characteristic

Table 1. Prevalence of Adverse Mental and Behavioral Health Symptoms, by Respondent Characteristics

Characteristic	No. (%)					
	Total respondents	Anxiety or depression	COVID-19 TSRD	Substance use	Suicidal ideation	≥1 of these
June 2020 ^a	5470 (100)	1692 (30.9)	1437 (26.3)	726 (13.3)	584 (10.7)	2238 (40.9)
September 2020	5186 (100)	1710 (33.0)	1536 (29.6)	781 (15.1)	618 (11.9)	2237 (43.1)
Sex						
Female	2641 (50.9)	887 (33.6)	764 (28.9)	327 (12.4)	240 (9.1)	1156 (43.8)
Male	2545 (49.1)	823 (32.3)	773 (30.4)	454 (17.8)	378 (14.9)	1081 (42.5)
Sexual orientation						
Heterosexual	4568 (88.1)	1373 (30.1)	1261 (27.6)	570 (12.5)	436 (9.5)	1818 (39.8)
Lesbian or gay	242 (4.7)	121 (50.0)	101 (41.9)	73 (30.4)	55 (22.7)	148 (61.1)
Bisexual	202 (3.9)	131 (64.8)	99 (48.8)	95 (47.1)	79 (39.0)	159 (78.6)
Other or unknown ^b	174 (3.4)	84 (48.5)	75 (43.3)	42 (24.1)	49 (28.0)	112 (64.2)
Age group, y						
18-24	593 (11.4)	376 (63.4)	309 (52.2)	168 (28.4)	118 (19.9)	441 (74.4)
25-44	1837 (35.4)	886 (48.2)	813 (44.2)	493 (26.8)	426 (23.2)	1122 (61.1)
45-64	1831 (35.3)	366 (20.0)	327 (17.8)	95 (5.2)	64 (3.5)	536 (29.3)
≥65	926 (17.9)	82 (8.9)	88 (9.5)	24 (2.6)	11 (1.2)	138 (14.9)
Race/ethnicity						
White non-Hispanic	3349 (64.6)	952 (28.4)	857 (25.6)	418 (12.5)	341 (10.2)	1238 (37.0)
Black non-Hispanic	634 (12.2)	244 (38.4)	243 (38.3)	117 (18.5)	92 (14.5)	346 (54.5)
Asian non-Hispanic	261 (5.0)	58 (22.3)	64 (24.6)	14 (5.3)	13 (4.8)	93 (35.7)
Other race or multiple races, non-Hispanic ^c	159 (3.1)	59 (36.8)	45 (28.1)	14 (8.7)	10 (6.6)	74 (46.7)
Hispanic, any race or races	782 (15.1)	397 (50.8)	328 (41.9)	218 (27.9)	163 (20.8)	486 (62.1)
Employment status						
Nonessential worker	1303 (25.1)	333 (25.5)	322 (24.7)	133 (10.2)	79 (6.1)	487 (37.4)
Essential worker	1767 (34.1)	876 (49.5)	805 (45.5)	536 (30.3)	472 (26.7)	1087 (61.5)
Unemployed	720 (13.9)	263 (36.5)	204 (28.3)	56 (7.8)	36 (4.9)	336 (46.8)
Retired	1242 (23.9)	161 (13.0)	142 (11.4)	42 (3.4)	17 (1.4)	239 (19.3)
Student	154 (3.0)	77 (49.8)	64 (41.2)	13 (8.1)	14 (9.2)	87 (56.2)
Unpaid caregiver status						
No	3259 (62.8)	705 (21.6)	632 (19.4)	163 (5.0)	93 (2.8)	1003 (30.8)
Children or adolescents <18 y	484 (9.3)	138 (28.6)	127 (26.1)	39 (8.0)	14 (3.0)	196 (40.4)
Adults ≥18 y	544 (10.5)	200 (36.7)	171 (31.5)	47 (8.6)	35 (6.4)	258 (47.4)
Both age groups	899 (17.3)	666 (74.1)	607 (67.5)	532 (59.2)	476 (53.0)	781 (86.8)
Disability status ^d						
Yes	1158 (22.3)	647 (55.9)	551 (47.6)	395 (34.1)	349 (30.1)	770 (66.5)
No	3812 (73.5)	982 (25.8)	926 (24.3)	365 (9.6)	262 (6.9)	1368 (35.9)
Prefer not to say	216 (4.2)	81 (37.3)	60 (27.5)	21 (9.6)	7 (3.2)	99 (45.7)
Symptoms of insomnia ^e						
Yes	899 (17.3)	512 (56.9)	460 (51.1)	202 (22.5)	170 (18.9)	617 (68.6)
No	4287 (82.7)	1197 (27.9)	1076 (25.1)	579 (13.5)	448 (10.5)	1621 (37.8)
Past psychiatric diagnosis ^f						
Yes	1919 (37.0)	1189 (62.0)	977 (50.9)	599 (31.2)	508 (26.5)	1380 (71.9)
No	3267 (63.0)	521 (15.9)	560 (17.1)	182 (5.6)	110 (3.4)	857 (26.2)

Abbreviations: COVID-19, coronavirus disease 2019; TSRD, trauma- and stressor-related disorder.

^a Data appeared in Czeisler et al,¹ 2020.

^b Includes responses of something else, I don't know the answer, and prefer not to say.

^c Includes American Indian or Alaskan Native, Native Hawaiian or other Pacific Islander, and other.

^d Includes physical, mental, and emotional conditions or health conditions that require special equipment.

^e Assessed via the 2-item Sleep Condition Indicator.

^f Includes current or prior diagnosis with an anxiety disorder, depression, posttraumatic stress disorder, or a substance use disorder.

describing the recruitment process, survey, screening tools, and analyses can be found in the eAppendix in the [Supplement](#).

Results

Overall, 5285 of 11 953 potential participants (44.2%) completed September 2020 surveys; 5186 of these respondents (98.1%) met secondary screening criteria and were analyzed (1155 [22.3%] were recontacted after April 2020; 1605 [30.9%] were recontacted after June 2020; 2426 [46.8%] were first-time respondents). Overall, 1710 (33.0%) reported anxiety or depression symptoms, 1536 (29.6%) reported COVID-19-related trauma- and stressor-related disorder symptoms, 781 (15.1%)

Table 19 (7.2). Characteristics Associated With Adverse Mental or Behavioral Health Symptoms, September 2020

Table 2. Characteristics Associated With Adverse Mental or Behavioral Health Symptoms, September 2020

Characteristic	aPR (95% CI) ^a
Age group, y	
≥65	1 [Reference]
18-24	3.56 (3.04-4.18)
25-44	3.15 (2.76-3.60)
45-64	1.81 (1.58-2.07)
Sexual orientation	
Heterosexual	1 [Reference]
Lesbian or gay	1.25 (1.13-1.39)
Bisexual	1.26 (1.14-1.39)
Employment ^b	
Nonessential worker	1 [Reference]
Essential worker	1.28 (1.17-1.41)
Unemployed	1.24 (1.10-1.40)
Student	1.28 (1.00-1.66)
Retired	0.59 (0.52-0.67)
Unpaid caregiver status	
No	1 [Reference]
Children or adolescents <18 y	1.06 (0.92-1.21)
Adults ≥18 y	1.38 (1.24-1.54)
Both age groups	1.93 (1.78-2.08)
Disability status ^c	
No	1 [Reference]
Yes	1.40 (1.30-1.49)
Symptoms of insomnia ^d	
No	1 [Reference]
Yes	1.64 (1.54-1.75)
Past psychiatric diagnosis ^e	
No	1 [Reference]
Yes	1.98 (1.83-2.15)

Abbreviation: aPR, adjusted prevalence ratio.

^a Adjusted for sex, age, sexual orientation, race/ethnicity, region, urban/rural residence, and unpaid caregiver status. Groups without significant aPR estimates are not shown.

^b Age was not adjusted for in the employment status model to avoid collinearity between these variables.

^c Includes physical, mental, and emotional conditions or health conditions that require special equipment.

^d Assessed via the 2-item Sleep Condition Indicator.

^e Includes current or prior diagnosis with an anxiety disorder, depression, posttraumatic stress disorder, or a substance use disorder.

reported increased substance use, 618 (11.9%) reported having seriously considered trying to kill themselves in August, and 2237 (43.1%) reported at least 1 of these symptoms (**Table 1**).

Adverse mental or behavioral health symptoms were more prevalent among adults younger than 65 years vs adults aged 65 years or older (eg, 18-24 years, aPR, 3.56 [95% CI, 3.04-4.18]) and among multigenerational caregivers vs noncaregivers (aPR, 1.93 [95% CI, 1.78-2.08]) and respondents with prior psychiatric diagnoses vs those with no prior diagnoses (aPR, 1.98 [95% CI, 1.83-2.15]) (**Table 2**). Prevalence of adverse mental or behavioral health symptoms was also higher among respondents with disabilities or insomnia symptoms vs those without, caregivers for adults vs noncaregivers, essential workers and unemployed respondents vs nonessential workers, and respondents who were lesbian, gay, or bisexual vs heterosexual. Among respondents who were recontacted after June 2020, prevalence of adverse mental health symptoms did not differ significantly between June 2020 and September 2020.

Discussion

In a later phase of the COVID-19 pandemic (September 2020), the prevalence of adverse mental health symptoms among US adults remained elevated compared with prepandemic estimates.^{1,2} This finding contradicts the notion that adverse mental health symptoms were transient, self-limiting responses. Despite increased COVID-19-related morbidity and mortality risk,⁴ adverse mental health symptoms among older adults remained less prevalent.^{1,2,5,6} Although quota sampling and survey weighting were used, internet-based survey samples are limited and may not fully represent the 2020 US population.¹ Nonetheless, evidence of sustained adverse mental health symptoms among more than 5000 community-dwelling US adults highlights the need to promote preventive behaviors, expand mental health care access, and integrate medical and behavioral health services to mitigate the mental health effects of COVID-19.

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Corresponding Author: Mark É. Czeisler, AB, Turner Institute for Brain and Mental Health, Monash University, 18 Innovation Walk, Clayton Campus, Level 5, Clayton, VIC 3800, Australia (mark.czeisler@fulbrightmail.org).

Author Affiliations: Turner Institute for Brain and Mental Health, Monash University, Clayton, Victoria, Australia (M. É. Czeisler, Wiley, Rajaratnam); US Centers for Disease Control and Prevention, Atlanta, Georgia (Lane); Division of Sleep and Circadian Disorders, Departments of Medicine and Neurology, Brigham and Women's Hospital, Harvard Medical School, Boston, Massachusetts (C. A. Czeisler); Institute for Breathing and Sleep, Austin Health, Heidelberg, Victoria, Australia (Howard).

Author Contributions: Mr Czeisler had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Concept and design: M. É. Czeisler, Lane, C. A. Czeisler, Howard, Rajaratnam.

Acquisition, analysis, or interpretation of data: M. É. Czeisler, Wiley, C. A. Czeisler, Howard, Rajaratnam.

Drafting of the manuscript: M. É. Czeisler, Lane.

Critical revision of the manuscript for important intellectual content: All authors.

Statistical analysis: M. É. Czeisler, Wiley.

Obtained funding: M. É. Czeisler, Lane, C. A. Czeisler, Howard, Rajaratnam.

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SUPPLEMENT.**eAppendix.** Supplementary Methods**eReferences.**

SUMMARY OF FINDINGS

The Original Investigation presented in Chapter Seven revealed 43.1% of 5,186 surveyed US adults reported adverse mental health symptoms or substance use in late August to early September 2020, indicating that the prevalence of such symptoms had not decreased from the 40.9% prevalence in June 2020 (**Czeisler, Lane, et al., 2020**). Consistent with the June 2020 data, in September 2020, younger adults more commonly experienced adverse mental health symptoms and substance use than did older adults (e.g., any symptoms, adults aged 18-24 years = 74.4%; adults aged ≥ 65 years = 14.9%; adjusted prevalence ratio = 3.56 [95% confidence interval = 3.04 to 4.18] (**Czeisler, Lane, et al., 2021**). Additional subgroups assessed for the first time revealed further disparities in any adverse mental health symptoms or substance use among people experiencing insomnia symptoms, adults with disabilities compared with adults without disabilities, and among adults who identified as bisexual or as lesbian or gay compared with adults who identified as heterosexual. The analysis also revealed that among unpaid caregivers of adults, persons who were also providing unpaid care to children or adolescents aged <18 years had particularly high levels of adverse mental health symptoms and substance use. Regarding the association of insomnia and adverse mental health symptoms, Killgore *et al.* found that their observed association between COVID-19 fears and suicidal ideation was fully accounted for by insomnia severity (**Killgore et al., 2020**). Interventions that reduce insomnia (**Christensen et al., 2016**) might therefore help to reduce suicidal ideation and other adverse mental health symptoms.

The findings presented in this Original Investigation suggest that the elevated levels of adverse mental health symptoms and substance use found in June 2020 were sustained through September 2020, refuting the notion that the acute elevations marked transient responses to the onset of the pandemic. Persistent adverse mental health symptoms are concerning given the potential that for

some persons, they could reflect a transition from acute experiences of adverse mental health symptoms to chronic mental illness, which is strongly associated with impaired long-term health and functioning **(Park et al., 2008)**. The findings were especially noteworthy given that many anticipated that mental health challenges in the US would grow in the coming months due to a combination of seasonal effects on mood **(Melrose, 2015)** and a projected increase in cases with seasonal changes limiting outdoor activities alongside increasing cases among younger adults **(Boehmer et al., 2020; Salvatore et al., 2020)**, who exhibited the lowest levels of adherence with COVID-19 prevention behaviours **(Hutchins et al., 2020)**.

CHAPTER 8: Uncovering survivorship bias in longitudinal mental health surveys during the COVID-19 pandemic

PREFACE TO CHAPTER 8

In February 2021, around the publication date of the Original Investigation presented in [Chapter Seven](#) on mental health among US adults based on data collected in August and September 2020 (Czeisler, Lane, et al., 2021), Fancourt *et al.* published results from a longitudinal analysis of mental health among adults in England (Fancourt et al., 2021). Contrary to our finding that the prevalence of adverse mental health symptoms had remained consistently high among US adults during April to September 2020 based on largely cross-sectional surveys, Fancourt *et al.* reported that a rapid decrease in adverse mental health symptoms within the first month of lockdowns in England based on an analytic sample restricted to participants who had completed three surveys. We hypothesised that these different conclusions could be due to regional differences between the US and England, or due to survivorship bias—a form of selection bias in which participants who consistently participate are systematically different than participants who are lost to follow-up.

The Original Investigation in Chapter Eight (Czeisler, Wiley, Czeisler, et al., 2021c), which was posted as a preprint on *medRxiv* (Czeisler, Wiley, Czeisler, et al., 2021b) and later published in *Epidemiology and Psychiatric Sciences*, presents findings from a systematic assessment of survivorship bias among 4,039 respondents who had completed April 2020 surveys and had been invited to complete follow-up surveys in May, June, and September 2020. The mental health and substance use measures included in the survivorship bias assessment were symptoms of anxiety, depression, and insomnia. Sources of survivorship assessed included the following: (1) demographic differences in survey retention, (2) adjusting for any demographic differences in participation, differences in baseline mental health based on response rates to follow-up surveys, and (3) differences in mental

health trajectories, which would be most challenging to address given the inability to characterize the missing data. The chapter concludes with a brief overview of findings from the Original Investigation.

CHAPTER EIGHT: Uncovering survivorship bias in longitudinal mental health surveys during the COVID-19 pandemic

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*Joint senior authors.

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Author for correspondence:

Mark É. Czeisler,

E-mail: mark.czeisler@fulbrightmail.org; mark.czeisler@monash.edu

Uncovering survivorship bias in longitudinal mental health surveys during the COVID-19 pandemic

Mark É. Czeisler^{1,2,3} , Joshua F. Wiley¹, Charles A. Czeisler^{1,4,5}, Shantha M.W. Rajaratnam^{1,2,4,5,*} and Mark E. Howard^{1,2,6,*}

¹Turner Institute for Brain and Mental Health and School of Psychological Sciences, Monash University, Melbourne, Victoria, Australia; ²Institute for Breathing and Sleep, Austin Health, Melbourne, Victoria, Australia; ³Department of Psychiatry, Brigham & Women's Hospital, Boston, Massachusetts, USA; ⁴Division of Sleep and Circadian Disorders, Departments of Medicine and Neurology, Brigham & Women's Hospital, Boston, Massachusetts, USA; ⁵Division of Sleep Medicine, Harvard Medical School, Boston, Massachusetts, USA and ⁶Division of Medicine, University of Melbourne, Melbourne, Victoria, Australia

Abstract

Aims. Markedly elevated adverse mental health symptoms were widely observed early in the coronavirus disease-2019 (COVID-19) pandemic. Unlike the U.S., where cross-sectional data indicate anxiety and depression symptoms have remained elevated, such symptoms reportedly declined in the U.K., according to analysis of repeated measures from a large-scale longitudinal study. However, nearly 40% of U.K. respondents (those who did not complete multiple follow-up surveys) were excluded from analysis, suggesting that survivorship bias might partially explain this discrepancy. We therefore sought to assess survivorship bias among participants in our longitudinal survey study as part of The COVID-19 Outbreak Public Evaluation (COPE) Initiative.

Methods. Survivorship bias was assessed in 4039 U.S. respondents who completed surveys including the assessment of mental health as part of The COPE Initiative in April 2020 and were invited to complete follow-up surveys. Participants completed validated screening instruments for symptoms of anxiety, depression and insomnia. Survivorship bias was assessed for (1) demographic differences in follow-up survey participation, (2) differences in initial adverse mental health symptom prevalence adjusted for demographic factors and (3) differences in follow-up survey participation based on mental health experiences adjusted for demographic factors.

Results. Adjusting for demographics, individuals who completed only one or two out of four surveys had significantly higher prevalence of anxiety and depression symptoms in April 2020 (e.g. one-survey *v.* four-survey, anxiety symptoms, adjusted prevalence ratio [aPR]: 1.30, 95% confidence interval [CI]: 1.08–1.55, $p = 0.0045$; depression symptoms, aPR: 1.43, 95% CI: 1.17–1.75, $p = 0.00052$). Moreover, individuals who experienced incident anxiety or depression symptoms had significantly higher adjusted odds of not completing follow-up surveys (adjusted odds ratio [aOR]: 1.68, 95% CI: 1.22–2.31, $p = 0.0015$, aOR: 1.56, 95% CI: 1.15–2.12, $p = 0.0046$, respectively).

Conclusions. Our findings reveal significant survivorship bias among longitudinal survey respondents, indicating that restricting analytic samples to only respondents who provide repeated assessments in longitudinal survey studies could lead to overly optimistic interpretations of mental health trends over time. Cross-sectional or planned missing data designs may provide more accurate estimates of population-level adverse mental health symptom prevalence than longitudinal surveys.

Introduction

Studies have documented acutely elevated prevalence of adverse mental health symptoms during the early months of the coronavirus disease 2019 (COVID-19) pandemic compared with pre-pandemic data (CDC, 2020; Ettman *et al.*, 2020; Li *et al.*, 2020; Vindegaard and Benros, 2020; Wang *et al.*, 2020; Pierce *et al.*, 2020a; Bonati *et al.*, 2021; Browning *et al.*, 2021; Czeisler *et al.*, 2021b). Prevalence of clinically significant mental distress rose by approximately 40% in the U.K. (Pierce *et al.*, 2020a), and prevalence of anxiety and depression symptoms more than tripled in the United States (Czeisler *et al.*, 2020; Ettman *et al.*, 2020; Czeisler *et al.*, 2021b). Analysis of longitudinal U.K. and U.S. survey data suggested that those increased prevalence may have been transient, with anxiety and depression symptoms declining among participants who completed several follow-up measures between March or April and August 2020 (Fancourt *et al.*, 2020; Riehm *et al.*, 2021). However, those longitudinal data from

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repeat-responders are not consistent with cross-sectional U.S. survey data, which indicate that levels of adverse mental health symptoms have remained persistently elevated (CDC, 2020; Vahratian *et al.*, 2021; Czeisler *et al.*, 2021c). As, for example, 38.5% of U.K. respondents were excluded from analysis because they did not complete multiple follow-up surveys, we analysed data from U.S. adults invited to complete surveys over a comparable time interval to determine if survivorship bias could account for the discrepancy between the published cross-sectional and longitudinal data from U.S. and U.K. This investigation has practical and theoretical implications. Reliable assessment of the prevalence of adverse mental health symptoms could both affect planning and resource allocation for mental health support services during the COVID-19 pandemic (Holmes *et al.*, 2020), and inform policymakers of the mental health implications of issuing and lifting COVID-19 prevention measures of varying duration and intensity to balance against the transmission dynamics of severe acute respiratory coronavirus syndrome 2 (SARS-CoV-2) (Kissler *et al.*, 2020; Batabyal, 2021; Batabyal and Batabyal, 2021). More broadly, given that survivorship bias has not previously been reported to affect large-scale internet-based mental health surveys, this investigation may influence mental health surveillance study design and interpretation of ongoing studies and previously published papers.

Survivorship bias occurs whenever missingness occurs by a non-random mechanism. Therefore, while bias induced by demographic differences in follow-up survey participation may be reduced by poststratification weighting for observed variables using population estimates (Corry *et al.*, 2017), this strategy cannot account for survivorship bias. Survivorship bias can be problematic if individuals who make it past a selection process are different than those who do not. In the context of longitudinal mental health surveys, bias introduced by non-random differences in baseline mental health or mental health trajectories could result from restricting an analytic sample to respondents who consistently participated in surveys, ignoring individuals who dropped out. If the people who dropped out (i.e. study non-survivors) were to have meaningfully different baseline mental health or mental health trajectories than those who remain active study participants (i.e. study survivors), the resulting analytic sample would be non-representative.

Longitudinal studies have provided evidence of survivorship bias related to mental health within specific populations (Herbert *et al.*, 1992; Neuner *et al.*, 2007; Kakudate *et al.*, 2010; Lamers *et al.*, 2012; de Graaf *et al.*, 2013; Mayeda *et al.*, 2018; Ramsey *et al.*, 2019; Kigawa *et al.*, 2019a, b; Cornish *et al.*, 2021). For example, diagnosed depression has been associated with lower participation in follow-up surveys in parents and children (Mayeda *et al.*, 2018; Cornish *et al.*, 2021) and a naturalistic cohort on depression and anxiety (Lamers *et al.*, 2012), while assessment of three-year follow-up surveys in the Netherlands general population reported no association between mental health status at baseline and attrition (de Graaf *et al.*, 2013). However, considerable effort was exerted by de Graaf *et al.* to optimise participation, including a two-year initial contact and follow-up intervals, multiple attempts to recontact participants and frequent contact between interviews. Other studies have found that cancer survivors who completed surveys at multiple time points had higher health-related quality of life scores than those who completed surveys at a single timepoint (Ramsey *et al.*, 2019) and pregnant persons with psychological distress had higher odds of not completing follow-up surveys compared with pregnant persons without such distress (Kigawa *et al.*, 2019b).

Additionally, non-participation in follow-up surveys has been associated with smoking and alcohol use among trauma patients (Neuner *et al.*, 2007), and with lower perceived oral healthcare-specific self-efficacy among patients with chronic periodontitis (Kakudate *et al.*, 2010). Finally, of 294 women who presented at an emergency department following sexual assault, 136 (46%) could not be reached within 48 h and 233 (79%) did not participate in six-month follow-up (Herbert *et al.*, 1992). While anxiety and depression symptom ratings were attenuated in the analytic sample of 61 women who completed six-month follow-up surveys, women with higher rape-trauma-symptom scores were more likely to decline follow-up surveys. If survivorship bias existed in that study, generalising data supporting declining adverse mental health levels from only those with lower initial rape-trauma-symptom scores could lead to an overly optimistic interpretation of mental health following sexual assault.

To our knowledge, survivorship bias assessment has not been described and is seldom addressed in longitudinal mental health internet-based survey data collected from the general population. As numerous studies have responded to the call for mental health research by launching longitudinal mental health survey studies, we undertook a robust assessment of potential survivorship bias in our longitudinal mental health survey study.

Methods

Study design

We conducted a retrospective analysis of U.S. participants in The COVID-19 Outbreak Public Evaluation (COPE) Initiative (www.thecopeinitiative.org) (Czeisler *et al.*, 2021a). Internet-based surveys were administered through Qualtrics, LLC (Qualtrics, 2020) to 4042 U.S. adults aged ≥ 18 years during 2–8 April 2020 (April-2020). For the April-2020 wave, demographic quota sampling for gender, age, race and ethnicity was employed to recruit respondents such that each cross-sectional sample matched 2010 U.S. Census national population estimates for these characteristics. The sample included 3010 (74.5%) from across the U.S., plus additional respondents from New York City (n : 507 [12.5%]) and Los Angeles (n : 525 [13.0%]) to recruit participants from cities with different prevalence of SARS-CoV-2 during the early months of the pandemic (Czeisler *et al.*, 2021b). All respondents were invited to complete follow-up surveys during 5–12 May 2020 (May-2020) and 24–30 June 2020 (June-2020). Respondents who completed at least one of these follow-up surveys were also invited to complete surveys during 28 August to 6 September 2020 (September-2020). To account for any deviations from the April-2020 demographic recruitment quotas, survey weighting (iterative proportional fitting) was employed to match improved sample representativeness by gender, age and combined race/ethnicity using Census population estimates. Given the bias-variance compromises associated with trimming survey weights (Lee *et al.*, 2011), no trimming was conducted on the primary analytic sample, which had minimum and maximum weights of 0.71 and 1.80, respectively. As gender data were not available in the 2010 U.S. Census, for this analysis, sex was used for weighting of dichotomised gender. One respondent who was inadvertently invited to and completed a September-2020 survey after not having participated in May-2020 or June-2020 surveys, and two respondents who identified as ‘Other’ gender, were not included in this analysis.

Surveys contained demographic questions and assessed public attitudes and behaviours related to the pandemic and its mitigation, along with mental health symptoms. Validated screening instruments and modified questions from instruments were used. Among the adverse mental health symptom screening instruments administered were the 4-item Patient Health Questionnaire (PHQ-4) (Löwe *et al.*, 2004, 2010), with subscales for assessment of anxiety (2-item Generalised Anxiety Disorder [GAD-2]) and depression (2-item PHQ [PHQ-2]) symptoms, and the 2-item Sleep Condition Indicator (SCI-02) for assessment of insomnia symptoms (Espie *et al.*, 2014).

Statistical analysis

We explored whether potential mental health survivorship bias could be explained by: (1) demographic differences in repeated-measures respondents (i.e. cross-sectional *v.* longitudinal respondents differing in their demographics, but mental health being similar among members of a demographic subgroup); or (2) differences being within demographic subgroups. Demographic survey weighting could considerably reduce bias in the first, but not second scenario.

Potential demographic differences in survey retention were assessed using Chi-square tests with design effect correction factors (Walker and Young, 2003) to assess for differences between the percentages of respondents who completed one, two, three or four surveys by gender, age group in years, combined race/ethnicity, education attainment and 2019 household income. Potential differences in baseline mental health measures were assessed using weighted Poisson regression models with robust standard error estimators to estimate prevalence ratios (PRs) and 95% confidence intervals (CIs) for April-2020 anxiety symptoms (≥ 3 out of 6 on the GAD-2 subscale of the PHQ-4), depression symptoms (≥ 3 out of 6 on the PHQ-2 subscale of the PHQ-4), and insomnia symptoms (≤ 2 out of 8 on the SCI-02). With the reference group as four-survey respondents (i.e. the group that would be included in a longitudinal analytic sample that excluded non-responders), PRs and aPRs were estimated for one-survey, two-survey and three-survey respondents. Adjusted Poisson regression models included gender, age group, race/ethnicity, education attainment and 2019 household income as covariates. Next, to assess for potential differences in population estimates for the prevalence of anxiety, depression and insomnia symptoms in April 2020 using samples with differing retention over time, the April-2020 sample was separated into four groups: respondents who completed one, two, three or four surveys through September 2020. Each group was separately weighted to match national U.S. population estimates by gender, age and race/ethnicity, with survey weights trimmed between 1/3 and 3 to account for otherwise-extreme weights due to demographic differences in survey completion rate (e.g. sample of respondents who completed four surveys, maximum weight before trimming: 17.24). Prevalence estimates for anxiety, depression and insomnia symptoms were made for each possible grouping (number of completed surveys, one *v.* two, one *v.* three, one *v.* four, two *v.* three, two *v.* four and three *v.* four) based on these demographically representative groups. Chi-square tests with design effect correction factors were used to assess for different point estimates for prevalence of April-2020 anxiety, depression and insomnia symptoms between groups.

To evaluate potential differences in trajectories of adverse mental health symptoms over time by number of completed

surveys, prevalence of symptoms of anxiety, depression and insomnia over two timepoints (April-2020 to May-2020 and April-2020 to June-2020) among respondents who completed all four surveys was compared with the prevalence among those who completed two total surveys (only April-2020 and May-2020 or only April-2020 and June-2020, which are the only two possible groupings of two-survey respondents, as April-2020 respondents who did not complete surveys in May-2020 or June-2020 were not invited to complete September-2020 surveys). Respondents who participated in all four surveys completed three of three follow-up surveys (100% retention rate), whereas respondents who participated in two surveys only completed one of three follow-up surveys (33% retention rate). Chi-square tests with design effect correction factors were used to assess for differences in initial (April-2020) prevalence between samples, and McNemar's Chi-square tests were used to test for differences over time among paired data within each sample (e.g. April-2020 *v.* May-2020 and April-2020 *v.* June-2020 among respondents who completed these surveys sequentially). Prevalence ratios were used to estimate differences in prevalence between subsamples over time.

Finally, to assess whether changes in mental health symptoms were associated with differential participation in follow-up surveys, weighted ordinal logistic regressions were used to estimate odds ratios for lower participation in June-2020 and September-2020 surveys among respondents who completed April-2020 and May-2020 surveys based on symptoms of anxiety, depression or insomnia reported in these two initial surveys. For each of these adverse mental health conditions over April-2020 and May-2020, respondents were categorised as having no symptoms at either timepoint (Neither), symptoms at both timepoints (Both), incident symptoms in May-2020 after not having experienced symptoms in April-2020 (Incidence), or remitted symptoms in May-2020 after having experienced symptoms in April-2020 (Remission). Odds ratios for lower participation in follow-up surveys were estimated with the dependent variables ordered as 0 (completed both follow-up surveys), 1 (completed one follow-up survey [either June-2020 or September-2020]), and 2 (completed neither follow-up survey). Odds were estimated both unadjusted and adjusted for gender, age group, race/ethnicity, education attainment and 2019 household income. Statistical significance was determined at α : 0.025 to account for multiple comparisons. The proportionality assumption of the outcomes in the ordinal logistic regression models was assessed using the Brant test (Brant, 1990), which indicated that the proportional odds assumption held for the Omnibus test for all models.

Study approval and informed consent

The Monash University Human Research Ethics Committee approved the study protocol. Participants provided electronic informed consent. Rounded weighted values are reported unless otherwise specified. Analyses were conducted in R (version 4.0.2; The R Foundation) with the R survey package (version 3.29) and Python (version 3.7.8).

Results

Overall, 4042 of 6548 (61.7%) eligible invited adults completed surveys during the first wave of The COVID-19 Outbreak Public Evaluation (COPE) Initiative, administered during 2–8 April 2020. Of 4039 (99.9%) who provided answers to questions

used for survey weighting and were therefore included in this analysis, 2098 (51.9%) completed May-2020 surveys, 1619 (40.1%) completed June-2020 surveys, and 1151 (28.5%) completed September-2020 surveys. In total, 1712 (42.4%) completed one survey, 725 (17.9%) completed two surveys, 663 (16.4%) completed three surveys, and 939 (23.2%) completed all four surveys (Table 1). By age, 76.0% of respondents aged 18–24 years completed one survey, whereas 7.3% completed three or four surveys. In contrast, just 12.1% of respondents aged ≥ 65 years completed one survey, compared with 72.5% who completed three of four surveys ($p < 2.20 \times 10^{-16}$). By race/ethnicity, non-Hispanic White and non-Hispanic Asian respondents had the lowest prevalence of one-survey respondents (33.4% and 32.3%, respectively) and highest prevalence of four-survey respondents (29.7% and 23.9%), whereas non-Hispanic Black and Latinx respondents had the highest prevalence of one-survey respondents (65.7% and 60.7%, respectively) and lowest prevalence of four-survey respondents (8.6% and 10.1%); $p < 2.20 \times 10^{-16}$. Percentage of completed surveys also increased significantly with higher education attainment (e.g. one-survey, high school diploma or less: 52.9%, after bachelor's degree: 33.1%, $p < 2.20 \times 10^{-16}$) and higher 2019 household income (e.g. one-survey, USD <25 000: 51.0%, ≥ 100 000: 37.0%, $p = 1.56 \times 10^{-9}$).

Compared with respondents who completed all four surveys, those who completed only one or two surveys had higher prevalence of anxiety and depression symptoms in April-2020 surveys (Fig. 1). Differences remained after adjusting for gender, age, race/ethnicity, education attainment and 2019 household income among respondents (e.g. one-survey *v.* four-survey, anxiety symptoms, aPR: 1.30, 95% CI: 1.08–1.55, $p = 0.0045$; depression symptoms, 1.43, 1.17–1.75, $p = 0.00052$). Adjusted prevalence of insomnia symptoms in April-2020 was higher among individuals who completed only one survey compared with those who completed all four surveys (aPR: 1.33, 95% CI: 1.09–1.62, $p = 0.0045$). Prevalence estimates for April-2020 adverse mental health symptoms among groups of respondents who completed one, two, three or four surveys—each separately weighted to improve group representativeness of the U.S. population by gender, age and race/ethnicity—revealed that estimates for anxiety, depression and insomnia symptoms based on respondents who completed only one survey were higher than those for respondents who completed three or four surveys (e.g. one-survey *v.* four-survey, anxiety symptoms: 25.7% *v.* 20.2%, $p = 0.088$; depression symptoms: 24.3% *v.* 15.9%, $p = 2.84 \times 10^{-5}$; insomnia symptoms: 19.9% *v.* 15.6%, $p = 0.022$) (Fig. 2). Prevalence estimates for these symptoms were similar between one- and two-survey respondents, and between three- and four-survey respondents. Estimates for depression symptoms were also greater among respondents who completed two surveys compared with those who completed three or four surveys, while estimates for anxiety symptoms were greater among respondents who completed two surveys compared with those who completed four surveys.

In the comparison of adverse mental health symptom prevalence among respondents who completed only two surveys *v.* those who completed all four surveys (n : 939), both two-survey groups (April-2020 and May-2020 only [April-and-May; n : 584], April-2020 and June-2020 only [April-and-June; n : 141]) started with higher April-2020 prevalence of anxiety and depression symptoms (April-and-May, anxiety symptoms PR: 1.57, depression symptoms PR: 1.66; April-and-June: 1.91 and 2.02, respectively), and the prevalence ratios increased for the second completed surveys (April-and-May: 2.15 and 1.99, respectively; April-and-June: 2.55

and 2.33, respectively) (Fig. 3). The prevalence of anxiety symptoms among April-and-May and April-and-June two-survey respondents was similar between surveys (April-and-May: 25.8% and 28.6%, respectively, $p = 0.19$; April-and-June: 31.3% and 33.9%, respectively, $p = 0.57$), whereas the prevalence of anxiety symptoms in four-survey respondents decreased over these intervals (April-and-May: 16.4% and 13.3%, $p = 0.012$; April-and-June: 16.4% and 11.1%, $p = 1.11 \times 10^{-5}$). The prevalence of depression symptoms increased among April-and-May two-survey respondents (21.4% and 27.5%, respectively, $p = 0.0017$), but not among four-survey respondents (12.9% and 13.8%, $p = 0.45$).

Analysis of respondents who completed April-2020 and May-2020 surveys revealed that, compared with individuals who did not experience anxiety or depression symptoms during these initial surveys, those who experienced incident anxiety or depression symptoms had increased odds of lower participation in future follow-up surveys (i.e. June-2020 and September-2020) (Fig. 4). Individuals who experienced anxiety symptoms and depression symptoms in May-2020 after not having done so in April-2020 had 1.68-times (1.22–2.31, $p = 0.0015$) and 1.56-times (1.15–2.12, $p = 0.0046$) increased adjusted odds, respectively, of lower participation in June-2020 and September-2020 surveys. Adjusted odds of follow-up survey participation did not differ on the basis of insomnia symptoms, or among those who experienced: (1) remission of anxiety or depression symptoms or (2) persistent depression symptoms compared with those who did not experience these symptoms in April-2020 or May-2020. Individuals who experienced persistent anxiety symptoms, on the other hand, did have higher adjusted odds of lower participation in subsequent surveys (1.37, 1.04–1.80, $p = 0.025$). Though the magnitude of the adjusted odds ratios were higher for individuals with incident *v.* persistent adverse mental health symptoms, those who experienced incident symptoms did not have significantly higher adjusted odds of loss to follow-up compared to individuals who experienced persistent symptoms.

Discussion

Analysis of mental health among survey respondents based on their participation in follow-up surveys revealed considerable survivorship bias related to: (1) demographic differences in survey retention; (2) differences in initial mental health, adjusted for gender, age, race/ethnicity, education and income and (3) higher odds of lower participation in follow-up surveys among respondents who experienced worsened mental health over time. The first of these forms of survivorship bias can be reduced by the application of poststratification weights. The second of these forms of survivorship bias precludes use of a longitudinal sample alone to estimate population prevalence of adverse mental health symptoms. However, simultaneous collection of cross-sectional data from representative samples of independent participants could inform strategies to mitigate differences in initial prevalence of adverse mental health symptoms, which could include adjustment for baseline differences in mental health between cross-sectional *v.* longitudinal respondents. The third of these forms of survivorship bias is most challenging to take into account given the unknown trajectories of respondents who do not consistently participate in follow-up surveys. Recognition that individuals who experienced incident anxiety or depression symptoms had higher odds of not completing follow-up surveys reveals the hazard of overlooking this form of survivorship bias, and should temper conclusions about trends of anxiety and depression symptoms in longitudinal mental health survey respondents, especially as generalising from

Table 20 (8.1) . Respondent characteristics, overall and by number of completed surveys

Table 1. Respondent characteristics, overall and by number of completed surveys

	Number of respondents				Number of completed surveys								Chi-Sq <i>p</i> ^a
	Unweighted		Weighted		One		Two		Three		Four		
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	
Total	4039	(100)	4039	(100)	1712	(42.4)	725	(17.9)	663	(16.4)	939	(23.2)	–
Gender													
Male	1814	(44.9)	1986	(49.2)	872	(43.9)	329	(16.6)	307	(15.5)	477	(24.0)	0.032
Female	2225	(55.1)	2053	(50.8)	840	(40.9)	395	(19.2)	356	(17.3)	462	(22.5)	
Age group in years													
18–24	456	(11.3)	528	(13.1)	401	(76.0)	88	(16.7)	22	(4.2)	17	(3.1)	<2.20 × 10 ^{–16b}
25–44	1335	(33.1)	1414	(35.0)	809	(57.2)	269	(19.0)	182	(12.8)	155	(11.0)	
45–64	1420	(35.2)	1403	(34.7)	418	(29.8)	261	(18.6)	291	(20.8)	433	(30.8)	
≥65	828	(20.5)	693	(17.2)	84	(12.1)	107	(15.4)	168	(24.2)	335	(48.3)	
Race/ethnicity ^c													
White, non-Hispanic	2937	(72.7)	2575	(63.7)	860	(33.4)	459	(17.8)	491	(19.1)	765	(29.7)	<2.20 × 10 ^{–16b}
Black, non-Hispanic	329	(8.1)	493	(12.2)	324	(65.7)	72	(14.6)	55	(11.1)	43	(8.6)	
Asian, non-Hispanic	224	(5.5)	189	(4.7)	61	(32.3)	45	(24.0)	37	(19.8)	45	(23.9)	
Other, non-Hispanic	126	(3.1)	122	(3.0)	66	(54.4)	22	(18.5)	13	(11.0)	20	(16.1)	
Latinx, any race or races	423	(10.5)	660	(16.3)	401	(60.7)	126	(19.0)	67	(10.1)	67	(10.1)	
Education attainment ^d													
≤ High school diploma	735	(18.2)	777	(19.2)	411	(52.9)	137	(17.7)	86	(11.0)	143	(18.4)	<2.20 × 10 ^{–16b}
College or some college	2484	(61.5)	2473	(61.2)	1023	(41.4)	445	(18.0)	426	(17.2)	579	(23.4)	
> Bachelor's degree	792	(19.6)	756	(18.7)	250	(33.1)	142	(18.8)	150	(19.8)	215	(28.4)	
2019 Household income (USD)													
< 25 000	578	(14.3)	607	(15.0)	309	(51.0)	111	(18.3)	86	(14.1)	101	(16.7)	1.56 × 10 ^{–9b}
25 000–49 999	816	(20.2)	834	(20.6)	395	(47.4)	155	(18.5)	112	(13.5)	172	(20.6)	
50 000–99 999	1291	(32.0)	1271	(31.5)	489	(38.5)	227	(17.9)	235	(18.5)	320	(25.1)	
≥100 000	1156	(28.6)	1125	(27.9)	416	(37.0)	202	(17.9)	203	(18.0)	305	(27.1)	
Unknown	198	(4.9)	202	(5.0)	103	(51.0)	31	(15.1)	27	(13.3)	42	(20.6)	

USD = United States Dollars.

^aChi-square *p* value across all groups within a demographic subgroup (e.g. across all age groups). Chi-square tests included design effect correction factors.^b*p* < 0.025.^cThe 'Other, non-Hispanic,' category includes respondents who identified as not Hispanic or Latino and as more than one race or as American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or Other.^dThe response option 'Unknown' is not shown due to small counts (*n* = 34 total).

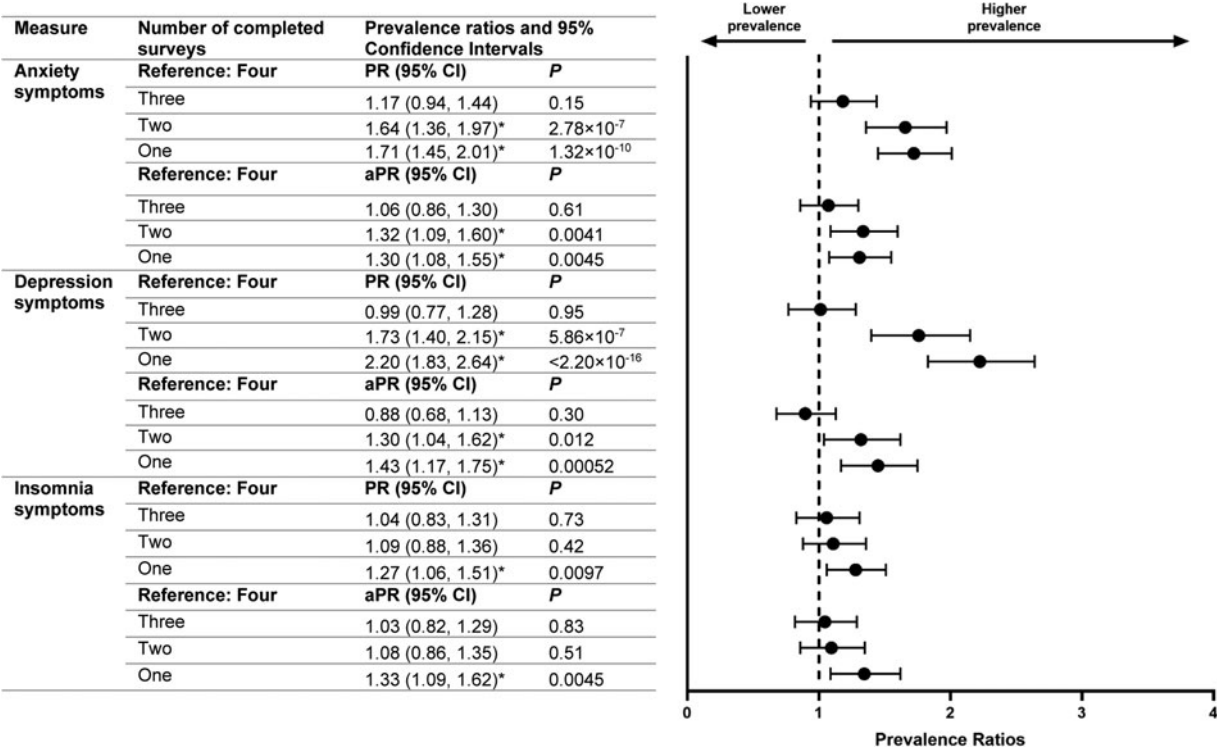


Fig. 1. Crude and adjusted prevalence ratios for anxiety, depression and insomnia symptoms in April 2020 by number of completed surveys. The marker * indicates that $p < 0.025$ (i.e. the prevalence ratio is statistically significant).

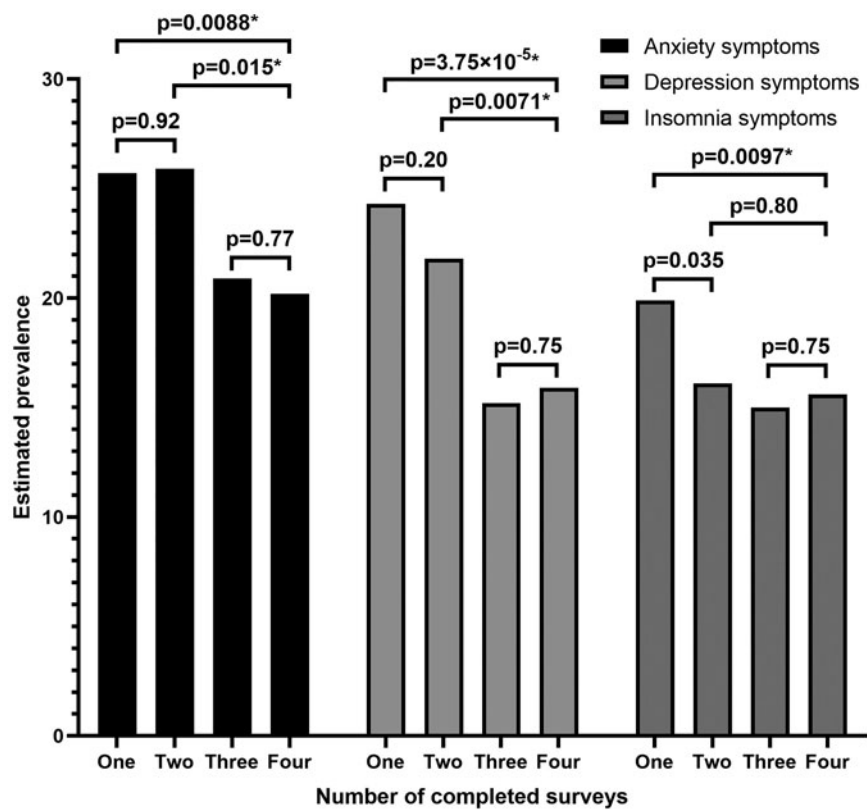


Figure 13 (8.2). Estimated prevalence of symptoms of anxiety, depression and insomnia in April 2020 based on total number of completed surveys, with each group weighted to population estimates for gender, for age, for race and for ethnicity.

Fig. 2. Estimated prevalence of symptoms of anxiety, depression and insomnia in April 2020 based on total number of completes surveys, with each group weighted to population estimates for gender, age and race/ethnicity. The marker * indicates that $p < 0.025$ (i.e. the difference in prevalence estimates is statistically significant). The rounded, weighted percentages of respondents shown in Fig. 2. based on the number of completed surveys may differ from those reported in Table 1 due to different survey weight raking and trimming.

repeated survey administration among longitudinal respondents without addressing these biases could lead to potentially erroneous conclusions (e.g. that adverse mental health symptom prevalence in a population are improving over time).

Understanding strengths and limitations of study approaches should inform the design and interpretation of findings (Pierce *et al.*, 2020b). Longitudinal studies have advantages, including increased power to detect causal pathways and mediating factors,

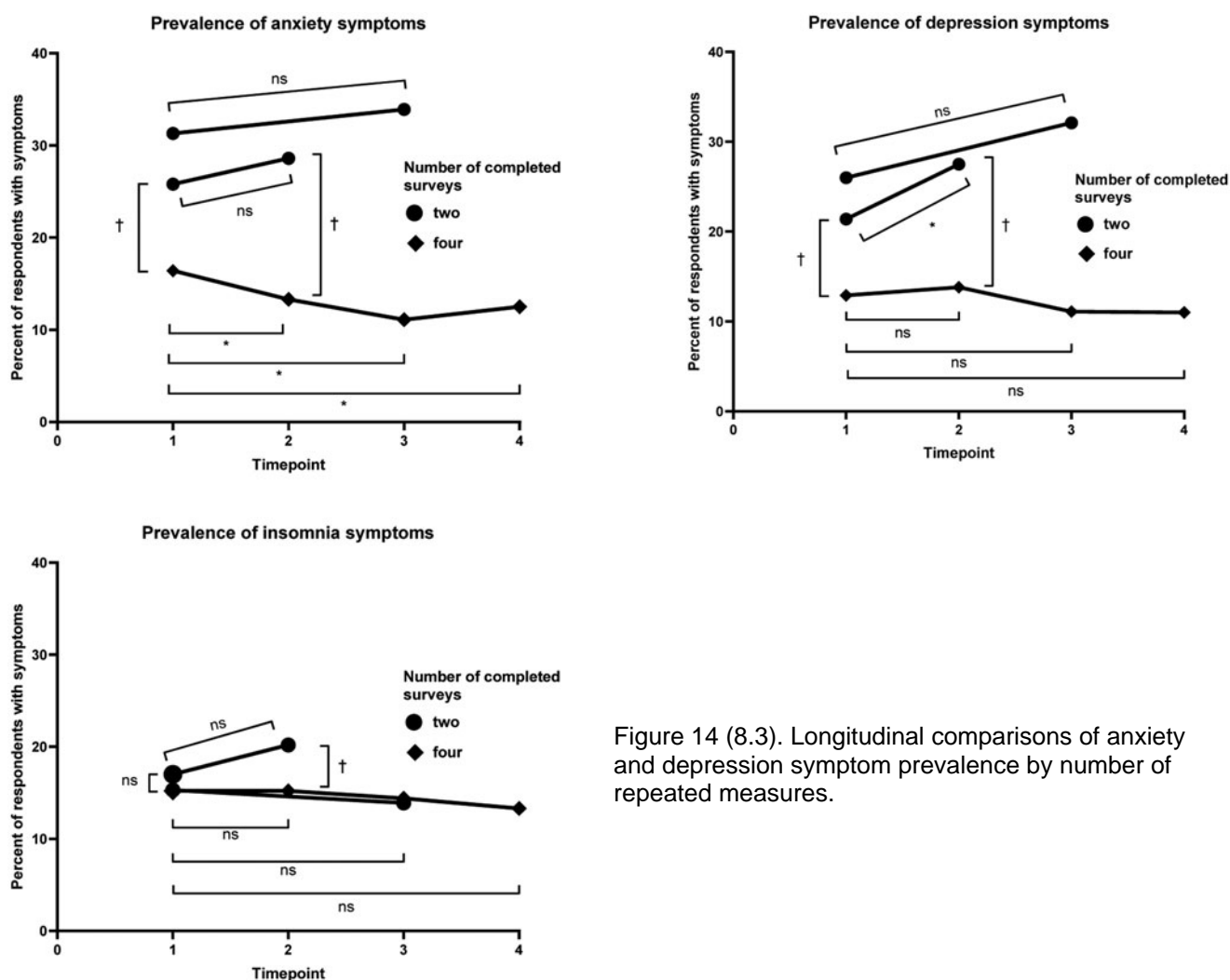


Figure 14 (8.3). Longitudinal comparisons of anxiety and depression symptom prevalence by number of repeated measures.

Fig. 3. Longitudinal comparisons of anxiety and depression symptom prevalence by number of repeated measures. The marker * indicates that $p < 0.025$ within the same group over the timepoints designated with brackets (i.e. the prevalence estimates differ with statistical significance). The marker † indicates that $p < 0.025$ between groups at a single timepoint, with the comparison designated with brackets (i.e. the prevalence estimates differ with statistical significance). The marker ns indicates that $p \geq 0.025$ (i.e. the prevalence estimates do not differ with statistical significance).

reduced reliance on recall bias, and establishment of the order in which events and outcomes occur. However, survivorship bias in longitudinal mental health surveys suggest that longitudinal samples may be non-representative of population-level mental health. While unable to determine causation, cross-sectional studies can more rapidly generate data, and our data provide further evidence that cross-sectional data may be more reliable for the assessment of population-level prevalence of adverse mental health symptoms at a given timepoint (Sedgwick, 2014). Future study designs could include planned missing data designs (Rioux *et al.*, 2020) to benefit from the strengths of these study designs while minimising associated biases. Researchers could explore different designs involving planned missingness in longitudinal mental health surveys, such as multiform (i.e. random assignment of participants to have missing questionnaire items), wave-missing (planned occasions of participants missing measurements), and two-method designs (using gold-standard methods on a random subset of respondents [e.g. clinical diagnosis of mental health conditions] of a large sample) (Rioux *et al.*, 2020). Such designs are of heightened importance for cohort studies investigating neuropsychiatric symptoms and

conditions among the myriad post-acute sequelae of COVID-19 (PASC) (Speth *et al.*, 2020; Boldrini *et al.*, 2021; Nalbandian *et al.*, 2021; Perlis *et al.*, 2021; Taquet *et al.*, 2021a, 2021b), as non-random loss to follow-up could influence estimates for incidence and presentations of PASC.

Strengths of this analysis include four timepoints to assess response bias, high initial response (61.7%) and retention (39.6% of respondents completed at least three of four surveys) rates, utilisation of clinically validated screening instruments, and implementation of quota sampling and survey weighting to improve sample representativeness by national estimates for gender, age and race/ethnicity. Moreover, multiple types of survivorship bias were assessed, including differential demographic attrition and demographic-adjusted assessment of both initial mental health as well as odds of participation in follow-up surveys based on changes to mental health over the initial two surveys. Finally, bias was assessed both cross-sectionally and longitudinally. The findings in this report are also subject to limitations. First, while this analysis focused on survivorship bias, these data may be subject to other biases, including recall and response

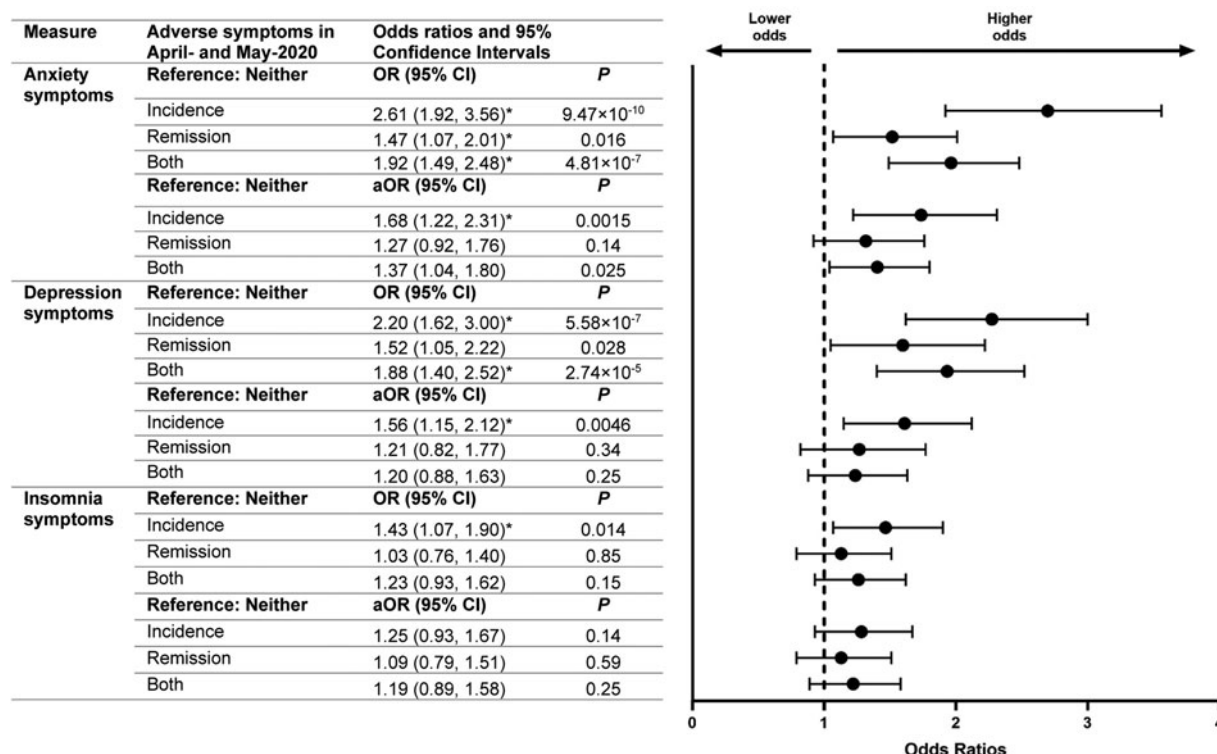


Fig. 4. Odds of lower participation in follow-up surveys based on mental health in earlier surveys. The marker * indicates that $p < 0.025$ (i.e. the odds ratio is statistically significant).

biases (Infante-Rivard and Cusson, 2018; Adams *et al.*, 2020); however, quota sampling and survey weighting were employed to reduce demographic-related response bias. Second, though strategies were used to improve sample representativeness, and this Internet-based survey sample should represent the adult U.S. population by gender, age and race/ethnicity, it may not fully represent all U.S. adults, especially with regards to Internet access. Third, April-2020 respondents who did not respond to invitations to complete surveys in either May-2020 or June-2020 were not invited to complete September-2020 surveys, so these respondents did not have the opportunity to complete September-2020 surveys. However, after having declined two successive invitations, it is unlikely that a substantial number of these respondents would have completed September-2020 surveys. Finally, portions of the sample were oversampled from the New York City and Los Angeles metropolitan areas. However, all 50 states and Washington D.C. were represented, and this analysis was not designed to produce national population estimates for adverse mental health symptoms. Nevertheless, sensitivity analyses were conducted for all regression models on the subset of 3008 nationwide respondents (i.e. excluding respondents intentionally recruited from the N.Y.C. and L.A. metropolitan areas). The magnitude and significance of associations between survey completion and adverse mental health symptoms were largely maintained, indicating that the inclusion of oversampled N.Y.C. and L.A. respondents did not systematically bias the findings.

Longitudinal survey-based assessment of mental health is a useful and widely used research method that can provide important insights gained from monitoring the same participants over time. However, our data demonstrate that analysing mental health trends among only individuals who consistently respond to longitudinal mental health surveys can lead to overly optimistic interpretations of mental

health trends by excluding individuals who less frequently respond to follow-up survey invitations. Survivorship bias assessment should therefore be among bias assessments (Sanderson *et al.*, 2007; Mayeda *et al.*, 2016; Griffith *et al.*, 2020; Czeisler *et al.*, 2021d) applied before conclusions based on repeated assessments from participants in a longitudinal study are generalised, and decisions regarding the allocation of mental health resources should be informed by studies with measures to reduce these various biases. These data have critical implications for the design of future studies and interpretation of data from published papers and ongoing surveillance studies with longitudinal study designs, both during and beyond the COVID-19 pandemic.

Data. All relevant data supporting the findings in this study are available from the corresponding author upon reasonable request. Reuse is permitted only following a written agreement from the corresponding author and primary Institution.

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Ethical standards. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

The protocol was approved by the Monash University Human Research Ethics Committee (MUHREC) (ref. no. 24036). This activity was also reviewed by the U.S. Centers for Disease Control and Prevention (C.D.C.) and was conducted consistent with applicable federal law and C.D.C. policy: 45 C.F.R. part 46, 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d); 5 U.S.C. Sect. 552a; 44 U.S.C. Sect. 3501 et seq.

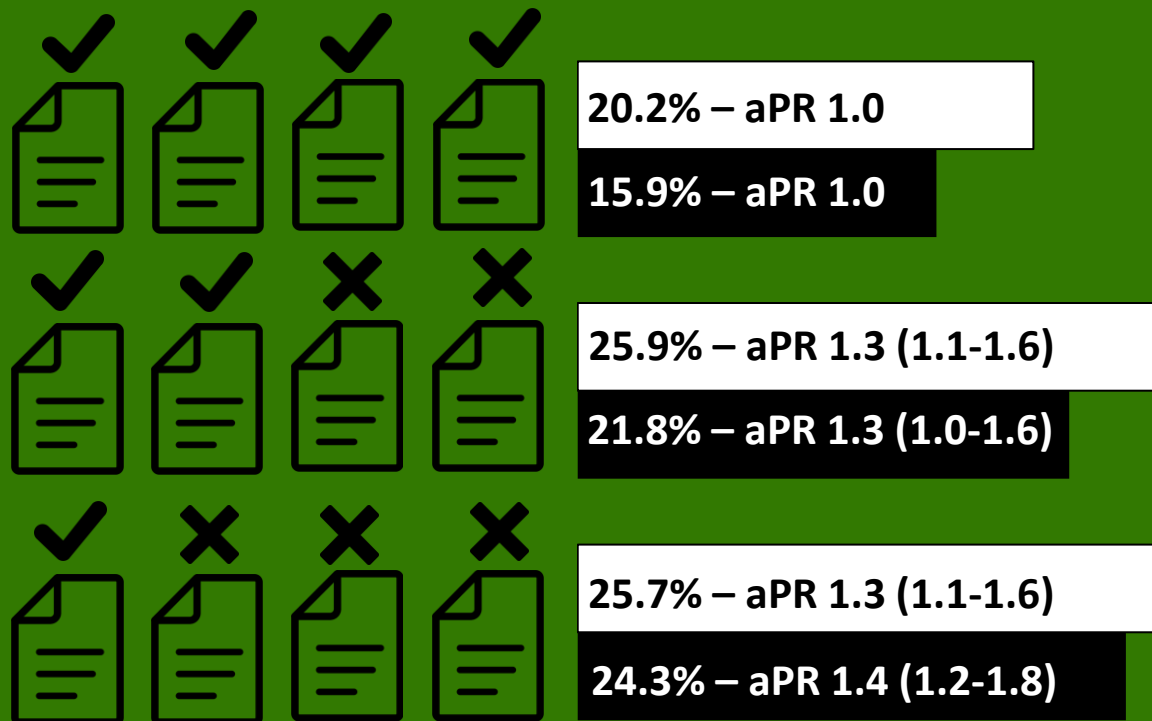
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Survivorship Bias in Longitudinal Surveys

Anxiety and **Depression** symptom prevalence and adjusted prevalence ratios (aPR)* during the 1st survey based on longitudinal study participation.



New adverse mental health symptoms at 2nd survey predict higher odds of not completing 3rd or 4th surveys.

adjusted odds ratios (95% CI)*

1.7 (1.2-2.3)

New anxiety symptoms...

1.6 (1.2-2.1)

New depression symptoms...



...during the 2nd survey, vs symptoms at neither the 1st nor 2nd surveys

*adjusted for gender, age, race/ethnicity, education, and income

SUMMARY OF FINDINGS

The Original Investigation presented in Chapter Eight revealed multiple types of survivorship bias. First, there were demographic differences in survey retention, as 76% of respondents aged 18-24 years completed only one out of four surveys, compared with 12% of those aged ≥ 65 years. By race and ethnicity, approximately 33% of participants who identified as non-Hispanic White or non-Hispanic Asian completed only one survey, compared with more than 60% of participants who identified as non-Hispanic Black race or Latinx ethnicity. Longitudinal participation rates also increased progressively with increasing levels of education attainment and household income. Second, adjusted for these demographic differences in survey retention, The COPE Initiative participants who completed only one or two out of four surveys had significantly worse mental health in April 2020 compared with participants who completed all four surveys. Finally, and most problematically, participants who experienced incident symptoms of anxiety or depression in May 2020 after not having screened positive for symptoms of these conditions in April 2020 had significantly lower odds of responding to invitations to complete surveys in June 2020 and September 2020. This final finding is most challenging to account for because the data are missing not at random (MNAR), meaning systematic differences between the missing and observed values cannot be accounted for using the observed data, which makes it impossible to confidently address the data missingness.

To our knowledge, this analysis represented the first systematic assessment of survivorship bias based on mental health conducted on a largescale survey sample of US adults. The results suggest that restricting analytic samples to only respondents who provide a certain number of repeated assessments in longitudinal survey studies could lead to overly optimistic interpretations of mental health trends over time, which could be especially problematic during the COVID-19 pandemic,

when mental health response planning and resource allocation during this public health emergency could be affected (**Holmes et al., 2020; M. Pierce, McManus, et al., 2020**).

Indeed, these findings have implications for the paper presented in Chapter Seven, which included a longitudinal subset of recontacted participants, among whom the “prevalence of adverse mental health symptoms did not differ significantly between June 2020 and September 2020” (**Czeisler, Lane, et al., 2021**). To assess whether survivorship bias was present in the Original Investigation presented in Chapter Seven, I conducted a secondary analysis of all of The COPE Initiative respondents in June 2020 who were recontacted and invited to participate in the September surveys. Retrospectively, after adjusting for the same characteristics used in multivariable models in the primary analyses, June 2020 respondents who did not versus those who did respond to the September 2020 surveys had an adjusted prevalence ratio of 1.3 (95% CI = 1.2 to 1.4, $P < 0.05$) for one or more of the adverse mental health symptoms or substance use analysed as outcomes for Chapter Seven (anxiety symptoms, depression symptoms, TSRD symptoms, past-month substance use, or past-month suicidal ideation). This analysis provides clear evidence of survivorship bias, suggesting the findings could underestimate population-level mental health trajectories at follow-up.

Although we did not generalize the results from this subset to conclude that population-wide levels of adverse mental health symptoms did not differ during this interval, our failure to either address or acknowledge survivorship bias might have led readers to incorrectly interpret the results as such, even though the longitudinal subset likely disproportionately retained individuals with relatively better mental health trajectories. The publication was featured in a Letter from the Editor of the *Journal of the American Academy of Dermatology (JAAD)* encouraging authors to address and readers to consider survivorship bias (**Elston, 2021**).

Fortunately, there are methods to account for missingness in longitudinal studies. Some, such as replacing missing data with values imputed from the observed data based on the mean of observed values or carrying forward the last measures value, are flawed given that they fail to account for uncertainty about the missing values **(Lachin, 2016; Sterne et al., 2009)**. If data were missing at random (MAR), including individuals with incomplete data could lead to unbiased and more powerful analyses than excluding such individuals. One such unbiased method is multiple imputation, which accounts for uncertainty of missingness by creating a number of plausible imputed datasets from which to generate estimates **(Sterne et al., 2009)**. However, if data were MNAR, multiple imputation might provide more biased results than complete cases. One robust method for longitudinal study design that takes advantage of multiple imputation while avoiding missingness biases is planned missing data (e.g., randomly assigning participants to miss items within a survey or to miss a subset of surveys within a study, randomly administering a gold-standard measurement to a subset of a larger sample) **(Rioux et al., 2020)**.

Given the intent of The COPE Initiative to provide the CDC with pulse estimates for adherence with and support for COVID-19 prevention measures, as well as mental health, these findings from our Original Investigation prompted us to revise our sampling methodology. We transitioned to inviting only first-time respondents to participate in future waves of The COPE Initiative, as cross-sectional data designs would not be susceptible to survivorship bias.

CHAPTER 9: Tempering optimism from repeated longitudinal mental health surveys

PREFACE TO CHAPTER 9

The Correspondence in Chapter Nine (**Czeisler, Wiley, Czeisler, et al., 2021a**), which was published in *The Lancet Psychiatry*, was written in response to the Fancourt *et al.* longitudinal mental health survey study publication (**Fancourt et al., 2021**). After finding robust evidence of significant survivorship bias in longitudinal mental health surveys, we submitted this Correspondence for two reasons. First, given the potential adverse consequences on mental health service planning and funding allocation of the premature conclusion that adverse mental health symptoms had rapidly declined within the first month of lockdown, we wanted to raise awareness about the possibility that the exclusion of 22,828 (38.5%) of 59,348 participants who completed at least one survey may have limited the generalizability of the findings and led to overly optimistic interpretations of the data. Second, given that many mental health researchers had initiated longitudinal surveys during the COVID-19 pandemic (**Holmes et al., 2020**), we wanted to share our experience with The COPE Initiative that led us to change our sampling methodology from a combination of longitudinal and cross-sectional respondents to entirely cross-sectional samples. Given that the chapter does not present new data, in lieu of an overview of findings, the chapter will conclude with a brief comment on a subsequent longitudinal study of mental health among adults in the UK (**M. Pierce et al., 2021**), and on a subsequent study of mental health among adults in the US (**Vahratian et al., 2021**).

CHAPTER NINE: Tempering optimism from repeated longitudinal mental health surveys

Czeisler MÉ, Wiley JF, Czeisler CA, Rajaratnam SM, Howard ME. Tempering optimism from repeated longitudinal mental health surveys. *Lancet Psychiatry*. 2021 Apr;8(4):274-275. doi: 10.1016/S2215-0366(21)00045-6. PMID: 33743874.

For more on The COPE Initiative
see www.thecopeinitiative.org

Tempering optimism from repeated longitudinal mental health surveys

The prevalence of adverse mental health symptoms increased during the initial phase of the COVID-19 pandemic.^{1,2} Establishing whether the rise in symptoms has persisted is crucial. The finding of Daisy Fancourt and colleagues³ was encouraging, in that anxiety and depression symptoms

decreased among participants with at least two longitudinal follow-up measures in the UCL COVID-19 Social Study. However, our optimism was tempered by our own data revealing non-response bias in a retrospective analysis⁴ of participants in The COVID-19 Outbreak Public Evaluation (COPE) Initiative. Adjusting for demographic differences in longitudinal survey participation, respondents who completed more than two out of four invited surveys between April and September, 2020, had significantly lower prevalence of adverse mental health symptoms at the first timepoint (April, 2020) than those who did not. Furthermore, respondents who had anxiety or depression symptoms in May, 2020, after not having had these symptoms in April, 2020, had higher odds of completing fewer follow-up surveys compared with respondents without these symptoms (anxiety symptoms, adjusted odds ratio [aOR] 1.7 [95% CI 1.2–2.3], $p=0.0015$; depression symptoms, aOR 1.6 [95% CI 1.2–2.1], $p=0.0046$).⁴ Together, these data suggest that respondents who consistently completed surveys had better mental health initially and had more favourable trajectories than those who did not do the follow-up surveys. Fancourt and colleagues analysed data from the subset of the UCL COVID-19 Social Study participants who completed at least three surveys.³ Although no response rate was reported, we do know that their criteria excluded 22 828 (38.5%) of 59 348 participants who completed at least one survey. This raises the question: were the 22 828 individuals who they excluded from analysis different from the participants analysed? If so, the reported mental health improvement might partially reflect survivorship bias.

The answer to this question is consequential, as a premature conclusion that adverse mental health

symptoms have decreased could affect mental health service planning. Assessment and management of mental health during the pandemic remain urgently needed. However, sampling and design choices should inform interpretation of findings. Although Fancourt and colleagues implemented measures to address biases, including population weighting and latent growth models to reduce sociodemographic and confounder biases, neither of these measures address potential survivorship bias. Our data suggest that individuals who completed more than two surveys in 2020 might be more resilient than those who did not. Future research should further characterise survivorship bias in longitudinal mental health surveys. Repeated cross-sectional surveillance can be used to estimate population-level mental health with time. Indeed, findings obtained by this design in the USA indicate that adverse mental health symptoms documented early in the pandemic have not abated.⁵

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*Mark É Czeisler, Joshua F Wiley,
Charles A Czeisler,
Shantha MW Rajaratnam,
Mark E Howard
mark.czeisler@fulbrightmail.org

Turner Institute for Brain and Mental Health,
Monash University, Melbourne, VIC 3800,
Australia (MÉC, JFW, CAC, SMWR, MEH); Institute
for Breathing and Sleep, Austin Health,
Melbourne, VIC, Australia (MÉC, SMWR, MEH);
Department of Psychiatry (MÉC) and Division of
Sleep and Circadian Disorders, Departments of
Medicine and Neurology (CAC, SMWR), Brigham
and Women's Hospital, Boston, MA, USA; Division
of Sleep Medicine, Harvard Medical School,
Boston, MA, USA (CAC, SMWR); Division of
Medicine, University of Melbourne, Melbourne,
VIC, Australia (MEH)

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BRIEF COMMENTARY

In May 2021, Pierce *et al.* published a secondary analysis of 19,763 adult respondents who had participated in five waves of the UK Household Longitudinal Study (**M. Pierce et al., 2021**). Across the sample in the Pierce *et al.* study, which cited the Original Investigation in **Chapter Eight** and included a higher proportion of respondents who had completed one or more surveys in the analytic sample (18,321 of 19,763 [92.7%]) than did the Fancourt *et al.* study (36,520 of 59,348 [61.5%]) (**Fancourt et al., 2021**), mental health did not start showing improvement until July 2020 rather than April 2020. The latent class mixed models applied by Pierce *et al.* revealed five distinct mental health trajectories during late April to October 2020 among adults in the UK: consistently very good, consistently good, recovering group (12.0%; i.e., worsened mental health during the first few months, followed by a recovery to pre-pandemic levels by October 2020), steady and sustained decline, and persistently poor. Our findings from the assessment of survivorship bias in longitudinal mental health surveys (**Czeisler, Wiley, Czeisler, et al., 2021c**) suggest that individuals in these last two groups (steady and sustained decline in mental health and persistently poor mental health) have the highest odds of non-response to follow-up. Taken together, the trajectories identified by Pierce *et al.* and survivorship bias characterised in longitudinal mental health surveys could partially account for the finding of a rapid decline in adverse mental health symptoms reported by Fancourt *et al.*, which was based on analysis of a dataset that excluded 38.5% of participants, many of whom likely experienced steady and sustained declines in mental health and persistently poor mental health. Moreover, despite a relatively high retention rate, survivorship bias could also result in Pierce *et al.* underestimating the sizes of the groups with a steady and sustained decline in mental health and persistently poor mental health.

In the US, on the other hand, Vahratian *et al.* published an analysis of 790,633 US adults surveyed during August 2020 through February 2021. The sample was recruited online using a probability-based approach developed by the Census Bureau in partnership with CDC's National Center for Health Statistics (NCHS) and drawn from the Census Bureau's Master Address File. The analysis revealed that prevalence estimates for anxiety or depression symptoms increased significantly over this interval, from 36.4% to 41.5% (**Vahratian et al., 2021**). The groups with the largest increases were among younger adults aged 18-29 years (8.0%, from 49.0% to 57.0%) and those without a high school diploma (7.8%, from 41.8% to 49.6%). These demographic groups with the highest increases in adverse mental health symptoms were also among the groups with the highest attrition rate in longitudinal mental health surveys (**Czeisler, Wiley, Czeisler, et al., 2021c**) and would therefore have a higher likelihood of being excluded from samples of repeated measures respondents.

Both studies, and Vahratian *et al.* in particular, highlight the persistence of high levels of adverse mental health symptoms and continued need for mental health surveillance during the COVID-19 pandemic.

CHAPTER 10: Mental health, substance use, and suicidal ideation during a prolonged COVID-19–related lockdown in a region with low SARS-CoV-2 prevalence

PREFACE TO CHAPTER 10

Mental health surveillance among individuals who had experienced SARS-CoV-2 infection began to reveal evidence consistent with potential direct mental health sequelae of COVID-19 (**Perlis et al., 2021; Taquet, Geddes, et al., 2021; Taquet, Luciano, et al., 2021; Varatharaj et al., 2020**), which could result from a combination of neuronal or astrocytic infection, microvascular, or inflammatory mechanisms (**Boldrini et al., 2021; Solomon, 2021**). Studying direct effects of COVID-19 versus indirect mental health effects of the COVID-19 pandemic (e.g., socio-economic and socio-behavioural disruptions) is difficult in the US, where policymakers implemented COVID-19 prevention measures with high variability, and where limited testing capacity led to an estimated four in five SARS-CoV-2 infections in 2020 going undetected (**Centers for Disease Control and Prevention, 2020a; Reese et al., 2020**). Having an estimated 80% of post-infection participants in the control group of a study could considerably confound investigations of direct mental health effects of SARS-CoV-2.

Fortunately, Australia has experienced low SARS-CoV-2 infection levels to this point despite widespread testing. While the availability of testing did not necessarily correspond with optimal testing utilisation, with only approximately one-half (53%) of 1,394 Australian adults surveyed in October 2020 indicated they would definitely seek testing for COVID-19 if experiencing mild symptoms (**Australian Bureau of Statistics, 2020c**), low positivity rates across Australia indicate a low true prevalence of both SARS-CoV-2 and COVID-19. Victoria, a state in the southeast of Australia, reported approximately 20,000 total SARS-CoV-2 infections with <1% test positivity

through late September 2020. Out of a population of 16.2 million people, the case count and positivity rate suggest that approximately 0.32% of the population had contracted SARS-CoV-2 **(Australian Government Department of Health, 2020b)**. Victoria also experienced a 111-day lockdown, one of the longest and most stringent COVID-19 lockdowns globally, affording an opportunity to assess levels of adverse mental health symptoms and substance use with minimal potential direct mental health effects of COVID-19.

The Original Investigation in Chapter Ten **(Czeisler et al., 2021)**, which was published in *Journal of Psychiatric Research*, presented findings from an evaluation of mental health and substance use among adults with residence in Victoria during 15 to 24 September 2020. Constructed similar to the US surveys, mental health measures included symptoms of anxiety or depression, symptoms of COVID-19 TSRDs, new or increased substance use, passive suicidal ideation, and serious suicidal ideation. In addition to demographic and employment characteristics, based on pre-pandemic literature describing associations between adverse mental health and impaired or insufficient sleep **(Braçe et al., 2021; Freeman et al., 2017; Irish et al., 2015)**, screen time **(Oswald et al., 2020)**, and media consumption during disasters **(R. R. Thompson et al., 2019)**, this study also included sleep and behavioural variables to assess for potential associations between changes to these behaviours and adverse mental health symptoms or substance use. Identifying associations between changes in these behaviours and adverse mental health could inform targets for reversible and modifiable behavioural risk factors for adverse mental health. The chapter concludes with a brief overview of findings from the Original Investigation.

CHAPTER TEN: Mental health, substance use, and suicidal ideation during a prolonged COVID-19–related lockdown in a region with low SARS-CoV-2 prevalence

Czeisler MÉ, Wiley JF, Facer-Childs ER, Robbins R, Weaver MD, Barger LK, Czeisler CA, Howard ME, Rajaratnam SMW. Mental health, substance use, and suicidal ideation during a prolonged COVID-19–related lockdown in a region with low SARS-CoV-2 prevalence. *J Psychiatr Res.* 2021 June 4. doi: 10.1016/j.jpsychires.2021.05.080. Epub ahead of print.



Mental health, substance use, and suicidal ideation during a prolonged COVID-19-related lockdown in a region with low SARS-CoV-2 prevalence

Mark É. Czeisler^{a,b,c,*}, Joshua F. Wiley^{a,1}, Elise R. Facer-Childs^a, Rebecca Robbins^{d,e},
Matthew D. Weaver^{a,d,e}, Laura K. Barger^{a,d,e}, Charles A. Czeisler^{a,b,f}, Mark E. Howard^{a,b,f},
Shantha M.W. Rajaratnam^{a,b,d,e}

^a Turner Institute for Brain and Mental Health and School of Psychological Sciences, Monash University, Melbourne, Victoria, Australia

^b Institute for Breathing and Sleep, Austin Health, Melbourne, Victoria, Australia

^c Department of Psychiatry, Brigham and Women's Hospital, Boston, MA, United States

^d Division of Sleep and Circadian Disorders, Departments of Medicine and Neurology, Brigham and Women's Hospital, Boston, MA, United States

^e Division of Sleep Medicine, Harvard Medical School, Boston, MA, United States

^f Department of Medicine, University of Melbourne, Melbourne, Victoria, Australia

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ABSTRACT

The coronavirus disease 2019 (COVID-19) pandemic has been associated with mental health consequences due to direct (i.e., SARS-CoV-2 infection, potentially due to neuronal or astrocytic infection, microvascular, or inflammatory mechanisms) and indirect (i.e., social and economic impacts of COVID-19 prevention measures) effects. Investigation of mental health in a region with one of the longest lockdowns and lowest COVID-19 prevalence globally (Victoria, Australia) allowed for evaluation of mental health in the absence of substantial direct pandemic mental health consequences. Surveys were administered during 15–24 September 2020 to Victorian residents aged ≥ 18 years for The COVID-19 Outbreak Public Evaluation (COPE) Initiative. Responses were compared cross-sectionally with April-2020 data, and longitudinally among respondents who completed both surveys. Multivariable Poisson regressions were used to estimate prevalence ratios for adverse mental health symptoms, substance use, and suicidal ideation adjusted for demographics, sleep, and behaviours (e.g., screen-time, outdoor-time). In September-2020, among 1157 Victorians, one-third reported anxiety or depressive disorder symptoms, one-fifth reported suicidal ideation, and one-tenth reported having seriously considered suicide in the prior 30 days. Young adults, unpaid caregivers, people with disabilities, and people with diagnosed psychiatric or sleep conditions showed increased prevalence of adverse mental health symptoms. Prevalence estimates of symptoms of burnout, anxiety, and depressive disorder were unchanged between April-2020 and September-2020. Persistently common experiences of adverse mental health symptoms despite low SARS-CoV-2 prevalence during prolonged lockdown highlight the urgent need for mental health support services.

1. Introduction

The coronavirus disease 2019 (COVID-19) pandemic, caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has been associated with adverse mental health consequences directly through SARS-CoV-2 infection and COVID-19 (i.e., through neuronal or astrocytic infection, microvascular, or inflammatory mechanisms), and indirectly through disruption of socio-behavioural health and socio-economic factors (i.e., from stay-at-home orders, nonessential business

closures, school closures, gathering bans, etc.). While such sequelae may seem specific to the Great Pandemic of 2019–2021, observations of both direct and indirect mental health consequences of infectious disease outbreaks date back more than six centuries (Czeisler et al., 2021 in press). Evidence of direct mental health effects of COVID-19 is emerging (Boldrini et al., 2021; Meinhardt et al., 2021; Perlis et al., 2021; Taquet et al., 2021a, 2021b; Woo et al., 2020). Analysis of U.S. electronic health records reveals that 18.1% of COVID-19 survivors were diagnosed with a neuropsychiatric condition within 14–90 days of diagnosis, including

* Corresponding author. Turner Institute for Brain and Mental Health and School of Psychological Sciences, Monash University, Melbourne, Victoria, Australia.
E-mail address: mark.czeisler@fulbrightmail.org (M.É. Czeisler).

¹ Indicates equal contribution.

5.8% among individuals with no psychiatric history (Taquet et al., 2021a, 2021b), consistent with evidence of neuropsychiatric symptoms following infection with other coronaviruses (Rogers et al., 2020).

Indirect mental health effects of the COVID-19 pandemic were also anticipated (Brooks et al., 2020; Galea et al., 2020). Non-pharmaceutical interventions to contain COVID-19 have necessitated considerable social and economic disruption. Simultaneously, with 3.75 million COVID-19 deaths globally (Dong et al., 2020), and considerable morbidity, many may face prolonged grief (Verdery et al., 2020). There is evidence of widespread adverse mental health symptoms (Ammerman et al., 2021), including increased prevalence of anxiety and depression symptoms, substance use, and suicidal ideation, compared with previous years (Czeisler et al., 2020, 2021a, 2021b; Ettman et al., 2020; Pierce et al., 2020; Pollard et al., 2020). Mental health disparities are apparent, with younger adults, people with pre-existing psychiatric conditions, unpaid caregivers, and essential workers disproportionately affected (Czeisler et al., 2020, 2021c; Ettman et al., 2020; Toh et al., 2021).

While evidence of adverse mental health symptoms is abundant, distinguishing between direct effects (i.e., of the disease COVID-19) and indirect effects (i.e., of SARS-CoV-2 and COVID-19 mitigation policies, COVID-19-related medical care delay or avoidance) of the pandemic is challenging, as many regions have inconsistently instituted or enforced mitigation policies alongside relatively high SARS-CoV-2 caseloads. Moreover, the U.S. Centers for Disease Control and Prevention (CDC) estimates that nearly 80% of SARS-CoV-2 infections in the U.S. in 2020 were undetected (C.D.C., 2020; Reese et al., 2020), which could complicate approaches seeking to distinguish between direct and indirect mental health effects by comparing individuals with and without histories of laboratory-confirmed SARS-CoV-2 infection. Victoria, Australia therefore presents a unique opportunity to assess robustly indirect mental health effects of the pandemic, as during 2020, the state instituted prolonged stringent lockdown policies and did not experience widespread community SARS-CoV-2 transmission. Victoria reported 20,

112 total SARS-CoV-2 cases (<1% positivity rate) between 25 January and 24 September 2020 with widespread testing, suggesting that approximately 0.32% of the population of 16.2 million Victorians contracted SARS-CoV-2 (Australian Government Department of Health, 2020). Even if the true infection prevalence were manyfold higher, it would likely remain below 2% of the population.

The low SARS-CoV-2 prevalence may be related to stringent mitigation policies (Fig. 1), including sustained border closures, enforced physical distancing, work-from-home directives, stay-at-home orders, education and industry closures, and both visitor and public gathering bans. After restrictions briefly began to ease in late May 2020, Victoria reimposed intensive restrictions following acute increases in SARS-CoV-2 cases. In August, Victoria escalated restrictions to include an 8:00pm to 5:00am curfew, 5-km distance-from-residence travel restriction, and 1-h outdoor-exercise limit. These lockdowns were maintained through the September-2020 survey interval, before staged reopening began in October.

Evidence about mental health during the COVID-19 pandemic in Victoria is sparse, though surveys have been conducted during the COVID-19 pandemic in Australia, including several that used versions of the Patient Health Questionnaire (Löwe et al., 2004, 2010) to screen for symptoms of anxiety and depression. Across Australia, in late March 2020 near the onset of the pandemic, a survey study reported prevalence estimates of anxiety and depression symptoms were 16.4% and 20.3%, respectively, with worse mental health among Australians of younger age and female gender, as well as people living with mental health disorders (Dawel et al., 2020) or employed as essential workers (Toh et al., 2021). In a survey of 1531 Australians in early April 2020, prevalence estimates of anxiety and depression symptoms were 22.1% and 21.9%, respectively, with 28.6% of respondents screening positive for symptoms of either condition (Czeisler et al., 2021a). A month-long survey study from April to May 2020 across Australia reported similar prevalence estimates, with 21.0% and 27.6% screening positive for

Figure 16 (10.1) Timeline of SARS-CoV-2 active cases and related restrictions in Victoria (Regional and Metropolitan Melbourne)

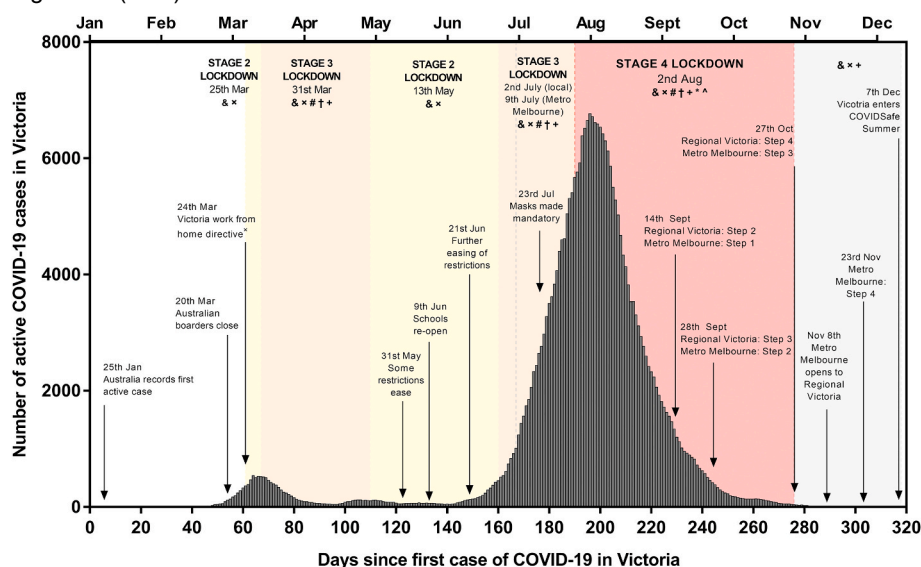


Fig. 1. Timeline of SARS-CoV-2 active cases and related restrictions in Victoria (Regional and Metropolitan Melbourne) Legend: The number of days since the first identified active case in Victoria is plotted on the horizontal axis and number of active cases per day on the vertical axis. Publicly available data were obtained from the Victorian State Government, Department of Health and Human Services. Stage 2 lockdown requirements are indicated by yellow shaded area, Stage 3 by orange and Stage 4 by red shaded area. Dotted line indicates when Stage 3 local lockdowns were imposed across Metro Melbourne. Symbols represent the type of restrictions in place as follows (only the most relevant restrictions are shown): Stage 2 lockdown: five visitors to the household, 10 people outdoors, no over-night stays, some retail industry open, hospitality is restricted to takeaway only (31 May: 20 patrons, 21 June: 50 patrons).

Key: & Social distancing in place (1.5 m apart and 4 m² per person)

x Work from home directive

Four reasons to leave home are shopping for essential supplies, care/caregiving, exercise and essential work (Step 1 = 1 h of daily exercise, Step 2 = 2 h, Steps 3 and 4 = no time limit).

† Education and Industry closed (Step 1 = all non-essential, Step 2 = schools staged return, childcare reopens, some industry reopens, Step 3 = hospitality opens for outdoor seating, some retail opens, Step 4 = most industry reopens with COVID Safe restrictions).

+ No visitors or public gatherings (Step 1 = two people from one household outside and one nominated visitor to the home/single 'social bubble', Step 2 = five people from two households outside and one nominated visitor to the home/single 'social bubble', Step 3 = 10 people outdoors, five visitors to the home from two households, Step 4 = 50 people outdoors, 20 visitors to the home).

* Curfew 8pm - 5am (Steps 1 and 2 = 9pm-5am, Steps 3 and 4 = no curfew).

~ Travel distance limit 5 km radius (Step 1/2 = 5 km, Step 3 = 25 km, Step 4 = no limit). (For interpretation of the references to colour in this figure legend, the reader is referred to the Web version of this article.)

anxiety and depression symptoms, respectively (Fisher et al., 2020). A global survey with a plurality of respondents (35.6%) from Australia found high levels of distress, depression, and poor sleep across the sample, with younger individuals and people with diagnosed mental health conditions disproportionately experiencing these symptoms (Varma et al., 2021). Though the lack of Victorian pre-pandemic survey data using these instruments makes comparisons with previous years challenging, national data from 2001 to 2014 using a validated instrument found that the combined prevalence of common mental health conditions (predominantly anxiety and depression) was stable at around 11%–13% during this interval (Harvey et al., 2017). Furthermore, evidence using other instruments (Neill et al., 2020; Toh et al., 2021; Van Rheenen et al., 2020) and longitudinal studies in other countries (Ettman et al., 2020; Pierce et al., 2020; Vahratian et al., 2020) suggest that population-level mental health has worsened during the COVID-19 pandemic. In an April 2020 convenience sample, most Australians perceived government restrictions had negatively impacted their mental health (70.0% and 54.8%, respectively, of those with vs without pre-existing mental health conditions) (Van Rheenen et al., 2020); surveys have also estimated that 20% (Tran et al., 2020) or 30% (Neill et al., 2020) of Australians reported drinking substantially more than pre-pandemic levels. Moreover, longitudinal data found a significantly increased prevalence of severe psychological distress in April 2020 compared with pre-pandemic data, with younger adults experiencing the largest increase (Biddle et al., 2020a). More recent data show that psychological distress worsened from May to August 2020—especially in Victoria—and that the level of psychological distress remained higher than it was prior to the pandemic (Biddle et al., 2020b).

Understanding the extent to which the high prevalence of adverse mental health symptoms persists during one of the longest and most stringent lockdowns is of critical global health importance. We sought to assess mental health, substance use, and suicidal ideation in a demographically diverse sample of Victorian adults in September 2020, before the conclusion of extended lockdowns. Cross-sectional and longitudinal surveys of the Victorian population were analysed to compare prevalence estimates of adverse mental and behavioural health during September 2020 with those during the acute phase of lockdowns in Victoria. We analysed the associations between adverse mental and behavioural health symptoms and demographic characteristics, sleep, and behavioural changes, with the aim of identifying areas for targeted interventions to improve mental health.

2. Methods

2.1. Study design

Internet-based surveys were collected during April 2–8, 2020 (April-2020) and September 15–24, 2020 (September-2020), as part of The COVID-19 Outbreak Public Evaluation (COPE) Initiative (www.thecopeinitiative.org). Surveys were administered to respondent panels maintained by Qualtrics (USA). Additional details about recruitment methodologies and quality screening are in the appendix (p 1).

2.2. Setting and participants

The April-2020 wave consisted of adults aged ≥ 18 years with Australian residence. This analysis focused on the subset of Victorian residents, given the extended lockdown in Victoria and potential for confounding across states due to differing lockdowns and SARS-CoV-2 prevalence. To enable cross-sectional sub-analyses within the Victorian sample the September-2020 wave consisted of adults aged ≥ 18 years with Victorian-only residence. Victorian residents who completed April-2020 surveys were re-contacted and invited to complete September-2020 surveys. Demographic quota sampling was used to improve sample representativeness of Victoria based on population estimates for sex, age, and ancestry. The study was reviewed and approved

by the Monash University Human Research Ethics Committee. Respondents provided electronic informed consent. Monte Carlo simulation power analyses showed that for $\alpha = 0.05$, base prevalence of adverse mental health symptoms between 15% and 40% in April 2020, and $\geq 9\%$ absolute difference in the September-2020 sample compared to the April-2020 sample, 300 participants in the April-2020 sample and 1200 in the September-2020 sample provided $\geq 78\%$ – 93% power, depending on the assumed prevalence in April and whether September had an absolute difference that was 9% higher or lower. Further details about the power analysis are provided in the appendix (p 2).

2.3. Outcome measures

Mental and behavioural health variables in both waves included anxiety or depressive disorder symptoms and burnout symptoms. In September-2020, additional variables included COVID-19-related trauma- and stressor-related disorder (COVID-19 TSRD) symptoms, psychological well-being, new or increase of substance use (e.g., alcohol, legal or illegal drugs, or prescriptions drugs) to cope with stress or emotions, past-month passive suicidal ideation (i.e., wished to be dead), and past-month serious suicidal ideation. Details are provided in the appendix (pp 3).

2.4. Explanatory measures

Demographic variables in both waves included sex, age, ancestry, educational attainment, employment status, political ideology, COVID-19 risk perception, diurnal preference, and previous medical history of psychiatric (anxiety, depression, post-traumatic stress disorder) and sleep (insomnia, narcolepsy, obstructive sleep apnoea, restless leg syndrome, shift work disorder, periodic limb movement disorder) conditions. In September-2020, sexual orientation, disability status, essential worker status, unpaid caregiver (caregiver) status, regional vs metropolitan postal code (corresponding to jurisdictional COVID-19 restrictions), and history of substance use disorder were also assessed. Sleep and behavioural variables in both waves included self-reported sleep duration per 24 h, insomnia symptoms, comparisons for several sleep-related variables (time in bed, trouble falling asleep, sleep regularity) during vs before the pandemic (October–December 2019), comparisons for time spent on screens and time spent outdoors during daylight hours during vs before the pandemic, and daily hours spent consuming information about COVID-19 (i.e., discussing, attending meetings, following news and announcements). Daytime sleepiness was also assessed in September 2020. Details are provided in the appendix (pp 3–6).

2.5. Statistical methods

Analyses were conducted on three samples: Victorian-April (the subset of the cross-sectional April sample from Victoria); Victorian-September (the cross-sectional September sample from Victoria); and Victorian-Longitudinal (the subset of the Victorian-September sample that completed April-2020 surveys). Iterative proportional fitting (raking) and weight trimming were employed using the R survey package (version 3.29) and R software (version 4.0.2; The R Foundation) to improve representativeness of cross-sectional samples by sex, age, and educational attainment according to the 2016 Census of Population and Housing General Community Profile Victorian population estimates. Prevalence estimates were used to summarize demographic characteristics, sleep, behavioural changes, and mental and behavioural health for samples. Rao-Scott-corrected Pearson Chi-squared tests were used to test for differences in observed and expected frequencies among groups by characteristic for sleep, behavioural changes, and mental and behavioural health variables between the Victorian-September sample and the Victorian-April samples. Given that Victorian-Longitudinal respondents completed both April-2020 and September-2020 surveys,

these respondents were included in the April samples only for cross-sectional comparisons (i.e., excluded from the Victorian-September sample) to eliminate survivorship bias. Bonferroni adjustments were applied to account for the 13 outcome comparisons (i.e., statistical significance was assessed as $p \times 13 < 0.05$).

With anxiety or depressive disorders symptoms, COVID-19 TSRD symptoms, having started or increased substance use, suicidal ideation (passive or active), and a composite outcome (i.e., one or more of these symptoms) as dependent variables for separate models, adjusted prevalence ratios (aPRs) and 95% confidence intervals (CIs) were estimated in the Victorian-September sample using weighted multivariable Poisson regressions. Models were adjusted for sex, age group, sexual orientation, ancestry, disability status, combined employment status, caregiver status, regional vs metropolitan postcode classification, political ideology, and COVID-19 risk perception. Additional models including all demographic explanatory variables plus one sleep- or behavioural-change variable each (to avoid collinearity) were used to estimate aPRs and 95% CIs for dependent variables. Crosstabs, bivariate Rao-Scott Pearson Chi-squared tests, and unadjusted prevalence ratios for adverse mental and behavioural health symptoms were also conducted for each explanatory variable. Exploratory longitudinal analyses are described in the appendix (p 6). Statistical significance was set at two-sided $p < 0.05$. Rounded, weighted numbers and percentages are reported unless otherwise specified.

3. Results

Overall, 1531 eligible invited adults completed surveys during April 2–8, 2020, including 334 (21.8%) Victorians, and 1269 eligible invited adults completed surveys during September 15–24, 2020, including 93 recontacted respondents. After supplementary cleaning (appendix p 1), 1580 of 1603 (98.6%) unique respondents were included in the final analysis (Victorian-April $n = 331$ [99.1%]; Victorian-September $n = 1249$ [98.4%]; Victorian-Longitudinal $n = 92$ [98.9%]). Demographics are summarized in Table 1 and in the appendix (pp 8–11).

Among 1157 Victorian-September adults (excluding recontacts), 387 (33.4%) reported anxiety or depressive disorder symptoms, 354 (30.6%) reported COVID-19 TSRD symptoms, and 305 (26.3%) reported burnout symptoms (Table 2). Additionally, 143 (12.3%) respondents reported having started or increased substance use to cope with the pandemic, 196 (16.9%) reported having wished they were dead in the prior 30 days, and 110 (9.5%) reported past-month serious suicidal ideation. Regarding sleep during the COVID-19 pandemic compared to before the pandemic, Victorian-September adults more commonly reported having spent more ($n = 353$ [30.5%]) versus less ($n = 66$ [5.7%]) time in bed and having more ($n = 277$ [23.9%]) versus less ($n = 67$ [5.8%]) trouble falling asleep. Insomnia symptoms were reported by 239 (20.6%) respondents, and excessive daytime sleepiness by 166 (14.3%). Regarding other behavioural changes during COVID-19 compared to before, >1-h increased screen time and >1-h reduced time spent outdoors during daylight hours were reported by 525 (45.4%) and 586 (50.7%) respondents, respectively, and 853 (73.7%) reported not consuming information about COVID-19, compared to 43 (3.8%) who reported spending ≥ 4 h doing so daily.

There were no significant differences in the prevalence of adverse mental health symptoms assessed in both April-2020 and September-2020 (anxiety or depressive disorder symptoms, burnout symptoms) or sleep measures between the Victorian-April and Victorian-September samples. There were, however, significant differences in behavioural outcomes between April-2020 and September-2020. Compared with the Victorian-April sample, significantly greater percentages of respondents in the Victorian-September sample reported >1-h increased screen time (+12.0% vs Victorian-April, $p = 0.013$) and not consuming COVID-19 information (+18.4% vs Victorian-April, $p < 0.0001$).

Multivariable Poisson regression models with demographic variables only in the Victorian-September sample ($n = 1249$) revealed differences

Table 21 (10.1) Respondent characteristics by sample

Table 1

Respondent characteristics by sample.

	Victorian-April		Victorian-September ^a		Victorian-Longitudinal	
	n ^b	(%) ^b	n ^b	(%) ^b	n ^b	(%) ^b
Demographics	331	(100)	1157	(100)	92	(100)
Sex						
Male	171	(51.7)	544	(47.0)	46	(49.5)
Female	160	(48.3)	613	(53.0)	46	(50.5)
Age group, years						
18–24	42	(12.8)	123	(10.6)	11	(12.3)
25–44	123	(37.2)	436	(37.6)	34	(36.5)
45–64	105	(31.7)	379	(32.8)	29	(31.1)
≥ 65	61	(18.4)	219	(18.9)	19	(20.2)
Sexual Orientation						
Heterosexual	–	–	1031	(89.1)	82	(88.9)
Lesbian or gay	–	–	45	(3.9)	3	(3.3)
Bisexual	–	–	44	(3.8)	2	(1.9)
Something else	–	–	6	(0.5)	3	(2.7)
I don't know the answer	–	–	11	(1.0)	3	(3.2)
Prefer not to say	–	–	20	(1.8)	0	(0.0)
Ancestry						
Oceanian	86	(26.1)	289	(25.0)	29	(32.0)
North-West European	82	(24.8)	386	(33.4)	22	(23.7)
South-East European	32	(9.6)	106	(9.2)	12	(12.9)
North-East Asian	19	(5.8)	49	(4.3)	8	(8.5)
South-East Asian	16	(4.8)	42	(3.6)	5	(5.0)
South and Central Asian	22	(6.7)	71	(6.1)	6	(6.2)
North African and Middle Eastern	9	(2.8)	14	(1.2)	1	(0.9)
Sub-Saharan African	0	(0.1)	2	(0.2)	0	(0.0)
Peoples of the Americas	4	(1.1)	10	(0.9)	2	(1.7)
North-West European, Oceanian	34	(10.4)	100	(8.7)	6	(6.5)
Other combination	25	(7.6)	77	(6.7)	3	(2.7)
Unknown	1	(0.2)	10	(0.9)	0	(0.0)
Disability status						
None	–	–	993	(85.8)	79	(85.4)
Yes, and receive support from the NDIS	–	–	37	(3.2)	1	(1.2)
Yes, but do not receive support from the NDIS	–	–	110	(9.5)	12	(13.4)
Unknown	–	–	17	(1.4)	0	(0.0)
Highest education attainment						
Secondary diploma or less	147	(44.4)	503	(43.4)	40	(43.6)
More than secondary diploma, less than Bachelor's degree	90	(27.2)	311	(26.9)	25	(27.0)
Bachelor's degree or more	94	(28.4)	344	(29.7)	27	(29.5)
Regional vs metropolitan postal code						
Regional	–	–	255	(22.0)	23	(25.1)
Metropolitan	–	–	902	(78.0)	69	(74.9)
Employment status						
Employed	183	(55.4)	651	(56.3)	46	(50.3)
Unemployed	47	(14.2)	210	(18.2)	17	(18.4)
Retired	70	(21.2)	251	(21.7)	22	(23.5)
Student	31	(9.2)	45	(3.9)	7	(7.8)
Essential worker status (among employed respondents)						
Essential	–	–	360	(55.4)	24	(51.1)
Nonessential	–	–	291	(44.6)	23	(48.9)
Unpaid caregiver status						
None	–	–	725	(62.7)	56	(61.1)
Unpaid caregiver of adults	–	–	156	(13.5)	8	(9.0)
Unpaid caregiver of children or adolescents	–	–	125	(10.8)	17	(18.1)
Multigenerational unpaid caregiver	–	–	151	(13.0)	11	(11.8)
Political ideology						
Far left	14	(4.4)	64	(5.5)	8	(9.2)
Slightly left	69	(20.8)	221	(19.1)	15	(16.0)
Centre	106	(32.0)	399	(34.5)	33	(36.1)
Slightly right	70	(21.2)	173	(14.9)	16	(17.7)
Far right	19	(5.7)	112	(9.7)	5	(5.9)
Apolitical and/or prefer not to answer	53	(16.0)	189	(16.3)	14	(15.2)
COVID-19 risk perception	64	(19.3)	194	(16.7)	16	(17.0)

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Table 1 (continued)

	Victorian-April		Victorian-September ^a		Victorian-Longitudinal	
	n ^b	(%) ^b	n ^b	(%) ^b	n ^b	(%) ^b
Believe to be at high risk for severe COVID-19						
Do not believe to be at high risk for severe COVID-19	267	(80.7)	963	(83.3)	76	(83.0)
Diurnal preference						
Definite morning type	90	(27.1)	296	(25.6)	20	(21.8)
Rather more of a morning type than evening type	67	(20.4)	312	(27.0)	24	(26.0)
Rather more of an evening type than morning type	98	(29.7)	332	(28.7)	23	(25.1)
Definite evening type	75	(22.8)	217	(18.7)	25	(27.1)
History of diagnosed sleep condition						
Yes	91	(27.5)	352	(30.5)	29	(31.5)
No	240	(72.5)	805	(69.5)	63	(68.5)
History of diagnosed psychiatric condition						
Yes	123	(37.1)	435	(37.6)	38	(41.4)
No	208	(62.9)	722	(62.4)	54	(58.6)

NDIS = National Disability Insurance Scheme, COVID-19 = coronavirus disease 2019.

^a Excludes recontacted respondents.

^b Weighted rounded counts and percentages may not sum to expected values.

in mental health by age, disability status, caregiver status, political ideology, and COVID-19 risk perception (Table 3, Fig. 2). Younger adults reported significantly higher adjusted prevalence of adverse mental or behavioural health conditions than older adults (e.g., aged 18–24 vs ≥ 65 years, suicidal ideation, aPR 5.59, 95% CI 2.62–11.95, $p < 0.0001$), as did people with vs without disabilities (e.g., individuals supported by the NDIS, suicidal ideation, 2.47, 1.70–3.58, $p < 0.0001$) and both multigenerational caregivers and caregivers of adults only vs non-caregivers (e.g., multigenerational caregivers, suicidal ideation, 2.95, 2.06–4.20, $p < 0.0001$). Victorians who identified as having Far Right political ideology had higher adjusted prevalence of all four adverse symptoms vs those who identified as Centre, including nearly twice the prevalence of suicidal ideation (1.88, 1.29–2.74, $p = 0.0010$). Finally, those who believed they were vs were not at high risk for severe COVID-19 also had higher prevalence of symptoms of anxiety or depressive disorder (1.28, 1.02–1.61, $p = 0.034$).

Multivariable Poisson regression models with demographic and additional variables in the Victorian-September sample revealed differences in mental and behavioural health by medical history, sleep, and behavioural changes (Table 4, Fig. 2). For example, suicidal ideation was nearly three times as prevalent among respondents with vs without previously diagnosed psychiatric conditions (2.88, 2.07–4.01, $p < 0.0001$), and nearly two times as prevalent among those with diagnosed sleep conditions (1.94, 1.46–2.57, $p = 0.0007$) and insomnia symptoms (1.86, 1.38–2.51, $p = 0.0001$). Adverse mental health symptoms were also significantly more prevalent among those with a self-reported sleep duration < 6 h (e.g., suicidal ideation, 1.46, 1.02–2.08, $p = 0.039$, vs > 7 h), and those who reported spending more time in bed (1.47, 1.12–1.92, $p = 0.0054$, vs no change) and having more trouble falling asleep (1.66, 1.25–2.20, $p = 0.0005$, vs no change). Those who reported maintaining a less regular sleep-wake schedule also more commonly reported adverse mental health symptoms (e.g., anxiety or depressive disorder symptoms, 1.44, 1.17–1.79, $p = 0.0008$). With respect to behavioural changes, significantly increased prevalence of adverse mental health symptoms were found for three of the four conditions among respondents who reported > 1 h per day reduction in time spent outdoors during daylight (e.g., suicidal ideation, 1.47, 1.02–2.11, $p = 0.039$), > 1 h per day increase in time on screens (e.g., substance use, 2.03, 1.29–3.17, $p = 0.0021$), and ≥ 4 h per day spent following COVID-19 media coverage (e.g., suicidal ideation, 1.44, 1.03–2.03, $p = 0.036$).

Fig. 2 shows key variables associated with increased prevalence of having experienced one or more adverse mental or behavioural health

Table 2

Estimated prevalence of adverse mental and behavioural health conditions, sleep, and behavioural changes during the pandemic during April 2020 and September 2020.

Sample	Victorian April		Victorian September (excluding recontacts)		September vs April 2020	
	n ^a	% (95% CI) ^a	n ^a	% (95% CI) ^a	Δ % (95% CI) ^a	P^b
Total Respondents	331		1157			
Mental or Behavioural Health Condition						
Symptoms of anxiety or depressive disorder	104	31.3 (26.0, 37.3)	387	33.4 (30.3, 36.7)	2.1 (–6.3 to 10.5)	> 0.99
Symptoms of a COVID-19 TSRD	–	–	354	30.6 (27.6, 33.8)		
Symptoms of burnout	74	22.4 (17.8, 27.9)	305	26.3 (23.4, 29.5)	3.9 (–3.7 to 11.5)	> 0.99
Started or increased substance use to cope with stress or emotions	–	–	143	12.3 (10.6, 14.9)		
Wished to be dead or not have woken up in previous 30 days	–	–	196	16.9 (14.5, 19.6)		
Seriously considered suicide in the previous 30 days	–	–	110	9.5 (7.6, 11.8)		
Seriously considered suicide or wished dead in the previous 30 days	–	–	202	17.5 (15.0, 20.2)		
Psychological well-being						
0–25%	–	–	220	19.1 (16.4, 22.0)		
26–50%	–	–	304	26.3 (23.5, 29.4)		
51–75%	–	–	375	32.4 (29.4, 35.7)		
76–100%	–	–	257	22.2 (19.7, 24.9)		
Sleep Duration						
< 6 h	48	14.6 (10.8, 19.6)	204	17.6 (15.1, 20.5)	3.0 (–3.5 to 9.5)	> 0.99
6–7 h	87	26.4 (21.5, 32.0)	285	24.7 (22.0, 27.5)	–1.7 (–9.6 to 6.2)	> 0.99
> 7 h	195	59.0 (52.8, 64.9)	668	57.7 (54.4, 61.0)	–1.3 (–10.1 to 7.6)	> 0.99
Comparison of sleep to before the pandemic						
Spend more time in bed	99	29.9 (24.9, 35.4)	353	30.5 (27.7, 33.5)	0.6 (–7.6 to 8.9)	> 0.99
Spend less time in bed	31	9.3 (6.2, 13.7)	66	5.7 (4.4, 7.4)	–3.6 (–8.6 to 1.5)	0.28
More trouble sleeping	69	20.7 (16.3, 25.9)	277	23.9 (21.2, 26.9)	3.2 (–4.2 to 10.6)	> 0.99
Less trouble sleeping	11		67			> 0.99

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Table 2 (continued)

Sample	Victorian April		Victorian September (excluding recontacts)		September vs April 2020	
	n ^a	% (95% CI) ^a	n ^a	% (95% CI) ^a	Δ % (95% CI) ^a	P ^b
More regular sleep	32	3.4 (1.8, 6.2)	154	5.8 (4.4, 7.6)	2.4 (−1.1 to 5.9)	0.91
Less regular sleep	54	16.4 (12.6, 21.1)	186	16.1 (13.7, 18.8)	−0.3 (−7.0 to 6.3)	>0.99
Symptoms of insomnia						
Yes	55	16.8 (12.7, 21.9)	239	20.6 (18.0, 23.6)	3.8 (−3.0 to 10.7)	>0.99
Epworth Sleepiness Scale...						
Normal	–	–	835	72.2 (69.0, 75.2)	–	–
Mild to moderate sleepiness	–	–	156	13.5 (11.4, 16.0)	–	–
Excessive sleepiness	–	–	166	14.3 (12.1, 16.9)	–	–
Time spent on screens compared with before the pandemic...						
Reduced by more than 1 h	25	7.5 (4.9, 11.3)	92	7.9 (6.2, 10.1)	0.4 (−4.3 to 5.2)	>0.99
Reduced by less than 1 h	11	3.4 (1.8, 6.3)	46	4.0 (2.8, 5.7)	0.6 (−2.8 to 3.9)	>0.99
About the same	162	49.1 (43.5, 54.7)	404	34.9 (31.9, 38.1)	−14.2 (−23.1 to −5.3)	<0.0001
Increased by less than 1 h	22	6.6 (4.1, 10.3)	90	7.8 (6.1, 9.7)	1.2 (−3.4 to 5.7)	>0.99
Increased by more than 1 h	111	33.4 (28.2, 39.0)	525	45.4 (42.1, 48.7)	12.0 (3.4 to 20.6)	0.0013
Time spent outside during daylight hours compared with before the pandemic...						
Reduced by more than 1 h	144	43.5 (37.6, 49.6)	586	50.7 (47.3, 54.0)	7.2 (−1.8 to 16.1)	0.27
Reduced by less than 1 h	26	7.8 (5.2, 11.6)	78	6.7 (5.2, 8.7)	−1.1 (−5.9 to 3.6)	>0.99
About the same	118	35.6 (30.1, 41.5)	357	30.9 (28.0, 34.0)	−4.7 (−13.2 to 3.9)	>0.99
Increased by less than 1 h	5	1.7 (0.7, 3.6)	49	4.2 (3.0, 6.0)	2.5 (−0.1 to 5.2)	0.36
Increased by more than 1 h	38	11.4 (8.0, 16.2)	87	7.5 (5.9, 9.4)	−3.9 (−9.5 to 1.6)	0.29
Daily hours spent following COVID-19						
0	183	55.3 (49.6, 61.2)	853	73.7 (70.8, 76.7)	18.4 (9.7 to 27.2)	<0.0001
1	56	16.9 (12.9, 21.9)	185	15.9 (13.7, 18.6)	−1.0 (−7.6 to 5.8)	>0.99
2–3	59	17.8 (13.7, 23.1)	73	6.3 (4.8, 8.3)	−11.5 (−17.9 to −5.1)	<0.0001
≥4	32	9.6 (6.7, 13.8)	43	3.8 (2.8, 5.0)	−5.8 (−10.8 to −0.9)	0.0002

VIC = Victoria, AUS = Australia, TSRD = trauma- and stressor-related disorder, NDIS = National Disability Insurance Scheme, COVID-19 = coronavirus disease 2019.

^a Weighted rounded counts and percentages may not sum to expected values.

^b CI and P-values are Bonferroni-adjusted to account for multiplicity (13 comparisons).

symptom, with two to three times the prevalence among adults aged 18–24, 25–44, or 45–64 vs ≥ 65 years (3.25, 2.11–5.00; 3.04, 2.05–4.52; 2.08, 1.43–3.00 respectively, all $p \leq 0.0001$), and significantly higher aPRs for those with vs without insomnia symptoms (1.78, 1.55–2.05, $p < 0.0001$), multigenerational caregivers vs non-caregivers (1.55, 1.30–1.84, $p < 0.0001$), and people with disabilities who did not qualify for NDIS vs people without disabilities (1.52, 1.24–1.87, $p < 0.0001$) (Fig. 2, appendix pp 16,17). In the model for any adverse mental or behavioural health symptoms, significant differences were not observed by sexual orientation, ancestry, regional vs metropolitan postal code, diurnal preference, spending less time in bed, having less trouble falling asleep, or maintaining a more regular sleep-wake schedule.

4. Discussion

In September 2020, during one of the longest global COVID-19 lockdowns in a region with low SARS-CoV-2 prevalence, approximately one-third of surveyed Victorian adults reported anxiety or depressive symptoms and COVID-19 TSRD symptoms, and about one-tenth reported new or increased substance use to cope. Most concerning, about one-tenth of adults reported serious past-month suicidal ideation. Prevalence estimates of poor mental health were similar to those in Victorians in April 2020, near the start of the lockdown, in the U.S. in April, June, and August 2020 through February 2021 (Czeisler et al., 2021a, 2021b, 2020; Ettman et al., 2020; Vahratian et al., 2020), and estimates from meta-analyses during the COVID-19 pandemic (Salari et al., 2020). Stability in rates of poor mental health across time and region stands in stark contrast to variation in SARS-CoV-2 infections and COVID-19 hospitalisations and deaths, suggesting that the indirect adverse mental health impact during the pandemic may be insensitive to objective COVID-19 risk. Given that high prevalences of adverse mental health symptoms were observed in a region with comparatively low SARS-CoV-2 prevalence, these findings may largely reflect indirect mental health effects of the pandemic and its mitigation.

Our findings demonstrate that poor mental health symptoms among adults in Victoria during the COVID-19 pandemic were not transient. Investment in mental health treatment, particularly for depression and anxiety, is cost-effective, with benefit-cost ratios of 2.3–3.0 for economic benefits (Chisholm et al., 2016) in addition to gains from ameliorating human misery and suffering. Australia has responded through reimbursement for telehealth delivery of mental health services, increased publicly funded mental health benefit allowances, and funding for community mental health telephone support services. Victorians have substantially increased mental health services utilization (Australian Government, 2020), which may reflect greater need for and access to these resources, and represent one reason that the prevalence of poor mental health in Victoria did not increase from April to September, despite one of the world's longest COVID-19 lockdowns.

Our findings also highlight mental health disparities. Adults aged <65 years, people with disabilities, and multigenerational unpaid caregivers experienced disproportionate burdens of almost all forms of adverse mental and behavioural health symptoms, consistent with results from U.S. studies of mental health during the COVID-19 pandemic (Czeisler et al., 2020, 2021b, 2021c). Moreover, diagnosed psychiatric or sleep disorders and insomnia symptoms were robustly associated with higher prevalence of poor outcomes, consistent with prior evidence during the pandemic (Czeisler et al., 2021b; Meaklim et al., 2021; Varma et al., 2021; Xiong et al., 2020). Examining behaviours, compared to April 2020, Victorians in September 2020 spent more time on screens

Table 23 (10.3) Estimated adjusted prevalence ratios for adverse mental and behavioural health conditions among Victorian adults in September 2020, by respondent characteristics.

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Table 3

Estimated adjusted prevalence ratios for adverse mental and behavioural health conditions among Victorian adults in September 2020, by respondent characteristics.

Mental or Behavioural Health Condition	Symptoms of Anxiety or Depressive Disorder		P	Symptoms of a COVID-19 TSRD		P	Started or Increased Substance Use		P	Suicidal ideation		P
Demographic	aPR	[95% CI]	–	aPR	[95% CI]	–	aPR	[95% CI]	–	aPR	[95% CI]	–
Sex (reference: Female)												
Male	0.89	[0.74, 1.08]	0.25	0.91	[0.74, 1.13]	0.39	0.83	[0.57, 1.20]	0.32	1.02	[0.76, 1.37]	0.90
Age Group, years (reference: ≥65)												
18–24	4.37	[2.48, 7.72]	<0.0001	3.00	[1.76, 5.11]	0.0001	1.89	[0.69, 5.19]	0.22	5.59	[2.62, 11.95]	<0.0001
25–44	4.03	[2.40, 6.76]	<0.0001	2.21	[1.37, 3.58]	0.0012	2.45	[1.04, 5.76]	0.04	3.51	[1.81, 6.79]	0.0002
45–64	2.35	[1.45, 3.82]	0.0006	1.56	[0.99, 2.47]	0.055	1.93	[0.86, 4.33]	0.11	2.05	[1.07, 3.95]	0.032
Disability Status (reference: None)												
Disability, with support from NDIS	1.58	[1.16, 2.14]	0.0033	1.54	[1.15, 2.08]	0.0042	2.38	[1.47, 3.85]	0.0005	2.47	[1.7, 3.58]	<0.0001
Disability, without support from NDIS	1.94	[1.51, 2.50]	<0.0001	1.40	[1.00, 1.97]	0.049	1.96	[1.11, 3.49]	0.022	2.40	[1.64, 3.52]	<0.0001
Employment Status (reference: Employed nonessential)												
Employed essential	1.15	[0.89, 1.48]	0.29	1.08	[0.83, 1.41]	0.57	0.83	[0.54, 1.29]	0.41	1.07	[0.72, 1.59]	0.72
Unemployed	1.32	[1.00, 1.75]	0.054	1.15	[0.84, 1.57]	0.38	0.65	[0.33, 1.25]	0.20	1.35	[0.84, 2.17]	0.22
Student	0.82	[0.46, 1.47]	0.51	1.05	[0.59, 1.88]	0.87	0.52	[0.17, 1.64]	0.27	0.68	[0.26, 1.74]	0.42
Retired	0.94	[0.60, 1.45]	0.77	0.66	[0.43, 1.03]	0.068	0.61	[0.28, 1.32]	0.21	1.03	[0.59, 1.81]	0.92
Unpaid Caregiver Status (reference: No)												
Unpaid caregiver of adults	1.31	[1.01, 1.71]	0.042	1.48	[1.11, 1.98]	0.0075	1.61	[0.89, 2.91]	0.12	1.55	[1.02, 2.37]	0.041
Unpaid caregiver of children or adolescents	1.01	[0.74, 1.38]	0.95	0.93	[0.61, 1.41]	0.73	3.15	[1.80, 5.51]	0.0001	1.05	[0.59, 1.89]	0.86
Multigenerational unpaid caregiver	1.54	[1.21, 1.97]	0.0005	2.11	[1.65, 2.70]	<0.0001	4.85	[2.98, 7.90]	<0.0001	2.95	[2.06, 4.20]	<0.0001
Political Ideology (reference: Centre)												
Far left	1.08	[0.75, 1.56]	0.69	0.99	[0.63, 1.56]	0.96	0.75	[0.34, 1.66]	0.48	1.78	[1.07, 2.96]	0.026
Slightly left	1.29	[0.98, 1.70]	0.069	0.97	[0.71, 1.32]	0.84	1.89	[1.13, 3.16]	0.016	1.32	[0.86, 2.03]	0.21
Slightly right	1.34	[1.02, 1.76]	0.039	1.13	[0.85, 1.50]	0.39	1.20	[0.73, 1.97]	0.47	1.55	[1.06, 2.29]	0.025
Far right	1.45	[1.08, 1.94]	0.013	1.67	[1.29, 2.18]	0.0001	2.01	[1.23, 3.30]	0.0054	1.88	[1.29, 2.74]	0.0010
Apolitical and/or prefer not to answer	1.32	[0.99, 1.75]	0.056	0.92	[0.66, 1.28]	0.62	0.98	[0.52, 1.84]	0.95	1.19	[0.72, 1.98]	0.49
Believed high risk for severe COVID-19 (reference: No)												
Yes	1.28	[1.02, 1.61]	0.034	1.11	[0.84, 1.47]	0.45	1.13	[0.75, 1.72]	0.55	1.11	[0.78, 1.59]	0.56

COVID-19 = coronavirus disease 2019, TSRD = trauma- and stressor-related disorder, aPR = adjusted prevalence ratio, CI = confidence interval, NDIS = National Disability Insurance Scheme.

and less time following COVID-19 media coverage. There was a trend, albeit not statistically significant after Bonferroni correction, for reduced outdoor time among Victorians during September compared to Victorians in April. Reduced outdoor time was associated with higher prevalence ratios for all assessed adverse mental health symptoms, and increased time on screens was associated with higher prevalence ratios for anxiety or depression symptoms. More regular sleep times and spending less time following COVID-19 were associated with lower prevalence ratios for anxiety or depression symptoms.

These results, which are consistent with findings related to mental health during the COVID-19 pandemic among Victorian athletes (Facer-Childs et al., 2021), show that a sustained lockdown does not have a unitary effect on behaviours, with some behaviour changes associated with better and others with worse mental health symptoms. Although our cross-sectional results do not demonstrate causality, they do suggest that in addition to interventions directly aimed at mental health, research should investigate whether interventions that target behaviour or the environment are associated with improved mental

health. As an alternative to targeting behaviours, given the disproportionate experience of adverse mental health symptoms among younger adults, caregivers, and individuals with pre-existing psychiatric conditions, prevention and intervention resources designed for these populations could be prioritized. For younger adults, programs that promote early engagement in mental health services may be particularly beneficial, as adolescents are the least likely age group to seek professional mental health care despite a high prevalence of mental health challenges (Burns and Birrell, 2014). For caregivers, effective interventions may include cognitive behavioural approaches (Wiegmann et al., 2021) or those with caregiving-related information and education with or without professional psychological support (Sherifali et al., 2018). Psychiatrists and mental health professionals can also provide support for individuals with psychiatric conditions by reducing interruptions to care, promoting care-seeking behaviour when advisable, ensuring safe in-person care through widespread testing and contact tracing programs (Brody et al., 2021), and managing evolving scenarios (e.g., opportunities for remote versus in-person care) (Kahl and Correll, 2020; Kavoov

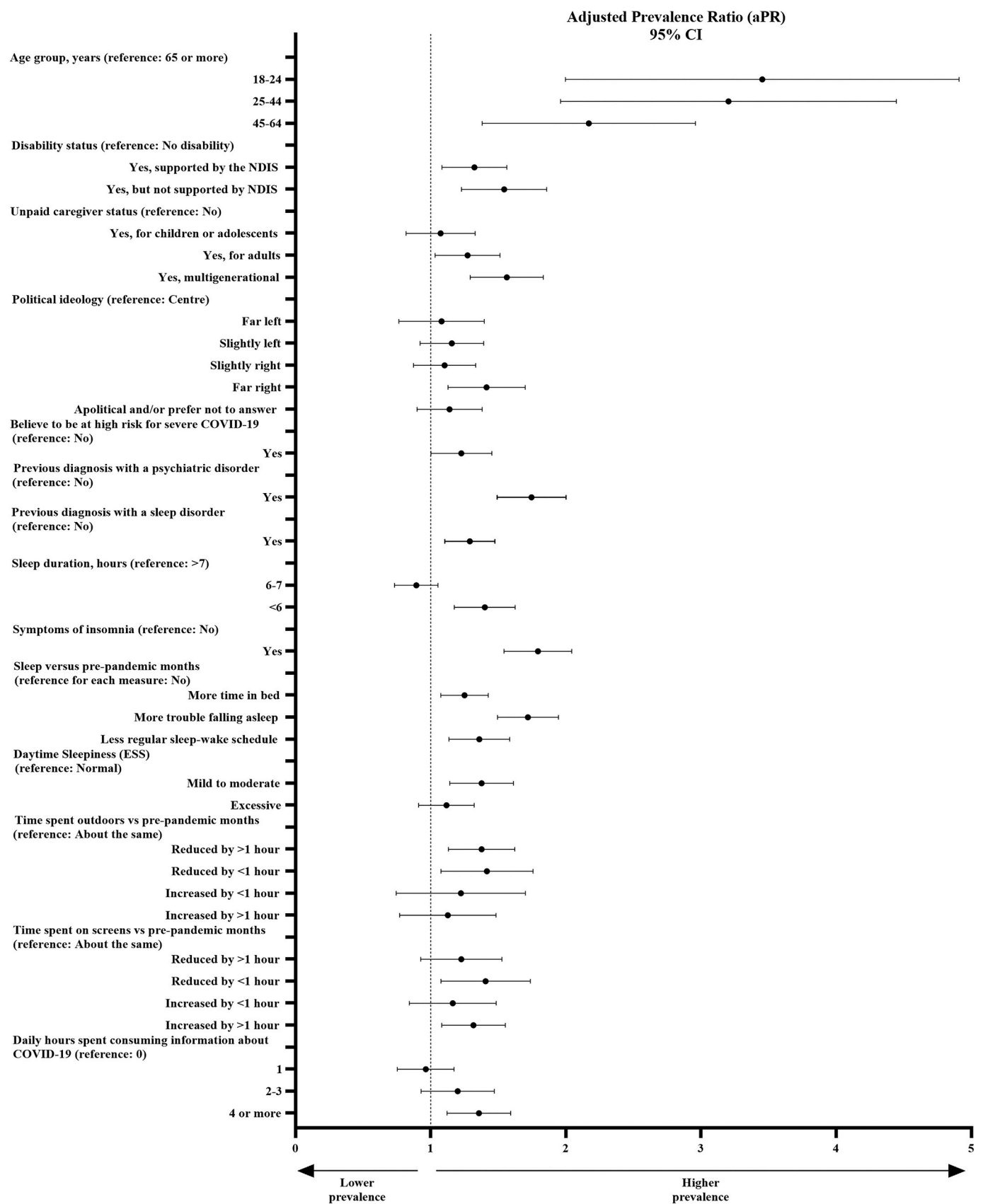


Fig. 2. Adjusted prevalence ratios for demographics, sleep, and changes in behaviour associated with at least one adverse mental and behavioural health symptom among Victorian adults in September 2020.

Fig. 17 (10.2). Adjusted prevalence ratios for demographics, sleep, and changes in behaviour associated with at least one adverse mental and behavioural health symptom among Victorian adults in September 2020.

Table 24 (10.4) Estimated adjusted prevalence ratios for adverse mental and behavioural health conditions among Victorian adults in September 2020, by medical history, sleep, and behavioural changes.

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Table 4

Estimated adjusted prevalence ratios for adverse mental and behavioural health conditions among Victorian adults in September 2020, by medical history, sleep, and behavioural changes.

Mental or Behavioural Health Condition	Anxiety or Depressive Disorder Symptoms		P	Symptoms of a COVID-19 TSRD		P	Started or Increased Substance Use		P	Suicidal Ideation		P
Medical conditions, Sleep, and Behavioural Changes	aPR	[95% CI]	–	aPR	[95% CI]	–	aPR	[95% CI]	–	aPR	[95% CI]	–
HISTORY OF OR CURRENT HEALTH CONDITIONS												
Diagnosed with a psychiatric condition (reference: No)												
Yes	2.19	[1.79, 2.66]	<0.0001	1.90	[1.53, 2.37]	<0.0001	1.85	[1.28, 2.68]	0.0011	2.88	[2.07, 4.01]	<0.0001
Diagnosed with a sleep condition (reference: No)												
Yes	1.77	[1.47, 2.13]	<0.0001	1.36	[1.11, 1.66]	0.0035	1.55	[1.10, 2.18]	0.012	1.94	[1.46, 2.57]	<0.0001
SLEEP MEASURES												
Diurnal preference (reference: Definite morning type)												
Rather morning type	1.17	[0.91, 1.49]	0.23	0.99	[0.78, 1.26]	0.96	0.73	[0.50, 1.05]	0.093	0.94	[0.68, 1.29]	0.70
Rather evening type	1.26	[0.97, 1.62]	0.082	1.02	[0.78, 1.33]	0.91	1.23	[0.80, 1.89]	0.34	0.87	[0.60, 1.26]	0.47
Definite evening type	1.15	[0.84, 1.57]	0.38	0.96	[0.69, 1.32]	0.80	0.71	[0.36, 1.42]	0.33	0.84	[0.51, 1.38]	0.49
Sleep duration, hours (reference: >7)												
<6	1.44	[1.15, 1.80]	0.0016	1.42	[1.11, 1.81]	0.0054	1.43	[0.92, 2.23]	0.11	1.46	[1.02, 2.08]	0.039
6–7	0.90	[0.72, 1.14]	0.40	0.76	[0.58, 0.99]	0.046	1.06	[0.70, 1.62]	0.78	0.85	[0.59, 1.22]	0.37
Symptoms of insomnia (reference: No)												
Yes	1.97	[1.63, 2.37]	<0.0001	2.23	[1.83, 2.72]	<0.0001	2.06	[1.49, 2.86]	<0.0001	1.86	[1.38, 2.51]	0.0001
Compared with October through December 2019...												
More time in bed (reference: No)												
Yes	1.39	[1.16, 1.66]	0.0003	1.39	[1.14, 1.69]	0.0011	1.44	[1.04, 1.99]	0.030	1.47	[1.12, 1.92]	0.0054
Less time in bed (reference: No)												
Yes	0.94	[0.69, 1.29]	0.71	0.99	[0.71, 1.36]	0.93	1.04	[0.66, 1.62]	0.88	1.15	[0.81, 1.63]	0.43
More trouble falling asleep (reference: No)												
Yes	2.14	[1.80, 2.55]	<0.0001	1.83	[1.52, 2.21]	<0.0001	1.64	[1.19, 2.26]	0.0026	1.66	[1.25, 2.20]	0.0005
Less trouble falling asleep (reference: No)												
Yes	0.94	[0.68, 1.32]	0.73	0.91	[0.64, 1.28]	0.58	1.05	[0.65, 1.70]	0.85	0.76	[0.53, 1.09]	0.14
More regular sleep schedule (reference: No)												
Yes	0.72	[0.54, 0.96]	0.024	1.00	[0.78, 1.29]	0.98	1.06	[0.68, 1.64]	0.80	0.76	[0.51, 1.15]	0.20
Less regular sleep schedule (reference: No)												
Yes	1.44	[1.17, 1.79]	0.0008	1.52	[1.20, 1.92]	0.0005	1.62	[1.08, 2.44]	0.019	1.31	[0.92, 1.85]	0.13
Daytime sleepiness (reference: Normal)												
Mild to moderate	1.67	[1.34, 2.09]	<0.0001	1.48	[1.16, 1.88]	0.0018	0.88	[0.60, 1.29]	0.51	1.28	[0.92, 1.78]	0.15
Excessive	1.21	[0.94, 1.55]	0.14	1.31	[1.02, 1.70]	0.038	0.92	[0.62, 1.37]	0.70	1.36	[0.93, 1.97]	0.11
BEHAVIOURAL CHANGES												
Compared with October through December 2019...												
Time spent outdoors (reference: About the same)												
Reduced by more than 1 h	1.42	[1.12, 1.80]	0.0041	1.25	[0.97, 1.60]	0.082	1.69	[1.08, 2.64]	0.021	1.47	[1.02, 2.11]	0.039
Reduced by less than 1 h	1.53	[1.10, 2.14]	0.012	1.36	[0.97, 1.91]	0.075	1.03	[0.58, 1.82]	0.93	1.55	[0.93, 2.58]	0.096
Increased by less than 1 h	0.84	[0.43, 1.65]	0.61	1.12	[0.69, 1.81]	0.65	1.83	[0.96, 3.50]	0.066	0.98	[0.50, 1.94]	0.96
Increased by more than 1 h	1.02	[0.66, 1.57]	0.94	1.06	[0.66, 1.69]	0.81	1.96	[0.98, 3.89]	0.057	1.53	[0.82, 2.86]	0.18
Time spent on screens (reference: About the same)												
Reduced by more than 1 h	1.47	[1.09, 1.99]	0.012	1.24	[0.89, 1.72]	0.20	1.45	[0.83, 2.52]	0.19	1.08	[0.70, 1.67]	0.73
Reduced by less than 1 h	1.21	[0.79, 1.85]	0.38	1.31	[0.90, 1.90]	0.16	1.49	[0.73, 3.04]	0.27	1.11	[0.67, 1.85]	0.69
Increased by less than 1 h	1.06	[0.74, 1.52]	0.75	1.07	[0.71, 1.61]	0.75	1.05	[0.55, 2.00]	0.88	1.24	[0.76, 2.00]	0.39
Increased by more than 1 h	1.28	[1.01, 1.62]	0.04	1.30	[1.01, 1.69]	0.044	2.03	[1.29, 3.17]	0.0021	0.84	[0.58, 1.23]	0.38
Daily hours spent following COVID-19 (reference: 0)												

(continued on next page)

Table 24 (10.4) (continued) Estimated adjusted prevalence ratios for adverse mental and behavioural health conditions among Victorian adults in September 2020, by medical history, sleep, and behavioural changes.

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Table 4 (continued)

Mental or Behavioural Health Condition	Anxiety or Depressive Disorder Symptoms		P	Symptoms of a COVID-19 TSRD		P	Started or Increased Substance Use		P	Suicidal Ideation		P
	aPR	[95% CI]	–	aPR	[95% CI]	–	aPR	[95% CI]	–	aPR	[95% CI]	–
1	0.92	[0.69, 1.24]	0.60	0.74	[0.51, 1.07]	0.11	0.81	[0.44, 1.50]	0.51	0.92	[0.56, 1.51]	0.73
2–3	1.19	[0.86, 1.64]	0.30	1.12	[0.75, 1.67]	0.58	0.95	[0.46, 1.95]	0.89	1.09	[0.61, 1.94]	0.78
≥4	1.25	[0.97, 1.62]	0.084	1.39	[1.06, 1.82]	0.016	1.82	[1.27, 2.59]	0.0010	1.44	[1.03, 2.03]	0.035

COVID-19 = coronavirus disease 2019, TSRD = trauma- and stressor-related disorder, aPR = adjusted prevalence ratio, CI = confidence interval.

et al., 2020; Moreno et al., 2020; The Lancet Infectious Diseases, 2020).

4.1. Limitations

This study had several limitations. Outcomes were self-reported rather than determined via diagnostic interviews, and it is possible that the survey instrument did not capture some changes in prevalence of adverse mental health symptoms. We did, however, use validated questionnaires for common mental health outcomes (anxiety, depression), which have shown high correspondence with diagnoses. Furthermore, data from participants willing to undergo lengthy diagnostic interviews may be less generalisable. Additionally, although quota sampling and survey weighting to Census data were used to strengthen generalisability, the sample may not generalise to the 2020 Victorian adult population due to potential residual differences between responders compared to the general population. Moreover, because we measured a cross-section of primarily different participants at each timepoint, we had limited power to examine longitudinal changes within individuals; however, evidence of significant survivorship bias in longitudinal mental health surveys may reduce the representativeness of such studies (Czeisler et al., 2021d). Seasonal variation in mood is a potential confounding factor in our study. Our data were, however, collected in April (mid-autumn) and September (spring), with photoperiod length differences of 46 min (longer in September than April) and average temperature differences of 2 °C (warmer in April than September). Previous longitudinal studies in Victoria found no seasonal variation in negative affect (Murray et al., 2001) and a population-based study of more than 150,000 participants in the UK suggest very small variations in depressive symptoms in women and none in men (Lyall et al., 2018). It is therefore unlikely seasonal variations in adverse mental health symptoms meaningfully altered our results. Assessment of this was not feasible while comparing the effect of the duration of exposure to the pandemic and related lockdowns. Finally, as we did not have pre-pandemic cross-sections of data, our findings do not answer the question as to whether these prevalence estimates represent increases compared with previous years; however, longitudinal surveys suggest that the prevalence of psychological distress increased in Australia, and particularly in Victoria (Biddle et al., 2020a, 2020b).

5. Conclusions

Despite a relatively low prevalence of SARS-CoV-2 and efforts to increase availability of mental health services, poor mental and behavioural health symptoms were common in Victoria, Australia in September 2020, during one of the longest lockdowns globally. Given evidence of direct mental health effects of COVID-19, policymakers should not subscribe to the false choice between COVID-19 containment and mental health, as failing to control the former could significantly worsen the latter. However, our findings suggest that adverse mental health symptoms were common, even in a region with low SARS-CoV-2 prevalence. Therefore, as policymakers worldwide deliberate about the

duration and intensity of COVID-19 mitigation policies now and during future waves of SARS-CoV-2 and other pathogens, it is essential that they account for the indirect mental health effects of such actions and implement strategies to attenuate them.

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CRedit authorship contribution statement

Mark É. Czeisler: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Visualization, Writing – original draft, Writing – review & editing. **Joshua F. Wiley:** Conceptualization, Formal analysis, Methodology, Writing – original draft, Writing – review & editing. **Elise R. Facer-Childs:** Methodology, Visualization, Writing – review & editing. **Rebecca Robbins:** Methodology, Writing – review & editing. **Matthew D. Weaver:** Methodology, Writing – review & editing. **Laura K. Barger:** Methodology, Writing – review & editing. **Charles A. Czeisler:** Conceptualization, Investigation, Methodology, Writing – review & editing. **Mark E. Howard:** Conceptualization, Investigation, Methodology, Supervision, Writing – review & editing. **Shantha M.W. Rajaratnam:** Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Supervision, Writing – review & editing.

Declaration of competing interest

M.É. Czeisler, C.A. Czeisler, M.E. Howard, and S.M.W. Rajaratnam reported receiving institutional contracts to Monash University to support The COVID-19 Outbreak Public Evaluation (COPE) Initiative from the CDC Foundation with funding from BNY Mellon and from WHOOP, Inc., as well as a gift from Hopelab, Inc. M.É. Czeisler reported receiving grants from the Australian-American Fulbright Commission administered through a 2020–2021 Fulbright Future Scholarship funded by The Kinghorn Foundation during the conduct of the study and receiving personal fees from Vanda Pharmaceuticals outside the submitted work. E.R. Facer-Childs reported a grant from the Science and Industry Endowment Fund Ross Metcalf STEM+ Business Fellowship administered by the Commonwealth Scientific and Industrial Research Organisation, Canberra, Australia. R. Robbins reported personal fees from

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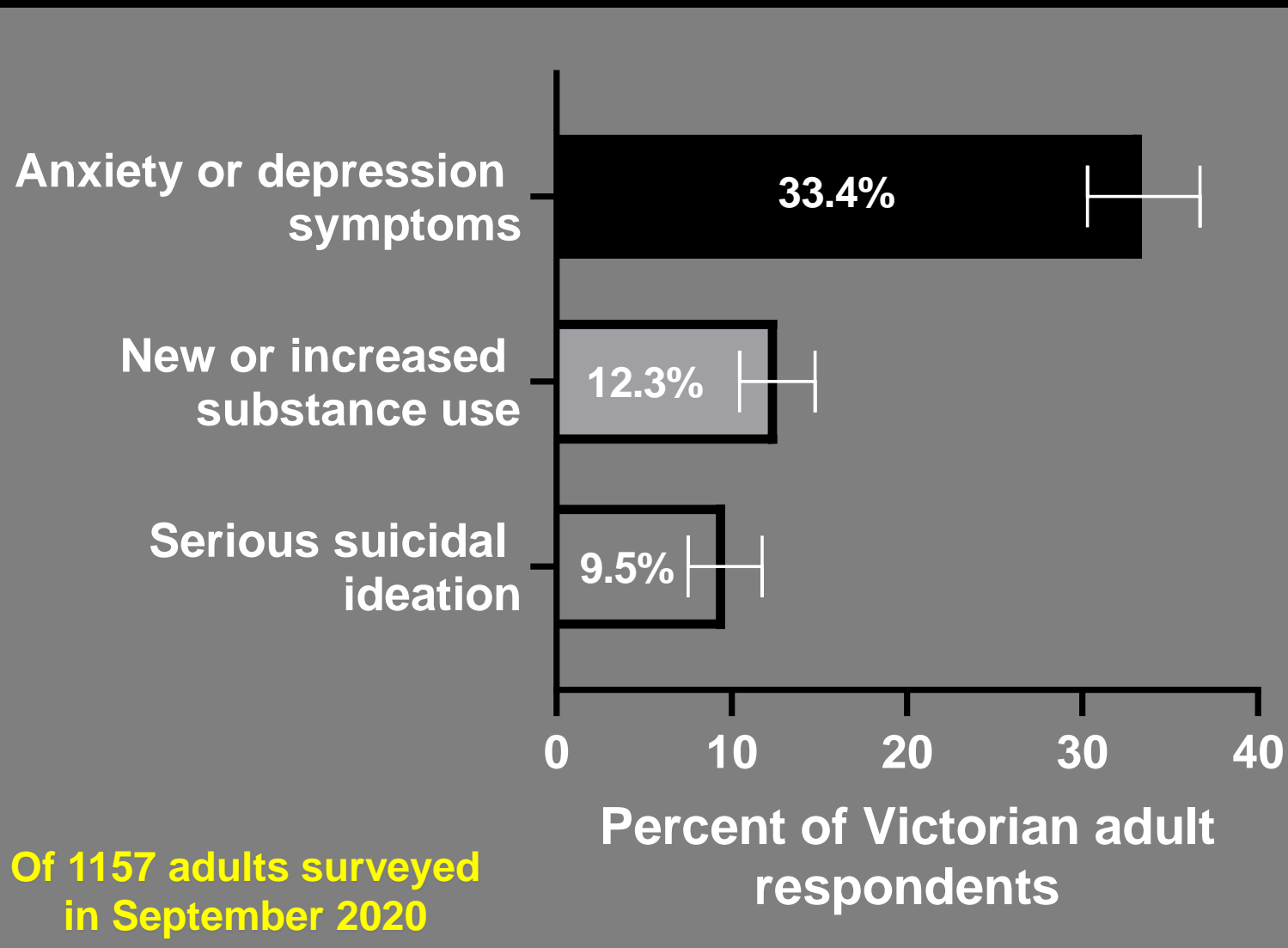
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Mental health, substance use, and suicidal ideation among adults in a region with low COVID-19 prevalence: Victoria, Australia



Disproportionately affected populations

People with disabilities

Young adults

People with far right political views

Unpaid caregivers

People who spent less time outdoors and more time on screens and consuming COVID-19 media

People with insufficient or impaired sleep

SUMMARY OF FINDINGS

The Original Investigation presented in Chapter Ten revealed that levels of adverse mental health symptoms among adult Victorian residents were similar to those observed among Australian adults in April, May, and August 2020 (**Biddle et al., 2020a, 2020b; Czeisler, Howard, et al., 2021**), and among US adults in April, June, and August 2020 through February 2021 (**Czeisler, Howard, et al., 2021; Czeisler, Lane, et al., 2020, 2021; Ettman et al., 2020; Holman et al., 2020; McKnight-Eily et al., 2021; Vahratian et al., 2021**). Moreover, the longitudinal subset of respondents displayed no significant differences in the prevalence of adverse mental health symptoms assessed in both April-2020 and September-2020 (anxiety or depressive disorder symptoms, burnout symptoms), though this analysis might be underpowered and susceptible to survivorship bias (**Czeisler, Wiley, Czeisler, et al., 2021c; Elston, 2021**). Through the end of September 2020, marked differences in SARS-CoV-2 infections and COVID-19 deaths were sustained between Victoria (plus all of Australia) and the US. At that time, Victoria reported approximately 20 thousand SARS-CoV-2 cases (3.0 per 1,000 population) and 800 deaths (0.1 per 1,000 population) (**Australian Government Department of Health, 2020c**). By comparison, the US had reported 4.2 million SARS-CoV-2 cases (12.7 per 1,000 population) and 210 thousand deaths (0.6 per 1,000 population) (**Centers for Disease Control and Prevention, 2020g, p. 39**).

Despite these differences in SARS-CoV-2 prevalence and COVID-19 mortality, regions displayed persistently and similarly high levels of adverse mental health symptoms over time. Our findings therefore suggest that the indirect mental health effects of the pandemic may be more tied to social and economic impacts than to objective COVID-19 risk. In addition to evidence of adverse mental health symptoms based on validated screening instruments revealed in Chapter Ten, the Australian Bureau of Statistics mid-August 2020 Household Impacts of COVID-19 Survey found

that among Australian adult respondents, referring to “at least some of the time” over past four weeks, nearly one-half had felt nervous, two-fifths had felt restless or fidgety or that everything was an effort, one-quarter had felt hopeless, and one-sixth had felt so depressed that nothing could cheer them up **(Australian Bureau of Statistics, 2020b)**. There were no significant differences in comparing adults with residence in Victoria with adults from other Australian states and territories.

One approach to considering the observation of highly prevalent poor mental and emotional wellbeing would be through a social-ecological framework, which integrates complex individual, relationship, community, and societal factors that predispose individuals to mental health risk or protect their well-being **(Cramer & Kapusta, 2017; Reupert, 2017)**. In this view, strategies to improve mental health must act across multiple domains of factors to create sustainable change and achieve population-level impact. Demographic differences reinforced findings from the US **(Czeisler, Howard, et al., 2021; Czeisler, Lane, et al., 2020, 2021; Czeisler, Rohan, et al., 2021; Ettman et al., 2020; Vahratian et al., 2021)** and other studies in Australia **(Meaklim et al., 2021; Van Rheenen et al., 2020; Varma et al., 2021)**, in that younger adults, unpaid caregivers, people with disabilities, and people with pre-existing psychiatric or substance use conditions experienced disproportionately worse mental health. Regarding behaviours, adverse mental health symptoms were generally associated with reduced time outdoors during daylight hours, increased time spent on screens, and increased media consumption about COVID-19—an effect demonstrated during prior traumatic exposures **(Garfin et al., 2020; Silver et al., 2021; R. R. Thompson et al., 2019)**. Interestingly, evidence from the Household Impacts of COVID-19 Survey during September 2020, administered by the Australian Bureau of Statistics, indicated that approximately three-quarters of surveyed Australian adults received information from Australian news sources, half from government health information sources, and one-third from social media (e.g., Facebook, YouTube) **(Australian Bureau of Statistics, 2020a)**. Social media, which was more commonly used by

younger than by older adults, has been associated with higher levels of misinformation **(Piltch-Loeb et al., 2021)**.

Adverse mental health symptoms were also associated with short sleep duration and insomnia symptoms, as well as the following perceived changes to sleep measures during the pandemic: more trouble falling asleep, more time in bed, and less regular sleep timing. In contrast, respondents who reported more regular sleep timing had lower odds of anxiety or depression symptoms compared with those who did not report increased regularity. These behavioural associations are consistent with studies highlighting robust inter-relationships between adverse mental health symptoms and insufficient or impaired sleep, including sleep duration **(Cox & Olatunji, 2020; Glozier et al., 2010; Khader et al., 2020; Ranum et al., 2019)**; sleep quality **(Buysse, 2013; Krystal, 2012; Tubbs et al., 2021)**; diurnal preference **(Asarnow et al., 2019; Daghlasi et al., 2021; Norbury, 2021)**; and the consistency of sleep timing **(Fang et al., 2021; Lyall et al., 2018)**. They also suggest merit in further investigation of sleep and circadian rhythms as modifiable risk factors **(Freeman et al., 2017; Harvey et al., 2015)**, which could be promoted at a population level to enhance mental health and wellness **(Irish et al., 2015)**, and to reduce strain on an overwhelmed mental health care systems around the globe. Altogether, further investigation of the directions and mechanisms underlying associative findings between demographics or behaviours and adverse mental health symptoms can be used to inform the design and delivery of effective mental health prevention and intervention trials.

CHAPTER 11: Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic among adult users of a wearable device in the United States

PREFACE TO CHAPTER 11

While the findings described in [Chapter Ten](#) were encouraging in that they provided evidence for sleep duration and the regularity of sleep timing as potentially modifiable risk factors for adverse mental health symptoms, self-reported sleep-wake data is subject to various biases and can vary definitionally (Cespedes et al., 2016; Jackson et al., 2018, 2020; Lauderdale et al., 2008). More importantly, comparisons between sleep before and during the pandemic based on self-reported data might suffer from recall bias, particularly if participants were asked to summarise sleep over varying intervals of time. For this reason, high-resolution sleep-wake data (e.g., daily sleep-wake diaries, continuous monitoring from wearables) are valuable for systematic before-and-after comparisons of sleep during the pandemic.

The Original Investigation in Chapter Eleven (Czeisler et al., 2021), which has been posted on the preprint server *medRxiv* and submitted for peer review, presents findings based on the second dataset for The COPE Initiative, which was generated as part of the WHOOP COVID-19 Resilience Project. Participants were active US adult subscribers to WHOOP wearables who were invited to complete surveys during June 2020. The WHOOP strap collects sleep onset, sleep offset, and staged sleep in 30-second epochs using a multisensory (tri-axial accelerometer, optical HR sensor, capacitive touch sensor and ambient temperature sensor) device that has demonstrated good performance in detecting sleep vs wake relative to polysomnography (Berryhill et al., 2020; Miller et al., 2020, 2021). Analysis of twelve healthy adult participants who wore WHOOP devices for a 10-day, laboratory-based protocol with the start of the sleep episode manually entered by research

staff showed that WHOOP overestimated total sleep time by 8.2 ± 32.9 minutes as compared with polysomnography (PSG), which is not a significant difference (**Miller et al., 2020**). For two-stage categorisation (wake or sleep), the agreement, sensitivity to sleep, specificity for wake, and Cohen's kappa for WHOOP compared with PSG were 89%, 95%, 51%, and 0.49, respectively. The Cohen's kappa coefficient (κ) of 0.49 represents moderate chance-corrected agreement between WHOOP and PSG, though this would likely have been higher if the WHOOP strap had been worn continuously, rather than just during sleep episodes. A follow-up performance assessment evaluated both the auto-detected sleep and manually entered sleep with PSG, and found similar two-stage agreement (86% and 90%, respectively), sensitivity (90% and 97%), and specificity measures compared with PSG (60% and 45%) (**Miller et al., 2021**). The WHOOP strap is among emerging sleep-tracking wearable technology that provides an opportunity to study real-world sleep using reliable objective measures, which affords the investigation of sleep-wake behaviours and associated outcomes in free-living situations (**Grandner et al., 2021**). Studies in free-living environments are more subject to confounders because it is more difficult to control environmental factors, though some findings might be more generalisable than studies in sleep laboratories.

For the COVID-19 Resilience Project, the dataset includes a variety of sleep-wake measures (sleep duration, sleep timing [e.g., onset and offset], regularity of sleep timing [consistency], and wake after sleep onset [a measure of sleep quality]) during January through June of 2020. The first aim of the paper was to characterise changes to sleep during the initial months of the pandemic using the set of sleep variables given that sleep health is comprised of multiple dimensions of sleep and circadian timing (**Buysse, 2014; Wallace et al., 2018**). We also collected demographic information and assessed mental health (symptoms of anxiety or depression, symptoms of burnout, and new or increased substance use) through surveys administered during June 2020.

The second aim of the paper was to determine relationships between adverse mental health symptoms and both sleep duration and sleep consistency before and during the pandemic. Sleep duration was chosen based on evidence that short sleep duration is associated with incident and persistent symptoms of depression (**Y. Li et al., 2017; Sun et al., 2018; Szklo-Coxe et al., 2010**), with a study of 10,704 adults in China estimating that participants with sleep duration below five hours or between five and six hours had higher odds of incident depression (aORs = 1.69 [95% confidence interval = 1.36 to 2.11] and 1.48 [95% confidence interval = 1.19 to 1.84], respectively) and recurrent depression compared with participants who had slept between seven and eight hours (**Sun et al., 2018**). Evidence about associations between long sleep duration (e.g., more than nine hours) and adverse mental health symptoms is mixed (**Sun et al., 2018; L. Zhai et al., 2015**). Sleep consistency was more of an exploratory analysis given emerging evidence that inconsistent sleep timing is associated with adverse mental health symptoms. For example, a study of 2,115 medical interns found that increased variability in sleep duration and sleep offset (proxies for sleep consistency) were associated with more symptoms of depression (**Fang et al., 2021**), consistent with associations between circadian disruption and adverse mental health (**Lyall et al., 2018**), more variable time in bed and negative mood (**Bei et al., 2017**) and variability in sleep timing with suicide ideation among adolescents at high risk for suicidality (**Bernert et al., 2017**). The chapter concludes with a brief overview of findings from the Original Investigation.

CHAPTER ELEVEN: Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic among adult users of a wearable device in the United States

Czeisler MÉ, Capodilupo ER, Weaver MD, Czeisler CA, Howard ME, Rajaratnam SMW. Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic among adult users of a wearable device in the United States. Original Investigation submitted for review.

Note: a prior version of this manuscript was posted as a preprint on medRxiv (citation below).

Czeisler MÉ, Capodilupo ER, Weaver MD, Czeisler CA, Howard ME, Rajaratnam SMW. Prior sleep-wake behavior predicts mental health resilience among adults in the United States during the COVID-19 pandemic. *medRxiv* [Preprint]. 2021 Jun 22:2021.06.15.21258983. doi: 10.1101/2021.06.15.21258983.

Chapter Eleven Original Investigation: Czeisler *et al.* Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic.

Title

Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic among adult users of a wearable device in the United States

Authors

Mark É Czeisler, AB¹⁻⁴; Emily R Capodilupo, MA⁵; Matthew D Weaver, PhD^{1,6,7}; Charles A Czeisler, PhD, MD^{1,6,7}; Mark E Howard, MBBS, PhD^{1,2,8}; Shantha MW Rajaratnam, PhD^{1,2,6,7}

Affiliations

¹Turner Institute for Brain and Mental Health, Monash University, Melbourne, Victoria, Australia

²Institute for Breathing and Sleep, Austin Health, Melbourne, Victoria, Australia

³Department of Psychiatry, Brigham & Women's Hospital, Boston, Massachusetts

⁴Harvard Medical School, Boston, Massachusetts

⁵WHOOP Inc., Department of Data Science and Research, Boston, Massachusetts

⁶Division of Sleep Medicine, Harvard Medical School, Boston, Massachusetts

⁷Division of Sleep and Circadian Disorders, Departments of Medicine and Neurology, Brigham & Women's Hospital, Boston, Massachusetts

⁸Division of Medicine, University of Melbourne, Melbourne, Victoria, Australia

Corresponding author

Mark É Czeisler, AB, Australian-American Fulbright Scholar and PhD Candidate

Turner Institute for Brain and Mental Health, Monash University

Level 5, 18 Innovation Walk, Clayton Campus, Clayton, 3800, Victoria, Australia

Telephone: +1 (617) 571 7887; Email: mark.czeisler@fulbrightmail.org

Abstract

Chapter Eleven Original Investigation: Czeisler *et al.* Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic.

Objectives: To characterize objective sleep patterns among U.S. adults before and during the COVID-19 pandemic, and to assess for associations between adverse mental health symptoms and (1) sleep duration and (2) the consistency of sleep timing before and during the pandemic.

Design: Longitudinal objective sleep-wake data during January through June 2020 were linked with mental health and substance use assessments conducted during June 2020 as part of The COVID-19 Outbreak Public Evaluation (COPE) Initiative.

Setting: Adult users of WHOOP—a commercial, digital sleep wearable.

Participants: U.S. adults residing in the U.S. and actively using WHOOP were recruited by WHOOP.

Intervention: The COVID-19 pandemic and its mitigation (e.g., stay-at-home orders, work-from-home directives).

Measurements: Anxiety or depression symptoms, burnout symptoms, and new or increased substance use to cope with stress or emotions.

Results: Of 4912 participants in the primary analytic sample (response rate, 14.9%), we observed acutely increased sleep duration (0.25h or 15m) and sleep consistency (3.51 points out of 100) and delayed sleep timing (onset, 18.70m; offset, 36.60m) during mid-March through mid-April 2020. Adjusting for demographic and lifestyle variables, participants with persistently insufficient sleep duration and inconsistent sleep timing had higher odds of adverse mental health symptoms.

Conclusions: Our findings extend studies on sleep and mental health during the pandemic, using objective sleep-wake data to find evidence supporting sleep duration

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and the consistency of sleep timing as modifiable risk factors that could be targeted by behavioral interventions designed to enhance mental health.

Keywords: Coronavirus; Anxiety; Depression; Substance Use; Wearable; Epidemiology

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Introduction

Absent widespread testing or safe and effective coronavirus disease 2019 (COVID-19) vaccines in early 2020, stringent mitigation policies (e.g., stay-at-home orders, business closures) were implemented in the United States and globally to contain severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the virus that causes COVID-19. Among the consequences of these measures were enhanced opportunities for the self-selection of sleep habits, resulting from work-at-home directives, reduced travel and commutes, school closures, and stay-at-home orders. Recognizing this opportunity, and the value of sleep health during an interval of profound disruption, the National Sleep Foundation published a Position Statement urging the public to follow healthy sleep habits and maintain regular sleep-wake schedules during the pandemic.¹

Survey data^{2–6} and longitudinal wearable or mobile application data^{7–12} have been used to report increased sleep duration and delayed sleep timing during the pandemic in the U.S. and other countries. More than half of 6,882 participants from 59 countries who completed online surveys conducted during mid-April to early May 2020 reported that they had delayed their sleep timing, according to a study published by Yuksel *et al.* in *Sleep Health*.² Similarly, among approximately 1,000 survey respondents in Argentina, Leone *et al.* found that participants slept longer and later on weekdays during the initial phase of Argentinian COVID-19 lockdowns compared with before the pandemic, and exhibited lower levels of social jetlag.³ Using wearable data, a *Sleep Health* publication by Rezaei and Grandner revealed similar changes to the trajectories of sleep duration and timing among 163,524 active Fitbit users from six major U.S. cities.⁷ Additionally, analysis of objective smartphone application users from five major

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metropolitan areas across four countries by Robbins *et al.* found that estimated sleep duration increased across regions. The authors observed a 14-minute increase in estimated sleep duration in March 2020 as compared with March 2019, and a 22-minute increase when comparing April 2020 with April 2019.⁸

Simultaneously, population-level surveillance studies revealed considerably elevated levels of adverse mental health symptoms and substance use among U.S. adults, including three to four times the prevalence of anxiety and depression symptoms and twice the prevalence of suicidal ideation in the second quarter of 2020 as compared to that of 2019.^{13–15} Adverse mental health symptoms were disproportionately reported by younger adults, unpaid caregivers, essential workers, and persons with psychiatric or substance use conditions.

Associations between mental health and multiple dimensions of impaired or insufficient sleep have been well-established,^{16–18} underscoring the importance of examining different sleep characteristics to inform strategies and interventions to improve population-level sleep health and patient-level clinical care. For example, evidence from the 2018 Behavioral Risk Factor Surveillance System data including 273,695 U.S. adults aged 18–64 years found that participants with an average sleep duration ≤ 6 h nightly had 2.5 times (95% CI, 2.3–2.7) the odds of frequent mental distress compared with individuals who slept > 6 h nightly.¹⁹ Separately, adjusting for sleep duration, a study of 451,025 individuals using multiple Mendelian Randomization techniques found robust evidence supporting early diurnal preference as protective for depression and wellbeing.²⁰ Poor sleep quality, including sleep disorders and sleep disturbances, commonly co-occurs with mental health conditions.²¹ Finally, relationships

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between inconsistent sleep timing and adverse mental health are increasingly recognized, including with mood disorders, depression, wellbeing, and cognitive function.^{22–25}

Indeed, during the initial phase of the COVID-19 pandemic, links between poor sleep and adverse mental health symptoms have been reported based on survey data,^{2,4,26–28} with poor sleep associated with anxiety and depression symptoms.² However, most surveys lack both high-resolution (e.g., 30-second epochs) sleep-wake measurement and pre-pandemic data. Moreover, sleep health has several dimensions (duration, timing, quality, regularity) linked with mental health,¹⁸ and published studies during the pandemic have not included measures of variability in sleep timing, which has been associated with depressed mood^{22,24} and other adverse health outcomes.^{29,30}

To address these knowledge gaps, we examined objective sleep and mental health among U.S. users of a sleep wearable (WHOOP, Boston, Massachusetts) before and during the COVID-19 pandemic using comprehensive sets of mental health (symptoms of anxiety or depression, burnout, and substance use to cope with stress or emotions) and sleep variables (duration, sleep onset, sleep offset, consistency of sleep timing, and wakefulness during time in bed). We characterized multiple dimensions of sleep before and during the pandemic and explored associations between mental health and (1) sleep duration and (2) consistency of sleep timing. Regarding sleep patterns overall, given prior survey and wearable data on various samples during the pandemic, we hypothesized that during as compared with before the pandemic, participants would exhibit acutely increased sleep duration, delayed sleep timing, and increased sleep consistency, without reduced sleep efficiency. Regarding sleep and mental health, we

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hypothesized that reduced sleep duration and lesser sleep consistency would each be associated with anxiety or depression symptoms, new or increased substance use, and burnout symptoms.

Participants and Methods

Study Design and Participant Details

U.S. WHOOP users aged ≥ 18 years who had recorded seven consecutive nocturnal sleep episodes prior to a prospective invitation were invited to participate in Internet-based surveys during June 24-30, 2020. The week was selected to align with a similar largescale, national survey to a demographically representative sample of U.S. adults.¹⁵ Participants provided informed electronic consent prior to enrollment and agreed to allow their deidentified wearable data to be used for research purposes, as outlined in the WHOOP Terms and Conditions. Investigators received anonymized responses, and survey responses were linked with wearable data using unique identifiers. The Monash University Human Research Ethics Committee reviewed and approved the study.

WHOOP measures

For this analysis, objective WHOOP variables included sleep duration in hours over 24h intervals (calculated as the sum of nocturnal sleep episodes plus nap sleep episodes, detected automatically or manually³¹), sleep consistency (a proprietary metric of the WHOOP platform adapted from the Sleep Regularity Index (SRI)^{30,32} for daily use by accounting for recency in weighting of comparator sleep-wake episodes), sleep onset and offset, and wakefulness during time in bed (calculated as the difference between time in bed and time asleep, which is equivalent to sleep latency plus wake

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after sleep onset [WASO]). The WHOOP sleep consistency measure, like the SRI developed by Phillips *et al.*,³² calculates the percentage of concordance of individuals being in the same state (asleep versus awake) at different timepoints. Whereas the SRI compares two timepoints 24h apart, WHOOP sleep consistency compares 24h timepoints over a 4-day interval (e.g., timepoint 1 [T1], T1 + 24h, T1 + 48h, T1 + 72h), with comparisons of intervals further apart assigned progressively lower weights in calculating sleep consistency scores for a given timepoint.³³ Scores are converted to a 0-100% scale, with higher consistency reflecting lower sleep timing variability.

Naps were included within 24h sleep measures to avoid erroneously categorizing individuals with comparatively more nap sleep duration during versus before the pandemic as having slept less on the basis of relatively decreased nocturnal sleep duration, especially given evidence of increased frequency of napping during the pandemic.⁶

Three performance evaluations of objective measurement of sleep by WHOOP have been published.^{31,34,35} Among 6 young, healthy participants, compared with polysomnography, both autodetected and manually entered WHOOP sleep measurements demonstrated high levels of agreement for 2-stage (sleep-wake) categorization, at 86% and 90%, respectively.³¹ Among 12 young, healthy adults, compared with polysomnography, total sleep time recorded by WHOOP did not differ significantly (WHOOP mean, 358.7±98.5m, polysomnography mean, 350.4±105.2m, mean difference, 8.2±32.9m, $P=0.54$). For 2-stage categorization, WHOOP demonstrated high levels of agreement with polysomnography and sensitivity to sleep

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(89% and 95%, respectively), and moderate specificity for wake and Cohen's kappa for chance-adjusted agreement (51% and 0.49, respectively).³⁴ Finally, among 32 young, health participants, WHOOP demonstrated low bias (13.8m) and precision (17.8m) errors for measuring sleep duration compared with polysomnography, and recorded a moderate intraclass correlation coefficient (0.67 ± 0.15).³⁵

Survey instrument

The survey instrument was developed for The COVID-19 Outbreak Public Evaluation (COPE) Initiative (www.thecopeinitiative.org). The survey has been administered to adults in the U.S. and Australia to assess public attitudes, behaviors, and beliefs about the COVID-19 pandemic and its mitigation,¹⁴ and to assess mental and behavioral health.^{15,27}

Demographic variables included in this analysis were race and ethnicity, Census region, 2019 household income, education attainment, employment status, unpaid caregiver of adults, political ideology. Ages were categorized as 18-29, 30-44, 45-64, or 65-plus years. Within the survey, demographic variables included race and ethnicity (assessed separately and analyzed in the combined categories of non-Hispanic White, non-Hispanic Black, non-Hispanic, Asian, non-Hispanic other race or multiple races, any race, Hispanic or Latino, or unknown), U.S. Census region (Northeast, Midwest, South, or West), 2019 household income in USD (categorized <25,000, 25,000-49,999, 50,000-99,999, 100,000-199,999, $\geq 200,000$, or unknown), highest education attainment (categorized as high school diploma or less, college or some college, bachelor's degree, professional degree, or unknown), employment status (categorized as

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employed as an essential worker, employed as a nonessential worker, unemployed, retired, or student), unpaid caregiver of adults (categorized as yes, no, or unknown), and political ideology (categorized as very liberal, slightly liberal, neither liberal nor conservative, slightly conservative, very conservative, or either apolitical or unknown).

Additional measures included weekly days with ≥ 30 min of physical activity and with alcoholic beverage consumption, plus diurnal preference. Physical activity was assessed using a validated single-item physical activity measure.³⁶ Weekly alcoholic beverage consumption was analyzed by multiplying 7 by the answer to the following question: “How many alcoholic beverages did you consume on a typical day in the past week?” Diurnal preference was assessed using Item 19 of the Horne & Östberg Morningness-Eveningness questionnaire.³⁷

Mental health and substance use variables included anxiety and depression symptoms assessed using the 4-item Patient Health Questionnaire (PHQ-4),³⁸ burnout symptoms assessed using the single-item Mini-Z burnout measure,³⁹ and past-month new or increased substance use to cope with stress or emotions. For the PHQ-4, participants who scored ≥ 3 out of 6 on the Generalized Anxiety Disorder (GAD-2) and Patient Health Questionnaire (PHQ-2) subscales were considered symptomatic for anxiety or depression, respectively.^{38,40} For the Mini-Z, participants who scored ≥ 3 out of 5 were considered symptomatic for the emotional exhaustion dimension of burnout symptoms.³⁹ Substance use was defined as use of “alcohol, legal or illegal drugs, or prescription drugs that are taken in a way not recommended by your doctor.”

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Participants were asked, “Have you started or increased using substances to help you cope with stress or emotions during the COVID-19 pandemic?”

Statistical Analysis

Study intervals were set as pre-pandemic (January 1-March 12, 2020) and pandemic (March 13-June 30, 2020). For the sleep analysis, the pandemic interval was subdivided into the acute pandemic onset (March 13-April 12, 2020), and mid-pandemic (April 13-June 30, 2020) intervals. Participants with WHOOP data for $\geq 70\%$ of nocturnal sleep episodes during the pre-pandemic, acute pandemic onset, and mid-pandemic intervals were included in the primary analytic sample. Participants who completed the PHQ-4 were included in the mental health analytic subsample. Chi-square tests were used to assess for demographic differences between participants who did versus did not complete the PHQ-4, with statistical significance set at 2-sided $P \times 9 < 0.05$ to account for nine comparisons (Bonferroni adjustment).

Means and standard deviations were calculated for each WHOOP variable for participants, overall and during each of the survey intervals. Paired t-tests were used to test for differences in mean values for sleep measures between the pre-pandemic and acute pandemic onset intervals, and the pre-pandemic and mid-pandemic intervals. Statistical significance was set at 2-sided $P \times 10 < 0.05$ and 95% confidence intervals were estimated at the 99.5% confidence level to account for 10 comparisons (Bonferroni adjustment). Continuous sleep measures were used to maximize resolution of the data.

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Means and standard deviations were also calculated for each WHOOP variable for deciles of participants (491) with the highest-magnitude changes in sleep measures comparing the pre-pandemic and pandemic intervals (i.e., combined acute pandemic onset and mid-pandemic intervals). Among each decile, paired t-tests were used to test for differences in mean values between these intervals. Statistical significance was set at 2-sided $P \times 10 < 0.05$ and 95% confidence intervals were estimated at the 99.5% confidence level to account for 10 comparisons (Bonferroni adjustment).

Finally, multivariable logistic regression models were used to estimate adjusted odds ratios (aORs) and 95% confidence intervals (CIs) for each of the assessed adverse mental health symptoms (anxiety or depression symptoms, new or onset substance use, burnout symptoms) based on pre-pandemic and mid-pandemic WHOOP measures for sleep duration and sleep consistency. The mid-pandemic interval was chosen rather than the acute pandemic onset interval both because it was a more stable interval (following acute pandemic-related disruptions) and because it captures sleep more temporally proximate to the measurement of mental health. Odds ratios for the sleep and mental health models were selected for public health interpretability.

Mean sleep duration during these intervals was categorized as <6h, 6-7h, or >7h, with >7h as the reference group reflecting optimal healthy sleep duration based on the Joint Consensus Statement of the American Academy of Sleep Medicine and Sleep Research Society,⁴¹ and based on a 13% higher all-cause mortality risk among individuals sleeping <6h as compared with those sleeping 7-9h.⁴² While a standard based on sleep consistency has not yet been established, more consistent sleep timing

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is generally associated with better health outcomes.^{22–24} Given the distribution of sleep consistency scores in the mental health sample (percentile: 25th=71.5; 50th=76.3; 75th=80.5), mean sleep consistency was categorized as <70, 70–80, or >80 out of 100, with >80 as the reference group reflecting optimal sleep consistency.

As there were two intervals for each variable, there were 9 categories per variable (e.g., sleep duration <6h during both intervals, sleep duration <6 hours during the pre-pandemic interval, 6–7h during the mid-pandemic interval, etc.). For these models, the reference groups were having recorded the longest mean duration (i.e., >7h) and highest sleep consistency (i.e., >80) during both intervals. Assessment of wakefulness during time in bed, sleep onset, and sleep offset for associations with adverse mental health symptoms was outside the scope of this paper and therefore not included in multivariable analyses.

Standard demographic covariates included sex, age, race and ethnicity, education attainment, and employment status. Additional covariates included Census region to adjust for potential regional confounding related to COVID-19 prevalence and associated government-imposed movement restrictions, as well as characteristics associated with mental health disparities—unpaid caregiver status,^{15,27} diurnal preference⁴³, alcohol consumption, and physical activity. Variables were identified *a priori* based on biologic plausibility and relevance to the study hypotheses. Statistical significance was set at 2-sided $P < 0.05$ and 95% confidence intervals were estimated at the 97.5% confidence level to account for two comparisons (Bonferroni adjustment).

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All calculations were performed in Python version 3.7.8 (Python Software Foundation) and R version 4.0.2 (The R Project for Statistical Computing) using the R survey package version 3.29. Detailed methods are in the Supplement.

Results

Sample Characteristics

During June 24-30, 2020, 20,717 of 139,237 eligible invited U.S. WHOOP users aged 18 years or older completed Internet-based surveys (response rate, 14.9%). Overall, 4912 (23.7%) participants recorded $\geq 70\%$ nocturnal sleep episodes throughout all three study intervals (pre-pandemic, acute pandemic onset, mid-pandemic) and were included in the primary analytic sample. Of these, 3845 (78.3%) completed the PHQ-4 to screen for symptoms of anxiety and depression and were included in the mental health subsample. The sample comprised 3471 (70.7%) male and 3802 (77.2%) non-Hispanic White (White) adults. Most participants were highly educated (4105 [83.6%] college-educated), employed (4417 [89.9%]), and reported high household income (e.g., \geq USD\$100,000, 3126 [65.5%]). Mean age was 39.7 ± 11.24 years. See eFigure for the survey flow and Table 1 for detailed participant characteristics.

Sleep Before and During the Pandemic

Overall, compared to the 6.95 ± 0.687 h or 416.94 ± 41.220 m mean sleep duration in the pre-pandemic interval, mean sleep duration was 0.25h (95% CI, 0.237-0.270, $P < 0.0001$) or 15.20m (95% CI, 14.197-16.212) longer in the acute pandemic interval, and 0.09h (95% CI, 0.076-0.107, $P < 0.0001$) or 5.48m (95% CI, 4.539-6.421) longer in the mid-pandemic interval (Fig. 1A, eTable 1). In the overall sample, mean sleep duration remained significantly longer on weekend nights compared with weeknights

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(except for holidays), though the magnitude of difference dampened with time (Fig. 1A).

Sleep consistency (0-100), which was generally lower on weekend nights compared to weeknights, increased during both COVID intervals compared to the pre-pandemic interval, by 3.51 points (95% CI, 3.295-3.728 $P<0.0001$) in the acute pandemic interval, and by 4.06 points (95% CI, 3.856-4.267, $P<0.0001$) in the mid-pandemic interval (Fig.

1B, eTable 1). Wakefulness during time in bed increased by 0.05h (95% CI, 0.031-

0.074, $P<0.0001$) or 3.16m (95% CI, 0.031-4.435) in the acute pandemic interval

compared to the pre-pandemic interval but did not between the mid-pandemic and pre-pandemic intervals (difference, 0.01h, 95% CI, -0.020 to 0.0393, $P>0.99$ or 0.57m, 95% CI, -1.221 to 2.360) (Fig. 1C, eTable 1). Finally, sleep timing abruptly shifted to a later

time (i.e., delayed) immediately following the declaration of the pandemic by the World Health Organization on March 12, 2020, which preceded subsequent government-imposed movement restrictions in many U.S. states.⁴⁴ Over the four weeks, mean sleep

onset was 18.70m later (95% CI, 17.378-20.045, $P<0.0001$) and sleep offset was

36.60m later (95% CI, 35.111-38.106, $P<0.0001$) compared to the pre-pandemic

interval (Fig. 1D, eTable 1). The delay in sleep onset was sustained throughout the mid-pandemic interval (17.87m [95% CI, 16.470-19.289, $P<0.0001$]), while the delay in sleep

offset attenuated to 25.17m by that time (95% CI, 23.629-26.714, $P<0.0001$).

Participants with High-Magnitude Changes to Sleep

While in the overall sample we observed longer sleep duration, increased consistency of sleep timing, relatively stable wakefulness during time in bed, and delayed timing during the COVID-19 pandemic intervals, a subset of participants experienced marked changes in the opposite directions (Fig. 2). We therefore examined

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deciles of participants with the highest-magnitude changes in sleep variables. The deciles with the highest-magnitude changes in sleep duration were lengthened and shortened by 0.77h (95% CI, 0.742-0.794, $P<0.0001$) or 46.10m (95% CI, 44.548-47.669) and 0.50h (95% CI, 0.522-0.470, $P<0.0001$) or 29.77m (95% CI, 31.349-28.200), respectively, while the deciles with the highest-magnitude changes in sleep consistency were increased and decreased by 12.85 points (95% CI, 12.480-13.214, $P<0.0001$) and 4.41 points (95% CI, 4.720-4.099, $P<0.0001$), respectively (eTable 2). Regarding sleep timing, the deciles with the largest delays in sleep onset and offset shifted by 1.35h (22:57 to 00:18, 95% CI, 1.288-1.414, $P<0.0001$) or 81.07m (95% CI, 77.284-84.861) and 1.65h, (06:40 to 08:19, 95% CI, 1.591-1.714, $P<0.0001$) or 99.13m (95% CI, 95.456-102.811) respectively. The deciles with the largest advances in sleep onset and offset shifted by 0.56h (07:12 to 06:43, 95% CI, 0.516-0.606, $P<0.0001$) or 33.67m (95% CI, 30.942-36.385) and 0.48h (23:29 to 22:55, 95% CI, 0.434-0.523, $P<0.0001$) or 28.70m (95% CI, 26.036-31.358), respectively.

Mental and Behavioral Health

Of 3845 participants who completed the PHQ-4, 755 (19.6%) screened positive for anxiety or depression symptoms, 1208 (32.4%) screened positive for burnout symptoms, and 856 (22.4%) reported new or increased substance use to cope with stress or emotions (Table 1). Multivariable analysis including demographic variables, sleep, physical activity, and alcohol use revealed that sleep duration and consistency were associated with mental health (Table 2).

Compared with participants who slept >7h in the pre-pandemic and pandemic (i.e.,) intervals, participants who slept <6h in both intervals had higher odds of anxiety or

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depression symptoms (aOR, 1.75 [95% CI, 1.14-2.69] $P=0.007$) and burnout symptoms (aOR, 1.57 [95% CI, 1.07-2.29] $P=0.016$), as did those who slept 6-7h and those who experienced a decrease in sleep duration to <6h during the pandemic from 6-7h in the pre-pandemic interval (e.g., burnout symptoms, aOR, 2.22 [95% CI, 1.32-3.71] $P=0.001$).

Compared with participants with sleep consistency >80 in both intervals, participants with sleep consistency <70 in both intervals had higher odds of all assessed adverse mental and behavioral health symptoms (e.g., new or increased substance use, aOR, 2.17 [95% CI, 1.48-3.19] $P<0.0001$). Odds of new or increased substance use were also higher among participants with sleep consistency of 70-80 during both intervals (aOR, 1.46 [95% CI, 1.06-2.01] $P=0.016$), and odds of anxiety or depression symptoms were higher among participants whose sleep consistency decreased from 70-80 in the pre-pandemic interval to <70 in the pandemic interval (aOR, 2.07 [95% CI, 1.17-3.67] $P=0.0009$). Odds of adverse mental or behavioral health symptoms were not higher for participants with decreases in sleep duration or sleep consistency who had optimal duration (>7h) or consistency (>80) in the pre-pandemic interval.

Discussion

Among nearly 5,000 active users of an objective sleep wearable with data preceding the COVID-19 pandemic, we found acutely increased sleep duration and delayed sleep timing in the first month during which stringent mitigation policies were implemented widely across the U.S., consistent with national and global literature.²⁻¹² Using a novel metric to quantify the consistency of sleep timing adapted from the SRI,^{30,32} we also found abrupt and sustained increases in sleep consistency during the pandemic. Across

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the sample, the magnitude of the increase in mean sleep duration decreased gradually in the subsequent two months, as mean sleep offset returned to near pre-pandemic times, while delayed sleep onset persisted.

Adverse mental and behavioral health symptoms, including anxiety or depression symptoms, new or increased substance use to cope with stress or emotions, and burnout symptoms were associated with pre-pandemic sleep deficiency and inconsistent sleep, but not acute decreases in sleep duration or sleep consistency experienced during the pandemic. Recent past sleep-wake behavior was therefore associated with comparatively better mental health in response to profound lifestyle changes, such as the stringent social and behavioral interventions (e.g., stay-at-home orders, work-from-home directives) implemented during the COVID-19 pandemic. Alternatively, given bidirectional relationships between sleep and mental health,¹⁶ persistently unhealthy sleep patterns in some individuals might have been associated with existing mental health conditions. Independent of the directionality, these findings provide further evidence of the important role of sleep during the pandemic as outlined in the National Sleep Foundation Position Statement,¹ and support continued investigation of behavioral interventions to improve sleep duration and the consistency of sleep timing as modifiable risk factors⁵ to enhance mental health.

With the prevalence of adverse mental and behavioral health symptoms among U.S. adults having increased several-fold,^{13–15}, modifiable mental health risk factors are of critical importance. Insufficient sleep duration and inconsistent sleep timing are highly prevalent in modern society.⁴⁵ Alongside many undesirable changes during the COVID-19 pandemic has been a unique opportunity for some to improve sleep behaviors.^{2–12}

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Our unique dataset linking mental health and objective, high-resolution pre-pandemic sleep-wake data enhances our understanding of relationships between sleep and mental health.^{41,46} Importantly, there is evidence supporting the efficacy of cognitive and behavioral interventions to improve sleep in adults without sleep disorders,⁴⁷ providing a precedent for effective measures, including for improvement of sleep to enhance mental health.⁴⁸ Furthermore, improving sleep may have benefits for other elements of health, including general health, cardiovascular and immune function, and metabolic performance.⁴⁶

Analysis of participants with high-magnitude changes to sleep measures revealed disparate changes to sleep-wake behavior during the pandemic, which could be explored through trajectory analyses in future work.

Strengths and Limitations

Strengths of this study include the use of objective sleep measures, inclusion of pre-pandemic comparator sleep data, large sample size, psychometrically validated mental health screening instruments, and inclusion of demographic and lifestyle-related variables (i.e., physical activity, alcohol consumption) in multivariable models assessing associations with a comprehensive set of sleep variables (i.e., duration, timing, consistency).^{18,49}

Limitations of this study include the 14.9% response rate, a lack of pre-pandemic comparator mental health data, non-random recruitment methods, uncertainties about

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objective measurement of sleep in this population and setting, and potential seasonal influences on sleep and mood.

Regarding the relatively low response rate, nonresponse could give rise to sampling bias if nonresponse were unequal among participants with respect to sleep and mental health measures.

Regarding reliance upon cross-sectional mental health measures, doing so precludes a causal interpretation of mental health findings, especially given evidence of bidirectional relationships with sleep.^{16,50} Additional studies are warranted to elucidate the directionality of these relationships. Moreover, some stressors might not have been captured, including employment disruptions, health declines, and SARS-CoV-2 infection or COVID-19 illness.

Regarding non-random recruitment, most sample participants were male, highly educated, employed, and reported higher-than-national-average household income. Given that income was highly predictive of changes in mobility during the pandemic, with wealthy areas exhibiting larger mobility reductions,⁵¹ this sample may overrepresent effects on sleep of stay-at-home orders. Moreover, there is evidence that social determinants of mental and sleep health include more assets such as income and employment requirements (e.g., remote-work options, essential-worker responsibilities).^{52,53} Sample-level prevalence estimates for anxiety or depression symptoms were considerably lower in this sample (19.6%) than in a largescale, demographically representative sample evaluated using the same screening instrument during the same time interval (30.9%),¹⁵ which might reflect demographic and

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socioeconomic differences in sample composition. However, multivariable analysis odds ratio estimates (not shown) suggest that most of the relative demographic differences in adverse mental health symptoms (e.g., by gender, age, and diurnal preference) were consistent with those of the general population.^{13–15,26}

Regarding objective sleep-wake measurement, although WHOOP has demonstrated high levels of agreement for sleep-wake with gold-standard polysomnography among young, healthy adults in laboratory assessments,^{31,34,35} its performance in free-living conditions within a more heterogeneous sample is less known, and participants did not complete daily sleep diaries to support sleep onset and offset measurements. Furthermore, the performance of WHOOP relative to polysomnography on some variables (sleep onset, sleep offset, wakefulness during time in bed) has not been reported. Given that WHOOP is a subscription tracker of sleep and fitness, participants may have been more knowledgeable about and motivated to pursue optimal sleep health and fitness than the U.S. adult population, which could limit the generalizability of findings.

Finally, it is possible that sleep and mental health responses to the onset of a pandemic may vary with season and be influenced by daylight savings time changes; however, 2019 and 2020 data on time in bed and sleep timing from both Ong *et al.* based on data from 20 countries (with variable daylight savings time presence and timing)¹¹ and Capodilupo and Miller in the U.S.¹² indicate that the magnitude of changes to sleep-wake behavior observed in the months after the COVID-19 pandemic were not observed the year before. For example, in 2019, time in bed was slightly shorter during

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March 10 through May 15 compared to January 1 through March 9, 2019 (by 0.05 ± 0.003 h), and sleep offset time did not differ significantly between the intervals.

Comparing the same intervals in 2020, time in bed was considerably longer during March 10 through May 15 (by 0.24 ± 0.003 h), and sleep offset was significantly later (by 29 ± 1 m).

Conclusions

As policymakers grapple with decisions about stringent mitigation measures during future waves of SARS-CoV-2 or other pathogens, community institutions, healthcare providers, and public health agencies should consider the potential roles of sleep and circadian rhythms in mitigating potential mental health consequences. Findings from this study of U.S. adult users of a wearable device support sleep duration and consistency as potential modifiable risk factors for adverse mental health in response to stressful life events. Future research should (1) explore the directionality and impact of prolonged physiological and behavioral changes observed following SARS-CoV-2 infection on mental health (2) determine predictors of counter-sample sleep patterns (e.g., reduced sleep duration, less consistent sleep timing) and (3) evaluate public health programs that include sleep and circadian health as primary prevention strategies for adverse mental health outcomes.

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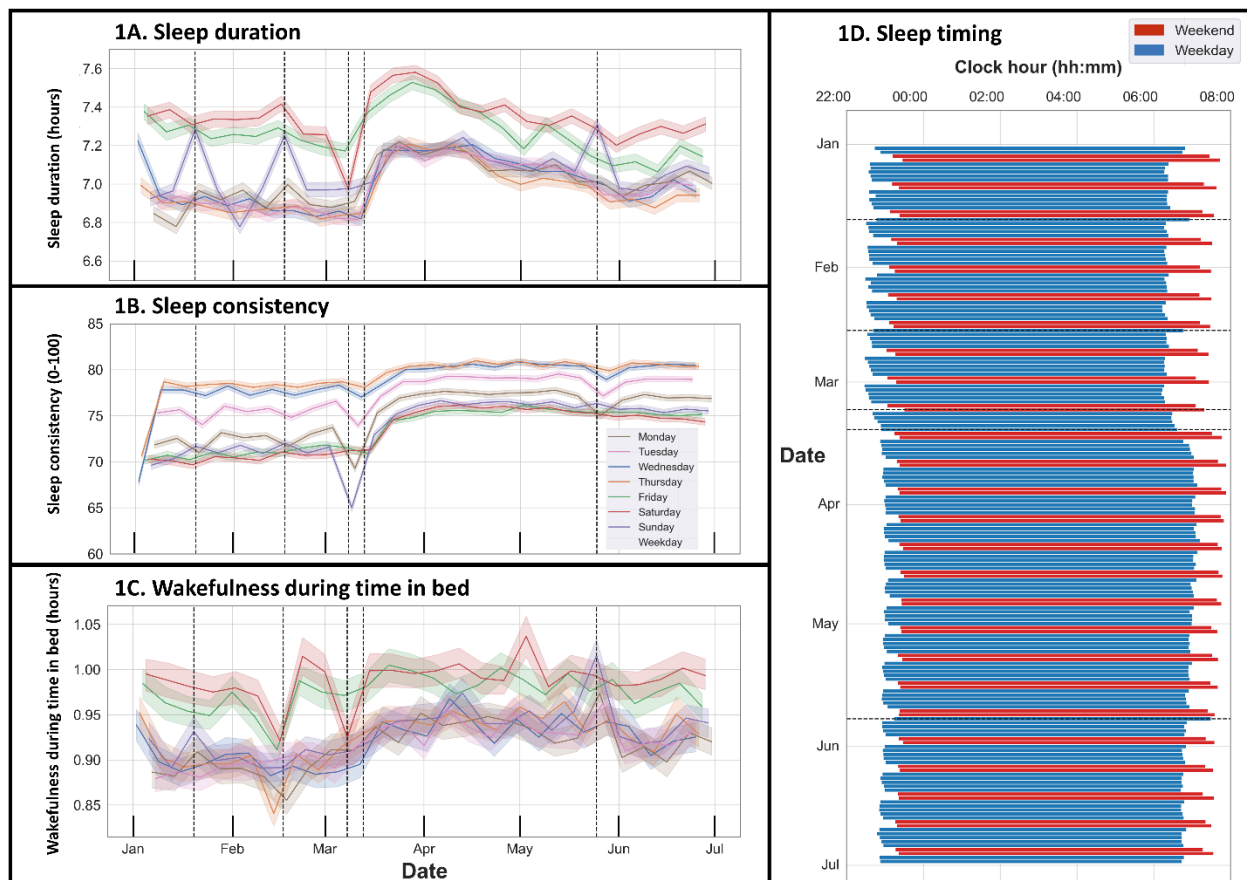
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Fig. 1. Sleep duration, consistency, wakefulness during time in bed, and timing, January 1, 2020—June 30, 2020.



The vertical (A-C) or horizontal (D) dashed lines represent major public holidays (L to R) Martin Luther King Jr. Day, President's Day, Daylight Saving Time (March), the declaration of the COVID-19 as a national emergency in the United States, and Memorial Day.

Figure 18 (11.1) Sleep duration, consistency, wakefulness during time in bed, and timing, January 1, 2020—June 30, 2020.

Chapter Eleven Original Investigation: Czeisler *et al.* Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic.

Fig. 2. Heterogeneity in changes to sleep duration, consistency, wakefulness during time in bed, sleep onset, and sleep offset.

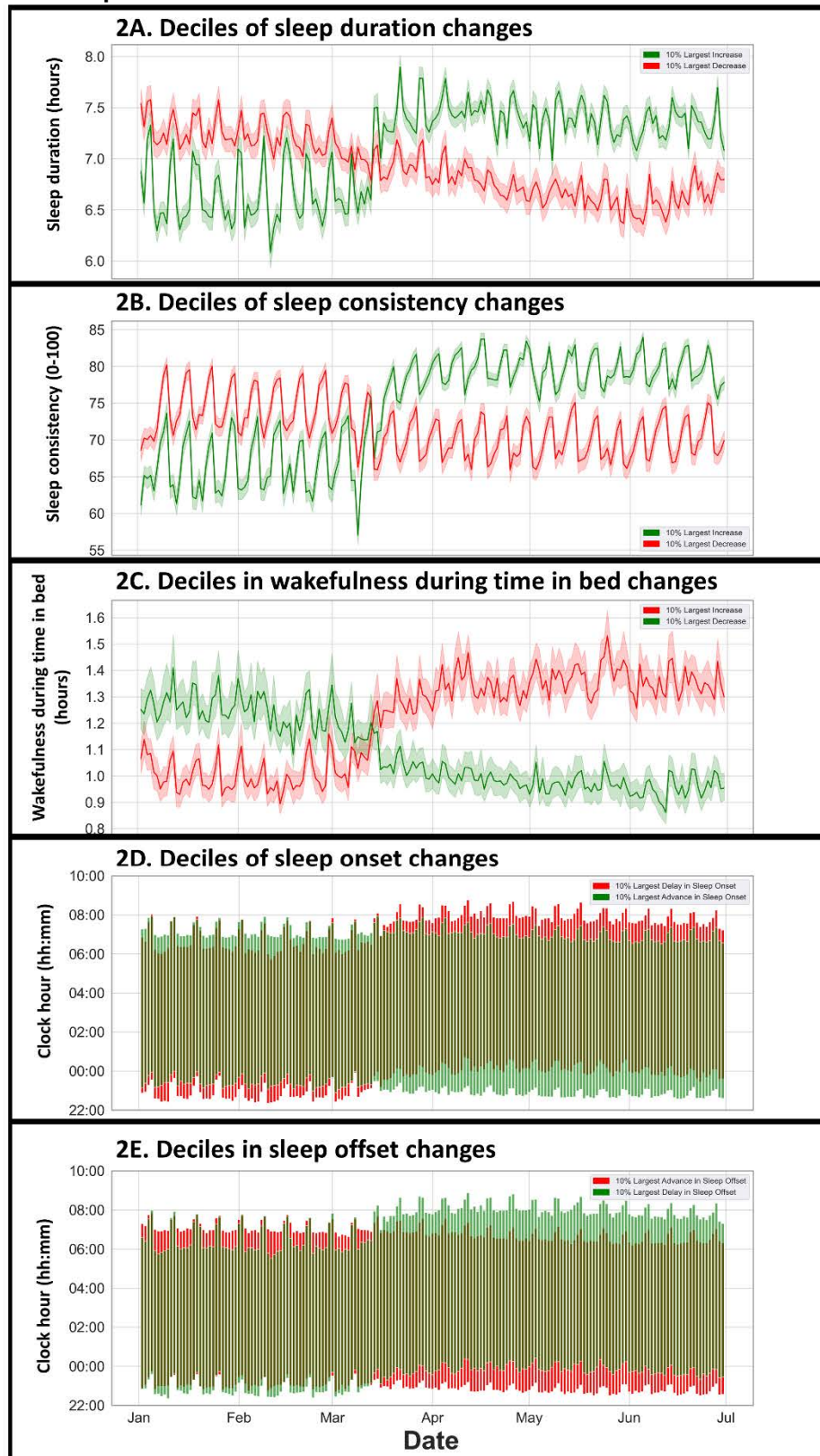


Figure 19 (11.2) Heterogeneity in changes to sleep duration, consistency, wakefulness during time in bed, sleep onset, and sleep offset.

Table 25 (11.1). Participant characteristics

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Table 1. Participant characteristics

	All participants		Did complete the PHQ-4		Did not complete PHQ-4		Chi-square test for difference between samples
	unweighted n (%)		unweighted n (%)		unweighted n (%)		P
Total Participants	4912	(100)	3845	(78.0)	1067	(22.0)	-
Gender							
Female	1441	(29.3)	1187	(30.9)	254	(23.8)	0.0001
Male	3471	(70.7)	2658	(69.1)	813	(76.2)	
Age group in years							
18-29	981	(20.0)	692	(18.0)	289	(27.1)	<0.0001
30-44	2357	(48.0)	1827	(47.5)	530	(49.7)	
45-64	1460	(29.7)	1221	(31.8)	239	(22.4)	
≥65	113	(2.3)	105	(2.7)	8	(0.7)	
Race and ethnicity							
White, non-Hispanic	3802	(77.4)	3062	(79.6)	740	(69.4)	<0.0001
Black, non-Hispanic	93	(1.9)	72	(1.9)	21	(2.0)	
Asian, non-Hispanic	174	(3.5)	122	(3.2)	52	(4.9)	
Other race or races, non-Hispanic	147	(3.0)	115	(3.0)	32	(3.0)	
Hispanic or Latino, any race or races	375	(7.6)	271	(7.0)	104	(9.7)	
Unknown	321	(6.5)	203	(5.3)	118	(11.1)	
US Census region							
Northeast	1211	(24.7)	942	(24.5)	269	(25.2)	>0.99
Midwest	780	(15.9)	601	(15.6)	179	(16.8)	
South	1588	(32.3)	1244	(32.4)	344	(32.2)	
West	1333	(27.1)	1058	(27.5)	275	(25.8)	
2019 household income (USD)							
<25,000	114	(2.3)	79	(2.1)	35	(3.3)	<0.0001
25,000-49,999	286	(5.8)	203	(5.3)	83	(7.8)	
50,000-99,999	876	(17.8)	681	(17.7)	195	(18.3)	
100,000-199,999	1503	(30.6)	1211	(31.5)	292	(27.4)	
≥200,000	1713	(34.9)	1374	(35.7)	339	(31.8)	
Unknown	420	(8.6)	297	(7.7)	123	(11.5)	
Education							
High school or less	118	(2.4)	82	(2.1)	36	(3.4)	0.029
Some college	663	(13.5)	498	(13.0)	165	(15.5)	
Bachelor's degree	2353	(47.9)	1836	(47.8)	517	(48.5)	
Professional degree	1752	(35.7)	1411	(36.7)	341	(32.0)	
Unknown	26	(0.5)	18	(0.5)	8	(0.7)	
Employment status							
Employed nonessential	2441	(49.7)	1910	(49.7)	531	(49.8)	.0004
Employed essential	1976	(40.2)	1551	(40.3)	425	(39.8)	
Retired	151	(3.1)	135	(3.5)	16	(1.5)	
Unemployed	203	(4.1)	157	(4.1)	46	(4.3)	
Student	141	(2.9)	92	(2.4)	49	(4.6)	
Unpaid caregiver of adults							
Yes	417	(8.5)	414	(10.8)	3	(0.3)	>0.99
No	3061	(62.3)	3046	(79.2)	15	(1.4)	
Missing or unknown	1434	(29.2)	385	(10.0)	1049	(98.3)	

Table 25 (11.1) (continued). Participant characteristics

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Political ideology							
Very liberal	669	(13.6)	555	(14.4)	114	(10.7)	<0.0001
Slightly liberal	1121	(22.8)	905	(23.5)	216	(20.2)	
Neither liberal nor conservative	1223	(24.9)	941	(24.5)	282	(26.4)	
Slightly conservative	999	(20.3)	803	(20.9)	196	(18.4)	
Very conservative	348	(7.1)	263	(6.8)	85	(8.0)	
Unknown or apolitical	552	(11.2)	378	(9.8)	174	(16.3)	

Note. As caregiving status was assessed in the third phase of the survey, along with the PHQ-4, most participants who did not complete the PHQ-4 did not complete the question regarding caregiving status. The “missing or unknown” group was therefore excluded from the prevalence comparison between groups.

Table 26 (11.2). Adjusted odds ratios (aORs) for adverse mental health symptoms by pre-pandemic and pandemic sleep characteristics.

Chapter Eleven Original Investigation: Czeisler *et al.* Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic.

Table 2. Adjusted odds ratios (aORs) for adverse mental health symptoms by pre-pandemic and pandemic sleep characteristics.

	Anxiety or depression symptoms				New or increased substance use				Burnout symptoms			
	Total N	N (%) positive screen	aOR (95% CI)	P	Total N	N (%) positive screen	aOR (95% CI)	P	Total N	N (%) positive screen	aOR (95% CI)	P
Sleep duration—mean over pre-pandemic and pandemic intervals												
Both >7 h (reference group)	1464	323 (22.1)	1.00 (Reference)		1720	376 (21.9)	1.00 (Reference)		1677	502 (29.9)	1.00 (Reference)	
Both <6 h	180	44 (24.4)	1.75 (1.14, 2.69)	0.007	179	37 (20.7)	1.11 (0.69, 1.78)	>0.99	177	64 (36.2)	1.57 (1.07, 2.29)	0.016
<6 h to 6-7 h	122	23 (18.9)	1.12 (0.64, 1.98)	>0.99	121	29 (24.0)	1.21 (0.71, 2.04)	0.845	120	40 (33.3)	1.22 (0.77, 1.93)	0.663
<6 h to >7 h	4	0 (0.0)	NO ESTIMATE		4	1 (25.0)	NO ESTIMATE		4	1 (25.0)	NO ESTIMATE	
Both 6-7 h	1058	212 (20.0)	1.30 (1.03, 1.65)	0.025	1052	249 (23.7)	1.21 (0.96, 1.52)	0.126	1033	358 (34.7)	1.39 (1.13, 1.70)	0.001
6-7 h to <6 h	90	24 (26.7)	1.96 (1.09, 3.54)	0.021	90	21 (23.3)	1.19 (0.65, 2.17)	>0.99	90	40 (44.4)	2.22 (1.32, 3.71)	0.001
6-7 h to >7 h	435	92 (21.1)	1.23 (0.90, 1.67)	0.265	435	90 (20.7)	0.96 (0.70, 1.31)	>0.99	421	143 (34.0)	1.22 (0.93, 1.6)	0.191
>7 h to <6 h	6	1 (16.7)	NO ESTIMATE	>0.99	6	3 (50.0)	NO ESTIMATE		6	6 (100)	NO ESTIMATE	
>7 h to 6-7 h	216	36 (16.7)	0.94 (0.60, 1.46)	>0.99	213	50 (23.5)	1.08 (0.72, 1.64)	>0.99	206	54 (26.2)	0.86 (0.59, 1.26)	0.750
Sleep consistency—mean over pre-pandemic and pandemic intervals												
Both >80 out of 100 (reference group)	595	87 (14.6)	1.00 (Reference)		588	92 (15.6)	1.00 (Reference)		570	153 (26.8)	1.00 (Reference)	
Both <70	427	110 (25.8)	1.74 (1.19, 2.55)	0.002	421	131 (31.1)	2.17 (1.48, 3.19)	<0.001	415	180 (43.4)	1.77 (1.28, 2.45)	<0.001
<70 to 70-80	540	117 (21.7)	1.38 (0.95, 1.99)	0.101	537	128 (23.8)	1.38 (0.95, 1.99)	0.103	525	186 (35.4)	1.27 (0.94, 1.73)	0.158
<70 to >80	84	17 (20.2)	1.13 (0.57, 2.25)	>0.99	84	20 (23.8)	1.35 (0.69, 2.65)	0.643	79	22 (27.8)	0.88 (0.48, 1.62)	>0.99
Both 70-80	1106	223 (20.2)	1.34 (0.97, 1.85)	0.088	1102	259 (23.5)	1.46 (1.06, 2.01)	0.016	1080	363 (33.6)	1.22 (0.93, 1.60)	0.191
70-80 to <70	104	31 (29.8)	2.07 (1.17, 3.67)	0.009	104	29 (27.9)	1.66 (0.91, 3.03)	0.119	103	34 (33.0)	1.08 (0.63, 1.84)	>0.99
70-80 to >80	909	154 (16.9)	1.11 (0.79, 1.56)	0.954	906	177 (19.5)	1.17 (0.84, 1.63)	0.598	888	246 (27.7)	0.99 (0.75, 1.31)	>0.99
>80 to <70	2	1 (50.0)	NO ESTIMATE		2	1 (50.0)	NO ESTIMATE		2	0 (0.0)	NO ESTIMATE	
>80 to 70-80	78	15 (19.2)	1.35 (0.66, 2.75)	0.700	76	19 (25.0)	1.62 (0.80, 3.30)	0.253	72	24 (33.3)	1.31 (0.71, 2.42)	0.649

Note. Scores ≥ 3 out of 6 on either the PHQ-2 or GAD-2 subscales of the PHQ-4 were considered positive screens for anxiety or depression symptoms. Affirmative answers to a question about having past-month new or increased substance use to cope with stress or emotions was considered positive screens for new or increased substance use. Scores ≥ 3 out of 5 on the single-item Mini-Z burnout measure were considered positive screens for burnout symptoms. Multivariable logistic regression models used to estimate odds ratios included the following covariates: sex, age, race and ethnicity, education attainment, employment status, Census region, unpaid caregiver status, diurnal preference, alcohol consumption, and physical activity. Estimates are not provided for outcomes with Total N < 10 respondents. Bolded values are significant at 2-

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sided $P \times 2 < 0.05$ and 95% confidence intervals were estimated at the 97.5% confidence level to account for two comparisons (Bonferroni adjustment).

SUMMARY OF FINDINGS

During the acute pandemic-onset interval (13 March to 12 April 2020) as compared to the pre-pandemic interval (1 January to 12 March 2020), the 4,912 US adult WHOOP users who were COVID-19 Resilience Project participants exhibited significantly increased mean sleep duration (0.25 hours), later sleep onset (18 minutes) and offset (36 minutes), and increased consistency of sleep timing (3.5 points out of 100). During the subsequent months (13 April to 30 June 2020), some sleep-wake behaviours began to return closer to pre-pandemic levels, as the mean increase in sleep duration decreased to 0.09 hours, and the delay in sleep offset lessened to 25 minutes. The delay in sleep onset and increase in sleep consistency, on the other hand, remained similarly changed through the study interval (17 minutes and 4.1 points, respectively). These findings were largely consistent in terms of the magnitude and direction of changes reported based on similar largescale assessments of sleep-wake patterns using objective measures during the pandemic (**Ong et al., 2021; Rezaei & Grandner, 2021; Robbins, Affouf, et al., 2021**).

Multivariable analysis revealed that, adjusting for demographic characteristics and lifestyle variables (physical activity and alcohol use), participants who persistently recorded short sleep duration or low sleep consistency had higher odds of adverse mental health symptoms during June 2020 compared with participants who persistently recorded long sleep duration or high sleep consistency. Decreases in sleep duration and sleep consistency during the pandemic (from intermediate to short or low) were also associated with adverse mental health symptoms. Sleep duration and consistency may therefore represent important predictors of risk of adverse mental health symptoms during intervals of life disruption, extending prior literature exploring these relationships during pre-pandemic times (**Bei et al., 2017; Bernert et al., 2017; Lyall et al., 2018; Sun et al., 2018; Szklo-Coxe et al., 2010**).

A key question regarding this Original Investigation is the extent to which findings from this non-representative findings of US adult WHOOP strap users would generalise to more diverse and heterogeneous populations. As described in the Original Investigation, approximately 21 thousand of 140 thousand eligible invited active WHOOP users completed surveys, and just under 5 thousand and 4 thousand were included in the sleep and combined sleep and mental health analytic samples, respectively. Generalisability might suffer from systematic biases associated with non-random factors associated with participation and representation in this sample, which differed from the US demographically (e.g., 71% male, 77% White, higher than national average education attainment, household income, employment), demonstrated interest in health and health education by investing in WHOOP straps (with USD\$30 monthly subscriptions), and, within the WHOOP userbase, met inclusion criteria of consistent use of WHOOP straps. Further investigation of relationships between the consistency of sleep timing and mental health in more diverse populations are therefore needed to contextualise these findings.

Nonetheless, the finding of robust associations between low sleep consistency and adverse mental health symptoms are particularly noteworthy given emerging evidence of relationships between the consistency of sleep timing and mental health (**Fang et al., 2021; Lyall et al., 2018**), self-reported health and wellness (**Fischer et al., 2020**) and performance (**Phillips et al., 2017**). Together, these studies support sleep consistency, along with sleep duration, could be further explored as potentially modifiable risk factors for adverse mental health.

CHAPTER 12: Mental Health, Substance Use, and Suicidal Ideation Among Unpaid Caregivers in the United States During the COVID-19 Pandemic: Relationships to Age, Race/Ethnicity, Employment, and Caregiver Intensity

PREFACE TO CHAPTER 12

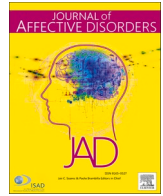
To address mental health during and beyond the COVID-19 pandemic, in addition to population-level resources and support, disproportionately affected populations merit further attention. Within these populations, identifying subpopulations at elevated risk and characteristics associated with adverse mental health symptoms can help to inform the optimal development of policies and distribution of resources and support services. Some of the largest mental health disparities were observed among adults who were providing unpaid care to adults (i.e., unpaid caregivers of adults) compared with adults who were not in this role ([Chapter Six](#)). We found that approximately two-thirds of surveyed US unpaid caregivers of adults experienced adverse mental health symptoms or substance use in June 2020, compared with one-third of adults without caregiving responsibilities, and that unpaid caregivers had higher odds of incident adverse mental health symptoms, indicating that their mental health was disproportionately worsening during the pandemic (Czeisler, Lane, et al., 2020).

The Original Investigation in Chapter Twelve (Czeisler et al., 2021), which has been posted as a preprint on *medRxiv* and later published in the *Journal of Affective Disorders*, was prepared to further characterize adverse mental health symptoms among unpaid caregivers of adults, and to identify specific factors related to caregiving that were associated with adverse mental health symptoms and substance use. The manuscript contains findings from a secondary analysis of the dataset used to produce the paper presented in [Chapter Six](#). In addition to standard demographic variables, caregiving-related variables that influence the nature of the role or have established links with health

effects were included (**Committee on Family Caregiving for Older Adults et al., 2016; Schulz & Sherwood, 2008**) (duration in caregiving role, weekly hours providing care, relationship to the recipient of care, and caregiving intensity). The chapter concludes with a brief overview of findings from the Original Investigation.

CHAPTER TWELVE: Mental Health, Substance Use, and Suicidal Ideation Among Unpaid Caregivers in the United States During the COVID-19 Pandemic: Relationships to Age, Race/Ethnicity, Employment, and Caregiver Intensity

Czeisler MÉ, Drane A, Winnay SS, Capodilupo ER, Czeisler CA, Rajaratnam SM, Howard ME. Mental health, substance use, and suicidal ideation among unpaid caregivers of adults in the United States during the COVID-19 pandemic: Relationships to age, race/ethnicity, employment, and caregiver intensity. *J Affect Disord.* 2021 Dec 1;295:1259-1268. doi: 10.1016/j.jad.2021.08.130. Epub 2021 Sep 3. PMID: 34706440; PMCID: PMC8413485.



Research paper

Mental health, substance use, and suicidal ideation among unpaid caregivers of adults in the United States during the COVID-19 pandemic: Relationships to age, race/ethnicity, employment, and caregiver intensity

Mark É Czeisler^{a,b,c,*}, Alexandra Drane^d, Sarah S Winnay^d, Emily R Capodilupo^{d,e}, Charles A Czeisler^{a,f,g}, Shantha MW Rajaratnam^{a,b,f,g}, Mark E Howard^{a,b,h}

^a Turner Institute for Brain and Mental Health and School of Psychological Sciences, Monash University, Melbourne, Victoria, Australia

^b Institute for Breathing and Sleep, Austin Health, Melbourne, Victoria, Australia

^c Department of Psychiatry, Brigham and Women's Hospital, Boston, Massachusetts, United States

^d ARCHANGELS, Boston, Massachusetts, United States

^e Whoop Inc., Boston, Massachusetts, United States

^f Division of Sleep and Circadian Disorders Departments of Medicine and Neurology Brigham & Women's Hospital, Boston, Massachusetts, United States

^g Division of Sleep Medicine, Harvard Medical School, Boston, Massachusetts, United States

^h Division of Medicine, Dentistry and Health Sciences, University of Melbourne, Melbourne, Victoria, Australia

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ABSTRACT

Background: Unpaid caregivers of adults play critical roles in health care systems by providing care to older adults and those with chronic conditions. The COVID-19 pandemic has heightened caregiving needs, forcing some into caregiving roles and disrupting others. We sought to estimate the prevalence of and identify factors associated with adverse mental health symptoms, substance use, and suicidal ideation amongst unpaid caregivers of adults versus non-caregivers.

Methods: During June 24–30, 2020, surveys were administered to U.S. adults. Quota sampling and survey weighting were implemented to improve sample representativeness of age, gender, and race/ethnicity.

Results: Of 9,896 eligible invited adults, 5,412 (54.7%) completed surveys and 5,011 (92.6%) met screening criteria and were analyzed, including 1,362 (27.2%) caregivers. Caregivers had higher adverse mental health symptom prevalences than non-caregivers, including suicidal ideation (33.4% vs 3.7%, $p < 0.0001$). Symptoms were more common among caregivers who were young vs older adults (e.g., aged 18–24 vs ≥ 65 years, aPR 2.75, 95% CI 1.95–3.88, $p < 0.0001$) and with moderate and high vs low Caregiver Intensity Index scores (2.31, 1.65–3.23; 2.81, 2.00–3.94; both $p < 0.0001$).

Limitations: Self-report data may be subject to recall, response, and social desirability biases; unpaid caregivers were self-identified; child caregiving roles were not assessed; and internet-based survey samples might not fully represent the U.S. population.

Conclusions: Caregivers experienced disproportionately high levels of adverse mental health symptoms. Younger caregivers and those with higher caregiving intensity were disproportionately affected. Increased visibility of and access to mental health care resources are urgently needed to address mental health challenges of caregiving.

1. Introduction

The coronavirus disease 2019 (COVID-19) pandemic, caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has been associated with mental health challenges related to direct effects of SARS-CoV-2 infection (Boldrini et al., 2021; Taquet et al., 2021) and to

indirect effects of social and economic impacts of COVID-19 prevention measures, fears about COVID-19 (Ornell et al., 2020), and bereavement from morbidity and mortality caused by the disease (Simon et al., 2020). Early studies have documented elevated levels of adverse mental health symptoms in the United States (Czeisler et al., 2020a, 2021a; Ettman et al., 2020; Holman et al., 2020) and around the globe (Czeisler et al.,

* Corresponding author.

E-mail address: mark.czeisler@fulbrightmail.org (M.É. Czeisler).

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2021e; Pierce et al., 2020, 2021; Shi et al., 2020; Varma et al., 2021) compared with previous years. Young adults and unpaid caregivers of adults (caregivers) were among highly affected populations.

A pre-pandemic meta-analysis found that caregivers, who perform activities such as assisting others with activities of daily living and medical tasks, experienced higher levels of depression and perceived stress and lower levels of general well-being than did non-caregivers (Pinquart and Sörensen, 2003). Subsequent studies have characterized an association between subjective caregiver burden and depressive symptoms (Del-Pino-Casado et al., 2019), which in some cases limited provision of care (Fekete et al., 2017).

During June 2020, caregivers reported a significantly higher prevalence of adverse mental and behavioral health symptoms than did non-caregivers, including symptoms of an anxiety disorder, depressive disorder, or COVID-19-related trauma- and stressor-related disorders (TSRDs), having started or increased substance use to cope with the pandemic, and suicidal ideation (Czeisler et al., 2020a). A study of 1,459 pediatric and adult brain tumor patients and 530 caregivers in 33 countries found that caregivers were significantly more anxious than patients, and that 42.8% of caregivers felt that their caregiver burden has significantly increased during the pandemic (Voisin et al., 2020).

Caregivers represent a significant demographic in the US. In 2020, the pre-pandemic prevalence estimate of caregivers was 19.2% of adults aged ≥ 18 years, or approximately 47.9 million Americans (The National Alliance for Caregiving and Public Policy Institute, 2020). This estimate represented an increase in the caregiving population of more than eight million compared with 2015 (The National Alliance for Caregiving and Public Policy Institute, 2015). People may have taken up unplanned caregiving roles during the pandemic due to mobility restrictions related to community mitigation activities designed to reduce potential exposure to SARS-CoV-2 for older adults. Moreover, some caregivers who had been providing care before the pandemic may have faced barriers and disruptions to their routines and livelihood. Both scenarios would require caregivers to care for others during a time when their own lives may have been disrupted.

Addressing the needs of the disproportionately affected population of caregivers is critically important for the health and well-being of caregivers, and, in turn, that of the persons for whom they provide care. To effectively address these needs during the COVID-19 pandemic and afterwards, studies are needed to determine the prevalence and characteristics of caregivers, and to identify stressors that may be targets for support systems and prevention and intervention efforts. This study had three specific aims: (1) to estimate the prevalence of U.S. caregivers during the COVID-19 pandemic and compare the demographic characteristics of this population with non-caregivers, (2) to evaluate demographic characteristics associated with adverse mental and behavioral health symptoms separately among caregivers and non-caregivers, and (3) to analyze caregiving characteristics associated with adverse mental and behavioral health symptoms among caregivers.

2. Methods

2.1. Study design and participants

To assess mental and behavioral health among adults aged ≥ 18 years with residence in the U.S. who had provided unpaid care for adults during the COVID-19 pandemic, we conducted a cross-sectional analysis of an Internet-based survey study conducted during June 24–30, 2020 for The COVID-19 Outbreak Public Evaluation (COPE) Initiative (www.thecopeinitiative.org). Surveys were administered by Qualtrics, LLC (Provo, Utah, and Seattle, Washington, U.S.), a commercial survey company with a network of participant pools consisting of hundreds of suppliers. Further details on Qualtrics recruitment and methodology are provided in the Supplement (p 1).

Participants included both first-time respondents and respondents who had completed related surveys during April 2–8, May 5–12, 2020,

or both intervals. Demographic quota sampling was used to recruit respondents based on national adult population estimates for age, gender, race, and ethnicity based on the 2010 U.S. Census. Potential respondents likely to qualify based on demographic characteristics listed in their Qualtrics panelist profile were targeted during recruitment; demographic questions were then included in the survey to determine their eligibility. Potential respondents received invitations and could opt to participate by activating a survey link directing them to the participant information and consent page preceding the survey. Ineligible respondents who did not meet inclusion criteria (e.g., age < 18 years, not a U.S. resident) or exceeded set quotas (i.e., maximum demographic characteristic quota already met) were not empaneled in the survey.

2.2. Survey instrument

The survey instruments included individual questions, validated questionnaires, and COVID-19-specific questionnaires used to assess respondent attitudes, behaviors, and beliefs related to COVID-19 and its mitigation, along with mental and behavioral health consequences of the COVID-19 pandemic.

Demographic variables included gender, categorized age, combined race/ethnicity, disability status, marital status, household occupancy, 2019 household income, U.S. Census region, urban/rural classification using self-reported ZIP codes, employment status, and, among employed respondents, self-identified essential worker status and weekly paid work hours. Caregiving variables included the method by which caregivers provided care (in-person in-home only; in-person out-of-home only; virtually only; and both in-person and virtually), the person for whom they were providing care, weekly unpaid caregiving hours, caregiver experience in months, and caregiving intensity assessed using the 12- or 14-item ARCHANGELS Caregiver Intensity Index (CII; see Supplement (p 1) for additional details), which is composed of three subscales: Caregiver Load based on four items (situation stability, impact on expenses, family strife, and preparedness), Caregiver Impacts based on four items (emotional state, work, personal time, and stress), and Caregiver Buffers based on six items (support, insurance knowledge, self-efficacy, financial knowledge, sense of purpose, and employer support). Caregivers who were also employed completed all 14 items, while those who were not employed completed all items except for the work and employer support items. The sum of items in each subscale is normalized from 0–100, and the normalized sum of the three subscales is used to categorize total CII scores as Low (0–25), Moderate (26–55), or High (≥ 56).

Symptoms of anxiety or depression were assessed via the four-item Patient Health Questionnaire (PHQ-4), a clinically validated screening instrument (Löwe et al., 2010, 2004). Symptoms of COVID-19 TSRDs were assessed via the six-item Impact of Event Scale (IES-6) to screen for overlapping symptoms of posttraumatic stress disorder (PTSD), acute stress disorder (ASD), and adjustment disorders (ADs) (Hosey et al., 2019). Respondents also reported whether they had started or increased substance use, (e.g., alcohol, drugs) to cope with stress or emotions related to COVID-19, or if they had seriously considered trying to kill themselves (suicidal ideation) in the prior 30 days. See Supplement (pp 1–2) for additional details.

2.3. Quality screening

All surveys underwent Qualtrics, LLC standard data quality screening procedures, and a secondary cleaning conducted by the investigators; see Supplement (p 2). Respondents who failed an attention or speed check, along with any responses that failed data quality screening procedures, were excluded from the analysis.

2.4. Statistical analysis

All statistical analyses were conducted using Python (version 3.7.8;

Python Software Foundation) and using R software (version 4.0.2; The R Foundation) with the R survey package (version 3.29). Iterative proportional fitting and weight trimming ($0.3 \leq \text{weight} \leq 3.0$) were employed to improve the cross-sectional sample representativeness of the 2010 U.S. population by age, gender, and combined race/ethnicity (Supplement p 2). Rounded, weighted values are reported unless otherwise specified.

2.4.1. Specific Aim 1: to estimate the prevalence of U.S. caregivers during the COVID-19 pandemic and compare the demographic characteristics of this population with non-caregivers

Summary statistics (counts and percentages) were used to describe the distribution of demographic characteristics among caregivers and non-caregivers. For each demographic category (e.g., gender, age group, race/ethnicity), univariable Rao-Scott adjusted Pearson chi-squared tests were used to test for differences in observed and expected frequencies among groups by characteristic with a Bonferroni adjustment and evaluated at a significance level of $\alpha = 0.05$.

2.4.2. Specific Aim 2: to evaluate demographic characteristics associated with adverse mental and behavioral health symptoms separately among caregivers and non-caregivers

Summary statistics (counts and percentages) were used to estimate the prevalence of adverse mental and behavioral health symptoms among caregivers and non-caregivers, overall and by demographic characteristics. Univariable Rao-Scott adjusted Pearson chi-squared tests were used to test for differences in observed and expected frequencies among groups by characteristic with a Bonferroni adjustment and evaluated at a significance level of $\alpha = 0.05$. Additionally, to identify whether specific demographic characteristics were independently associated with adverse mental and behavioral health symptoms within these populations, multivariable Poisson regressions with robust standard errors were used to estimate adjusted prevalence ratios (aPRs) and 95% confidence intervals (95% CIs) for adverse mental and behavioral health symptoms among caregivers, evaluated at a significance level of $\alpha = 0.05$.

2.4.3. Specific Aim 3: to analyze caregiving-specific characteristics associated with adverse mental and behavioral health symptoms among caregivers

Summary statistics (counts and percentages) were used to estimate the prevalence of adverse mental and behavioral health symptoms among caregivers, overall and by caregiving characteristics. Univariable Rao-Scott adjusted Pearson chi-squared tests were used to test for differences in observed and expected frequencies among caregivers by characteristic with a Bonferroni adjustment and evaluated at a significance level of $\alpha = 0.05$. To identify whether specific caregiving characteristics were independently associated with adverse mental and behavioral health symptoms, multivariable Poisson regressions with robust standard errors were used to estimate aPRs and 95% CIs for adverse mental and behavioral health symptoms, evaluated at a significance level of $\alpha = 0.05$.

As an exploratory analysis of individual CII items to determine the relative strength of correlations between caregiver perceptions and adverse mental and behavioral health symptoms, non-parametric Spearman correlations were calculated between each CII item and mental and behavioral health measures.

2.5. Study approval and informed consent

The Monash University Human Research Ethics Committee reviewed and approved the study protocol (ID #24036). All participants provided informed electronic consent prior to study commencement. Investigators received anonymized responses.

3. Results

3.1. Prevalence estimates of U.S. caregivers and demographic characteristics of caregivers and non-caregivers

Of 9,896 eligible invited adults, 5,412 (54.7%) completed Internet-based surveys during June 24–30, 2020, including 3,638 (68.1%) first-time respondents and 1,729 (31.9%) respondents who first completed a survey for The COPE Initiative during April 2–8, 2020. Among the 5,412 respondents, 5,011 (92.6%) met secondary screening criteria and were included in this analysis (Figure S1). These 5,011 respondents included 1,362 (27.2%) caregivers and 3,649 (72.8%) non-caregivers (Table 1). There was not a significant difference in caregiver status by gender or 2019 household income, though compared with non-caregivers, caregivers were significantly more commonly of young age (e.g., 18–24 years = 26.6% vs 8.0%, respectively, group $p < 0.0001$) and either Black or Hispanic race/ethnicity (Black = 18.8% vs 9.7%; Hispanic = 29.0% vs 11.6%, group $p < 0.0001$). White respondents accounted for 44.5% of caregivers and 70.8% of non-caregivers. Caregivers also more commonly reported living with a disability than not (37.9% vs 17.0%, $p < 0.0001$), and, among employed caregivers, essential than nonessential worker status (73.7% vs 47.8%, $p < 0.0001$) (Table 1).

3.2. Adverse mental and behavioral health symptoms by demographic characteristics of caregivers and non-caregivers

Adverse mental and behavioral health symptoms were more prevalent among caregivers than among non-caregivers (symptoms of anxiety or depressive disorder = 57.6% vs 21.5%, respectively; symptoms of a COVID-19-related TSRD = 49.0% vs 17.9%; having started or increased substance use to cope with the pandemic = 35.0% vs 6.3%; suicidal ideation = 33.4% vs 3.7%; one or more of these symptoms = 69.6% vs 31.0%; all $p < 0.0001$) (Tables 2,3).

Among caregivers, adverse mental and behavioral health symptoms were most prevalent among adults aged 18–24 years (e.g., one or more symptom, vs those aged ≥ 65 years; 88.5% vs 18.8%, group $p < 0.0001$), and were more prevalent among Black and Hispanic caregivers than White caregivers (80.2% and 89.4%, respectively, vs 53.4%, group $p < 0.0001$) and among those with than those without disabilities (85.8% vs 59.8%, $p < 0.0001$) (Table 2). There were also differences by employment status, as caregivers who were employed (76.1%) or students (79.0%) had higher prevalences of adverse mental and behavioral health symptoms than those who were retired (29.9%) or unemployed (59.3%) (group $p < 0.0001$). Among employed caregivers, adverse mental and behavioral health symptoms were more common among essential than among nonessential workers (81.6% vs 60.6%, $p < 0.0001$), and were most prevalent among those who worked >60 hours in the previous week and decreased with weekly work hours (e.g., vs those who worked ≤ 20 h; 96.9% vs 59.3%, group $p < 0.0001$). Overall, demographic characteristics associated with adverse mental and behavioral health symptoms among caregivers were also observed among non-caregivers (Table 3).

Adjusted prevalence ratios for select demographic variables associated with significantly different prevalences of symptoms of anxiety or depressive disorder, suicidal ideation, and one or more adverse mental or behavioral health symptom, are shown in Figure S2. Specifically, adjusted prevalence ratios for adverse mental health symptoms were higher among young caregivers aged 18–24 years vs caregivers aged 45–64 years (e.g., anxiety or depressive disorder symptoms, aPR 1.47, 95% CI 1.21–1.79, $p = 0.0001$; suicidal ideation, 1.88, 1.26–2.82, $p = 0.0023$; one or more of these symptoms, 1.48, 1.28–1.71, $p < 0.0001$) and those with vs without disabilities (1.22, 1.10–1.35, $p = 0.0002$; 2.01, 1.65–2.46, $p < 0.0001$; 1.18, 1.10–1.26, $p < 0.0001$, respectively). Suicidal ideation was more prevalent among Black vs White caregivers (1.48, 1.15–1.90, $p = 0.0022$), as was one or more of these symptoms

Table 27 (12.1). Respondent Characteristics by Caregiver Status**Table 1**

Respondent Characteristics by Caregiver Status.

	All respondents		All respondents		Unpaid caregivers of adults		Not unpaid caregivers of adults		Unpaid caregivers versus non-Caregivers
	unweighted n (%)	(100)	weighted n (%)	(100)	weighted n (%)	(27.2)	weighted n (%)	(72.8)	χ^2 p-value*
Total Respondents	5011	(100)	5011	(100)	1362	(27.2)	3649	(72.8)	-
Gender									
Female	2613	(52.1)	2546	(50.8)	683	(50.1)	1863	(51.1)	>0.99
Male	2398	(47.9)	2465	(49.2)	679	(49.9)	1786	(48.9)	
Age group, years									
18–24	399	(8.0)	655	(13.1)	362	(26.6)	293	(8.0)	<0.0001
25–44	1185	(23.6)	1753	(35.0)	566	(41.6)	1187	(32.5)	
45–64	1783	(35.6)	1739	(34.7)	335	(24.6)	1404	(38.5)	
≥65	1644	(32.8)	864	(17.2)	99	(7.2)	766	(21.0)	
Race/ethnicity [†]									
White, non-Hispanic	3365	(67.2)	3191	(63.7)	606	(44.5)	2584	(70.8)	<0.0001
Black, non-Hispanic	500	(10.0)	611	(12.2)	256	(18.8)	355	(9.7)	
Asian, non-Hispanic	538	(10.7)	240	(4.8)	55	(4.1)	184	(5.1)	
Other race or multiple races, non-Hispanic	163	(3.3)	151	(3.0)	50	(3.7)	101	(2.8)	
Hispanic, any race or races	445	(8.9)	819	(16.3)	395	(29.0)	424	(11.6)	
Disability status [‡]									
Yes	1051	(21.0)	1134	(22.6)	516	(37.9)	619	(17.0)	<0.0001
No	3960	(79.0)	3877	(77.4)	846	(62.1)	3030	(83.0)	
Marital status									
Married or living with partner	3084	(61.5)	2971	(59.3)	809	(59.4)	2162	(59.2)	0.0005
Divorced or separated	547	(10.9)	468	(9.3)	99	(7.3)	369	(10.1)	
Never married	1132	(22.6)	1399	(27.9)	428	(31.5)	971	(26.6)	
Widowed/widower	248	(4.9)	173	(3.5)	25	(1.8)	148	(4.1)	
2019 household income (USD)									
<25,000	615	(12.3)	669	(13.3)	155	(11.3)	514	(14.1)	0.8336
25,000–49,999	1018	(20.3)	1039	(20.7)	306	(22.5)	733	(20.1)	
50,000–99,999	1742	(34.8)	1722	(34.4)	487	(35.7)	1235	(33.9)	
≥100,000	1636	(32.6)	1581	(31.5)	414	(30.4)	1167	(32.0)	
Employment status									
Employed	2590	(51.7)	3069	(61.3)	1018	(74.8)	2051	(56.2)	<0.0001
Retired	1740	(34.7)	1138	(22.7)	147	(10.8)	991	(27.1)	
Unemployed	563	(11.2)	633	(12.6)	130	(9.6)	503	(13.8)	
Student	118	(2.4)	170	(3.4)	66	(4.8)	104	(2.9)	
Essential worker									
Yes	1343	(51.9)	1732	(56.4)	751	(73.7)	981	(47.8)	<0.0001
No	1247	(48.1)	1337	(43.6)	268	(26.3)	1070	(52.2)	
Hours of paid work in previous week									
≤20	455	(17.6)	468	(15.2)	124	(12.2)	344	(16.8)	<0.0001
21–40	1425	(55.0)	1673	(54.5)	472	(46.3)	1201	(58.5)	
41–60	585	(22.6)	741	(24.1)	290	(28.5)	450	(22.0)	
>60	125	(4.8)	188	(6.1)	132	(13.0)	56	(2.7)	

* Bonferroni-corrected Rao-Scott adjusted Pearson chi-squared test was used to test for differences in observed and expected frequencies among groups. Significance was assessed at $p < 0.05$.

[†] “Other” race includes American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or Other.

[‡] Persons who had a disability were defined as such based on a qualifying response to either one of two questions: “Are you limited in any way in any activities because of physical, mental, or emotional condition?” and “Do you have any health conditions that require you to use special equipment, such as a cane, wheelchair, special bed, or special telephone?” <https://www.cdc.gov/brfss/questionnaires/pdf-ques/2015-brfss-questionnaire-12-29-14.pdf>.

among Hispanic vs White caregivers (1.14, 1.04–1.25, $p = 0.0044$). Conversely, adjusted prevalence ratios for adverse mental health symptoms were significantly lower among older adults aged ≥65 years vs caregivers aged 45–64 years (e.g., one or more adverse mental health symptom, 0.54, 0.39–0.74, $p = 0.0002$).

3.3. Adverse mental and behavioral health symptoms by caregiving characteristics of caregivers

Among caregivers, mental and behavioral health also differed by caregiving characteristics (Table 2); 93.0% of 126 caregivers providing care to multiple types of relationships reported adverse mental or behavioral health symptoms, compared with 55.6% of 261 caregivers providing care for a parent or parent-in-law (group $p < 0.0001$). Similarly, 89.0% of 370 who had been providing care for 4–6 months, compared with 44.7% of 199 caregivers who had been providing care for more than 12 months (group $p < 0.0001$) (Table 4). There were also difference by CII score; 91.1% of 335 caregivers with high CII scores reported one or more adverse mental or behavioral health symptom,

compared with 20.7% of 31 caregivers with low CII scores (group $p < 0.0001$).

The multivariable analysis revealed that adjusted prevalence ratios for adverse mental health symptoms were higher among caregivers with ≤12 vs those with >12 months of experience (anxiety or depressive disorder symptoms, 1.24, 1.06–1.44, $p = 0.0059$; suicidal ideation, 1.75, 1.27–2.41, $p = 0.0006$; one or more of these symptoms, 1.25, 1.12–1.40, $p = 0.0001$), those with >6- vs ≤6-hour weekly caregiving commitment (1.34, 1.16–1.56, $p = 0.0001$; 1.58, 1.19–2.11, $p = 0.0018$; 1.19, 1.07–1.31, $p = 0.0009$, respectively), and, compared with those in the low-intensity CII group, caregivers in the moderate-intensity (2.52, 1.61–3.94, $p < 0.0001$; 1.92, 0.95–3.88, $p = 0.070$; 2.30, 1.64–3.23, $p < 0.0001$, respectively) and high-intensity (3.34, 2.12–5.26, $p < 0.0001$; 2.91, 1.43–5.93, $p = 0.0034$; 2.80, 1.99–3.93, $p < 0.0001$, respectively) groups.

In the exploratory analysis of the correlation of individual CII items with adverse mental and behavioral health symptoms, the strongest average positive correlations among all adverse symptoms were observed for employment absenteeism (ρ s between 0.36 and 0.46, all p

Table 28 (12.2) Adverse Mental and Behavioral Health Symptoms Among Unpaid Caregivers of Adults During June 24-30, 2020, by Select Respondent Demographics

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Table 2

Adverse Mental and Behavioral Health Symptoms Among Unpaid Caregivers of Adults During June 24-30, 2020, by Select Respondent Demographics*.

Caregiver Demographics	All respondents		All respondents		Symptoms of an anxiety or depressive disorder		Symptoms of a COVID-19 TSRD		Started or increased substance use		Seriously considered suicide in previous 30 days		≥1 adverse mental or behavioral health symptom	
	unweighted n	(%)	weighted n (%)		weighted n (%)		weighted n (%)		weighted n (%)		weighted n (%)		weighted n (%)	
Total Caregivers	1100	(22.0)	1362	(27.2)	785	(57.6) [†]	667	(49.0) [†]	477	(35.0) [†]	454	(33.4) [†]	948	(69.6) [†]
Gender														
Female	586	(53.3)	683	(50.1)	396	(58.0)	320	(46.8)	209	(30.7)	209	(30.6)	478	(70.0)
Male	514	(46.7)	679	(49.9)	389	(57.2)	348	(51.2)	267	(39.3)	245	(36.1)	470	(69.2)
Age group, years														
18-24	210	(19.1)	362	(26.6)	255	(70.5)	211	(58.2)	152	(41.9)	164	(45.3)	320	(88.5)
25-44	357	(32.5)	566	(41.6)	402	(71.0)	354	(62.5)	274	(48.3)	258	(45.6)	467	(82.5)
45-64	343	(31.2)	335	(24.6)	113	(33.7)	90	(27.0)	46	(13.8)	29	(8.7)	143	(42.5)
≥65	190	(17.3)	99	(7.2)	14	(14.4)	13	(13.0)	5	(5.4)	3	(3.2)	19	(18.8)
Race/ethnicity [‡]														
White, non-Hispanic	552	(50.2)	606	(44.5)	277	(45.6)	236	(38.9)	142	(23.4)	118	(19.5)	324	(53.4)
Black, non-Hispanic	189	(17.2)	256	(18.8)	164	(64.2)	142	(55.4)	117	(45.8)	119	(46.4)	205	(80.2)
Asian, non-Hispanic	118	(10.7)	55	(4.1)	23	(41.6)	24	(42.6)	10	(18.2)	11	(19.1)	33	(59.6)
Other race or multiple races, non-Hispanic	47	(4.3)	50	(3.7)	28	(56.1)	23	(46.6)	14	(27.8)	15	(30.3)	33	(67.1)
Hispanic, any race(s)	194	(17.6)	395	(29.0)	293	(74.2)	243	(61.6)	194	(49.1)	191	(48.5)	353	(89.4)
Disability**														
Yes	364	(33.1)	516	(37.9)	374	(72.5)	317	(61.4)	276	(53.5)	299	(57.9)	442	(85.8)
No	736	(66.9)	846	(62.1)	411	(48.5)	351	(41.4)	201	(23.7)	156	(18.4)	506	(59.8)
Marital status														
Married or living with partner	680	(61.8)	809	(59.4)	458	(56.6)	409	(50.5)	295	(36.4)	281	(34.7)	555	(68.6)
Divorced or separated	85	(7.7)	99	(7.3)	58	(58.3)	45	(45.4)	42	(41.8)	40	(40.1)	72	(72.5)
Never married	307	(27.9)	428	(31.5)	253	(59.0)	207	(48.2)	134	(31.2)	124	(29.0)	303	(70.8)
Widowed/widower	28	(2.5)	25	(1.8)	16	(64.3)	7	(26.7)	7	(26.2)	9	(35.8)	18	(70.5)
2019 household income (USD)														
<25,000	115	(10.5)	155	(11.3)	85	(55.2)	64	(41.5)	49	(31.7)	41	(26.5)	107	(69.3)
25,000-49,999	242	(22.0)	306	(22.5)	171	(55.9)	155	(50.7)	96	(31.3)	82	(26.9)	216	(70.3)
50,000-99,999	396	(36.0)	487	(35.7)	299	(61.5)	241	(49.5)	167	(34.3)	161	(33.1)	345	(70.8)
≥100,000	347	(31.5)	414	(30.4)	229	(55.3)	207	(50.0)	165	(39.8)	170	(41.1)	281	(67.8)
Employment status														
Employed	739	(67.2)	1018	(74.8)	638	(62.7)	551	(54.2)	423	(41.6)	410	(40.3)	775	(76.1)
Retired	207	(18.8)	147	(10.8)	33	(22.6)	28	(19.1)	8	(5.7)	4	(2.7)	44	(29.9)
Unemployed	114	(10.4)	130	(9.6)	66	(50.4)	48	(37.1)	23	(17.4)	14	(11.1)	77	(59.3)
Student	40	(3.6)	66	(4.8)	47	(72.0)	40	(59.9)	22	(33.8)	26	(39.4)	52	(79.0)
Essential worker														
Yes	501	(67.8)	751	(73.7)	512	(68.2)	449	(59.9)	366	(48.8)	355	(47.3)	613	(81.6)
No	238	(32.2)	268	(26.3)	127	(47.3)	102	(38.2)	57	(21.2)	55	(20.6)	162	(60.6)
Hours of paid work in previous week														
≤20	105	(14.2)	124	(12.2)	61	(49.0)	51	(41.4)	33	(26.5)	29	(23.7)	73	(59.3)
21-40	359	(48.6)	472	(46.3)	280	(59.4)	255	(54.1)	182	(38.5)	147	(31.1)	343	(72.6)
41-60	196	(26.5)	290	(28.5)	188	(64.9)	147	(50.7)	136	(46.8)	139	(48.0)	231	(79.5)
>60	79	(10.7)	132	(13.0)	109	(82.4)	97	(73.7)	73	(55.2)	95	(71.7)	128	(96.6)

* See Table 3 for the adverse mental and behavioral health symptoms among those who were not unpaid caregivers of adults, by select respondent demographics.

[†] $p < 0.05$ for Bonferroni-corrected Rao-Scott adjusted Pearson chi-squared test between caregivers and non-caregivers.

[‡] $p < 0.05$ for Bonferroni-corrected Rao-Scott adjusted Pearson chi-squared test between demographics among caregivers.

[§] “Other” race includes American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or Other.

** Persons who had a disability were defined as such based on a qualifying response to either one of two questions: “Are you limited in any way in any activities because of physical, mental, or emotional condition?” and “Do you have any health conditions that require you to use special equipment, such as a cane, wheelchair, special bed, or special telephone?” <https://www.cdc.gov/brfss/questionnaires/pdf-ques/2015-brfss-questionnaire-12-29-14.pdf>.

< 0.0001), preparedness (ρ s between 0.25 and 0.45, all $p < 0.0001$), resentment (ρ s between 0.30 and 0.40, all $p < 0.0001$), impact on expenses (ρ s between 0.26 and 0.45, all $p < 0.0001$), and family strife (ρ s between 0.24 and 0.42, all $p < 0.0001$) (Table S1). The strongest average negative correlation was observed for sense of purpose (ρ s between -0.11 and -0.22, all $p \leq 0.0002$). All correlations were in the expected direction based on their subscale categorization, except for employer support, which had a positive correlation with all adverse mental or behavioral health symptoms (ρ s between 0.16 and 0.26, all $p < 0.0001$) despite being in the Buffer subscale.

4. Discussion

More than one-quarter (1,362 [27.2%]) of 5,011 U.S. adult respondents identified as having had roles as unpaid caregivers of adults in

the three months preceding the survey in June 2020. This estimated prevalence of caregivers in the U.S. during the COVID-19 pandemic represents an increase over the 19.2% estimate based on data collected in 2019 (The National Alliance for Caregiving and Public Policy Institute, 2020). While differences in survey sampling methodologies limit direct comparisons between these figures, this increase might partially reflect an increased need for caregivers during the pandemic. Overall, 7 in 10 (948 of 1,362 [69.6%]) caregivers reported having experienced one or more adverse mental or behavioral health symptom. More than one-half of caregivers screened positive for symptoms of an anxiety or depressive disorder (785 [57.2%]), and more than one-third reported having started or increased substance use to cope with the stress or emotions related to COVID-19 (477 [35.0%]) or seriously considered suicide in the prior month (454 [33.4%]). Caregivers reported having experienced elevated levels of adverse mental and behavioral health

Table 29 (12.3) Adverse Mental and Behavioral Health Symptoms Among People Who Were Not Unpaid Caregivers of Adults During June 24-30, 2020, by Select Respondent Demographics

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Table 3

Adverse Mental and Behavioral Health Symptoms Among People Who Were Not Unpaid Caregivers of Adults During June 24-30, 2020, by Select Respondent Demographics*.

Non-Caregiver Demographics	All respondents		All respondents		Symptoms of an anxiety or depressive disorder		Symptoms of a COVID-19 TSRD		Started or increased substance use		Seriously considered suicide in previous 30 days		≥1 adverse mental or behavioral health symptom	
	unweighted n (%)		weighted n (%)		weighted n (%)		weighted n (%)		weighted n (%)		weighted n (%)		weighted n (%)	
Total Non-Caregivers	3911	(78.0)	3649	(72.8)	785	(21.5) [†]	653	(17.9) [†]	231	(6.3) [†]	135	(3.7) [†]	1130	(31.0) [†]
Gender														
Female	2027	(51.8)	1863	(51.1)	475	(25.5)	355	(19.1)	134	(7.2)	76	(4.1)	655	(35.2)
Male	1884	(48.2)	1786	(48.9)	310	(17.4)	298	(16.7)	97	(5.4)	60	(3.3)	475	(26.6)
Age group, years														
18-24	189	(4.8)	293	(8.0)	161	(54.9)	116	(39.7)	35	(11.8)	41	(13.9)	198	(67.6)
25-44	828	(21.2)	1187	(32.5)	334	(28.1)	303	(25.5)	105	(8.9)	56	(4.7)	474	(39.9)
45-64	1440	(36.8)	1404	(38.5)	225	(16.0)	178	(12.7)	72	(5.2)	27	(1.9)	347	(24.7)
65+	1454	(37.2)	766	(21.0)	66	(8.6)	56	(7.3)	19	(2.5)	12	(1.6)	112	(14.6)
Race/ethnicity [§]														
White, non-Hispanic	2813	(71.9)	2584	(70.8)	479	(18.5)	369	(14.3)	131	(5.1)	63	(2.4)	684	(26.5)
Black, non-Hispanic	311	(8.0)	355	(9.7)	98	(27.6)	100	(28.1)	38	(10.7)	24	(6.7)	151	(42.4)
Asian, non-Hispanic	420	(10.7)	184	(5.1)	30	(16.5)	31	(16.8)	10	(5.5)	7	(3.8)	52	(28.2)
Other race or multiple races, non-Hispanic	116	(3.0)	101	(2.8)	31	(31.1)	27	(26.4)	4	(3.9)	5	(4.9)	44	(43.6)
Hispanic, any race(s)	251	(6.4)	424	(11.6)	146	(34.4)	127	(29.9)	48	(11.2)	36	(8.6)	200	(47.1)
Disability status**														
Yes	687	(17.6)	619	(17.0)	241	(38.9)	173	(27.9)	62	(10.1)	49	(8.0)	293	(47.3)
No	3224	(82.4)	3030	(83.0)	544	(18.0)	481	(15.9)	169	(5.6)	86	(2.8)	837	(27.6)
Marital status														
Married or living with partner	2404	(61.5)	2162	(59.2)	366	(16.9)	330	(15.3)	106	(4.9)	52	(2.4)	563	(26.0)
Divorced or separated	462	(11.8)	369	(10.1)	73	(19.8)	51	(13.9)	25	(6.7)	15	(4.2)	105	(28.5)
Never married	825	(21.1)	971	(26.6)	314	(32.4)	248	(25.5)	90	(9.3)	61	(6.3)	422	(43.4)
Widowed/widower	220	(5.6)	148	(4.1)	31	(20.9)	25	(16.6)	10	(6.8)	7	(4.7)	41	(27.6)
2019 household income (USD)														
<25,000	500	(12.8)	514	(14.1)	176	(34.1)	136	(26.5)	47	(9.1)	30	(5.9)	225	(43.8)
25,000-49,999	776	(19.8)	733	(20.1)	188	(25.7)	146	(19.9)	44	(6.0)	40	(5.4)	262	(35.8)
50,000-99,999	1346	(34.4)	1235	(33.9)	250	(20.2)	208	(16.8)	72	(5.8)	44	(3.6)	352	(28.5)
≥100,000	1289	(33.0)	1167	(32.0)	171	(14.7)	163	(14.0)	69	(5.9)	21	(1.8)	291	(25.0)
Employment status														
Employed	1851	(47.3)	2051	(56.2)	455	(22.2)	436	(21.2)	154	(7.5)	86	(4.2)	686	(33.5)
Retired	1533	(39.2)	991	(27.1)	109	(11.0)	91	(9.2)	33	(3.4)	20	(2.0)	175	(17.7)
Unemployed	449	(11.5)	503	(13.8)	177	(35.1)	96	(19.1)	30	(6.0)	20	(3.9)	214	(42.6)
Student	78	(2.0)	104	(2.9)	44	(42.0)	30	(29.2)	14	(13.4)	10	(9.7)	54	(51.6)
Essential worker														
Yes	842	(45.5)	981	(47.8)	225	(22.9)	223	(22.8)	86	(8.7)	50	(5.1)	345	(35.2)
No	1009	(54.5)	1070	(52.2)	230	(21.5)	212	(19.9)	68	(6.3)	35	(3.3)	341	(31.9)
Hours of paid work in previous week														
≤20	350	(18.9)	344	(16.8)	69	(20.1)	63	(18.4)	22	(6.4)	13	(3.8)	109	(31.7)
21-40	1066	(57.6)	1201	(58.5)	269	(22.4)	261	(21.8)	92	(7.7)	53	(4.4)	411	(34.2)
41-60	389	(21.0)	450	(22.0)	99	(22.0)	91	(20.2)	31	(6.9)	17	(3.8)	142	(31.4)
>60	46	(2.5)	56	(2.7)	18	(32.3)	20	(36.3)	8	(14.5)	2	(2.9)	25	(44.6)

* See Table 2 for the adverse mental and behavioral health symptoms among those who were unpaid caregivers of adults, by select respondent demographics.

[†] $p < 0.05$ for Bonferroni-corrected Rao-Scott adjusted Pearson chi-squared test between caregivers and non-caregivers.

[‡] $p < 0.05$ for Bonferroni-corrected Rao-Scott adjusted Pearson chi-squared test between demographics among caregivers.

[§] “Other” race includes American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or Other.

** Persons who had a disability were defined as such based on a qualifying response to either one of two questions: “Are you limited in any way in any activities because of physical, mental, or emotional condition?” and “Do you have any health conditions that require you to use special equipment, such as a cane, wheelchair, special bed, or special telephone?” <https://www.cdc.gov/brfss/questionnaires/pdf-ques/2015-brfss-questionnaire-12-29-14.pdf>.

symptoms compared with non-caregivers in this study, including three times the prevalence of symptoms of anxiety or depressive disorder or a COVID-19-related TSRD, six times the prevalence of having started or increased substance use to cope with the pandemic, and nine times the prevalence of having seriously considered suicide.

Both caregivers and non-caregivers who were young, Black, Hispanic, living with disabilities, essential workers, and working long hours had disproportionately high levels of adverse mental health, consistent with findings during the pandemic (Czeisler et al., 2020a, 2021c; Gold, 2020; Son et al., 2020; Varma et al., 2021; Wang et al., 2020). However, caregivers more commonly identified as members of these disproportionately affected populations than non-caregivers. Of caregivers, more than two-thirds (928 [68.1%]) were aged below 45 years, more than one-half (756 [55.5%]) non-White, more than one-third living with disabilities (516 [37.9%]), and nearly three-quarters employed as

essential workers (751 of 1,018 [73.7%]). These demographic characteristics could be associated with additional stressors. Long work hours, which were also common among employed caregivers, were associated with increased odds of adverse health outcomes, including depression, anxiety, and impaired sleep (Wong et al., 2019), an effect that may be exacerbated by caregiving roles outside of work. Committing long hours to paid work and unpaid care limits opportunities for core elements of health, including sleep, exercise, nutrition, social interaction, and medical care. Among caregivers, those who had provided care for more hours and those who had been caregiving for fewer than 12 months had higher prevalences of adverse mental health symptoms, which may reflect stressors from being forced into a caregiving role, starting as a caregiver during the pandemic, or survival bias (Czeisler et al., 2021d), whereby those who were still providing care after 12 months were more resilient to stressors associated with the role.

Table 30 (12.4) Adverse Mental and Behavioral Health Symptoms Among Unpaid Caregivers of Adults During June 24-30, 2020, by Caregiving Roles and Intensity.

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Table 4

Adverse Mental and Behavioral Health Symptoms Among Unpaid Caregivers of Adults During June 24-30, 2020, by Caregiving Roles and Intensity.

	All respondents		All respondents		Symptoms of an anxiety or depressive disorder	Symptoms of a COVID-19 TSRD	Started or increased substance use	Serious suicidal ideation in previous 30 days	≥1 adverse mental or behavioral health symptom
	unweighted n (%)		weighted n (%)		weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)	weighted n (%)
Total Caregivers	1100 (22.0)		1362 (27.2)		785 (57.6)	667 (49.0)	477 (35.0)	454 (33.4)	948 (69.6)
Caregiving method							*	*	
In-person in-home only	462 (42.0)		553 (40.6)		318 (57.4)	293 (53.0)	193 (35.0)	187 (33.8)	385 (69.6)
In-person out of home only	455 (41.4)		570 (41.8)		346 (60.7)	268 (47.0)	223 (39.2)	211 (37.1)	404 (70.9)
Virtually only	81 (7.4)		110 (8.0)		59 (54.0)	49 (44.5)	39 (35.7)	40 (36.7)	77 (70.4)
Both in-person and virtually	102 (9.3)		130 (9.5)		62 (48.1)	58 (44.6)	21 (16.0)	16 (12.2)	82 (63.2)
Person receiving care					*	*	*	*	*
Parent or parent-in-law	425 (38.6)		470 (34.5)		209 (44.4)	160 (34.1)	99 (21.0)	88 (18.7)	261 (55.6)
Spouse or partner	204 (18.5)		236 (17.3)		135 (57.0)	133 (56.2)	102 (43.1)	105 (44.6)	165 (70.0)
Older related adult	140 (12.7)		206 (15.1)		142 (68.8)	124 (60.1)	86 (41.9)	76 (36.7)	169 (82.0)
Older unrelated adult	124 (11.3)		148 (10.9)		80 (54.0)	75 (50.6)	34 (23.0)	33 (22.7)	101 (68.2)
Sibling	75 (6.8)		108 (7.9)		65 (60.4)	59 (55.0)	51 (47.0)	46 (42.3)	85 (78.6)
Young unrelated adult	53 (4.8)		59 (4.3)		39 (67.2)	25 (42.8)	19 (32.4)	19 (32.2)	41 (69.7)
More than one of these relationships	79 (7.2)		136 (10.0)		115 (85.0)	92 (67.4)	86 (63.3)	88 (64.6)	126 (93.0)
Hours of unpaid caregiving per week					*	*	*	*	*
<6	324 (29.5)		361 (26.5)		137 (37.8)	138 (38.1)	71 (19.5)	55 (15.2)	187 (51.9)
6-10	331 (30.1)		442 (32.5)		295 (66.8)	241 (54.6)	178 (40.2)	178 (40.1)	353 (79.9)
11-20	229 (20.8)		310 (22.8)		217 (69.8)	176 (56.7)	146 (47.2)	140 (45.3)	246 (79.4)
>20	216 (19.6)		248 (18.2)		136 (54.9)	113 (45.3)	82 (32.9)	82 (32.8)	161 (65.0)
Duration of role as caregiver, months					*	*	*	*	*
≤3	229 (20.8)		314 (23.1)		189 (60.3)	171 (54.4)	105 (33.5)	113 (36.0)	236 (75.2)
4-6	268 (24.4)		416 (30.5)		303 (73.0)	275 (66.3)	227 (54.7)	222 (53.5)	370 (89.0)
7-12	140 (12.7)		188 (13.8)		129 (68.9)	91 (48.4)	80 (42.8)	73 (38.9)	143 (76.3)
>12	463 (42.1)		445 (32.6)		162 (36.5)	130 (29.3)	64 (14.4)	46 (10.3)	199 (44.7)
CII Total Score					*	*	*	*	*
Low (0-25)	166 (15.1)		151 (11.1)		22 (14.5)	17 (11.2)	7 (4.4)	9 (5.7)	31 (20.7)
Moderate (26-55)	679 (61.7)		843 (61.9)		464 (55.0)	374 (44.4)	283 (33.6)	247 (29.2)	582 (69.0)
High (56 or above)	255 (23.2)		368 (27.0)		299 (81.2)	276 (75.1)	187 (50.8)	199 (54.1)	335 (91.1)
CII Burden Subscale					*	*	*	*	*
Low (0-25)	263 (23.9)		261 (19.2)		72 (27.5)	49 (18.7)	54 (20.6)	52 (19.9)	92 (35.1)
Moderate (26-55)	417 (37.9)		519 (38.1)		265 (51.0)	220 (42.5)	154 (29.8)	145 (27.9)	350 (67.5)
High (56 or above)	420 (38.2)		582 (42.7)		448 (77.1)	398 (68.4)	268 (46.1)	257 (44.3)	506 (87.0)
CII Consequences Subscale					*	*	*	*	*
Low (0-25)	279 (25.4)		284 (20.8)		93 (32.7)	69 (24.3)	62 (21.9)	47 (16.5)	118 (41.6)
Moderate (26-55)	409 (37.2)		500 (36.7)		254 (50.9)	213 (42.6)	125 (25.0)	112 (22.3)	327 (65.4)
High (56 or above)	412 (37.5)		579 (42.5)		438 (75.6)	386 (66.7)	289 (50.0)	296 (51.2)	504 (87.0)
CII Buffer Subscale					*				*
Low (0-25)	33 (3.0)		44 (3.2)		37 (83.4)	24 (53.6)	26 (57.7)	19 (42.8)	39 (87.1)
Moderate (26-55)	309 (28.1)		404 (29.7)		241 (59.5)	194 (48.0)	130 (32.2)	124 (30.7)	312 (77.2)
High (56 or above)	758 (68.9)		913 (67.1)		507 (55.5)	449 (49.2)	321 (35.2)	311 (34.1)	597 (65.4)

* $p < 0.05$ for Bonferroni-corrected Rao-Scott adjusted Pearson chi-squared test between groups among caregivers.

The findings in this report reveal that unpaid caregiving for adults is common, has likely increased during the COVID-19 pandemic, and is represented broadly across demographics. Further, the report underscores the significant impact associated with caregiving on mental and behavioral health and highlights the compounding impact of intersectionality with those who identify in multiple groups having elevated experiences of adverse mental and behavioral health. Addressing mental health among caregivers represents an urgent unmet medical and public health need, and group-specific interventions and communication strategies are needed to increase awareness of, comfort with, and access to resources for the diagnosis and treatment of adverse mental and behavioral health conditions, especially given the time constraints faced by caregivers, many of whom are also employed.

Effective communication strategies may include promoting recognition of caregivers so that they feel seen (O'Connor, 2007), addressing stigma associated with mental healthcare (Horsfield et al., 2020; Picco et al., 2018; Schomerus et al., 2019), and continuing to expand telehealth (Koonin et al., 2020), which has delivered promising results in treatment for depression, substance use disorder, and suicidal ideation (Hailey et al., 2008). However, telehealth may not address all needs, with barriers to access (e.g., English-language proficiency, lack of Internet access) and limitations to provision of some care (Gajrawala and Pelkowski, 2021; Pierce and Stevermer, 2020; Rodriguez et al.,

2021). Campaigns to increase help-seeking behavior may also be beneficial, as caregivers more commonly avoided medical care due to concerns about COVID-19 (Czeisler et al., 2020b, 2021b), which may be related to a combination of their own perceived risk of SARS-CoV-2 infection and to their perceived risk and grief about potentially infecting the person for whom they are caring.

4.1. Strengths and limitations

Strengths of this study include recruitment of a large sample of unpaid caregivers from a demographically diverse sample of U.S. adults and utilization of validated screening instruments for mental health. Limitations of this study follow. First, unpaid caregivers of adults were self-identified, and whether they were caregivers of children or adolescents was not assessed; future research could continue to assess mental health among multigenerational caregivers. Second, a diagnostic evaluation for anxiety disorder or depressive disorder was not conducted; however, clinically validated screening instruments were used to assess symptoms. Third, substance use was self-reported; therefore, responses might be subject to recall, response, and social desirability biases. Fourth, the novel nature of the ARCHANGELS Caregiver Intensity Index and the specific use within this research precludes exact comparisons with normative data on caregiving intensity before the

pandemic. Finally, Internet-based survey samples might not be fully representative of the 2020 U.S. population and may therefore have limited generalizability. However, standardized and supplementary data quality screening procedures were applied, and the prevalence of symptoms of anxiety disorder and depressive disorder were largely consistent with findings from the Household Pulse Survey during June 2020 (Centers for Disease Control and Prevention, 2020).

The COVID-19 pandemic both introduced new challenges (e.g., barriers to in-person care provision, COVID-19 concerns) and exacerbated longstanding challenges (e.g., financial and time strains) associated with caregiving. Therefore, prevention efforts and cultural changes may be required both during and beyond the pandemic to properly address the factors associated with caregiving that contribute to elevated experiences of adverse mental health. This is of increasing importance to the economy, as even before the pandemic, a 2015 study estimated the value of unpaid caregiver labor to be USD\$470 billion (Beltrán-Sánchez et al., 2015).

Given the high prevalence of employed caregivers and its compounding mental health impact, reducing the stigma that can be associated with caregiver status and establishing visible and easily accessible workplace programs should be prioritized. Employee Assistance Programs, Workplace Health Promotion Programs, personalized flexible work arrangements, and expanded options for leave that may reduce caregiving intensity if expanded (Robbins et al., 2021) and effectively utilized (Lilly, 2011). Assistive technologies may also decrease workloads required from caregivers, though may inadvertently increase the load if mismanaged or improperly designed (Marasinghe et al., 2015). Beyond these institutional changes, given the protective benefit of a caregiver's sense of purpose and evidence that self-esteem and positive aspects of caregiving are associated with improved mental health (Fauziana et al., 2018), creating a culture that more openly celebrates caregivers and their efforts may lead to communities of caregivers that reduce the mental health risks associated with social disconnectedness and isolation (Bhatti and Haq, 2017; Newman and Zainal, 2020). Caregivers might also benefit from preparation for specific caregiving roles. For example, a largescale survey of adults in the U.S. found that caregivers who were providing care to adults with mental health or substance use conditions, or with active COVID-19 illness, had the highest odds of adverse mental health symptoms (Czeisler et al., 2021c). Similarly, a study of 350 caregivers of people with COVID-19 in Iran reported prevalence estimates of anxiety, depression, and stress between 75% and 80%, with higher levels among those who were younger, not exercising, or employed as in a health-related occupation (Jafari-Oori et al., 2021). Finally, given that approximately 20% of bereaved caregivers experience psychiatric symptoms following the passing of their loved ones, including of depression and complicated grief (Schulz et al., 2008), caregivers might benefit from preparation for and support during this experience.

5. Conclusion

Further characterization of caregivers and assessment of mental health, substance use, and suicidal ideation will be required to determine the extent to which increased prevalence of caregiving and elevated adverse mental and behavioral health symptoms progress over the course of the pandemic and beyond. Investment in support systems that reflect the diverse caregiving population and improves their ability to provide care will improve societal health and well-being during this critical health crisis and beyond.

Author statement

All authors contributed to the study concept and design. MÉC, CAC, SMWR, and MEH collected the data, and MÉC conducted all analyses and wrote the first manuscript draft. All authors provided critical intellectual input and revision. SMWR and MEH provided supervision.

MÉC, SMWR, and MEH had access to the underlying data.

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Declaration of Competing Interest

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:[10.1016/j.jad.2021.08.130](https://doi.org/10.1016/j.jad.2021.08.130).

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SUMMARY OF FINDINGS

This caregiver-focused analysis revealed differences in mental health among unpaid caregivers of adults, who represented approximately one-quarter of surveyed US adults, based on demographics and caregiving-related variables. Given that studies of caregivers are commonly focused on caregivers for persons with a specific health condition or include an otherwise narrow definition (**American Psychological Association, 2010**), the screening question used to identify unpaid caregivers of adults was intentionally broadly defined to include all persons who had provided unpaid care to adults in the prior three months, regardless of the condition of the person for whom they were providing care. The definition was used based on wording used in national reports produced by the National Alliance for Caregiving (**The National Alliance for Caregiving & Public Policy Institute, 2020**). To the extent that the prevalence estimates for unpaid caregivers of adults are comparable, our estimate of 27.2% would represent an acute 42% increase over the 19.2% estimated using a similar question from the National Alliance for Caregiving (NAC) and AARP Caregiving in the U.S. 2020 report based on data collected in 2019 (**The National Alliance for Caregiving & Public Policy Institute, 2020**). This shift could represent increased need for unpaid caregivers given mobility restrictions and stay-at-home orders early in the pandemic, with particular focus on older adults, who were at elevated risk of COVID-19 morbidity and mortality and faced disruptions to long-term services and supports via formal care systems. Alternatively, it could reflect differences in the survey samples, which employed different recruitment strategies, or increased self-identification of unpaid caregivers. Additional studies using similar screening questions will be required to determine the contributions of each of these factors.

Consistent with observations of the general population, adverse mental health symptoms were more common among younger unpaid caregivers than among older unpaid caregivers, and among

unpaid caregivers with disabilities compared with those without disabilities. By race and ethnicity, compared with non-Hispanic White unpaid caregivers, those who identified as Latinx had higher adjusted odds of any adverse mental health symptoms (adjusted odds ratio = 1.14 [95% confidence interval = 1.04 to 1.25]; $p = 0.0044$), and those who identified as non-Hispanic Black had higher adjusted odds of suicidal ideation (adjusted odds ratio = 1.48 [95% confidence interval = 1.15 to 1.90]; $p = 0.0022$). Regarding caregiving-related variables, adverse mental health symptoms were associated with more weekly hours devoted to unpaid caregiving, less experience as a caregiver (measured in months caregiving), and higher cumulative caregiving intensity as assessed by the short-form ARCHANGELS Caregiver Intensity Index (**ARCHANGELS, 2021**), which is a questionnaire designed to assess caregiver load (situational stability, impact on expenses, family strife, preparedness), impact (resentment, employment absenteeism, personal time), and buffers (support network, health insurance knowledge and literacy, self-efficacy, financial knowledge, purpose, and employer support).

These findings could be used to tailor mental health resources and support services for unpaid caregivers of adults, particularly to caregivers who were of younger age, Latinx ethnicity, Black race, and who had recently entered a caregiving role. However, for as well as the caregivers were characterised, the June 2020 data raised the question as to whether the mental health of persons caring for children or adolescents, including adults in both roles. Indeed, data from The COPE Initiative collected among adults the US and Australia in September 2020 suggested that adverse mental health symptoms were elevated among all unpaid caregivers (i.e., for adults in roles as caregivers for children or adolescents, for adults, or for persons in both age groups) (**Czeisler et al., 2021; Czeisler, Lane, et al., 2021**). Adults in the role of caring for both persons in both age groups had particularly high levels of adverse mental health symptoms. This prompted interest by members of the CDC COVID-19 Response Disproportionately Affected Populations Team within the

Community Interventions and Critical Populations Task Force to further investigate mental health among unpaid caregivers during the COVID-19 pandemic, which led to the study presented in Chapter Thirteen.

CHAPTER 13: Mental Health Among Parents of Children Aged <18 Years and Unpaid Caregivers of Adults During the COVID-19 Pandemic - United States, December 2020 and February-March 2021

PREFACE TO CHAPTER 13

The Original Investigation in Chapter Thirteen (Czeisler, Rohan, et al., 2021), which was published in the *Morbidity and Mortality Weekly Report*, was prepared based on data collected from 10,444 surveyed US adults during December 2020 and February to March 2021 as part of The COPE Initiative. The aims were to characterize the prevalence of adverse mental health symptoms among adults based on unpaid caregiving roles (for children or adolescents, for adults, for both, or for neither) and to identify caregiving sentiments associated with adverse mental health symptoms. This paper was a collaborative effort between The COPE Initiative investigators, public health officials serving on the CDC COVID-19 Response, and ARCHANGELS. The chapter concludes with a brief overview of findings from the Original Investigation.

In contrast to other papers on unpaid caregivers reported in this thesis, in the Original Investigation presented in Chapter Thirteen, unpaid caregivers of children or adolescents aged <18 years are referred to as parents. Our prior use of unpaid caregivers of children or adolescents was based on the screening question, which intentionally broadened the scope of such caregivers to include persons who were not necessarily the biologic or legal parents or guardians of the children for whom they were providing care. To avoid confusion with unpaid caregivers of children with disabilities or chronic health conditions (the conventional definition of unpaid caregivers of children), we used the term *parents* to describe this group of adults, even though it includes both parents and non-parents providing unpaid care to children and adolescents with and without disabilities or chronic health conditions.

CHAPTER THIRTEEN: Mental Health Among Parents of Children Aged <18 Years and Unpaid Caregivers of Adults During the COVID-19 Pandemic - United States, December 2020 and February-March 2021

Czeisler MÉ, Rohan EA, Melillo S, Matjasko JL, DePadilla L, Patel CG, Weaver MD, Drane A, Winnay SS, Capodilupo ER, Robbins R, Wiley JF, Facer-Childs ER, Barger LK, Czeisler CA, Howard ME, Rajaratnam SMW. Mental Health Among Parents of Children Aged <18 Years and Unpaid Caregivers of Adults During the COVID-19 Pandemic - United States, December 2020 and February-March 2021. *MMWR Morb Mortal Wkly Rep.* 2021 Jun 18;70(24):879-887. doi: 10.15585/mmwr.mm7024a3. PMID: 34138835.

Mental Health Among Parents of Children Aged <18 Years and Unpaid Caregivers of Adults During the COVID-19 Pandemic — United States, December 2020 and February–March 2021

Mark É. Czeisler^{1,2,3}; Elizabeth A. Rohan, PhD⁴; Stephanie Melillo, MPH⁴; Jennifer L. Matjasko, PhD⁴; Lara DePadilla, PhD⁴; Chirag G. Patel, DC⁴; Matthew D. Weaver, PhD^{1,3,5}; Alexandra Drane⁶; Sarah S. Winney⁶; Emily R. Capodilupo^{6,7}; Rebecca Robbins, PhD^{3,5}; Joshua F. Wiley, PhD¹; Elise R. Facer-Childs, PhD¹; Laura K. Barger, PhD^{1,3,5}; Charles A. Czeisler, PhD, MD^{1,3,5}; Mark E. Howard, PhD^{1,2,8*}; Shantha M.W. Rajaratnam, PhD^{1,2,3,5*}

Early during the COVID-19 pandemic, nearly two thirds of unpaid caregivers of adults reported adverse mental or behavioral health symptoms, compared with approximately one third of noncaregivers[†] (1). In addition, 27% of parents of children aged <18 years reported that their mental health had worsened during the pandemic (2). To examine mental health during the COVID-19 pandemic among U.S. adults on the basis of their classification as having a parenting role (i.e., unpaid persons caring for children and adolescents aged <18 years, referred to as children in this report) or being an unpaid caregiver of adults (i.e., persons caring for adults aged ≥18 years),[§] CDC analyzed data from cross-sectional surveys that were administered during December 2020 and February–March 2021 for The COVID-19 Outbreak Public Evaluation (COPE) Initiative.[¶] Respondents were categorized as parents only, caregivers of adults only, parents-caregivers (persons in both roles), or nonparents/noncaregivers (persons in neither role). Adjusted odds ratios (aORs) for any adverse mental health symptoms, particularly suicidal ideation, were higher among all respondents who were parents, caregivers of adults, or both compared with respondents who were nonparents/noncaregivers and were highest among persons in both roles

(parents-caregivers) (any adverse mental health symptoms: aOR = 5.1, 95% confidence interval [CI] = 4.1–6.2; serious suicidal ideation: aOR = 8.2, 95% CI = 6.5–10.4). These findings highlight that parents and caregivers, especially those balancing roles both as parents and caregivers, experienced higher levels of adverse mental health symptoms during the COVID-19 pandemic than adults without these responsibilities. Caregivers who had someone to rely on for support had lower odds of experiencing any adverse mental health symptoms. Additional measures are needed to improve mental health among parents, caregivers, and parents-caregivers.

Among 16,384 eligible and invited unique respondents,** 10,469 (63.9%) completed English-language, Internet-based surveys administered to Qualtrics panels for The COPE Initiative during distinct intervals (December 6–27, 2020, and February 16–March 8, 2021). The nonprobability demographic quota sample was weighted to closely align with the distribution of the U.S. population by sex, age, and race/ethnicity.^{††} Data for explanatory and outcome variables were obtained from 10,444 (99.8%) respondents. Respondents described their parenting and caregiving roles, completed screening instruments for symptoms of anxiety and depression^{§§} and COVID-19 trauma- and stressor-related disorders

*These authors contributed equally to this report.

[†] <https://www.medrxiv.org/content/10.1101/2021.02.02.21251042v1>

[§] Parents and unpaid caregivers of adults were self-identified. Parents were defined as persons who had provided unpaid care to relatives or friends aged <18 years to help them take care of themselves at any time during the last 3 months. Unpaid caregivers of adults were defined as persons who had provided unpaid care to relatives or friends aged ≥18 years to help them take care of themselves at any time during the last 3 months. Respondents answered questions about these two roles separately. Respondents were categorized as parents only, caregivers of adults only, parents-caregivers (persons in both roles), or nonparents/noncaregivers. Whether adults who reported they were in parenting roles were biologic or legal parents or guardians of the children for whom they were providing care is not known, nor is it known whether adults were legal dependents of their caregivers.

[¶] The COPE Initiative (<https://www.thecopeinitiative.org/>) is designed to assess public attitudes, behaviors, and beliefs related to the COVID-19 pandemic and to evaluate the mental and physical health consequences of the pandemic. The COPE Initiative surveys included in this analysis were administered by Qualtrics, LLC (<https://www.qualtrics.com>), a commercial survey company with a network of participant pools comprising hundreds of suppliers and with varying recruitment methodologies that include digital advertisements and promotions, word-of-mouth and membership referrals, social networks, television and radio advertisements, and offline mail-based approaches.

** Eligibility to complete surveys was determined after electronic contact with potential participants who met criteria of age ≥18 years and U.S. residence. Age and residence were assessed using screening questions without indication of eligibility criteria before survey commencement. Country-specific geolocation verification via IP address mapping was used to ensure respondents were in the United States. Qualtrics, LLC, conducted data quality screening including algorithmic and keystroke analysis for attention patterns, click-through behavior, duplicate responses, machine responses, and inattentiveness.

^{††} Additional information on quota sampling, a nonprobabilistic sampling method, is available at <https://www.qualtrics.com/experience-management/research/sampling-methods/>. Demographic quotas were set for sex, age, race, and ethnicity using questions and national U.S. adult population estimates from the 2019 American Community Survey. After the surveys were conducted, iterative proportional fitting and weight trimming were applied to the overall sample to match 2019 American Community Survey estimates for sex, age, and combined race/ethnicity. Survey weighting was performed using the R survey package (version 3.29; R Foundation).

^{§§} Symptoms of anxiety and depression were assessed via the four-item Patient Health Questionnaire (PHQ-4), which refer to anxiety and depression symptoms experienced over the past 2 weeks. Those who scored ≥3 out of 6 on the Generalized Anxiety Disorder (GAD-2) or Patient Health Questionnaire (PHQ-2) subscales were considered symptomatic for these respective conditions.

(TSRDs),^{¶¶} and reported whether during the past 30 days they had wished they were dead or could go to sleep and not wake up (passive suicidal ideation) or had seriously considered trying to kill themselves (serious suicidal ideation).^{***}

Respondents were grouped based on their roles as 1) only parents of children aged <18 years (parents only), 2) only caregivers of adults aged ≥18 years (caregivers only), 3) having both roles (parents-caregivers), or 4) having neither role (nonparents/noncaregivers). Multivariable weighted logistic regression was used to estimate aORs by group for symptoms of anxiety or depression or COVID-19 TSRDs, passive suicidal ideation, serious suicidal ideation, or any of these symptoms. Covariates included gender, age, race/ethnicity, sexual orientation, disability status,^{†††} education, U.S. Census region^{§§§} and urbanicity^{¶¶¶} of residence, employment characteristics,^{****} and survey wave. Models also estimated aORs for adverse mental health symptoms by the following reasons for providing care for adults: 1) age-related health decline, 2) cognitive impairments (e.g., Alzheimer disease), 3) chronic medical conditions (e.g., cancer), 4) acute medical conditions (e.g., recovery after surgery), 5) mental health or substance use conditions, 6) active COVID-19 illness, 7) risk for severe COVID-19–associated

illness, or 8) other. Additional models among all caregivers of adults, which also adjusted for parenting, duration of caregiving, hours of caregiving per week, and person receiving care, were used to estimate aORs by level of agreement with statements about caregiving-related financial strain, family strife, preparedness, support, confidence, personal freedom, positive feelings, and resentment.^{††††} Variance inflation factors for all variables with aOR estimates were less than six, indicating acceptable multicollinearity.^{§§§§}

Participants provided informed electronic consent. Two-sided p values <0.05 were considered statistically significant. Rounded, weighted values are reported. Analyses were conducted using Python (version 3.7.8; Python Software Foundation) and R (version 4.0.2; R Foundation) using the R survey package (version 3.29; R Foundation). The Monash University Human Research Ethics Committee reviewed and approved the study. This activity was also reviewed by CDC and was conducted consistent with applicable federal law and CDC policy.^{¶¶¶¶}

Overall, 42.5% of the 10,444 U.S. adult respondents identified as parents of children, caregivers of adults, or both, including 8.4% as parents only, 11.2% as caregivers only, and 22.9% as parents-caregivers (Table 1). Among all respondents who were parents, caregivers, or parents-caregivers, 45.0% were women and 50.2% were aged 25–44 years. The distribution by race/ethnicity was similar to those of the overall sample and the U.S. adult population. A total of 71.4% of parents or caregivers reported paid employment in addition to their parenting or unpaid caregiving roles.

Approximately 70% of all caregivers (parents only, caregivers of adults only, or those with both roles) reported adverse mental health symptoms, including symptoms of anxiety or depression (55.3%), COVID-19 TSRDs (53.8%), or passive (39.3%) or serious (32.2%) suicidal ideation (Table 2). Among 2,391 parents-caregivers, approximately 85% experienced one or more adverse mental health symptoms, and approximately 50% reported past-month serious suicidal ideation. Parenting and caregiving were significantly positively associated with

^{¶¶} Disorders classified as TSRDs in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, include posttraumatic stress disorder (PTSD), acute stress disorder (ASD), and adjustment disorders, among others. Symptoms of a TSRD attributed to the COVID-19 pandemic were assessed via the six-item Impact of Event scale (IES-6) to screen for overlapping symptoms of PTSD, ASD, and adjustment disorders. The COVID-19 pandemic was specified as the traumatic exposure to record peritraumatic and posttraumatic symptoms associated with the range of stressors introduced by the COVID-19 pandemic. Those who scored ≥1.75 out of 4 were considered symptomatic.

^{***} For questions related to suicidal ideation, participants were informed that responses were deidentified and that direct support could not be provided to those who reported substance use behavior or suicidal ideation. Regarding suicidal ideation, all respondents were provided the following: “This survey is anonymous, so we cannot provide direct support. If you would like crisis support, please contact the National Suicide Prevention Lifeline, 1-800-273-TALK (8255, or chat line) for help for yourself or for others.” Passive suicidal ideation was assessed using an item from the Columbia-Suicide Severity Rating Scale adapted to refer to the past 30 days: “At any time in the past 30 days, have you wished you were dead or wished you could go to sleep and not wake up?” Serious suicidal ideation was assessed using an item from the National Survey on Drug Use and Health adapted to refer to the past 30 days: “At any time in the past 30 days, did you seriously think about trying to kill yourself?”

^{†††} Persons who had a disability were defined as such based on a qualifying response to either one of the two following questions: “Are you limited in any way in any activities because of physical, mental, or emotional condition?” and “Do you have any health conditions that require you to use special equipment, such as a cane, wheelchair, special bed, or special telephone?” <https://www.cdc.gov/brfss/questionnaires/pdf-ques/2015-brfss-questionnaire-12-29-14.pdf>

^{§§§} https://www2.census.gov/geo/pdfs/maps-data/maps/reference/us_regdiv.pdf

^{¶¶¶} <https://www.hrsa.gov/rural-health/about-us/definition/datafiles.html>

^{****} Employment characteristics included employment status (employed, unemployed, retired, or student only), weekly paid work hours, and percentage of work hours completed remotely versus on-site.

^{††††} Respondents rated their level of agreement to statements using a five-item Likert scale (1 = strongly disagree; 2 = disagree; 3 = neither agree nor disagree; 4 = agree; 5 = strongly agree) taken from the ARCHANGELS short-form Caregiver Intensity Index (CII), a copyrighted instrument available for use only with permission. Responses were trichotomized to disagree (1 and 2), neutral (3), or agree (4 and 5). CII was administered to all unpaid caregivers of adults.

^{§§§§} The maximum acceptable level of variance inflation factor cutoff was set at 10, which signals high multicollinearity (i.e., when two or more explanatory variables in a multivariable model are highly correlated). <https://www.itl.nist.gov/div898/software/dataplot/refman2/auxillar/vif.htm>

^{¶¶¶¶} 45 C.F.R. part 46, 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d); 5 U.S.C. Sect. 552a; 44 U.S.C. Sect. 3501 et seq.

Table 31 (13.1) Demographic characteristics of respondents, by parent/caregiver role — The COVID-19 Outbreak Public Evaluation Initiative, United States, December 2020 and February–March 2021

TABLE 1. Demographic characteristics of respondents, by parent/caregiver role — The COVID-19 Outbreak Public Evaluation Initiative, United States, December 2020 and February–March 2021

Characteristic	Weighted no. (%)*					
	Total	Nonparents/ Noncaregivers	Parents only, caregivers of adults only, and parents-caregivers†	Parents only	Caregivers of adults only	Parents- caregivers
Total	10,444 (100)	6,008 (57.5)	4,436 (42.5)	875 (8.4)	1,170 (11.2)	2,391 (22.9)
Gender§						
Female	5,138 (49.2)	3,144 (52.3)	1,995 (45.0)	510 (58.2)	611 (52.2)	874 (36.6)
Male	5,227 (50.1)	2,827 (47.1)	2,400 (54.1)	360 (41.2)	552 (47.2)	1,487 (62.2)
Transgender	58 (0.6)	26 (0.4)	32 (0.7)	—	—	26 (1.1)
Age group, yrs						
18–24	1,248 (11.9)	549 (9.1)	699 (15.7)	91 (10.5)	145 (12.4)	462 (19.3)
25–44	3,605 (34.5)	1,377 (22.9)	2,227 (50.2)	426 (48.6)	393 (33.6)	1,409 (58.9)
45–64	3,419 (32.7)	2,293 (38.2)	1,126 (25.4)	266 (30.4)	427 (36.5)	433 (18.1)
≥65	2,172 (20.8)	1,789 (29.8)	384 (8.6)	92 (10.5)	205 (17.5)	87 (3.7)
Race/Ethnicity						
White, non-Hispanic	6,297 (60.3)	3,660 (60.9)	2,637 (59.5)	550 (62.9)	711 (60.7)	1,376 (57.6)
Black, non-Hispanic	1,297 (12.4)	766 (12.7)	531 (12.0)	103 (11.8)	135 (11.5)	293 (12.2)
Asian, non-Hispanic	589 (5.6)	408 (6.8)	181 (4.1)	43 (4.9)	67 (5.7)	71 (3.0)
Other, multiple races, non-Hispanic¶	382 (3.7)	220 (3.7)	162 (3.6)	36 (4.2)	61 (5.2)	64 (2.7)
Hispanic, any race	1,880 (18.0)	955 (15.9)	925 (20.9)	142 (16.3)	196 (16.8)	587 (24.5)
Employment status						
Employed	5,813 (55.7)	2,645 (44.0)	3,167 (71.4)	518 (59.2)	654 (55.9)	1,995 (83.4)
≤40 hrs, <20% remote	1,500 (14.4)	970 (16.1)	531 (12.0)	153 (17.5)	179 (15.3)	199 (8.3)
≤40 hrs, 20%–80% remote	1,209 (11.6)	448 (7.5)	761 (17.2)	102 (11.7)	144 (12.3)	515 (21.5)
≤40 hrs, >80% remote	877 (8.4)	490 (8.2)	387 (8.7)	76 (8.7)	82 (7.0)	228 (9.5)
>40 hrs, <20% remote	568 (5.4)	341 (5.7)	227 (5.1)	66 (7.6)	79 (6.8)	81 (3.4)
>40 hrs, 20%–80% remote	1,120 (10.7)	224 (3.7)	896 (20.2)	80 (9.1)	117 (10.0)	699 (29.2)
>40 hrs, >80% remote	539 (5.2)	172 (2.9)	366 (8.3)	41 (4.7)	53 (4.6)	272 (11.4)
Unemployed	1,791 (17.2)	1,160 (19.3)	632 (14.2)	208 (23.8)	215 (18.4)	208 (8.7)
Retired	2,517 (24.1)	2,010 (33.5)	508 (11.4)	124 (14.2)	265 (22.7)	119 (5.0)
Student	322 (3.1)	193 (3.2)	129 (2.9)	24 (2.8)	36 (3.0)	69 (2.9)
Duration in parenting/caregiving role						
<3 mos	—	—	993 (22.4)	183 (20.9)	357 (30.5)	454 (19.0)
4–12 mos	—	—	1,368 (30.8)	180 (20.5)	264 (22.6)	924 (38.6)
>1 yr	—	—	2,075 (46.8)	513 (58.6)	549 (46.9)	1,013 (42.4)
Parenting, hrs/wk						
<10	—	—	—	145 (16.5)	—	261 (10.9)
10–20	—	—	—	207 (23.7)	—	377 (15.8)
21–40	—	—	—	211 (24.1)	—	570 (23.8)
41–60	—	—	—	92 (10.5)	—	374 (15.7)
>60	—	—	—	220 (25.2)	—	808 (33.8)
Adult caregiving, hrs/wk						
<10	—	—	—	—	317 (27.1)	239 (10.0)
10–20	—	—	—	—	363 (31.0)	457 (19.1)
21–40	—	—	—	—	229 (19.6)	606 (25.4)
41–60	—	—	—	—	80 (6.8)	352 (14.7)
>60	—	—	—	—	182 (15.6)	737 (30.8)
Reason for providing care for adults**						
Age-related health decline	—	—	—	—	477 (40.8)	587 (24.5)
Cognitive impairments	—	—	—	—	188 (16.1)	339 (14.2)
Chronic health condition	—	—	—	—	303 (25.9)	662 (27.7)
Acute health condition	—	—	—	—	118 (10.1)	405 (16.9)
Mental health or substance use condition	—	—	—	—	162 (13.9)	573 (24.0)
Active case of COVID-19	—	—	—	—	96 (8.2)	659 (27.5)
Risk for severe COVID-19	—	—	—	—	190 (16.3)	637 (26.6)
Other	—	—	—	—	165 (14.1)	155 (6.5)

See table footnotes on the next page.

Table 31 (13.1) (continued) Demographic characteristics of respondents, by parent/caregiver role — The COVID-19 Outbreak Public Evaluation Initiative, United States, December 2020 and February–March 2021

TABLE 1. (Continued) Demographic characteristics of respondents, by parent/caregiver role — The COVID-19 Outbreak Public Evaluation Initiative, United States, December 2020 and February–March 2021

* Weighted numbers and percentages might not sum to expected values because of rounding.

† Parents and unpaid caregivers of adults were self-identified. Parents were defined as persons who had provided unpaid care to relatives or friends aged <18 years to help them take care of themselves at any time in the last 3 months. Unpaid caregivers of adults were defined as persons who had provided unpaid care to relatives or friends aged ≥18 years to help them take care of themselves at any time in the last 3 months. Respondents answered questions about parenting and caregiving separately. Respondents were categorized as parents only, caregivers (of adults) only, parents-caregivers (persons in both roles), or nonparents/noncaregivers. Whether adults in parenting roles were biologic or legal parents or guardians of the children for whom they were providing care is not known, nor is it known whether adults were legal dependents of their caregivers. This column includes all parents, caregivers of adults, and parents-caregivers listed in the next three columns. Weighted numbers and percentages might not sum to expected values because of rounding. Unweighted numbers and percentages for key demographic variables were as follows: survey wave (December 2020: 5,188 [49.7%]; February–March 2021: 5,256 [50.3%]), gender (female: 5,429 [52.0%]; male: 4,958 [47.5%]; transgender: 35 [0.3%]; none of these: 22 [0.2%]), age group (18–24 years: 867 [8.3%]; 25–44 years: 3,681 [35.2%]; 45–64 years: 2,994 [28.7%]; ≥65 years: 2,902 [27.8%]), and race/ethnicity (non-Hispanic White: 7,737 [74.1%]; non-Hispanic Black: 1,058 [10.1%]; non-Hispanic Asian: 529 [5.1%]; non-Hispanic other or multiple races: 353 [3.4%]; Hispanic or Latino: any race or races, 767 [7.3%]).

‡ Respondents who chose “none of these” are not shown because of small numbers (total respondents: weighted $n = 20$, caregivers: weighted $n = 10$). Cells with counts <10 are not shown for privacy reasons.

§ Includes respondents who identified as non-Hispanic and as more than one race or as American Indian or Alaska Native, Native Hawaiian or Other Pacific Islander, or all other races.

** Caregivers of adults could select multiple answers.

each adverse mental health symptom compared with being a nonparent/noncaregiver (for one or more symptoms, parents only: aOR = 1.5; caregivers only: aOR = 1.8; parents-caregivers: aOR = 5.1) and was particularly high for serious suicidal ideation among parents-caregivers compared with nonparents/noncaregivers (aOR = 8.2). Among respondents providing care for an adult for a given health condition compared with those not providing care for that condition, the highest aORs for adverse mental health symptoms were observed for caregivers of adults with mental health or substance use conditions (e.g., one or more symptoms: aOR = 5.0), adults with an active case of COVID-19 (aOR = 4.4), or adults at risk for severe COVID-19 (aOR = 3.9) (Table 2). Higher aORs for all adverse mental health symptoms were also observed for caregivers who were caring for adults with acute health conditions, chronic health conditions, cognitive impairments, and age-related health decline.

Among all caregivers of adults (adult caregivers only and parents-caregivers), those who agreed with the statements that they had experienced caregiving-related family disagreements or resented their caregiving responsibilities had approximately three times the odds for any adverse mental health symptoms (Figure) compared with those who disagreed with these statements. Similarly, aORs for any adverse mental health symptoms were approximately twice as high for caregivers who agreed that they felt underprepared as a caregiver, did not have the personal freedom they desired, or had to decrease living expenses to help pay for things, compared with caregivers who did not agree with these statements. Conversely, persons who had someone to rely on for support had lower odds of experiencing any adverse mental health symptoms.

Discussion

Approximately 40% of U.S. adults surveyed in late 2020 or early 2021 reported having parenting responsibilities, adult caregiving responsibilities, or both. Overall, 70% of all caregivers (parents only, caregivers of adults only, or those with both roles) reported recent adverse mental health symptoms, including symptoms of anxiety or depression, COVID-19 TSRDs, or suicidal ideation. Of particular concern, 85% of respondents with both parenting responsibilities and adult caregiving responsibilities experienced adverse mental health symptoms, and approximately 50% reported past-month serious suicidal ideation, with eight times the odds of serious suicidal ideation compared with nonparents/noncaregivers.

Caregivers of adults with mental health or substance use conditions, adults currently ill with COVID-19, or adults at risk for severe COVID-19 reported more adverse mental health symptoms than did caregivers of adults with other conditions, highlighting the need for education and support for caregivers in these roles. Social factors, such as financial strain, feeling a lack of preparedness for or resentment of caregiving, a lack of freedom, and family conflict were also associated with adverse mental health. The lower odds of having any adverse mental health symptoms based on the perception of having a person to rely on for support is encouraging. Because employment and caregiving responsibilities might limit the time available to seek help, telehealth and Internet-based interventions (3) might improve caregiver mental health; however, Internet access might be limited for some populations, particularly those with lower incomes. In addition, adult day services centers might benefit the mental health of caregivers and of those for whom they are providing care (4).***** Finally,

***** <https://www.cdc.gov/coronavirus/2019-ncov/community/adult-day-care-service-centers.html>

Table 32 (13.2) . Prevalence of and adjusted odds ratios for adverse mental health symptoms, by parent/caregiver role and reason for providing care for adults — The COVID-19 Outbreak Public Evaluation Initiative, United States, December 2020 and February–March 2021

TABLE 2. Prevalence of and adjusted odds ratios for adverse mental health symptoms, by parent/caregiver role and reason for providing care for adults — The COVID-19 Outbreak Public Evaluation Initiative, United States, December 2020 and February–March 2021

Caregiver role and reason for providing care	Symptoms											
	Total		Anxiety or depression*		COVID-19 TSRD†		Past-month passive suicidal ideation§		Past-month serious suicidal ideation§		Any of these symptoms	
Total, no. (%) (95% CI)¶	10,444 (100)	—	3,780 (36.2)	(35.1–37.3)	3,596 (34.4)	(33.3–35.5)	2,321 (22.2)	(21.2–23.2)	1,697 (16.2)	(15.4–17.1)	5,001 (47.9)	(46.8–49.0)
Parent role/caregiver role,** no. (%) (95% CI)¶												
Nonparent/ Noncaregiver	6,008 (57.5)	(56.4–58.7)	1,327 (22.1)	(20.8–23.4)	1,209 (20.1)	(18.8–21.4)	580 (9.6)	(8.7–10.7)	269 (4.5)	(3.8–5.3)	1,925 (32.0)	(30.6–33.5)
Parent only, caregiver of adults only, or parent-caregiver	4,436 (42.5)	(41.3–43.6)	2,453 (55.3)	(53.4–57.2)	2,387 (53.8)	(51.9–55.7)	1,741 (39.3)	(37.4–41.1)	1,428 (32.2)	(30.4–34.0)	3,076 (69.3)	(67.6–71.0)
Parent only	875 (8.4)	(7.8–9.0)	315 (35.9)	(32.2–39.8)	304 (34.8)	(31.0–38.7)	162 (18.5)	(15.2–22.2)	79 (9.0)	(6.9–11.4)	443 (50.6)	(46.6–54.6)
Caregiver of adults only	1,170 (11.2)	(10.4–12.0)	454 (38.8)	(35.2–42.5)	425 (36.3)	(32.8–40.0)	187 (16.0)	(13.5–18.7)	118 (10.1)	(8.1–12.4)	591 (50.5)	(46.8–54.2)
Parent-caregiver	2,391 (22.9)	(21.9–23.9)	1,685 (70.5)	(67.9–72.9)	1,658 (69.3)	(66.8–71.8)	1,392 (58.2)	(55.6–60.9)	1,232 (51.5)	(48.8–54.2)	2,043 (85.4)	(83.5–87.2)
Parent role/caregiver role,** aOR (95% CI)††												
Parent only	—	—		1.4 (1.1–1.7)		1.5 (1.2–1.9)		1.5 (1.2–2.0)		1.6 (1.1–2.2)		1.5 (1.2–1.8)
Adult caregiver only	—	—		1.9 (1.6–2.3)		1.8 (1.5–2.2)		1.3 (1.0–1.7)		1.7 (1.2–2.3)		1.8 (1.5–2.1)
Parent-caregiver	—	—		3.7 (3.1–4.5)		3.6 (3.1–4.3)		5.8 (4.8–7.1)		8.2 (6.5–10.4)		5.1 (4.1–6.2)
Reason for care for adults, aOR (95% CI)§§												
Age-related health decline	—	—		1.8 (1.4–2.3)		1.8 (1.5–2.3)		1.4 (1.1–1.8)		1.8 (1.3–2.3)		1.9 (1.5–2.4)
Cognitive challenges	—	—		2.0 (1.5–2.7)		2.0 (1.5–2.6)		2.3 (1.7–3.0)		3.1 (2.2–4.4)		2.2 (1.7–2.8)
Chronic health condition	—	—		2.8 (2.2–3.5)		1.9 (1.6–2.4)		2.8 (2.2–3.5)		3.3 (2.5–4.3)		2.3 (1.8–2.9)
Acute health condition	—	—		2.7 (1.9–3.7)		2.8 (2.1–3.7)		2.4 (1.8–3.2)		3.6 (2.6–4.9)		3.0 (2.1–4.3)
Mental health or substance use condition	—	—		3.7 (2.8–5.0)		3.7 (2.8–4.8)		3.0 (2.3–3.9)		3.8 (2.9–5.0)		5.0 (3.7–6.9)
Active case of COVID-19	—	—		3.8 (2.7–5.1)		3.1 (2.3–4.1)		4.2 (3.2–5.6)		5.5 (4.1–7.5)		4.4 (3.0–6.4)
Risk for severe COVID-19	—	—		3.4 (2.6–4.4)		2.8 (2.2–3.6)		3.5 (2.8–4.5)		4.7 (3.6–6.1)		3.9 (3.0–5.2)
Other	—	—		1.6 (1.1–2.5)		1.4 (1.0–1.9)		1.2 (0.8–1.9)		2.4 (1.6–3.6)		1.5 (1.0–2.2)

Abbreviations: aOR = adjusted odds ratio; ASD = acute stress disorder; CI = confidence interval; CII = Caregiving Intensity Index; GAD-2 = two-item Generalized Anxiety Disorder scale; IES-6 = six-item Impact of Event scale; PHQ-2 = two-item Patient Health Questionnaire; PHQ-4 = four-item Patient Health Questionnaire; PTSD = posttraumatic stress disorder; TSRD = trauma- and stressor-related disorder.

* Symptoms of anxiety and depression were assessed via PHQ-4. Those who scored ≥ 3 out of 6 on the GAD-2 or PHQ-2 subscales were considered symptomatic for anxiety or depression symptoms.

† Disorders classified as TSRDs in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, include PTSD, ASD, and adjustment disorders, among others. Symptoms of a TSRD attributed to the COVID-19 pandemic were assessed via IES-6 to screen for overlapping symptoms of PTSD, ASD, and adjustment disorders. The COVID-19 pandemic was specified as the traumatic exposure to record peritraumatic and posttraumatic symptoms associated with the range of stressors introduced by the COVID-19 pandemic. Those who scored ≥ 1.75 out of 4 were considered symptomatic.

§ Passive suicidal ideation was assessed using an item from the Columbia-Suicide Severity Rating Scale adapted to refer to the past 30 days: "At any time in the past 30 days, have you wished you were dead or wished you could go to sleep and not wake up?" Serious suicidal ideation was assessed using an item from the National Survey on Drug Use and Health adapted to refer to the past 30 days: "At any time in the past 30 days, did you seriously think about trying to kill yourself?"

¶ Weighted numbers and percentages might not sum to expected values because of rounding.

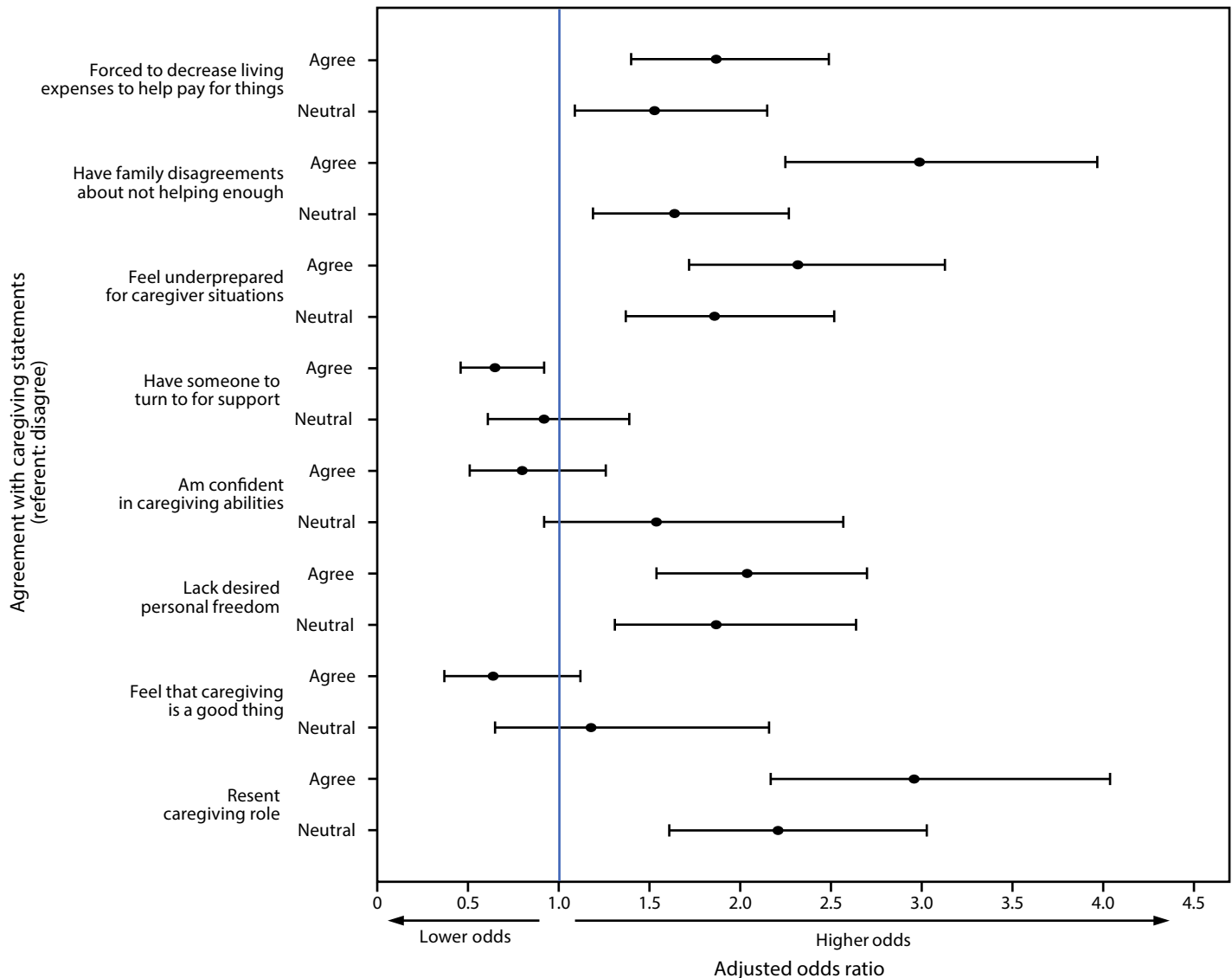
** Parents and unpaid caregivers of adults were self-identified. For this analysis, parents were defined as persons who had provided unpaid care to relatives or friends aged <18 years to help them take care of themselves at any time in the last 3 months. Unpaid caregivers of adults were defined as persons who had provided unpaid care to relatives or friends aged ≥ 18 years to help them take care of themselves at any time in the last 3 months. Respondents answered questions about these two roles separately. Respondents were categorized as parents only, caregivers of adults only, parents-caregivers (persons in both roles), or nonparents/noncaregivers. Whether adults in parenting roles were biologic or legal parents or guardians of the children for whom they were providing care is not known, nor is it known whether adults were legal dependents of their caregivers.

†† Referent: nonparent/noncaregiver. Weighted multivariable logistic regression models were used to estimate aORs for each adverse mental health symptom, with survey wave, gender, age group, race/ethnicity, sexual orientation, disability status, education attainment, region, urbanicity, and employment (work hours per week and remote work percentage) as covariates. P values <0.05 were considered statistically significant. Models with all unpaid caregiver statuses included 10,017 respondents because persons who answered "prefer not to say" for sexual orientation or disability status and those who reported invalid zip codes were excluded. Models with unpaid caregivers of adults included 3,155 respondents; respondents were excluded for the same reasons.

§§ Referent: not providing care to an adult for this reason. This referent group includes all adults not providing care for the listed reason, including those who were nonparents/noncaregivers, parents only, and caregivers of adults who were providing care for different reasons.

Figure 20 (13.1) Factors associated with adverse mental health symptoms among unpaid caregivers of adults and parent-caregivers — The COVID-19 Outbreak Public Evaluation Initiative, United States, December 2020 and February–March 2021

FIGURE. Factors* associated† with adverse mental health symptoms‡ among unpaid caregivers of adults and parents-caregivers§ — The COVID-19 Outbreak Public Evaluation Initiative, United States, December 2020 and February–March 2021



Abbreviations: ASD = acute stress disorder; CII = Caregiving Intensity Index; GAD-2 = two-item Generalized Anxiety Disorder scale; IES-6 = six-item Impact of Event scale; PHQ-2 = two-item Patient Health Questionnaire; PHQ-4 = four-item Patient Health Questionnaire; PTSD = posttraumatic stress disorder; TSRD = trauma- and stressor-related disorder.

* Caregiving statements were taken from the ARCHANGELS short-form CII, a copyrighted instrument available for use only with permission.

† Adjusted odds ratios, with 95% confidence intervals indicated by error bars, were estimated using weighted multivariable logistic regression models. The primary model is adjusted for survey wave, gender, age group, race/ethnicity, sexual orientation, disability status, education attainment, region, urbanicity, and employment (including work hours per week and remote work percentage), parental status (i.e., whether caregivers were parents-caregivers), duration of caregiving, hours of caregiving per week, and person receiving care. Additional separate models were analyzed for each CII item that was based on perceived levels of agreement with statements regarding caregiving-related financial strain, family strife, preparedness, support, confidence, personal freedom, positive feelings, and resentment.

‡ The presence of one or more of the following was considered an adverse mental health symptom: anxiety symptoms, depression symptoms, COVID-19 TSRD symptoms, passive suicidal ideation, or having seriously considered suicide in the past 30 days. Symptoms of anxiety and depression were assessed via PHQ-4. Those who scored ≥ 3 out of 6 on the GAD-2 and PHQ-2 subscales were considered symptomatic for these respective conditions. Disorders classified as TSRDs in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, include PTSD, ASD, and adjustment disorders, among others. Symptoms of a TSRD attributed to the COVID-19 pandemic were assessed via IES-6 to screen for overlapping symptoms of PTSD, ASD, and adjustment disorders. The COVID-19 pandemic was specified as the traumatic exposure to record peritraumatic and posttraumatic symptoms associated with the range of stressors introduced by the COVID-19 pandemic. Those who scored ≥ 1.75 out of 4 were considered symptomatic. Passive suicidal ideation was assessed using an item from the Columbia-Suicide Severity Rating Scale adapted to refer to the past 30 days: "At any time in the past 30 days, have you wished you were dead or wished you could go to sleep and not wake up?" Serious suicidal ideation was assessed using an item from the National Survey on Drug Use and Health, adapted to refer to the past 30 days: "At any time in the past 30 days, did you seriously think about trying to kill yourself?"

§ Parents and unpaid caregivers of adults were self-identified. Unpaid caregivers of adults were defined as persons who had provided unpaid care to relatives or friends aged ≥ 18 years to help them take care of themselves at any time in the last 3 months. Parents were defined as persons who had provided unpaid care to relatives or friends aged < 18 years to help them take care of themselves at any time in the last 3 months. Parents-caregivers had both roles. All unpaid caregivers of adults were included in this analysis, including caregivers of adults only (i.e., not parents) and parents-caregivers.

suicide prevention^{†††††} and mental health disaster support services^{§§§§§,¶¶¶¶¶,*****} are needed for parents and caregivers.

During the pandemic, parents and caregivers have had worse mental health than adults without parenting and caregiving responsibilities (5). Managing mental health might be especially challenging for parents balancing employment and remote education; virtual instruction during the COVID-19 pandemic has presented risks for mental health both among children and parents (6). For caregivers of adults, these findings reinforce prepandemic data on poor mental health among caregivers (7). The results also support AmeriSpeak Omnibus survey findings that during the COVID-19 pandemic, caregivers had substantial concerns about their own mental health and the health and well-being of their care recipients, were worried about their finances, and needed respite from caregiving (8). Adverse mental health consequences for persons in both roles (i.e., parents-caregivers) support an urgent need to tailor public health efforts to this population. Together, these results suggest that parents and caregivers might benefit from tailored mental health services. For caregivers, and especially persons with dual responsibilities of parenting while also caring for adults, increasing access to, awareness of, and use of support groups and respite services^{†††††} might help to alleviate the caregiving workload^{§§§§§} (9).

The findings in this report are subject to at least six limitations. First, this study did not fully characterize parenting roles (e.g., age and number of children, whether children had chronic health conditions, and whether children were in virtual rather than in-person school). Whether the mental health of adults differs based on these factors could be explored. Second, diagnostic evaluations for anxiety and depression were not conducted; however, clinically validated instruments were used to measure symptoms of anxiety and depression. Third, responses might be subject to social desirability bias, particularly regarding negative feelings about caregiving roles, which might be underreported. Fourth, without prepandemic mental health data in this sample, whether adverse mental health symptoms were caused by or worsened by the pandemic is unknown. However, caregivers of adults had higher odds of new adverse mental or behavioral health symptoms during the pandemic than did noncaregivers

Summary

What is already known about this topic?

Parents of children aged <18 years and unpaid caregivers of adults have had mental health challenges before and during the COVID-19 pandemic.

What is added by this report?

Among 10,444 U.S. adults surveyed during December 6–27, 2020, and February 16–March 8, 2021, parents, unpaid caregivers of adults, and parents-caregivers (persons in both roles) had significantly worse mental health than adults not in these roles, including five times the odds of any adverse mental health symptoms (parents-caregivers). Persons who had someone to rely on for support had lower odds of experiencing any adverse mental health symptoms.

What are the implications for public health practice?

Parents and unpaid caregivers of adults, and particularly those in both roles, might benefit from mental health support and services tailored to their roles.

(1). Fifth, the survey did not assess support systems for parents or caregivers (e.g., child care or support from family members), which could have affected the intensity of their caregiving roles. Finally, because the surveys were English-language only and quota sampling and survey weighting might not have eliminated inherent biases in Internet-based survey samples,^{¶¶¶¶¶} this sample might not fully represent the U.S. population, particularly regarding English-language fluency and Internet access. This might partially account for the finding that more parents, caregivers, or parents-caregivers were male. However, previous studies have estimated that up to 47% of caregivers are male. Furthermore, the infrequency of assessments of both parental and caregiving roles makes comparing these estimates difficult.^{*****} The prevalence and trajectories of anxiety and depression symptoms were consistent with results from the Household Pulse Survey^{†††††††} (10), and robust associations between parenting and caregiving roles and adverse mental health symptoms in the large, demographically diverse COPE Initiative sample merit additional research.

Caregivers, particularly persons with both parenting and adult caregiving responsibilities, will continue to face mental health challenges, and the need for caregivers is projected to increase as the U.S. population ages.^{§§§§§§§} Additional research can assess differences in coping and help-seeking behaviors among parents and caregivers to further guide tailored support and services to meet their needs during and after the COVID-19 pandemic.

^{†††††} National Suicide Prevention Lifeline (<https://suicidepreventionlifeline.org/>) or Lifeline Crisis Chat (<https://suicidepreventionlifeline.org/chat/>).

^{§§§§§} Substance Abuse and Mental Health Services Administration National Helpline (also known as the Treatment Referral Routing Service) for persons and families facing mental disorders, substance use disorders, or both (<https://www.samhsa.gov/find-help/national-helpline>).

^{¶¶¶¶¶} Disaster Distress Helpline (<https://www.samhsa.gov/disaster-preparedness>).

^{*****} Crisis Text Line (<https://www.crisistextline.org/>).

^{†††††††} <https://www.cdc.gov/aging/publications/features/caring-for-yourself.html>; <https://www.norc.umd.edu/PDFs/Maintaining%20Physical%20and%20Mental%20Well/OACCaregiverOnePager.pdf>

^{§§§§§§§} <https://www.caregiving.org/resources/>

^{¶¶¶¶¶} <https://www.pewresearch.org/politics/methodology/collecting-survey-data/internet-surveys/>

^{*****} <https://www.apa.org/pi/about/publications/caregivers/faq/statistics>

^{†††††††} <https://www.cdc.gov/nchs/covid19/pulse/mental-health.htm>

^{§§§§§§§} <https://www.cdc.gov/aging/caregiving/index.htm>

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Corresponding author: Elizabeth Rohan, Erohan@cdc.gov.

¹Turner Institute for Brain and Mental Health and School of Psychological Sciences, Monash University, Melbourne, Australia; ²Austin Health, Melbourne, Australia; ³Brigham & Women's Hospital, Boston, Massachusetts; ⁴CDC COVID-19 Response Team; ⁵Harvard Medical School, Boston, Massachusetts; ⁶ARCHANGELS, Boston, Massachusetts; ⁷WHOO, Inc., Boston, Massachusetts; ⁸University of Melbourne, Melbourne, Australia.

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70% of parents and caregivers of adults* reported adverse mental health symptoms during the COVID-19 pandemic



Anxiety or depression **(55%)**



COVID-19 trauma- and stressor-related disorders **(54%)**



Passive **(39%)** or serious **(32%)** suicidal thoughts

Parents and unpaid caregivers of adults could benefit from increased access to mental health support and resources

* COPE Initiative, Internet survey sample of 10,444 demographically diverse U.S. adults, December 2020 and February–March 2021.

SUMMARY OF FINDINGS

The Original Investigation presented in Chapter Thirteen revealed that adverse mental health symptoms were more common among all unpaid caregiving groups (parenting role only, caregiving of adults role only, and parenting-caregiving role) compared with adults in neither parenting nor caregiving roles. Adults in the role of both parenting for children and caregiving for adults had the highest odds of any adverse mental health symptoms (adjusted odds ratio = 5.1 [95% confidence interval = 4.1 to 6.2]), with particularly high odds of serious suicidal ideation (adjusted odds ratio = 8.2 [95% confidence interval = 6.5 to 10.4]). Prior literature suggests that the finding of disproportionate adverse mental health levels among persons in parent-caregiver roles (sometimes referred to as sandwich caregiver roles) might be related to role conflict between some combination of employment, a spousal relationship, caregiving for children, and caregiving for adults (O’Sullivan, 2015; Stephens et al., 2001). Within- and between-role strategies (e.g., living with integrity, being the best you can, doing what you love, loving what you do, remembering why, searching for signs of success) have helped some women with employment and parent-caregiver roles to achieve role balance (Evans et al., 2016). Beyond these within- and between-role strategies, external supports and services to assist parent-caregivers might be dependent upon socioeconomic status, as associations between caregiving and poor health were strongest in persons with lower income (E. K. Do et al., 2014).

Among unpaid caregivers of adults, persons who were providing unpaid care for adults with mental health or substance use conditions or COVID-19 had the highest odds of adverse mental health symptoms. A grounded theory study suggests that over time, caregivers of people with mental health conditions transition from being overwhelmed and consumed by the role to finding balance with that role in relation to other areas of their lives (Wynaden, 2007). Consistent with our finding of high levels of anxiety or depression in caregivers of adults with COVID-19, a survey of such

unpaid caregivers in Iran found high levels of depression (78%), anxiety (75%), and stress (80%) (**Jafari-Oori et al., 2021**). Finally, we found that adverse mental health symptoms were associated with caregiving-related family disagreements, resentment for caregiver responsibilities, feelings of under-preparedness for caregiving, less personal freedom, and reduced living expenses to help pay for things as part of the caregiving role. Conversely, caregivers who identified as having someone to turn to for support had lower odds of adverse mental health symptoms.

Future research could explore parental and caregiver mental health in relation to school closures, which were implemented at various times during the pandemic. Indeed, a CDC-led study of parents of children aged 5-12 years found that virtual instruction presented more potential risks related to child and parental mental and emotional health and some health-supporting behaviours than did in-person education (**Verlenden et al., 2021**). On the other hand, a study by the Circadian Light in Adolescence, Sleep and School (CLASS) Study team found that among 59 participants in their first year of secondary schooling in Melbourne, Australia, participating students slept 22 minutes longer, reported significantly lower sleepiness, and lower anxiety symptoms during remote learning as compared with in-person learning (**Stone et al., 2021**). Improved mental health and well-being of children and adolescents could influence the mental health of their parents and caregivers. Additional investigation is warranted.

The findings of this report were particularly meaningful given that it was the first caregiving-focused COVID-19 report in the CDC's *MMWR* and the first-ever report focused on mental health among unpaid caregivers in the *MMWR* (**Edwards, 2020**). Moreover, poor mental health among caregivers is associated with physical health morbidities (**H.-Y. Chang et al., 2010**). Given that the need for unpaid caregivers is projected to increase with an ageing global population (**United Nations Department of Economic and Social Affairs, 2020**), recognising and supporting this

population is of critical importance. Continued surveillance of mental health among people in unpaid caregiver roles will help to raise awareness about the experiences of this population and to ensure that sufficient resources and support services are made available, which will provide the dual benefit of helping unpaid caregivers and thereby helping the people for whom they care.

CHAPTER 14: Mental Health and Substance Use During the COVID-19 Pandemic Among Adults with Disabilities — United States, February–March 2021

PREFACE TO CHAPTER 14

People with disabilities have been disproportionately impacted by the COVID-19 pandemic, including increased risk of adverse COVID-19 health outcomes and reduced access to routine health care and rehabilitation (**Shakespeare et al., 2021**). In 2020, a study of nearly 65 million patients across 547 health care organizations revealed that intellectual disabilities were the strongest independent risk factor for a COVID-19 diagnosis, and the second-strongest risk factor for mortality behind age, as people with intellectual disabilities had six times the odds of COVID-19 mortality compared with people without such disabilities (**Gleason et al., 2021**). People with disabilities have also historically experienced higher levels of adverse mental distress compared to adults without disabilities (**Cree et al., 2020**), and evidence from April and May of 2020 indicated that this population continued to report elevated levels of adverse mental health symptoms and substance use during the first months of the COVID-19 pandemic (**Okoro et al., 2021**). Moreover, depression and substance use are bidirectionally related in the general population (**Pacek et al., 2013**), and depression-related stigma is associated with emotion dysregulation, and in turn substance use to cope (**K. Wang et al., 2018**). Given higher levels of pre-pandemic substance use among people with disabilities compared to people without disabilities (**Glazier & Kling, 2013**), and population-level increases in substance use during the pandemic in the US and several other countries (**Jacob et al., 2021; Pollard et al., 2020; T. D. Tran et al., 2020**), we sought to compare levels of substance use among these populations.

The Original Investigation in Chapter Fourteen (**Czeisler et al., 2021**), which was published in the *MMWR*, was prepared in collaboration with members of the CDC's Disproportionately Affected Populations Team within the Community Interventions and Critical Populations Task Force. The aims of the manuscript were to identify factors associated with adverse mental health symptoms and substance use among people with disabilities compared to people without disabilities, and to assess self-reported changes in substance use before and during the COVID-19 pandemic by type of substance (alcohol, marijuana, cocaine, methamphetamine, prescription or illicit opioids, benzodiazepines, and prescription drugs other than opioids used in a way not directed by a doctor).

The two-question disability screener was selected at the recommendation of the CDC's Disproportionately Affected Populations Team. Given the large scope of The COPE Initiative and scarcity of literature on the pandemic experience of people with disabilities at the time, detecting the population of adults with disabilities broadly was prioritized over specific conditions (e.g., sensory, mobility, cognitive). Therefore, differentiation between disability types was not possible, and remains an area that warrants research attention. Specific substances were assessed given varying trends of drug use and drug overdose deaths in the US, with particularly concerning trends with a 1,040% increase in opioid-involved drug overdose deaths and 206% increase in cocaine-involved overdose deaths in 2019 as compared with 2013 (**Mattson et al., 2021**). In addition to reported individual changes, polysubstance use (i.e., more than one substance) was also assessed given that polysubstance use is common among persons with opioid use disorder (**Cicero et al., 2020**). Substance-specific findings could have implications for screening programs and treatment services. The chapter concludes with a brief overview of findings from the Original Investigation.

CHAPTER FOURTEEN: Mental Health and Substance Use During the COVID-19 Pandemic Among Adults with Disabilities — United States, February–March 2021

Czeisler MÉ, Board A, Thierry JM, Czeisler CA, Rajaratnam SMW, Howard ME, Clarke KEN. Mental Health and Substance Use Among Adults with Disabilities During the COVID-19 Pandemic - United States, February-March 2021. *MMWR Morb Mortal Wkly Rep*. 2021 Aug 27;70(34):1142-1149. doi: 10.15585/mmwr.mm7034a3. PMID: 34437518; PMCID: PMC8389385.

Mental Health and Substance Use Among Adults with Disabilities During the COVID-19 Pandemic — United States, February–March 2021

Mark É. Czeisler^{1,2,3,4}; Amy Board, DrPH^{5,6,7}; JoAnn M. Thierry, PhD⁵; Charles A. Czeisler, PhD, MD^{1,3,4}; Shantha M.W. Rajaratnam, PhD^{1,2,3,4}; Mark E. Howard, MBBS, PhD^{1,2,8}; Kristie E.N. Clarke, MD⁵

Adults with disabilities, a group including >25% of U.S. adults (1), experience higher levels of mental health and substance use conditions and lower treatment rates than do adults without disabilities* (2,3). Survey data collected during April–September 2020 revealed elevated adverse mental health symptoms among adults with disabilities (4) compared with the general adult population (5). Despite disproportionate risk for infection with SARS-CoV-2, the virus that causes COVID-19, and COVID-19–associated hospitalization and mortality among some adults with disabilities (6), information about mental health and substance use in this population during the pandemic is limited. To identify factors associated with adverse mental health symptoms and substance use among adults with disabilities, the COVID-19 Outbreak Public Evaluation (COPE) Initiative[†] administered nonprobability-based Internet surveys to 5,256 U.S. adults during February–March 2021 (response rate = 62.1%). Among 5,119 respondents who completed a two-item disability screener, nearly one-third (1,648; 32.2%) screened as adults with disabilities. These adults more frequently experienced symptoms of anxiety or depression (56.6% versus 28.7%, respectively), new or increased substance use (38.8% versus 17.5%), and suicidal ideation (30.6% versus 8.3%) than did adults without disabilities. Among all adults who had received a diagnosis of mental health or substance use conditions, adults with disabilities more frequently (42.6% versus 35.3%; $p < 0.001$) reported that the pandemic made it harder for them to access related care or medication. Enhanced mental health and substance use screening among adults with disabilities and improved access to medical services are critical during public health emergencies such as the COVID-19 pandemic.

During February 16–March 8, 2021, among 8,475 eligible invited respondents aged ≥ 18 years, 5,261 (62.1%) completed nonprobability based, English-language, Internet-based

Qualtrics surveys for COPE.[§] Participants provided informed consent electronically. Quota sampling and survey weighting were used to match U.S. Census Bureau's 2019 American Community Survey adult U.S. population estimates for sex, age, and race/ethnicity to enhance the representativeness of this nonrandom sample.

Among 5,256 respondents who answered questions for weighting variables, 5,119 (97.4%) completed a two-question disability screener.[¶] Respondents completed clinically validated self-screening instruments for symptoms of anxiety and depression** and reported past-month new or increased substance use to cope with stress or emotions and serious suicidal ideation.^{††} Respondents also indicated prepandemic and past-month use of seven classes^{§§} of substances to cope with stress or emotions. Adults with diagnosed anxiety, depression, posttraumatic stress disorder, or substance use disorders indicated whether their ability to access care or medications for these conditions was easier, harder, or unaffected because of the pandemic. Prevalence estimates for adverse mental health symptoms and substance use were compared among adults with and without disabilities using chi-square tests. Multivariable Poisson regression models with robust standard error estimators were used to estimate adjusted prevalence ratios (aPRs) by symptom type among adults with and without disabilities. To calculate associations between disability status and adverse

[§] Eligibility to complete surveys was determined after electronic contact of potential participants with inclusion criteria of age ≥ 18 years and residence within the United States.

[¶] Disability was defined as such based on a qualifying response by an adult to either one of two questions: "Are you limited in any way in any activities because of physical, mental, or emotional condition?" and "Do you have any health conditions that require you to use special equipment, such as a cane, wheelchair, special bed, or special telephone?" <https://www.cdc.gov/brfss/questionnaires/pdf-ques/2015-brfss-questionnaire-12-29-14.pdf>

^{**} Symptoms of anxiety and depression were assessed with the four-item Patient Health Questionnaire (PHQ-4). Respondents who scored ≥ 3 out of 6 on the Generalized Anxiety Disorder (GAD-2) and Patient Health Questionnaire (PHQ-2) subscales were considered symptomatic for the respective conditions.

^{††} New or increased substance use was assessed with the question, "Have you started or increased using substances to help you cope with stress or emotions during the COVID-19 pandemic? Substance use includes alcohol, legal or illegal drugs, or prescription drug use in any way not directed by a doctor." Suicidal ideation was assessed with an item from the National Survey on Drug Use and Health (<https://nsduhweb.rti.org/respweb/homepage.cfm>) adapted to refer to the preceding 30 days, "At any time in the past 30 days, did you seriously think about trying to kill yourself?"

^{§§} Alcohol, marijuana, cocaine, methamphetamine, prescription or illicit opioids, benzodiazepines, and prescription drugs other than opioids used in a way not directed by a doctor.

* https://store.samhsa.gov/sites/default/files/d7/priv/pep19-02-00-002_508_022620.pdf

[†] The COVID-19 Outbreak Public Evaluation (COPE) Initiative (<https://www.thecopeinitiative.org/>) is designed to assess public attitudes, behaviors, and beliefs related to COVID-19 pandemic and to evaluate mental and behavioral health during the pandemic. The COPE Initiative surveys included in this analysis were administered by Qualtrics, LLC (<https://www.qualtrics.com>), a commercial survey company with a network of participant pools with varying recruitment methodologies that include digital advertisements and promotions, word-of-mouth and membership referrals, social networks, television and radio advertisements, and offline mail-based approaches.

mental health symptoms or substance use over time, aPRs were estimated for symptoms among unique participants in previous COPE survey waves (June, September, and December 2020). Covariates^{¶¶} included sex, age group, race/ethnicity, income, U.S. Census region, urbanicity, and parental or unpaid caregiving roles.*** McNemar's test assessed prepandemic and past-month substance use among adults with and without disabilities. Analyses were conducted using Python software (version 3.7.8; Python Software Foundation) and R statistical software (version 4.0.2; R Foundation) using the R survey package (version 3.29; R Foundation). The Monash University Human Research Ethics Committee reviewed and approved the study. This activity was reviewed by CDC and conducted consistent with applicable federal law and CDC policy.^{†††}

Among a total of 5,119 respondents, 1,648 (32.2%) respondents reported living with disabilities (778 [47.2%] with limiting physical, mental, or emotional conditions only; 171 [10.4%] with health conditions requiring special equipment only; and 669 [42.4%] with both types of conditions) (Table). Overall, 64.1% of adults with disabilities reported adverse mental health symptoms or substance use compared with 36.0% of adults without disabilities; past-month substance use was higher among adults with disabilities (40.6%) than among adults without disabilities (24.5%). Prevalence estimates of each of the following were higher among adults with disabilities than among adults without disabilities: symptoms of anxiety or depression (56.6% versus 28.7%, respectively), new or increased substance use (38.8% versus 17.5%), and serious suicidal ideation (30.6% versus 8.3%) (Supplementary Table, <https://stacks.cdc.gov/view/cdc/108999>). At all timepoints, aPRs for all symptom types were significantly higher among adults with disabilities than among adults without disabilities (Figure 1). During February 16–March 8, 2021, among adults with disabilities, aPRs for symptoms of anxiety or depression and new or increased substance use were approximately

1.5 times as high, and the aPR for serious suicidal ideation was approximately 2.5 times as high as in adults without disabilities. Comparing subgroups of adults with and without disabilities, symptoms of anxiety or depression were approximately twice as prevalent among adults with disabilities who were aged ≥ 50 years (aPR = 2.4; 95% confidence interval [CI] = 1.7–3.2), those of non-Hispanic Asian race/ethnicity (2.4; 95% CI = 1.3–4.8), those of Hispanic or Latino (Hispanic) ethnicity (2.1; 95% CI = 1.4–3.0), and those who were not in parental or caregiver roles (2.1; 95% CI = 1.7–2.6). New or increased substance use was approximately twice as prevalent among adults with disabilities in parental roles only (2.4; 95% CI = 1.5–3.9) and among essential workers (2.3; 95% CI = 2.0–2.7). Suicidal ideation was also more prevalent among adults with disabilities aged ≥ 50 years (4.0; 95% CI = 2.1–7.8), those of Hispanic ethnicity (3.4; 95% CI = 1.9–6.0), adults in unpaid caregiving roles (3.4; 95% CI = 1.5–7.7), and essential (3.5; 95% CI = 2.8–4.4) or nonessential (5.3; 95% CI = 2.8–10.1) workers.

The prevalence of substance use to cope with stress or emotions among adults with disabilities was higher than that among adults without disabilities, both prepandemic (39.7% versus 25.3%, respectively) and in the past month (40.6% versus 24.5%; both $p < 0.001$) (Figure 2). Among adults with disabilities, the past-month prevalence of methamphetamine use (8.4%), nonopioid prescription drug misuse (4.9%), and polysubstance use (16.9%) was approximately twice as high, and the prevalence of cocaine use (6.4%) and prescription or illicit opioid use (9.1%) were nearly three times as high compared with those among adults without disabilities (methamphetamine use 3.4%; nonopioid prescription drug misuse 2.0%; polysubstance use 7.9%; cocaine use 2.2%; prescription or illicit opioid use 3.2%). Past-month methamphetamine use prevalence increased significantly compared with prepandemic use prevalence among all respondents (with disabilities, 45.6% increase, $p < 0.001$; without disabilities, 40.6% increase, $p = 0.003$). Among respondents who reported a diagnosed mental health or substance use condition, a higher percentage of adults with (versus without) disabilities reported that accessing care or medication was harder because of the COVID-19 pandemic (42.6% versus 35.3%, respectively, $p < 0.001$).

Discussion

Nearly two thirds of surveyed adults with disabilities (who represented approximately 32% of the sample) reported adverse mental health symptoms or substance use in early 2021, compared with approximately one third of adults without disabilities. Serious suicidal ideation was approximately 2.5 times as high among adults with disabilities, and methamphetamine use, opioid use, nonopioid prescription drug misuse, and polysubstance use were at least twice as

^{¶¶} Models to estimate aPRs for adverse mental health symptoms and substance use were run with each of the collinear variables income and education during preliminary analysis. Estimated aPRs did not differ meaningfully. In the report, the models including income were included to account for potential differences in access to health care more directly. To avoid collinearity with age, employment status was included in a separate model, and aPRs were not estimated for retired status or student employment status.

*** Adults who were in parental or unpaid caregiving roles were self-identified. For this analysis, the definition of unpaid caregivers of adults was having provided unpaid care to a relative or friend aged ≥ 18 years to help them take care of themselves at any time during the three months before the survey. The definition of someone in a parental role was having provided unpaid care to a relative or friend aged < 18 years. Respondents were categorized as being in a parental role only, a caregiver of adults role only, having both parental and caregiving roles, or having neither parental nor caregiving roles. Adults in parenting roles might not have been biologic or adoptive parents of the children.

^{†††} 45 C.F.R. part 46, 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d); 5 U.S.C. Sect. 552a; 44 U.S.C. Sect. 3501 et seq.

Table 33 (14.1) Prevalence of symptoms of anxiety or depression, substance use, and suicidal ideation among adults with disabilities, by disability status and other characteristics — United States, February 16–March 8, 2021

TABLE. Prevalence of symptoms of anxiety or depression, substance use, and suicidal ideation among adults with disabilities, by disability status and other characteristics — United States, February 16–March 8, 2021

Characteristic	No. (%)		Adults with disabilities, No. (%)*			
	All respondents	Adults with disabilities	Symptoms of anxiety or depression [†]	New or increased substance use to cope [§]	Seriously considered suicide [¶]	One or more of these symptoms
Total	5,119 (100)	1,648 (32.2)	932 (56.6)	640 (38.8)	504 (30.6)	1,057 (64.1)
Disability screener**						
Limited by a physical, mental, or emotional condition	778 (15.2)	778 (47.2)	417 (53.7)	218 (28.0)	148 (19.0)	465 (59.8)
Limited by a health condition that requires special equipment	171 (3.3)	171 (10.4)	104 (60.5)	88 (51.5)	65 (38.2)	123 (71.8)
Both of above	699 (13.7)	669 (42.4)	411 (58.8)	334 (47.8)	291 (41.5)	469 (67.1)
Neither of above	3,471 (67.8)	0 (—)	N/A	N/A	N/A	N/A
Sex^{††}						
Female	2,499 (48.8)	789 (47.9)	445 (56.5)	260 (32.9)	178 (22.6)	501 (63.5)
Male	2,583 (50.5)	838 (50.8)	469 (55.9)	369 (44.0)	314 (37.4)	537 (64.1)
Age group, yrs						
18–29	938 (18.3)	314 (19.0)	250 (79.8)	185 (59.1)	136 (43.3)	276 (87.8)
30–39	967 (18.9)	325 (19.7)	259 (79.8)	198 (60.9)	166 (51.1)	281 (86.6)
40–49	818 (16.0)	253 (15.4)	180 (70.9)	137 (54.0)	125 (49.5)	202 (79.6)
50–59	972 (19.0)	309 (18.8)	132 (42.6)	80 (25.9)	54 (17.5)	158 (51.2)
60–69	790 (15.4)	235 (14.2)	59 (25.2)	21 (8.9)	4 (1.8)	72 (30.7)
≥70	634 (12.4)	213 (12.9)	52 (24.7)	19 (8.8)	19 (8.8)	68 (31.9)
Race/Ethnicity						
White, non-Hispanic	3,103 (60.6)	975 (59.2)	522 (53.6)	327 (33.5)	266 (27.3)	585 (60.0)
Black, non-Hispanic	638 (12.5)	181 (11.0)	99 (54.6)	68 (37.9)	35 (19.3)	110 (60.9)
Asian, non-Hispanic	289 (5.6)	65 (3.9)	39 (61.1)	18 (27.8)	14 (21.0)	47 (72.1)
Multiple/other race, non-Hispanic ^{§§}	188 (3.7)	70 (4.3)	32 (45.2)	16 (23.3)	13 (18.3)	32 (45.8)
Hispanic or Latino, any race	902 (17.6)	357 (21.7)	240 (67.2)	210 (58.8)	177 (49.5)	283 (79.3)
2020 Household income, USD^{¶¶}						
<25,000	1,182 (23.1)	544 (33.0)	286 (52.6)	151 (27.8)	107 (19.7)	327 (60.0)
25,000–49,999	1,203 (23.5)	355 (21.5)	179 (50.4)	110 (30.9)	82 (23.2)	202 (56.9)
50,000–99,999	1,306 (25.5)	350 (21.2)	191 (54.6)	134 (38.2)	103 (29.5)	218 (62.1)
≥100,000	1,204 (23.5)	341 (20.7)	253 (74.1)	232 (68.1)	205 (60.1)	286 (83.8)
Education						
High school diploma or less	1,379 (26.9)	485 (29.4)	264 (54.4)	155 (31.8)	135 (27.9)	309 (63.7)
College or some college	2,876 (56.2)	865 (52.5)	463 (53.5)	312 (36.0)	213 (24.6)	520 (60.1)
After bachelor's degree	865 (16.9)	298 (18.1)	206 (69.0)	174 (58.2)	156 (52.3)	228 (76.4)
Employment status						
Employed (essential employee)	1,797 (35.1)	605 (36.7)	475 (78.6)	448 (74.2)	371 (61.4)	542 (89.6)
Employed (nonessential employee)	941 (18.4)	151 (9.1)	87 (57.9)	53 (35.2)	38 (25.4)	103 (68.3)
Unemployed	936 (18.3)	349 (21.2)	190 (54.5)	77 (22.2)	55 (15.9)	207 (59.3)
Retired	1,263 (24.7)	493 (29.9)	142 (28.8)	45 (9.1)	24 (4.8)	167 (33.8)
Student	182 (3.6)	51 (3.1)	38 (73.7)	16 (31.9)	15 (29.8)	38 (74.5)
Parental role and unpaid caregiving status***						
Neither parent nor caregiver	2,882 (56.3)	741 (44.9)	294 (39.7)	90 (12.2)	70 (9.4)	323 (43.6)
Parent only	611 (11.9)	189 (11.5)	97 (51.3)	48 (25.1)	21 (11.3)	110 (58.0)
Caregiver role of adults only	426 (8.3)	117 (7.1)	57 (48.6)	39 (33.1)	24 (20.9)	71 (60.5)
Parental and caregiver roles	1,201 (23.5)	602 (36.5)	485 (80.5)	463 (77.0)	389 (64.6)	553 (92.0)
U.S. Census region^{†††}						
Northeast	899 (17.6)	267 (16.2)	177 (66.0)	119 (44.7)	109 (40.6)	188 (70.5)
Midwest	1,069 (20.9)	349 (21.1)	208 (59.8)	126 (36.0)	94 (27.1)	222 (63.6)
South	2,074 (40.5)	700 (42.5)	367 (52.4)	262 (37.4)	195 (27.9)	442 (63.1)
West	1,077 (21.0)	333 (20.2)	180 (54.2)	133 (40.1)	106 (31.8)	205 (61.7)
Urbanicity (n = 5,091)^{§§§}						
Urban	4,241 (83.3)	1,313 (79.6)	761 (58.0)	544 (41.4)	440 (33.5)	866 (66.0)
Rural	850 (16.7)	322 (19.5)	158 (49.1)	87 (27.1)	56 (17.4)	178 (55.2)

See table footnotes on the next page.

Table 33 (14.1) (continued) Prevalence of symptoms of anxiety or depression, substance use, and suicidal ideation among adults with disabilities, by disability status and other characteristics — United States, February 16–March 8, 2021

TABLE. (Continued) Prevalence of symptoms of anxiety or depression, substance use, and suicidal ideation among adults with disabilities, by disability status and other characteristics — United States, February 16–March 8, 2021

Abbreviations: N/A = not applicable; USD = U.S. dollars.

* Weighted rounded counts and percentages might not sum to expected values.

† Symptoms of anxiety and depression were assessed via the four-item Patient Health Questionnaire (PHQ-4). Respondents who scored ≥ 3 out of 6 on the Generalized Anxiety Disorder (GAD-2) and Patient Health Questionnaire (PHQ-2) subscales were considered symptomatic for these respective conditions.

§ New or increased substance use was assessed by using the question, "Have you started or increased using substances to help you cope with stress or emotions during the COVID-19 pandemic? Substance use includes alcohol, legal or illegal drugs, or prescription drug use in any way not directed by a doctor."

¶ Suicidal ideation was assessed by using an item from the National Survey on Drug Use and Health (<https://nsduhweb.rti.org/respsweb/homepage.cfm>) adapted to refer to the previous 30 days, "At any time in the past 30 days, did you seriously think about trying to kill yourself?"** Adults who had a disability were defined as such based on a qualifying response to either one of two questions: "Are you limited in any way in any activities because of physical, mental, or emotional condition?" and "Do you have any health conditions that require you to use special equipment, such as a cane, wheelchair, special bed, or special telephone?" Respondents who completed only one of the two disability screening questions (limited by a physical, mental, or emotional condition: 17); limited by a health condition that requires special equipment: 12) were classified as living with only that disability. <https://www.cdc.gov/brfss/questionnaires/pdf-ques/2015-brfss-questionnaire-12-29-14.pdf>

†† Gender responses of "Transgender" (22; 0.4%) and "None of these" (15; 0.3%) are not shown because of small counts.

§§ The non-Hispanic, multiple/other race or multiple races category includes respondents who identified as not Hispanic and as more than one race or as American Indian or Alaska Native, Native Hawaiian or Other Pacific Islander, or any other race.

¶¶ Household income responses of "Prefer not to say" (225) are not shown because of an inability to sufficiently characterize these responses.

*** Adults who were in parental or unpaid caregiving roles were self-identified. For this analysis, the definition of unpaid caregivers of adults was having provided unpaid care to a relative or friend ≥ 18 years to help them take care of themselves at any time during the 3 months before the survey. The definition of someone in a parental role was having provided unpaid care to a relative or friend < 18 years. Respondents answered these questions separately. During analysis, all respondents were categorized as being in a parental role only, caregivers of adults only, having both parental and caregiving roles, or having neither parental nor caregiving roles. Adults in parenting roles might not have been natural or legal parents of children in their care.††† https://www2.census.gov/geo/pdfs/maps-data/maps/reference/us_regdiv.pdf§§§ Invalid postcodes were provided by 28 respondents, for whom urbanicity was not categorized. <https://www.hrsa.gov/rural-health/about-us/definition/datafiles.html>

prevalent among adults with disabilities. These findings suggest value in enhanced mental health screening among adults with disabilities and in ensuring accessibility of routine and crisis services, particularly given that many adults reported that the COVID-19 pandemic had reduced mental health and substance use care or medication accessibility. Mental health disparities among adults with disabilities were observed across demographic groups, highlighting the importance of ensuring access to disaster distress^{§§§} and suicide prevention^{¶¶¶} resources in this population. Important strategies to prevent persons from becoming suicidal include strengthening economic supports, promoting connectedness, and teaching coping skills.^{****} Health care providers could incorporate trauma-informed care, because adults with disabilities might have encountered stigma and trauma in previous health care interactions. Adults with disabilities more frequently reported pre-pandemic and past-month substance use to cope with stress or emotions compared with adults without disabilities. The substance with the largest increase in use was methamphetamine, which is particularly concerning given the increase in amphetamine overdoses^{††††} (7). Drug overdose deaths rose in 2020, driven by synthetic opioids.^{§§§§} Consistent with previous research,

adults with disabilities disproportionately reported opioid use and nonopioid prescription drug misuse (8), highlighting the importance of educating patients and ensuring clinician access to prescription drug monitoring programs.^{¶¶¶¶} Nearly one in ten adults with disabilities reported past-month opioid use, and opioid use among adults without disabilities increased. Policies that reduce barriers to evidence-based treatment, including recently updated buprenorphine practice guidelines,^{*****} might improve access.

The findings in this report are subject to at least four limitations. First, self-reported mental health and substance use might be subject to social desirability biases and stigma, which could lead to underreporting. Second, because the surveys were English-language only and data were obtained using nonprobability-based sampling, despite quota sampling and survey weighting, the findings from this nonrandom sample might not be generalizable. However, the proportion and demographics of surveyed adults with disabilities were similar to those of recent samples from other sources with the same or similar screening questions (1,2,4), and prevalence estimates of symptoms of anxiety and depression were largely consistent with those from other sources for the U.S. adult population (9) and adults with disabilities (4) including the U.S. Census Bureau's probability-based Household Pulse Survey (64.3% among adults with disabilities compared with 27.4% among

§§§ Substance Abuse and Mental Health Services Administration National Helpline (<https://www.samhsa.gov/find-help/national-helpline>); Disaster Distress Helpline (<https://www.samhsa.gov/disaster-preparedness>).

¶¶¶ National Suicide Prevention Lifeline: 1-800-273-TALK for English, 1-888-628-9454 for Spanish, or Lifeline Crisis Chat (<https://suicidepreventionlifeline.org/chat/>).

**** <https://www.cdc.gov/violenceprevention/pdf/suicideTechnicalPackage.pdf>

†††† <https://emergency.cdc.gov/han/2020/han00438.asp>

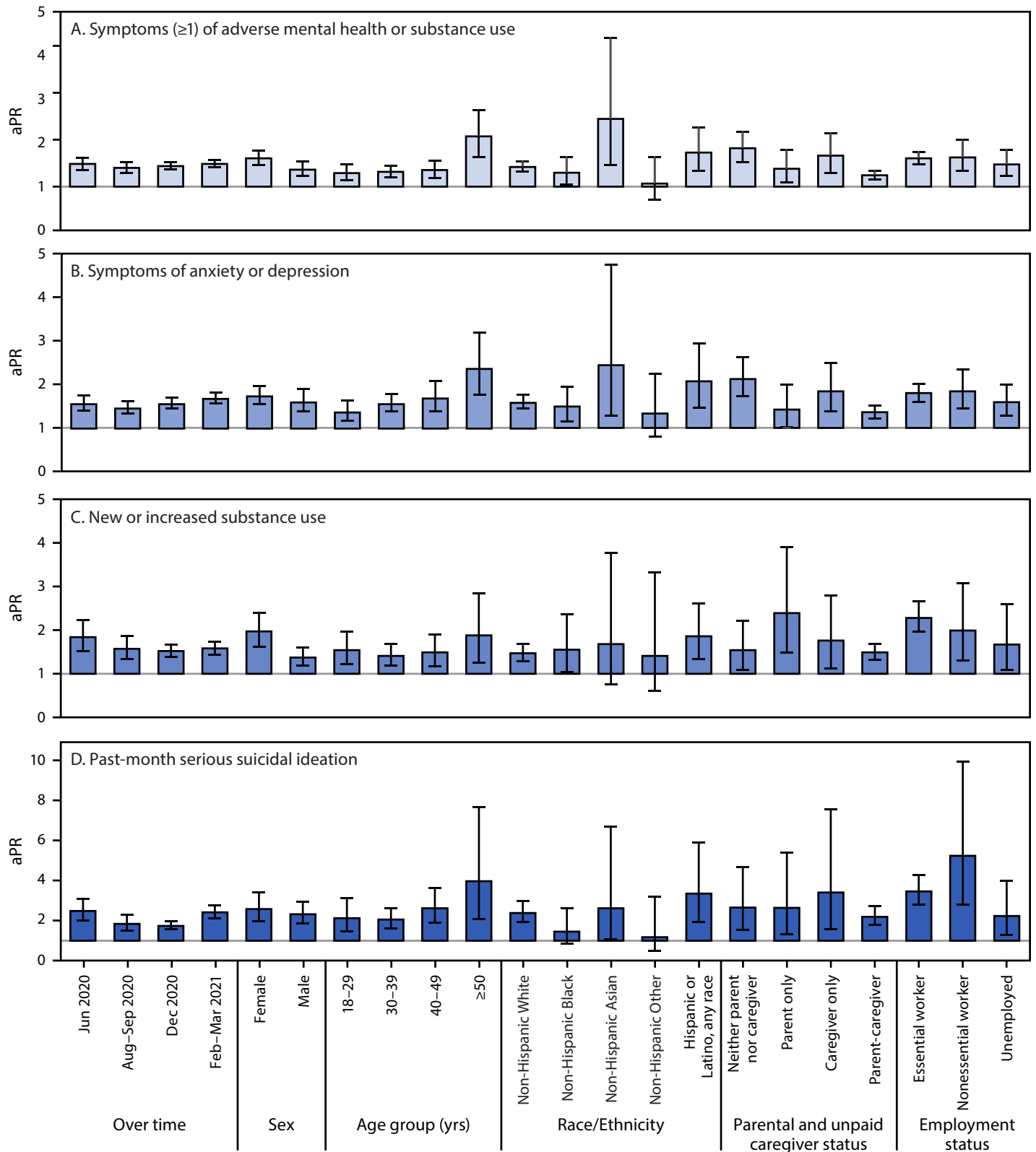
§§§§ <https://www.cdc.gov/media/releases/2020/p1218-overdose-deaths-covid-19.html>

¶¶¶¶ <https://www.cdc.gov/drugoverdose/pdmp/states.html>

***** <https://www.federalregister.gov/documents/2021/04/28/2021-08961/practice-guidelines-for-the-administration-of-buprenorphine-for-treating-opioid-use-disorder>

Figure 21 (14.1) Adjusted prevalence ratios* and 95% confidence intervals† for ≥1 symptoms of adverse mental health or substance use (A), symptoms of anxiety or depression (B), new or increased substance use (C), and suicidal ideation (D) among adults with disabilities, compared with adults without disabilities (referent group) — U.S., Feb 16–Mar 8, 2021

FIGURE 1. Adjusted prevalence ratios* and 95% confidence intervals† for ≥1 symptoms of adverse mental health or substance use (A), symptoms of anxiety or depression (B), new or increased substance use (C), and suicidal ideation (D) among adults with disabilities, compared with adults without disabilities (referent group)§ — United States, February 16–March 8, 2021¶



See figure footnotes on the next page.

Figure 21 (14.1) (continued) Adjusted prevalence ratios* and 95% confidence intervals† for ≥1 symptoms of adverse mental health or substance use (A), symptoms of anxiety or depression (B), new or increased substance use (C), and suicidal ideation (D) among adults with disabilities, compared with adults without disabilities (referent group) — United States, February 16–March 8, 2021

FIGURE 1. (Continued) Adjusted prevalence ratios* and 95% confidence intervals† for ≥1 symptoms of adverse mental health or substance use (A), symptoms of anxiety or depression (B), new or increased substance use (C), and suicidal ideation (D) among adults with disabilities, compared with adults without disabilities (referent group)§ — United States, February 16–March 8, 2021¶

Abbreviations: aPR = adjusted prevalence ratio; CI = confidence interval.

* With 95% CIs indicated by error bars. Multivariable Poisson regression models included sex, age group in years, race/ethnicity, income, U.S. Census region, urbanicity, and parental or unpaid caregiving roles (parental roles were not assessed in June 2020; only unpaid caregiving roles were considered for this variable in the June 2020 models). Separate, additional models were run to estimate aPRs for the following employment statuses: essential worker, nonessential worker, and unemployed. Estimates were not made for retired or student employment statuses because of collinearity between these employment statuses and age.

† For panels A, B, and C, the y-axis range for aPR estimates is 0–5, which contains all aPRs and 95% CIs for these panels with maximal view of differences in model estimates.

For panel D, given the relative rarity of suicidal ideation among some demographic subgroups that results in wide CIs for aPR estimates, the y-axis range is 0–10.

§ Within each subgroup, adults without disabilities are the reference group used to estimate aPRs for outcomes among adults with disabilities.

¶ Estimated aPRs are during February 16–March 8, 2021, except for the “over time” estimates, which also include estimates based on data collected during June 24–30, 2020, August 28–September 6, 2020, and December 6–27, 2020.

adults without disabilities in April 2021).†††† Third, the respondents with disabilities might not be representative of all adults with disabilities, some of whom might lack access to hardware or assistive technologies required to independently complete the survey. Finally, adverse mental health symptoms might, in some cases, represent respondents’ disabling mental health conditions, which could confound associations with other comorbid disabling conditions (e.g., physical, cognitive, sensory); however, sensitivity analyses excluding adults with disabilities who had mental health or substance use diagnoses yielded consistent findings.

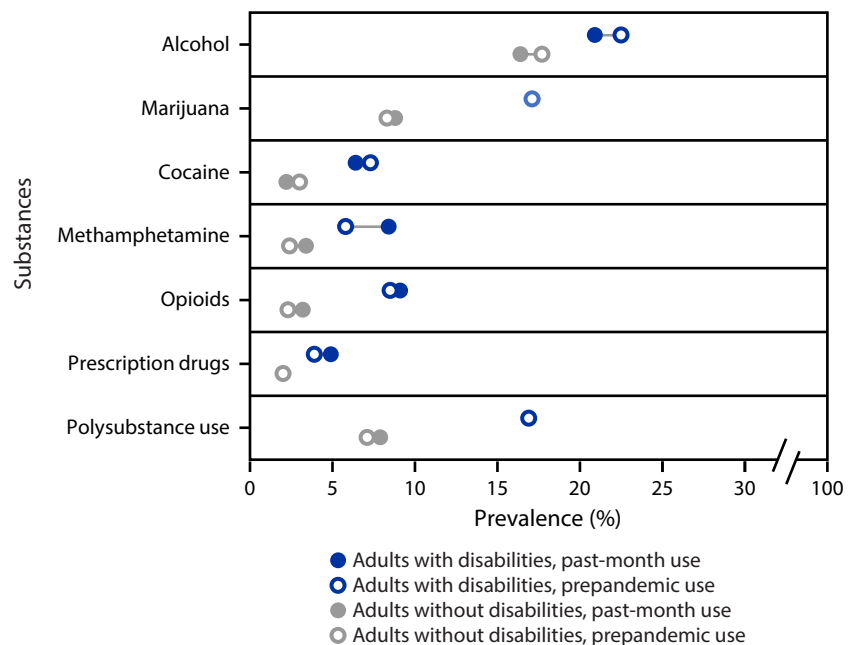
Adults with disabilities have been disproportionately affected by adverse mental health symptoms and substance use during the COVID-19 pandemic, highlighting the importance of improved access to treatment for this population. Clinicians might consider screening all patients for mental health and substance use conditions during and after the pandemic.§§§§ Behavioral health care providers might also consider facility, policy, and procedural pathway analyses to ensure accessibility for clients with physical, sensory, or cognitive disabilities.¶¶¶¶ Strategies designed to increase access to care and medication during public health emergencies, such as telehealth, might consider telemedicine platform and system accessibility for adults with disabilities (10); further research to identify and address health disparities among adults with disabilities could help guide additional evidence-based strategies.

†††† <https://www.cdc.gov/nchs/covid19/pulse/functioning-and-disability.htm>

§§§§ <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/drug-use-illicit-screening>; <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/depression-in-adults-screening>

¶¶¶¶ <http://cct.org/wp-content/uploads/2015/08/2015ADACComplianceGuide.pdf>

FIGURE 2. Prevalence of pre-pandemic and past-month substance use to cope with stress or emotions among adults, by disability status and type of substance — United States, February 16–March 8, 2021*,†,§



* Overall, pre-pandemic and past-month use of any of these substances were reported by 39.7% and 40.6%, respectively, of adults with disabilities, and by 25.3% and 24.5%, respectively, of adults without disabilities.

† All differences between adults with disabilities and adults without disabilities were significant (chi-square p-value <0.05).

§ Circles for use of marijuana, (among adults with disabilities), use of prescription drugs (among adults without disabilities), and polysubstance use (among adults with disabilities) might appear overlapping because of very small changes in reported prevalence (<1% in all cases).

Figure 22 (14.2) Prevalence of pre-pandemic and past-month substance use to cope with stress or emotions among adults, by disability status and type of substance — United States, February 16–March 8, 2021

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Summary

What is already known about this topic?

Adults with disabilities experience higher levels of mental health conditions and substance use than do adults without disabilities.

What is added by this report?

During February–March 2021, 64.1% of surveyed U.S. adults with disabilities reported adverse mental health symptoms or substance use; past-month substance use was higher than that among adults without disabilities (40.6% versus 24.5%, respectively). Among adults with a diagnosis of mental health or substance use conditions, adults with disabilities more frequently (43% versus 35%) reported pandemic-related difficulty accessing related care and medications.

What are the implications for public health practice?

During public health emergencies, including the COVID-19 pandemic, enhanced mental health and substance use screening among adults with disabilities and improved access to related health care services are critical.

Corresponding author: Amy Board, aboard@cdc.gov.

¹Turner Institute for Brain and Mental Health and School of Psychological Sciences, Monash University, Melbourne, Australia; ²Austin Health, Melbourne, Australia; ³Brigham and Women's Hospital, Boston, Massachusetts; ⁴Harvard Medical School, Boston, Massachusetts; ⁵CDC COVID-19 Response Team; ⁶National Center for Injury Prevention and Control, CDC; ⁷Epidemic Intelligence Service, CDC; ⁸University of Melbourne, Melbourne, Australia.

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SUMMARY OF FINDINGS

Overall, nearly two-thirds of surveyed US adults with disabilities reported adverse mental health symptoms or substance use in February to March of 2021, compared with approximately one-third of adults without disabilities. These comparative levels were consistent with findings from earlier in the pandemic (**Czeisler, Lane, et al., 2021; Okoro et al., 2021**). By type of substance use, methamphetamine use, opioid use, nonopioid prescription drug misuse, and polysubstance use were twice as prevalent among adults with disabilities compared to adults without disabilities.

The findings are particularly concerning given that in a study of Medicare enrollees with disabilities aged below 65 years using data from 2012 through 2016, participants who had substance use, psychiatric conditions, and chronic pain had 23.4 times the rate of opioid-involved overdose deaths compared with individuals who had none of these conditions (363.7 versus 15.5 per 100,000 population) (**Kuo et al., 2019**). Finally, among people with diagnosed mental health or substance use conditions, a significantly higher percentage of adults with disabilities reported that the pandemic had reduced their ability to access treatment for these conditions compared to adults without disabilities (42.6% versus 35.3%, respectively, $P < 0.0001$). While this finding identifies adults with disabilities as having disproportionately experienced disruptions in access to care as compared with adults without disabilities, more than one-third of the latter group reported disruptions, highlighting that pandemic-related barriers to accessing care extends beyond people with disabilities.

The finding that among people with diagnosed mental health or substance use conditions, a large portion of individuals (both with and without disabilities) reported increased difficulty accessing desired treatment due to the pandemic has actionable and critical public health implications. The WHO reported that 93% of 130 surveyed countries reported disrupted or halted critical mental

health services due to the pandemic, including disrupted opioid agonist maintenance treatment for opioid dependence in 45% of countries **(World Health Organization, 2020j)**. Such disruptions of care could predispose individuals with these conditions to higher risk for mental health emergencies or substance use relapses. Indeed, our finding that people with disabilities disproportionately experienced pandemic-related disruptions of care is augmented by evidence that people with disabilities also more commonly delayed or avoided routine and urgent or emergency medical care due to concerns about COVID-19 **(Czeisler et al., 2021; Czeisler, Marynak, et al., 2020)**. Moreover, despite increased substance use levels and overdose deaths in the US **(Centers for Disease Control and Prevention, 2020i; Pollard et al., 2020)**, addiction treatment initiations in the US state of California had declined by 28% through October 2020 as compared with before the pandemic **(Mark et al., 2021)**.

This Original Investigation was the first COVID-19 *MMWR* centred upon people with disabilities. The paper characterised and raised awareness about disparities in mental health and substance use among adults with disabilities compared to adults without disabilities during the COVID-19 pandemic. Public health recommendations included in this Original Investigation therefore included suggestions for behavioural health care providers to consider facility, policy and procedural pathway analyses to ensure that clients with physical, sensory or cognitive disabilities would have access to care.

CHAPTER 15: GENERAL DISCUSSION

15.1. SUPPORT FOR, ADHERENCE WITH, AND IMPACT OF NONPHARMACEUTICAL INTERVENTIONS ON THE PANDEMIC COURSE IN DIFFERENT REGIONS

The primary aim of Part I of this thesis was to assess public attitudes, behaviours, and beliefs about the COVID-19 pandemic and its mitigation. In the year 2020, in the absence of a safe, effective, and approved COVID-19 vaccine, mitigation efforts were centred upon NPIs. Public health surveillance activities were conducted to assess support for and adherence with COVID-19 prevention measures (e.g., stay-at-home orders, hand hygiene, mask usage) in regions experiencing relatively widespread community transmission of SARS-CoV-2 (New York City in April 2020 and the US) and in regions minimally experiencing such transmission (Los Angeles in April 2020 and Australia).

15.1.1. SUMMARY OF RESEARCH FINDINGS

The Original Investigation in [Chapter Two](#) presents findings from surveillance of adults across the US in May 2020, with oversampling in New York City and Los Angeles, with regards to public support for and adherence with COVID-19 prevention measures (**Czeisler, Tynan, et al., 2020**). Overall, the vast majority of respondents reported support for stay-at-home orders and nonessential business closures, along with high levels of adherence with gathering bans, and with public health recommendations to maintain a two-metre physical distance from other people and to wear masks in public areas. These findings were highlighted in June 2020 by CDC Director Dr Robert Redfield and CDC Deputy Director for Infectious Diseases Dr Jay Butler to encourage continued community engagement in COVID-19 prevention measures in the first CDC press conference since COVID-19

was declared a pandemic by the WHO and a National Emergency in the US in March 2020 (Centers for Disease Control and Prevention, 2020e, 2020f, 2021a).

There were, however, demographic differences, as young adults and men reported less frequent adherence with public health recommendations—including mask wearing. Similar demographic differences in behavioural adherence with COVID-19 prevention measures during June 2020 were found in the Original Investigation presented in [Chapter Three](#) with regard to hand hygiene (Czeisler, Garcia-Williams, et al., 2020). The age differential was particularly pronounced, as 83% of adults aged ≥ 65 years reported frequent practice of hand hygiene, compared with only 65% of adults aged 18-24 years. Risk perception was also associated with adherence with hand hygiene, such that 90% of adults who were extremely concerned about their risk of SARS-CoV-2 infection reported frequent hand hygiene, compared with 68% of those who were not at all concerned. These findings informed the tailoring of health promotion messaging prepared by the CDC's WASH Team.

High levels of adherence with and support for stringent COVID-19 prevention measures were not unique to regions with widespread community transmission of SARS-CoV-2, such as the US. The Original Investigation in [Chapter Four](#) revealed that nine-tenths of surveyed adults supported government-imposed stay-at-home orders in early April 2020 based on samples recruited from New York City, Los Angeles, across the US, and Australia (range of samples = 88.9% to 93.1%) (Czeisler, Howard, et al., 2021). Such widespread support was reported despite elevated levels of adverse mental health symptoms across samples [e.g., depression symptoms, overall = 21.0%; range of samples = 20.0% to 22.7%, compared with a prevalence estimate of 8.5% among US adults in the second quarter of 2019 (Ettman et al., 2020)]. Consistent with evidence from prior infectious disease outbreaks (S. K. Brooks et al., 2020; Galea et al., 2020; Hawryluck et al., 2004), our

findings revealed an association between anxiety or depression symptoms and spending most of the time at home (adjusted odds ratio = 1.3 [95% confidence interval = 1.1 to 1.5]) or being in quarantine (adjusted odds ratio = 1.8 [95% confidence interval = 1.5 to 2.1]), serving as an early indicator of potential indirect mental health effects of the pandemic.

15.1.2. COVID-19 MITIGATION APPROACH IN THE UNITED STATES, AUSTRALIA, AND COUNTRIES WORLDWIDE

Despite similarly high levels of support for stringent COVID-19 prevention measures in the early months of the COVID-19 pandemic (**Czeisler, Howard, et al., 2021**), mitigation approaches and public health communication about the pandemic differed considerably in the US and Australia. In the US, the initial COVID-19 prevention plan was presented on 16 March 2020 as “15 Days to Slow the Spread” setting the bar for a short interval of pandemic-related life disruptions (**The White House, 2021b**). In contrast, that same day, the Victorian Premier announced four weeks of a State of Emergency with personal fines up to AUD\$20,000 for failure to comply with requests to isolate (**Premier of Victoria, 2020**). The Victorian Premier also warned, “Make no mistake, the next few weeks and months will be tough for everyone, but we’re doing what is necessary to protect Victorians”, while the Victorian Minister of Health declared “This is the biggest public health challenge we’ve faced in our lifetimes – that’s why it’s so important that we have the right tools at our disposal to minimise the impact of this virus.”

In the early stages of the pandemic, the US struggled to ramp up capacity for COVID-19 testing, unlike Australia (**Schneider, 2020**). The lack of COVID-19 tests in the US both made it challenging to identify clusters of infections before it was too late to reasonably contain them and limited the accuracy of epidemiological models due to uncertainties about the prevalence of infections, and especially asymptomatic infections—the prevalence of which was unknown and consequential given

that people with asymptomatic infections would be least likely to self-isolate. Limited testing may partially explain how SARS-CoV-2 ribonucleic acid was collected from patients in New York City hospitals as early as 25 January 2020 (**Hernandez et al., 2021**), more than one month before the first official documented SARS-CoV-2 infection in New York—which would progress to become a COVID-19 epicentre in March 2020 (**Dong et al., 2020**).

Interestingly, despite these differences, in the early months of the pandemic, masks were not recommended for the general public in either the US or Australia (**60 Minutes, 2020; Australian Government, 2020; Dwyer & Aubrey, 2020; Trump, 2020**). However, after the guidance was changed in the US and Australia, as described in the [Introduction](#), mask mandates and other public health directives were more universally applied and enforced in a greater fraction of Australian states than in the US.

Elsewhere around the world, public health officials and policymakers varied widely in their implementation of COVID-19 mitigation measures. Some countries, such as Sweden, elected to abstain from economic lockdowns and stringent mitigation policies, electing instead to attempt to reach herd immunity through infection. Supporters of this type of approach authored the Great Barrington Declaration in October 2020. This declaration endorsed Focused Protection, which advocated for intense mitigation for older adults and high-risk populations, while allowing younger adults and low-risk groups to resume normality (**Kulldorff et al., 2020**). The Great Barrington Declaration was met with ferocious opposition based on the premise that relying upon post-infection immunity to control the COVID-19 pandemic is flawed, and that uncontrolled infection with SARS-CoV-2 among younger persons could lead to significant morbidity and mortality across the entire population, including from acute COVID-19 illness, post-acute sequelae of COVID-19 (PASC) (**Nalbandian et al., 2021**), and the consequences of overwhelmed healthcare systems

resulting from mass infection (**Aschwanden, 2020, 2020**). Just over one week later, the John Snow Memorandum was prepared in response (**Alwan et al., 2020; John Snow Memorandum, 2020**).

In July 2021, nine months after the John Snow Memorandum was published, several of the same authors wrote the John Snow Declaration, signed by more than 120 scientists (**Gurdasani et al., 2021; John Snow Memorandum, 2021**). The letter conveyed concerns about the stoppage of NPIs in the UK scheduled for mid-July 2021 amid surging SARS-CoV-2 infections and emphasised the potential consequences of mass infection on children and adolescents, most of whom had not had the option to receive COVID-19 vaccines in advance of clinical trial results.

In summary, despite high levels of adherence with and support for NPIs during early stages of the pandemic in the US and Australia, jurisdictions within these regions and around the world implemented different approaches to COVID-19 containment over time. To understand the implications of non-implementation of or non-adherence with NPIs, it is important to consider the effectiveness of these measures in reducing SARS-CoV-2 transmission and COVID-19 hospitalisations and deaths. Therefore, while evaluating the effectiveness of NPIs was outside the scope of this thesis, studies using various methodologies to estimate the effectiveness of NPIs for COVID-19 containment are described in Section 15.1.3.

15.1.3. EFFICACY OF NONPHARMACEUTICAL INTERVENTIONS

Nonpharmaceutical interventions can be broadly categorised as being designed to (1) reduce person-to-person interactions (e.g., stay-at-home orders, business closures or lockdowns, educational institution closures, gathering bans, cancellation of elective medical procedures), or (2) reduce the potential for SARS-CoV-2 transmission during person-to-person interactions (e.g., mask usage, physical distancing, hand hygiene). The next two sections of the General Discussion, 15.1.3.1. and 15.1.3.2., briefly summarise evidence about the effectiveness of each group of NPIs.

15.1.3.1. Evaluation of the Effectiveness of Nonpharmaceutical Interventions Designed to Reduce Person-to-Person Interactions: Stay-at-Home Orders, Business Closures or Lockdowns, Educational Institution Closures, and Gathering Bans

One of the earliest evaluations of NPIs during the COVID-19 pandemic was published by Lai *et al.* based on a COVID-19 containment effort in mainland China (**S. Lai et al., 2020**). Using anonymised human mobility and COVID-19 surveillance data, the authors estimate that the combination of NPIs implemented in China reduced the number of projected cases 67-fold (interquartile range = 44-fold to 94-fold). Early detection and isolation of persons infected with SARS-CoV-2 was associated with a 5.0-fold reduction in subsequent infections, while contact reduction (e.g., lockdowns and travel restrictions) and physical distancing measures were associated with a 2.6-fold reduction in subsequent infections. The timing of the implementation of these measures had considerable consequences, as well, as the proposed model estimated progressively larger reductions in subsequent infections if the NPIs had been introduced one (66% [interquartile range = 50% to 82%]), two (86% [interquartile range = 81% to 90%]), or three (95% [interquartile range = 93% to 97%]) weeks earlier.

More generally, the effectiveness of prevention measures can be dependent both upon the implementation or adherence with the measure and upon the true efficacy of the measure to reduce SARS-CoV-2 transmission. Anonymised location data from mobile devices in the US revealed significantly decreased median population movement following the onset of stay-at-home orders in 97.6% of 2,351 US counties studied (**Moreland et al., 2020**), suggesting that these orders were associated with reduced community mobility. Analysis of stay-at-home orders and COVID-19 hospitalisations in four US states (Colorado, Minnesota, Ohio, and Virginia) revealed that COVID-19 hospitalisations decreased below projected exponential growth rates in all four states (**Sen et al., 2020**), reflective of slowed SARS-CoV-2 spread and reduced COVID-19-related hospital burden.

Furthermore, analysis of a county-level NPI dataset led by Ebrahim *et al.* found that workplace closures—which were highly correlated with stay-at-home orders (Pearson’s $r = 0.835$)—were associated with reduced SARS-CoV-2 transmission **(Ebrahim et al., 2020)**.

However, following the relaxation of the first stay-at-home order on 24 April 2020 by Alaska, median population movement increased even in states wherein stay-at-home orders had not been relaxed, limiting the mechanism of reduced community mobility in reducing SARS-CoV-2 transmission **(Moreland et al., 2020)**. In the Blackfeet Tribal Reservation (home of the sovereign Blackfeet Nation in Montana [US]), however, strict enforcement of stay-at-home orders and mask use was followed by a 33-fold reduction of COVID-19 incidence in one month (from 6.4 new SARS-CoV-2 infections per one thousand residents per day in early October to 0.2 per thousand in early November) **(Pratt et al., 2021)**. Together, these studies provide evidence supporting stay-at-home orders in reducing SARS-CoV-2 transmission, which was somewhat dependent upon adherence with or enforcement of such measures. However, factors including socioeconomic and racial inequities can also influence adherence with and efficacy of stay-at-home orders and other NPIs, as lesser reductions in mobility were observed in disadvantaged communities in the US, which were in turn associated with higher SARS-CoV-2 infection risk **(S. Chang et al., 2021)**. Indeed, a CDC study found that counties with higher scores on the 2018 CDC social vulnerability index (SVI) were both more likely to be COVID-19 hotspots, and to have sustained SARS-CoV-2 transmission after identification as a hotspot **(Dasgupta et al., 2020)**.

Most multinational studies also support the efficacy of stay-at-home orders in reducing SARS-CoV-2 transmission, and offer evidence supporting additional measures. A study of 130 countries by Liu *et al.* found strong associations between educational institution closures and internal movement restrictions and reduced SARS-CoV-2 time-varying reproductive value **(J. Liu et al., 2020, p. 130)**.

Liu *et al.* also found strong evidence supporting the effectiveness in reducing SARS-CoV-2 transmission of business closures, income support, and debt/contract relief *independent* of intensity, and of public events cancellations and gathering bans *dependent* upon the intensity of their implementation. A similar study by Haug *et al.* in 79 territories evaluated the relative efficacy of approximately six thousand NPIs and estimated the largest reductions in the SARS-CoV-2 time-varying reproduction value from small gathering cancellations (83%), educational institution closures (73%), border restrictions (56%), increasing health care and public health capacities (51%), individual movement restrictions (42%), and national lockdown or stay-at-home orders (25%) **(Haug et al., 2020)**. Retrospective analysis tracing observed deaths to estimate transmission in view of NPIs, Flaxman *et al.* and the Imperial College COVID-19 Response Team found an 82% pooled reduction in SARS-CoV-2 time-varying reproduction values following major NPIs compared with the pre-intervention values, with large contributions from national lockdowns **(Flaxman et al., 2020)**.

In contrast, Bendavid *et al.* concluded that more restrictive NPIs (e.g., stay-at-home orders and business closures) did not yield significant benefits for SARS-CoV-2 transmission reduction after controlling for the effect of the epidemic and less restrictive NPIs **(Bendavid et al., 2021, p. 19)**. However, two Letters strongly criticising the methods and conclusions point out that a reduction of ~ 0.30 of the logarithmic growth rate, which Bendavid *et al.* classify as modest, would yield a 35% reduction of the infection number in one day and 58% in two days **(Fuchs, 2021)**—a reduction that the authors state would neutralize “the most dramatic exponential increase in COVID-19-infected cases observed” **(Besançon et al., 2021)**. One explanation for such discrepancies is dependence on models, as both Chin *et al.* and Soltesz *et al.* suggest that the model implemented by Imperial College COVID-19 Response Team **(Flaxman et al., 2020)** had assumptions that largely influenced the conclusions **(Chin et al., 2021; Soltesz et al., 2020)**, whereas Chin *et al.* demonstrated differing

conclusions based on the same NPIs and epidemic curves depending upon the model used to quantify the effect of the NPIs (**Chin et al., 2021**).

Regarding the timing of policy implementation, a document-based analysis of 10 countries (Iran, China, Japan, South Korea, Singapore, Germany, the US, the UK, Spain, and Italy) found that widespread testing, comprehensive contact tracing, and early implementation of measures relative to the identification of emerging clusters of infections were the most effective policy-based interventions (**Raoofi et al., 2021**). Similarly, an analysis of 37 European countries found that earlier timing of policy implementation was strongly associated with reduced cumulative COVID-19 mortality during the subsequent months (**Fuller et al., 2021**).

Overall, the available evidence largely supports the effectiveness in containing COVID-19 of NPIs designed to reduce person-to-person interactions (e.g., stay-at-home orders, business closures or lockdowns, educational institution closures, gathering bans). Such major containment efforts are, however, not always feasible or practical, as some person-to-person interactions are inevitable. Mask wearing and physical distancing are designed to mitigate the risk of transmitting SARS-CoV-2 or other pathogens during person-to-person interactions.

15.1.3.2. Evaluation of the Effectiveness of Nonpharmaceutical Interventions Designed for Person-to-Person Interactions: Mask Usage and Physical Distancing

Despite abundant evidence of the effectiveness of masks in reducing exposure hazards for infectious diseases (**Bin-Reza et al., 2012; Jefferson et al., 2008; A. C. K. Lai et al., 2012; Y. Li et al., 2008; Offeddu et al., 2017; Tracht et al., 2010**), absent robust studies evaluating the effectiveness of masks to protect against COVID-19, early public health recommendations advised against the use of masks for the general public.

Given considerable evidence of the efficacy of masks to protect against diverse pathogens, the decision by many public health institutions to advise against masks to protect against SARS-CoV-2 and COVID-19 until proven effective leads to debate about the Precautionary Principle (**Goldstein, 2001; Goldstein & Carruth, 2004; Kriebel & Tickner, 2001**). Embracing the Precautionary Principle involves abstaining from decision-making in situations in which there is the possibility of morally unacceptable harm that is scientifically plausible but uncertain, action shall be taken to avoid or diminish that harm, with the judgement of plausibility grounded in scientific analysis (e.g., waiting to release a vaccine until clinical trials demonstrating safety and efficacy are completed, per regulations) (**UNESCO, 2022**).

While it is undoubtedly easier to reflect upon this decision than it must have been to make at the time, in the contexts of masks, it is difficult to imagine that the plausibility of morally unacceptable harm from recommending masks would outweigh the potential benefits of recommending a potentially highly effective NPI early in the pandemic, when there were still hopes for containment. Conversely, overriding the Precautionary Principle in a situation in which morally unacceptable harm is an unintended consequence could cause irreparable damage to public health systems. Nevertheless, when implementing the Precautionary Principle for mask recommendations, long-term trust in the efficacy of masks might have benefited from clear communication about the decision-making process beyond a complete absence of evidence of the efficacy of masks for SARS-CoV-2, which has persisted as an anti-masking rebuttal despite a body of literature supporting the efficacy of masks during the pandemic.

Perhaps unsurprisingly, case reports and studies have found overwhelming evidence supporting the high efficacy of masks in reducing SARS-CoV-2 transmission (**J. T. Brooks & Butler, 2021**). Fitted filtration efficiency tests revealed that many common consumer-grade and improvised face

masks provided highly effective filtration (**Clapp et al., 2021**), as did face mask alternatives (**Sickbert-Bennett et al., 2020**). Wearing two masks and ensuring a tighter fit of the mask also increased the effectiveness of filtration (**J. T. Brooks et al., 2021**).

In the field, contact tracing of clients of two symptomatic hair stylists with laboratory-confirmed COVID-19 and a universal masking policy found no evidence that any of the 139 clients were infected with SARS-CoV-2 (**Hendrix et al., 2020**). None of the clients experienced COVID-19-like symptoms within two weeks of the exposure, and none of the 67 clients tested for SARS-CoV-2 were positive. Mask wearing also reduced the odds of SARS-CoV-2 infection among US Naval service members during an outbreak aboard the USS Theodore Roosevelt aircraft carrier in Guam (**Payne et al., 2020**), and SARS-CoV-2 incidence was 37% lower in elementary schools in the US state of Georgia that required teachers and staff members to wear masks compared with schools without mask policies (**Gettings et al., 2021**). At the US county and state levels, jurisdictions with mask mandates experienced declines in SARS-CoV-2 transmission and COVID-19 hospitalizations and deaths, whereas infections and hospitalizations did not decrease in jurisdictions without such mandates (**Gallaway et al., 2020; Guy et al., 2021; Joo et al., 2021; Lyu & Wehby, 2020; Van Dyke et al., 2020**). Moreover, serial cross-sectional surveys of 380 thousand US adult residents revealed that, adjusting for physical distancing and population demographics, a 10% increase in self-reported mask-wearing corresponded to 3.5 (95% confidence interval = 2.0 to 6.4) times the odds of SARS-CoV-2 transmission control (**Rader et al., 2021**).

Multinational studies have also provided strong evidence for mask usage in reducing SARS-CoV-2 transmission. A study of 1.9 million laboratory-confirmed SARS-CoV-2 infections across 190 countries conducted by Bo *et al.* revealed that mask mandates were associated with a 15% (95% confidence interval = 8% to 22%) reduction in the time-varying reproduction value of SARS-CoV-2

(Bo et al., 2021), while a systematic review and meta-analysis by Chu *et al.* of 172 observational studies across 16 countries found that mask usage was associated with considerably reduced odds of SARS-CoV-2 infection (adjusted odds ratio = 0.15 [95% confidence interval = 0.07 to 0.34], risk difference = -14.3% [95% confidence interval = -15.9% to -10.7%]) (Chu et al., 2020). Of note, Chu *et al.* also estimated that SARS-CoV-2 transmission was lower with physical distancing of one or more metres between persons compared with a distance of less than one metre (adjusted odds ratio = 0.18 [95% confidence interval = 0.09 to 0.38], risk difference = -10.2% [95% confidence interval = -11.5% to -7.5%]).

Epidemiological modelling studies have estimated the potential for mask usage to reduce SARS-CoV-2 transmission and COVID-19 morbidity and mortality in the US (Eikenberry et al., 2020; IHME COVID-19 Forecasting Team, 2021). In an April 2020 modelling study of mask usage in two early epidemic centres in the US (Washington state and New York state), Eikenberry *et al.* estimate that—in the absence of any other interventions—immediate 80% adoption of highly (80%) effective masks on 2 April 2020 could have reduced cumulative COVID-19 mortality projections in these states by 95% and 55%, respectively (Eikenberry et al., 2020). With 80% adherence, even moderately (50%) effective masks were estimated to reduce cumulative COVID-19 mortality by 17% and 91%, respectively.

A later study conducted by the University of Washington Institute for Health Metrics and Evaluation COVID-19 Forecasting Team used data from 1 February to 21 September 2020 to model possible SARS-CoV-2 infection trajectories and COVID-19 deaths through 28 February 2021 (IHME COVID-19 Forecasting Team, 2021). The authors estimate that if the then-current NPIs were maintained and unchanged, the cumulative death toll was projected at 511 thousand (95% confidence interval = 470 thousand to 578 thousand) by the end of February 2021, and that in the

absence of any NPIs, the cumulative COVID-19 death toll could exceed one million (1.05 million [95% confidence interval = 0.76 million to 1.45 million]). The authors estimate that the addition of mask usage by 95% of the population to the then-current NPIs would save approximately 130 thousand (95% confidence interval = 85 thousand to 171 thousand) lives through this interval, while mask usage by 85% of the population could save 95 thousand (95% confidence interval = 61 thousand to 133 thousand) lives.

In the absence of safe, effective, and available COVID-19 vaccines, NPIs offered the best protection against community COVID-19 transmission. While determining the effect of individual NPIs is somewhat difficult given varying epidemic growth curves, jurisdictions, and concomitant measures, the available evidence generally supports the efficacy of multicomponent bundles of NPIs. Some measures (e.g., stay-at-home orders, business closures) inevitably induce considerable life disruption, while others (e.g., mask usage, hand hygiene) offer the opportunity to maintain a semblance of normality while reducing risk of pandemic transmission. The reliance on personal engagement of these measures underscores the importance of understanding public support for and adherence with these measures.

15.1.4. ADHERENCE WITH NONPHARMACUETICAL INTERVENTIONS TO REDUCE SARS-CoV-2 TRANSMISSION

The findings about high self-reported adherence with NPIs in the US (with lower levels among younger adults) presented in Chapters [Two](#), [Three](#), and [Four](#) of this thesis are consistent with estimates of high levels of adherence early during the pandemic (**Fisher, Barile, et al., 2020**). However, longitudinal studies revealed that adherence with NPIs declined in the later months of 2020 (**Crane et al., 2021**) despite the occurrence of a second wave of SARS-CoV-2 in the US (**Dong et al., 2020**). Consistent with our data on lower levels of adherence with a range of NPIs

among younger adults and male persons (**Czeisler, Garcia-Williams, et al., 2020; Czeisler, Howard, et al., 2021; Czeisler, Tynan, et al., 2020**), mask usage among US shoppers entering retail stores in June 2020 (41% overall) was higher among persons of female than of male gender, and increased with age (**Haischer et al., 2020**). Mask mandates demonstrated efficacy in improving adherence, as Haischer *et al.* found that enactment of mask mandates in late July and August 2020 was associated with an increase in mask usage to above 90% across genders and age groups. Similar findings were reported by Adjodah *et al.*, who estimated that mask mandates were linked with a 23.4% increase in mask adherence across four US states, and that ending of mask mandates in these states was associated with a decrease in mask adherence and, in turn, increase in SARS-CoV-2 transmission (**Adjodah et al., 2021**).

As the COVID-19 pandemic persisted, the notion of behavioural fatigue associated with adherence to COVID-19 NPIs and restrictions—termed pandemic fatigue—emerged. Mixed evidence for this phenomenon was provided by Petherick *et al.*, who analysed self-report behaviours totalling nearly 240 thousand participants from representative samples of populations of 14 countries, as well as mobility and policy data for 124 countries (**Petherick et al., 2021**). The authors reported linear rises in adherence with low-cost and habituating behaviour (e.g., mask-wearing), as well as declines in high-cost and sensitizing behaviour (e.g., physical distancing). Pandemic fatigue has also been rejected by psychologists and epidemiologists, including in a *BMJ* Editorial by Reicher and Drury, who suggested that perceived pandemic fatigue masks public health failures, and that non-adherence is a matter of practicality rather than psychology (**Reicher & Drury, 2021**). Either way, focus groups of young adults revealed that this population felt highly responsible for protecting themselves and others, though faced confusion due to inconsistent messaging and seemingly arbitrary recommendations (**T. Cheng et al., 2021**).

Studies of barriers to adherence with NPIs found that caregiving responsibilities and socialising to avoid feeling lonely were commonly reported across North America and Europe, whereas desire to protect oneself, feeling social responsibility, and having the ability to work or study remotely facilitated NPI adherence **(Coroiu et al., 2020)**. A qualitative study of adults in Alberta, Canada revealed that many respondents felt that the public health messaging they had received was conflicting, and that consistent messaging would be beneficial **(Benham et al., 2021)**. Regarding masks specifically, residents of the US state of North Carolina identified barriers to usage as physical and social discomfort, along with low risk perception for COVID-19 **(Shelus et al., 2020)**. To minimise these barriers, the authors recommended that messaging should be positive and focus on the mutual beneficence of and rationale for masks and aim to normalise the behaviour. Among young adults, exposure to misinformation and disinformation, conflicting messaging, and social or peer pressure to not wear a mask were drivers of non-adherence, reinforcing the findings of Beham *et al.* and Shelus *et al.* and potential value of social media to tailor messaging appealing to social responsibility for younger adults **(Benham et al., 2021)**.

Though outside the scope of this thesis, there have also been mixed levels of support for and adherence with policies and recommendations for COVID-19 testing, as well as contact tracing and isolation following a positive SARS-CoV-2 test **(Smith et al., 2021)**. Implementation of and adherence with NPIs are among many factors that contribute to the regional course of a pandemic. Subsection 15.1.5. provides a brief characterisation of the pandemic in the US, Australia, and countries around the world using different measures of impact.

15.1.5. PANDEMIC COURSE IN THE UNITED STATES, AUSTRALIA, AND COUNTRIES WORLDWIDE

Overall, as of 21 July 2021, there have been more than 190 million detected SARS-CoV-2 infections globally (**Dong et al., 2020**), though that figure underreports the true number of infections due to testing limitations (**Centers for Disease Control and Prevention, 2020a; Reese et al., 2020**), which has been estimated up to two billion (**Ioannidis, 2021b**). There have also been approximately four million COVID-19 deaths (**Dong et al., 2020**). Following infection fatality rate estimates of 5.6% in China and 15.2% outside of China early during the pandemic (**Baud et al., 2020**), which suffered from various biases (**D. D. Kim & Goel, 2020; Lipsitch, 2020; Shen et al., 2021, p. 19**), more recent estimates range from 0.15% to 0.68% (**Ioannidis, 2021a, 2021b; Meyerowitz-Katz & Merone, 2020**). However, age-specific infection fatality rate estimates vary by orders of magnitude, from 0.002% among persons aged 10 years to 0.01% among persons aged 25 years, and from 1.4% among persons aged 65 years to 15% among persons aged 85 years (**Levin et al., 2020**). Infection fatality rates also vary considerably by region (**Ioannidis, 2021b**).

Measured by SARS-CoV-2 infections, the US and Australia were on opposite ends of the spectrum. As of 1 December 2020, in the US, out of a population of 330 million, there were approximately 13.4 million confirmed SARS-CoV-2 infections (41,500 per one million population, the highest global infection incidence) (**Child et al., 2020**). In Australia, on the other hand, out of a population of 25 million, there were approximately 28 thousand confirmed infections (1,000 per one million population)—despite widespread testing as evidenced by low test positivity.

These figures do not account for undetected infections, which were estimated to be common in the US, especially during the early months of the pandemic. Indeed, the CDC estimated that during February 2020 through March 2021, there were actually 115 million (95% confidence interval = 99

million to 134 million) SARS-CoV-2 infections (348,500 per one million population, with 1 in 4.3 [95% confidence interval = 1 in 3.7 to 1 in 5.0] reported) and 5.6 million COVID-19 hospitalisations (95% confidence interval = 5.0 million to 6.3 million) in the US (**Centers for Disease Control and Prevention, 2020a; Reese et al., 2020**).

In terms of mortality, during the interval of 26 January 2020 to 3 October 2020, the CDC identified nearly 300 thousand excess deaths in the US compared with expected deaths based on average deaths during 2015 to 2019, with approximately two-thirds of these directly associated with COVID-19 (**Rossen et al., 2020; Woolf, Chapman, Sabo, Weinberger, Hill, et al., 2020**). Excess deaths in 2020 reflect disparate impacts of the pandemic on mortality by age and race and ethnicity. By age, adults aged 25 to 44 years experienced the largest increase in deaths in 2020 compared with deaths in this age group during 2015 through 2019. By comparison, adults in older age groups experienced increases in deaths ranging from 14.4% to 24.1%, while adults aged below 25 years experienced a 2.0% decrease in deaths in 2020. By race and ethnicity, the average percentage increase during this interval was highest among Hispanic persons (53.6%) and was approximately 33% higher among persons who identified as Black or Asian race and people with unknown race and ethnicity and were 11.9% higher among persons who identified as non-Hispanic White. In the same interval extended to 27 February 2021, the CDC estimate for excess deaths increased to between 545.6 thousand and 660.2 thousand, with approximately 75% to 85% of such deaths directly associated with COVID-19, and the remaining 63.7 thousand to 162.4 thousand deaths from other causes (**Rossen et al., 2021**). Altogether, COVID-19 was the third-leading cause of death in the US in 2020, behind only heart disease and cancer (**Ahmad et al., 2021; Ahmad & Anderson, 2021**).

In contrast, substantial excess deaths did not occur in Australia in the year 2020, as the 141.1 thousand total registered deaths in 2020 were comparable to the 140.9 thousand death average (range = 137.3 thousand to 144.1 thousand) from the years 2015 through 2019, according to the Australian Bureau of Statistics **(Australian Bureau of Statistics, 2021)**. Overall, there were 832 decedents for whom COVID-19 was the cause of death, while there were declines in deaths due to other respiratory diseases (2020 = 12 thousand, 2015 through 2019 average = 14.4 thousand) and due to influenza and pneumonia (2020 = 2.1 thousand, 2015 through 2019 average = 3.3 thousand).

As of the end of June 2021, the US, which accounts for approximately four percent of the global population, had reported 15% of all COVID-19 deaths **(Dong et al., 2020)**. Estimates for the number of preventable deaths vary but are considerable. Redlener *et al.* estimate that through October 2020, between 130 thousand and 210 thousand deaths had been preventable if COVID-19 prevention policies had mirrored those of similar high-income countries, including Australia **(Redlener et al., 2020)**. In a report released in March 2021, Atkeson estimates that just under 400 thousand deaths were preventable (292 thousand, rather than the projected 672 thousand with vaccines) with more effective mitigation, and that as many as 1,270 thousand deaths were possible if not for introduction and distributions of COVID-19 vaccines **(Atkeson, 2021)**. In comparing COVID-19 in the US to the disease in other G-7 nations, a study published in *The Lancet* estimated that approximately 40% of the then-500 thousand COVID-19 deaths in the US had been avoidable **(Woolhandler et al., 2021)**. Without an exact estimate, a senior White House coronavirus response coordinator estimated that following the initial 100 thousand COVID-19 deaths, all subsequent deaths could have been avoided or considerably reduced by earlier and more stringent mitigation measures **(Brown, 2021)**.

Regardless, hundreds of thousands of US COVID-19 deaths were avoidable, and the arrival of COVID-19 pandemic and its sequelae have corresponded with the greatest decrease in life expectancy in the US since World War II—with disproportionate impact on Black persons and Latinx persons—according to a number of estimates based on provisional mortality data **(Andrasfay & Goldman, 2021; Arias et al., 2021; Barbieri, 2021; Woolf et al., 2021)**. Comparing January through June of 2020 with the same interval in 2019, the NCHS estimated a decline of life expectancy by one year (1.2 and 0.9 years, respectively, for individuals of male and female sex), with larger increases in populations of persons who were Black (2.7 years) or Latinx (1.9 years) versus White (0.8 years) **(Arias et al., 2021)**, reversing 10 years of progress in closing the Black-to-White gap in life expectancy **(Andrasfay & Goldman, 2021)**. The US decline in life expectancy was considerably larger than that observed in comparable high-income countries **(Barbieri, 2021; Woolf et al., 2021)**. Comparing 2020 with 2018 in the US and 16 other high-income countries, the life expectancy gap between the US and these countries widened from 3.1 years to 4.7, driven by 8.5 times the average decrease in life expectancy observed in peer countries (the US = 1.87 years; average across 16 other countries = 0.22 years). Racial and ethnic disparities observed in the NCHS data widened. Compared with the 1.4-year decline observed in the White population, the Black and Latinx populations experienced declines of 3.3 and 3.9 years, respectively, with life expectancy among Black men (67.7 years)—which had already been about four years shorter than among White men—reaching its lowest level since 1998. Declines in life expectancy among Black and Latinx persons in the US by sex ranged between 12.3 to 22.5 times higher than those observed in peer countries.

Comparing the impact of government and public health actions and inactions across regions is limited by social, political, cultural, and geographical differences, among others. However, the available evidence strongly suggests that the COVID-19 pandemic was associated with hundreds of

thousands of excess deaths in the US, which were disproportionately borne by historically oppressed and marginalised groups. In contrast, substantial excess deaths were not observed in Australia or other high-income countries. Given evidence of NPIs as being effective in containing COVID-19 ([Section 15.1.3.](#)) and having the potential to save more than 100 thousand US lives (**Brown, 2021; Redlener et al., 2020; Woolhandler et al., 2021**), it is unfortunate that the US did not capitalise on widespread public support for and adherence with NPIs observed in the US early during the pandemic and reported in Chapters [Two](#), [Three](#), and [Four](#) of this thesis (**Czeisler, Tynan, et al., 2020; Czeisler, Garcia-Williams, et al., 2020; Czeisler, Howard, et al., 2021; Fisher, Barile, et al., 2020; Haston et al., 2020; Moreland et al., 2020; Nelson et al., 2020**).

Excess deaths and declines in life expectancy are two measures that reflect a combination of direct and indirect consequences of the COVID-19 pandemic on human health. However, some of the indirect health effects of the pandemic might not be reflected in mortality data, at least in the short term. For example, each of the 600 thousand US COVID-19 deaths is estimated to leave approximately nine survivors bereaved (**Verdery et al., 2020**). Moreover, approximately 40 thousand US children lost a parent to COVID-19 during the pandemic (**Kidman et al., 2021**), with an estimated 1.1 million children globally having experienced the death of a primary caregiver (**Hillis et al., 2021**). Related mental health effects of events proximal to COVID-19 (**Simon et al., 2020**), plus the potential for challenges related to the social and financial impacts of COVID-19 prevention measures (**S. K. Brooks et al., 2020; Galea et al., 2020; Holmes et al., 2020**), underscore the possibility of adverse mental health impacts among the indirect effects of the pandemic. Section 15.2. of the General Discussion reviews and contextualises findings presented in this thesis regarding mental health and substance use during the COVID-19 pandemic.

15.2. MENTAL HEALTH AND SUBSTANCE USE DURING THE COVID-19 PANDEMIC IN THE UNITED STATES, AUSTRALIA, AND COUNTRIES WORLDWIDE

The primary aim of Part II of this thesis was to monitor mental and behavioural health during the COVID-19 pandemic in the US and Australia. Mental health challenges during infectious disease outbreaks have historical precedence (**Czeisler, Howard, & Rajaratnam, 2021; Hawryluck et al., 2004**) and were anticipated during the COVID-19 pandemic (**S. K. Brooks et al., 2020; Galea et al., 2020; Holmes et al., 2020**). Mental health surveillance was therefore conducted as part of The COPE Initiative to estimate the prevalence of adverse mental health symptoms, identify populations disproportionately affected, and evaluate factors associated with adverse mental health symptoms and substance use.

15.2.1. SUMMARY OF RESEARCH FINDINGS FROM POPULATION-LEVEL MENTAL HEALTH SURVEILLANCE

Despite vastly different COVID-19 experiences in the US and Australia, high levels of adverse mental health symptoms and substance use were observed in both regions and around the globe, both early and well into the pandemic. Some of the earliest evidence of this during the COVID-19 pandemic is described in the summary of research findings from [Chapter Four](#) of this thesis and findings by Ettman *et al.* in Section 15.1.1., including the tripled prevalence of depression symptoms among US adults in April 2020 shortly after the declaration of the pandemic as compared with estimates from 2019—and similarly high levels of adverse mental health symptoms observed in Australia (**Czeisler, Howard, et al., 2021; Ettman et al., 2020**). Both studies found that younger adults more commonly experienced adverse mental health symptoms than did older adults, with the Original Investigation in [Chapter Four](#) estimating an adjusted prevalence ratio of 2.2 (95% confidence interval = 1.9 to 2.6) for symptoms of anxiety or depression among adults aged 18 to 24

years compared with those aged 65 years or older (**Czeisler, Howard, et al., 2021**). These findings, together with the longitudinal analysis with pre-pandemic data by Ettman *et al.*, provide evidence that adverse mental health symptoms were acutely elevated in the US by early April 2020.

The Original Investigation in [Chapter Six](#) revealed that as of June 2020, 40.9% of more than 5,000 surveyed adults in the US had experienced anxiety or depression symptoms (30.9%), started or increased substance use to cope with stress or emotions (13.3%), or seriously considered trying to kill themselves (10.7%) (**Czeisler, Lane, et al., 2020**). By this time, the prevalence ratio for anxiety or depression symptoms among adults aged 18 to 24 years compared with those aged 65 years or older had risen to 7.7 (95% confidence interval = 6.2 to 9.7), which may partially reflect differences in mental health resilience by age (**Vahia et al., 2020**). However, that is not to say that older adults did not have emotional responses to the pandemic. Data from a nationally representative survey of US Medicare beneficiaries aged 65 years or older revealed that feelings of anxiety and depression about the COVID-19 pandemic were reported by 28.3% and 22.7%, respectively, of respondents (**Robbins, Weaver, et al., 2021**).

Data from September 2020 reported in [Chapter Seven](#) (US adults) and [Chapter Ten](#) (Victorian adults) provided evidence that observations of high levels of adverse mental health symptoms were not transient, and remained similarly high in the US and Australia despite considerably different pandemic trajectories to that point (**Czeisler et al., 2021; Czeisler, Lane, et al., 2021**). At the time, the US was eclipsing Australia, with six million laboratory-confirmed SARS-CoV-2 infections out of a population of 330 million, while the Australian state of Victoria had approximately 20 thousand cumulative laboratory-confirmed infections out of a population of more than six million (**Dong et al., 2020**). However, Victoria was in the final stretch of one of the longest and most stringent COVID-19 lockdowns globally. In both the US and Australia, approximately one-third of surveyed

adults screened positive for anxiety or depression, and the prevalence estimates for suicidal ideation were approximately 12% and 10%, respectively. In both regions, younger adults, unpaid caregivers, and people with sleep, psychiatric, or substance use conditions disproportionately experienced adverse mental health symptoms and substance use.

15.2.2. Mental Health During the COVID-19 Pandemic: Challenges, Populations at Risk, Implications, and Opportunities

PREFACE TO SECTION 15.2.2.

The Editorial presented in Section 15.2.2. of the General Discussion was prepared following an invitation to contribute to the *Knowing Well, Being Well* Special Issue of the *American Journal of Health Promotion*. The Editorial was written based on evidence on mental health during the COVID-19 pandemic through mid-December 2020 and focused on mental health challenges, disproportionately affected populations, short-term and long-term implications of an elevated global mental health burden, and steps taken to address mental health.

CHAPTER FIFTEEN: Mental Health During the COVID-19 Pandemic: Challenges, Populations at Risk, Implications, and Opportunities

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Mental Health During the COVID-19 Pandemic: Challenges, Populations at Risk, Implications, and Opportunities

Mark É. Czeisler, AB^{1,2,3}, Mark E. Howard, MBBS, PhD^{1,2,4}, and Shantha M. W. Rajaratnam, PhD^{1,2,5,6}

Introduction

The coronavirus disease 2019 (COVID-19) pandemic has had a profound worldwide impact on health. As of mid-December 2020, 77 million confirmed cases of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the virus that causes COVID-19, have contributed to 1.7 million deaths worldwide, with the United States accounting for nearly 18 million cases and 320,000 deaths.¹ Data from the U.S. Centers for Disease Control and Prevention revealed deaths from COVID-19 accounted for just 66% of excess deaths in the U.S. through October 2020,² highlighting the broad consequences of the pandemic on morbidity and mortality.³ These consequences may be related to reductions in provision of care for non-COVID-19-related health conditions,⁴ and to delay or avoidance of medical care due to concerns about COVID-19.⁵⁻¹¹ A recent meta-analysis estimates that for every 4 weeks cancer treatment is delayed, the risk of death increases by approximately 10%.¹² Beyond excess

¹ Turner Institute for Brain and Mental Health, Monash University, Melbourne, Victoria, Australia

² Institute for Breathing and Sleep, Austin Health, Melbourne, Victoria, Australia

³ Department of Psychiatry, Brigham and Women's Hospital, Boston, MA, USA

⁴ Department of Medicine, University of Melbourne, Melbourne, Victoria, Australia

⁵ Division of Sleep and Circadian Disorders, Departments of Medicine and Neurology, Brigham and Women's Hospital, Boston, MA, USA

⁶ Division of Sleep Medicine, Harvard Medical School, Boston, MA, USA

Corresponding Author:

Mark É. Czeisler, Turner Institute for Brain and Mental Health, Monash University, Level 5, 18 Innovation Walk, Clayton Campus, Clayton, 3800, Victoria, Australia.

Email: mark.czeisler@fulbrightmail.org

deaths during the pandemic, delay or avoidance of routine and maintenance care may drive long-term health consequences and burden our healthcare system for decades.

Unaccounted for in these grim statistics is the toll the COVID-19 pandemic has taken on mental health. Public health measures implemented to reduce transmission of SARS-CoV-2 have been associated with profound social and economic disruption across the globe.¹³⁻¹⁶ Adverse mental health is among the most prevalent challenges experienced during the pandemic. Early evidence of adverse mental health experienced in Wuhan, China, the initial epicenter of the outbreak, was found among healthcare workers,¹⁷⁻²⁰ working adults in the general population²¹, and hospitalized COVID-19 patients.²² As SARS-CoV-2 and COVID-19 have spread to more than 200 countries,¹ elevated levels of adverse mental health symptoms have been observed in the U.S.²³⁻²⁶ and around the globe.²⁷⁻³³

In June 2020, 40.9% of 5,412 U.S. adults in a nationally representative survey study reported having experienced adverse mental or behavioral health symptoms, including those of an anxiety or depressive disorder (30.9%), a trauma- and stressor-related disorder (TSRD) attributed to COVID-19 (26.3%), having started or increased substance use (e.g., alcohol, legal or illegal drugs, or prescriptions drugs that are taken in a way not recommended by a doctor) to cope with stress or emotions related to COVID-19 (13.3%), and having seriously considered suicide (10.7%).²³ Prevalence of symptoms of anxiety and depressive disorder were 3- and 4-fold higher, respectively, than those experienced during the second quarter of 2019 (anxiety disorder = 25.5% versus 8.1%; depressive disorder = 24.3% versus 6.5%), and suicidal ideation was more than twice as prevalent than in 2018 (10.7% versus 4.3%).²³

Similarly elevated prevalence of adverse mental health has been reported by additional research in the U.S.,^{24,25} along with increased sexual and physical violence.²⁶ Alternative indicators also point to elevated psychological distress, including increased Internet searches for anxiety-related terms,^{34,35} volume for distress helplines,³⁶ and psychological or psychiatric emergency department visits,^{5,37} along with mental health and substance use disorder hospital visits during COVID-19 surges.³⁸ With more than 2 in 5 Americans having experienced adverse mental and behavioral health symptoms in June 2020, mental health should be prioritized in response to the pandemic.

Contributors to Psychological Distress

While much attention has been placed on economic lockdowns and stay-at-home orders as causes for adverse mental health, challenges for mental health associated with COVID-19 may arise via either indirect experiences with the virus (e.g., bereavement; social isolation and loneliness; uncertainty; socioeconomic distress) or from personal infection with SARS-CoV-2.

Evidence of psychological consequences of infection with respiratory illness date back to an influenza epidemic in Germany in 1385 and were described in the U.S. during the 1918 influenza pandemic by Dr. Karl Menninger.³⁹⁻⁴¹ Moreover, there is evidence of mental health consequences associated with severe acute respiratory syndrome (SARS) and middle eastern respiratory syndrome (MERS), the 2 infectious disease outbreaks from coronaviruses (SARS by severe acute respiratory syndrome coronavirus 1 [SARS-CoV-1] beginning in 2002 and MERS by middle eastern respiratory syndrome coronavirus [MERS-CoV] beginning in 2012) that preceded the COVID-19 pandemic.⁴² In a meta-analysis of patients hospitalized for either SARS or MERS, there was a high prevalence of acute symptoms including confusion (27.9%), depressed mood (32.6%), anxiety

(35.7%), impaired memory (34.1%), and insomnia (41.9%). Loneliness, boredom, and frustration from isolation were prominent features of patient experiences, as were concerns of death and possible guilt for having spread the virus to family members and acquaintances. Survivors commonly experienced post-illness symptoms including irritability (12.8%), memory impairment (18.9%), fatigue (19.3%), insomnia (12.1%), traumatic memories (30.4%), and high post-illness prevalences of post-traumatic stress disorder (PTSD) (32.2%), depression (14.9%), and anxiety (14.8%).⁴² An early surveillance study of neurologic and neuropsychiatric sequelae of COVID-19 conducted in the United Kingdom found 153 cases of COVID-19 patients exhibiting symptoms.⁴³ Nearly one-third of 125 patients with complete clinical datasets had altered mental status, 59% of whom fulfilled clinical definitions for psychiatric diagnoses. Alarming, 92% of these psychiatric diagnoses were new-onset psychosis, and more than half of them occurred in patients aged below 60 years. A smaller study of 64 COVID-19 patients found that 20.3% met the criteria for PTSD following hospitalization.⁴⁴

Since then, a study of the electronic health records of nearly 70 million patients from 54 healthcare organizations in U.S. found that 18.1% of patients hospitalized for COVID-19 were diagnosed with a psychiatric condition in the 14 to 90 days following COVID-19 diagnosis, including 5.8% who received first-time psychiatric diagnosis.⁴⁵ By comparison, less than half the percentage (2.8%) of individuals from a matched cohort of hospitalized influenza patients were diagnosed with a psychiatric condition in the same interval. Notably, psychiatric diagnosis is a measure that likely underestimates that prevalence of adverse mental health experienced post-hospitalization. Among all patients with no psychiatric history, those who were hospitalized for COVID-19 had increased incidence of first-time psychiatric diagnosis compared to those who were hospitalized for other health events assessed, with the highest increase in anxiety disorders, insomnia, and dementia. With modeling based on previous coronaviruses supporting the possibility of multiyear dynamics of SARS-CoV-2 resurgences as far into the future as 2025,⁴⁶ and the Imperial College COVID-19 Response Team proposing that more than 80% of Americans could eventually be infected with SARS-CoV-2,⁴⁷ it is critical to consider the potential psychiatric and neuropsychiatric consequences of SARS-CoV-2 infection, even in cases that are otherwise asymptomatic.

The COVID-19 pandemic has also been associated with mental health challenges for those who are not infected with SARS-CoV-2, including the social and economic impacts of quarantine, physical distancing, stay-at-home orders, gathering bans, nonessential business closures, and additional measures introduced to reduce community transmission of the virus. Quarantine, the most extreme form of isolation, has been advised during the COVID-19 pandemic for those who were infected and not hospitalized, travelers, and close contacts of those infected. Evidence from previous quarantining during previous infectious disease outbreaks highlights negative psychological effects, including TSRD symptoms, confusion, and anger, especially in cases of long quarantine duration, infection fears, financial loss, stigma, and inadequate support, supplies, and information.⁴⁸⁻⁵² This prompted psychologists to advise public health officials to employ quarantine as an infection control measure only when it is deemed necessary and to consider these primary stressors.⁵³

There are also stressors associated with the rest of these measures,⁵⁴ especially among those who do not have high perceived risk of infection or severe COVID-19 illness. U.S. Army Major George Soper is best known for his discovery of the first asymptomatic carrier of disease (Typhoid fever) in America in maid and family cook Mary

Mallon or “Typhoid Mary” and for his role in her forcible long-term quarantine on North Brother Island, which totaled 26 years.^{55,56} Dr. Soper recognized public indifference and the unconscious, invisible, and unsuspecting nature of viral transmission as 2 principle barriers to effective mitigation during the 1918 influenza pandemic: “It does not lie in human nature for a man who thinks he has only a slight cold to shut himself up in rigid isolation as a means of protecting others on the bare chance that his cold may turn out to be a really dangerous infection.”⁵⁷

Just as there are disparities in risk for SARS-CoV-2 infection and COVID-19 hospitalization and mortality, there are disparities for the mental health consequences associated with COVID-19 and its mitigation. However, there are some striking differences in the groups at greatest risk of infection, hospitalization, and death versus those at greatest risk of adverse mental health.

At-Risk Populations in the United States

With regard to mental health, a disproportionately high prevalence of adverse mental and behavioral health symptoms was reported by young persons, Black persons, Hispanic persons, essential workers, unpaid caregivers for adults, and those with pre-existing psychiatric conditions (anxiety disorder, depressive disorder, PTSD).²³ Symptoms of depression specifically were also observed among those with lower income, fewer than \$5000 in savings, and greater exposure to stressors, such as losing a job, interpersonal loss, and financial problems.²⁴

Among adults, adverse mental and behavioral health is most common among those aged 18-24 years and decreases with age.^{23,24} Symptoms of at least one mental and behavioral health condition were present in 74.9% of young adults, a significantly higher fraction than those 25-44 years (51.9%), 45-64 years (29.5%), and ≥65 years (15.1%). Alarming, the largest differential was observed by recent serious suicidal ideation, which was reported by 25.5% of those aged 18-24 years, compared to 2.0% of those aged ≥65 years. This is in stark contrast to the risk of COVID-19 hospitalization and mortality, which is highest among those aged ≥65 years and smallest among those aged 18-24 years,⁵⁸ despite younger adults accounting for an increasing proportion of cases.⁵⁹⁻⁶¹ Several factors have been proposed to support the paradoxical relationship between risk of severe COVID-19 and mental health during the pandemic. Studies have found that older people self-report better managing their emotions with age;⁶² exhibit greater day-to-day emotional stability;⁶³ and have enhanced emotional well-being,⁶⁴ suggesting that older adults may be better emotionally prepared to handle stressors amid the pandemic. Mental health is also intricately linked to sleep health. Older adults better tolerate sleep deprivation and circadian disruption than younger adults,^{65,66} which is particularly relevant given disrupted sleep patterns reported by the general population¹⁶ and by young adults.⁶⁷ Concerns about academic performance⁶⁷ and increased loneliness⁶⁸ have also been commonly reported by U.S. college-aged students and have been associated with psychological distress.

Inequities in the social determinants of health and distribution of resources have disproportionately affected persons belonging to historically oppressed and marginalized racial and ethnic groups, most notably Black persons, Hispanic or Latinx persons, and native persons,⁶⁹ and have been exacerbated during the COVID-19 pandemic. In June 2020, serious suicidal ideation was reported by 18.6% of surveyed U.S. adults who were Hispanic and 15.1% of those who were Black, compared to 7.9% of White adults.²³ Salient systemic racism, institutional racism, and discrimination affect health outcomes broadly^{70,71} through healthcare access and utilization, disproportional representation in essential

workforces and hazardous occupations, education, income, and wealth, as well as housing and living conditions. These circumstances also affect mental and behavioral health, driven in part by a lack of diversity in the mental health workforce and stigma in non-White communities.⁷²⁻⁷⁴ These findings highlight the need for culturally and linguistically tailored messaging to address these disparities.

Disadvantaged racial and socioeconomic groups are also at increased risk of infection, hospitalization, and death from COVID-19, which may reflect structural violence as socioeconomic and sociopolitical forces constrain agency of disadvantaged populations.⁷⁵ With COVID-19, models of cell phone mobility data alone can predict higher infection rates among these disadvantaged groups, suggesting these groups may be unable to reduce mobility as effectively and therefore face increased potential SARS-CoV-2 exposures. Beyond higher risk of infection, disparities in health insurance coverage^{76,77} and underlying health conditions⁷⁸ may contribute to differences in hospitalization and mortality rates. These phenomena are reflected in COVID-19 morbidity and mortality, with Black persons, Hispanic or Latinx persons, and American Indian or Alaskan Native persons having 2.6-2.8 times higher case prevalence, 4.6-5.3 times higher rates of hospitalization, and 1.1-2.1 times higher mortality than non-Hispanic White persons.⁷⁹⁻⁸³

Findings from early in the pandemic suggest financial insecurity associated with the pandemic is prevalent among Americans. In April 2020, 77.8% of U.S. adults were moderately to extremely concerned about the potential for an economic recession, and 55.1% were similarly concerned about personal financial losses due to the COVID-19 pandemic.¹⁶ Largescale layoffs and furloughs and record unemployment claims since then validate the concerns of many, and increase financial strain on individuals and households, adding a stressor associated with adverse mental health. Prevalences of anxiety or depressive disorder symptoms were nearly double among those with a household income of fewer than \$25,000 versus \$200,000 or more (30.8% versus 17.0%, respectively), consistent with pre-pandemic evidence that low household income was associated with increased incidence of mood disorders.⁸⁴ Wealth may also be a factor, as having less than \$5,000 in savings was associated with increased odds of depression during the pandemic compared to those with at least \$5,000 in savings.²⁴

Essential workers also experienced worse adverse mental and behavioral health compared to other employed respondents, with more than twice the prevalence of having started or increased substance use (24.7% versus 10.5%, respectively), and nearly 3 times the prevalence of serious suicidal ideation (21.7% versus 7.8%, respectively).²³ Healthcare personnel may face increased psychological distress related to caring for patients with COVID-19 and operating with limited resources that may directly influence patient survival and their own risk for infection. These healthcare personnel may also experience burnout due to prolonged high hospitalization rates during COVID-19 surges, and as treatment needs for non-COVID-19-related conditions bottleneck due to delay of elective and routine procedures. These conditions may be associated with symptoms of depressive or anxiety disorder, insomnia, and a TSRD, plus guilt and moral injury in resource-limited settings. Poor mental health and sleep disturbance may be detrimental for the healthcare personnel and their patients, as positive screenings for sleep disorders and anxiety or depression have been associated with increased incidence of adverse safety outcomes by 83% and 63%, respectively.⁸⁵ Similarly, law enforcement personnel with diagnosed or undiagnosed sleep disorders had higher odds of serious errors, including making an error or safety violation and uncontrolled anger toward suspects.⁸⁶

Unpaid caregivers for adults are often overlooked as an at-risk population, yet there was a near-3-fold increased prevalence of symptoms of anxiety or depressive disorder and 9-fold increased prevalence of suicidal ideation among unpaid caregivers than among non-caregivers.²³ These findings are particularly noteworthy given that an estimated 47.9 million Americans played roles as unpaid caregivers for adults before the pandemic.⁸⁷ That figure represented an increase from the estimate of 39.8 million Americans in 2015,⁸⁸ attributable in part to an aging baby boomer population and workforce shortages in healthcare and long term services & supports formal care systems. The demand for unpaid caregiving has been accelerated due to the COVID-19 pandemic. Research is needed to better understand the factors contributing to adverse mental health among caregivers, though some stressors include managing a job, especially as an essential worker, and continuing to care for adults, especially those of older age or with underlying medical conditions that increase their risk of severe COVID-19.

Moreover, as expected, adverse mental health symptoms were highly prevalent among those with a diagnosed psychiatric disorder. Most notably, suicidal ideation was present in approximately one quarter of those with anxiety disorder and depressive disorder, and nearly half of those with PTSD.²³ With regard to COVID-19, there is evidence that a psychiatric diagnosis is associated with higher incidence of COVID-19 hospitalization, independent of physical health risk factors, though this may be confounded by socioeconomic factors.⁴⁵

Finally, with the large number of hospitalizations and deaths, many have experienced sudden interpersonal loss with limited opportunities to come together and grieve, leading to warranted concerns about the progression of normal grief and distress into prolonged grief and psychiatric disorders.⁸⁹ Simon, Saxe, and Marmar estimate that prolonged grief disorder—characterized by ≥ 6 months of intense longing and preoccupation with the deceased, and by emotional pain, loneliness, difficulty reengaging in life, avoidance, feeling life is meaningless, and increased suicide risk—had a 10% pre-pandemic prevalence among bereaved individuals.⁹⁰ These estimates, however, do not account for the isolated nature of many COVID-19 deaths. With each COVID-19 death leaving an estimated 9 family members bereaved,⁹¹ and a projected cumulative death toll across the U.S. of more than 510,000 by the end of February 2021,⁹² there could be as many as 4.6 million bereaved Americans, leading to an estimated prevalence of 460,000 Americans with prolonged grief due to COVID-19.

There may be additional risk factors not presented above that will be important to identify and address. Given the distinct dimensions of stressors associated with each of these characteristics or circumstances, it is important to consider the complexities of intersectionality that may account for overlapping experiences that may contribute to psychological distress during the pandemic.

Implications

Adverse mental and behavioral health has implications for the economic and health sectors. From an economic perspective, the pre-COVID-19 estimate for the cost of adverse mental health for the global economy from 2010-2030 by the World Economic Forum and Harvard School of Public Health was \$16 trillion, attributable to the early age of onset and prolonged loss of productivity.^{93,94} Loss of productivity can be characterized by costs of mental-health-related absenteeism (i.e., missed work due to adverse mental health) and presenteeism (i.e., productivity losses and exhaustion from working despite adverse mental health). In the U.S., mean annual per-person

costs of absenteeism and presenteeism due to diagnosed depression were \$390 and \$5,524, respectively.⁹⁵ If the 4-fold increased prevalence of symptoms of depression were to translate to diagnoses and be sustained, the average total labor force costs of absenteeism and presenteeism due to depression alone (accounting for prevalence) would be raised from \$8 to \$32 billion and \$177 to \$708 billion, respectively. There are comparable figures for the costs of insomnia; with an estimated prevalence of 23.2% and mean annual per-person costs of presenteeism due to diagnosed insomnia of \$2,280, the total annual pre-pandemic labor force cost was an estimated \$65 billion.⁹⁶ From a health perspective, as of 2010, mental and substance use disorders were the leading cause of years lived with disability among all disease groups and accounted for more than 10% of the global burden of disease,⁹⁷⁻⁹⁹ a figure that is projected to increase with longer life expectancy.¹⁰⁰

For corporations, with mounting financial pressure amid the pandemic, employers can hardly afford to support these massive costs. Using a global multiregional and macroeconomic model, Lenzen et al. estimated that as of May 2020, direct and indirect effects of the pandemic had amounted to global consumption and income losses of \$3.8 trillion and \$2.1 trillion, respectively, along with 147 million full-time equivalent job losses.¹⁵ Among the most consequential manifestations of these losses is the looming homelessness crisis, with tens of millions of Americans at risk of eviction due to the pandemic.¹⁰¹ For individuals, in a comparison between households with at least one member with a mental and behavioral health disorder versus those without, those with mental and behavioral health disorders had significantly lower household income, effective income, non-health consumption, and asset-based wealth, along with higher healthcare expenditure and greater deleterious financial coping strategies.¹⁰² Early evidence of deleterious financial (and health) coping strategies include a 54% increase in national sales of alcohol immediately following stay-at-home orders in the U.S., with online sales increased 262% from 2019,¹⁰³ corresponding to a 14% increase in frequency of alcohol consumption and 41% increase in frequency of heavy drinking for women.¹⁰⁴ There has also been an acute increase in opioid-related overdoses, an acceleration of an epidemic that was already worsening before the pandemic.¹⁰⁵

Simultaneously, firearm purchases have soared during the COVID-19 pandemic, with 17 million new firearm purchases as of the end of October according to estimates from Small Arms Analytics,¹⁰⁶ more than any full year on record. Beyond concerns related to early findings of increased firearm violence¹⁰⁷ and anticipated increased gun murder in the U.S., increased prevalence of guns and first-time gun owners may be associated with increased suicides, as more than 60% of U.S. gun deaths are suicides.¹⁰⁸ Those who own handguns have considerably higher overall risk of suicide than those who do not own handguns, an effect driven by firearm suicides, as handgun owners do not have higher rates of suicide by other methods.¹⁰⁹ Of note, men accounted for 70% of suicides and 83% of firearm suicides. While the risk of suicide peaked within a month of acquiring a firearm, more than half of all suicides occurred more than 1 year after acquisition, as did the elevated risk of suicidal behavior. Although it is difficult to anticipate and will take years to comprehensively estimate the conversion rate between serious suicidal ideation, suicide attempts, and completed suicides during and beyond the pandemic, the combination of more-than-doubling of suicidal ideation, increased firearm purchases, and social and economic disruption put many Americans at greater risk for suicide during and after the COVID-19 pandemic. Suicide was already the 10th-leading cause of death overall in the U.S., accounting for approximately 1.7% of all deaths.¹¹⁰

These considerations highlight the potential for profound consequences of adverse mental health, substance use, and suicidal ideation on economics and health, and underscore the urgent need for prevention and intervention efforts to reduce morbidity and mortality during the COVID-19 pandemic. They also underscore the benefit of investing in mental and behavioral health infrastructure to support these needs in the post-pandemic era.

Response

A multicomponent bundle of prevention and intervention efforts has been employed to contain COVID-19 (e.g., hand hygiene, mask usage, physical distancing, symptom checking, contact tracing, testing, self-isolation and quarantine of those infected and close contacts). Given the multitude and complexity of stressors contributing to the widely varying symptom presentations of psychological distress, addressing mental health during the COVID-19 pandemic will require a series of strategies aimed at prevention, surveillance (targeting in particular at-risk groups), diagnosis, early intervention, continuity of care for those with pre-existing conditions, and mental and behavioral health crisis management.

Prevention efforts should include community and employer programs to strengthen social and economic supports to reduce financial strain and promote social connectedness. This will require culturally tailored messaging focused on the promotion of healthy behaviors, including sufficient regular sleep¹¹¹⁻¹¹⁵ and exercise,¹¹⁶⁻¹¹⁸ along with avoidance of unhealthy coping mechanisms.¹¹⁹⁻¹²¹ Employers can contribute through investment in employee assistance programs (EAPs) and workplace health promotion programs (WHPPs). Specifically, increased visibility and promotion of EAP and WHPP utilization will be necessary to boost engagement with these resources.¹²² EAPs can be cost-effective, as the average cost of conducting screening in EAPs was \$0.64, most of which was the cost of the time the client spent completing the screening, while the average cost of a brief intervention was \$1.86.¹²³ Adoption of more tailored, evidence-based WHPP programs should be encouraged. Notably, less than 1 in 10 U.S. worksites offer a sleep enhancement or fatigue reduction WHPP.¹²⁴ These may be particularly valuable for occupations with requirements that are associated with increased risk for sleep deficiency and circadian disruption, including healthcare and emergency services, and transportation.¹²⁵⁻¹³¹ Other creative strategies for risk reduction include programs such as temporary gun storage facilities, a program initiated by the Colorado Firearm Safety Coalition to allow users to look online for gun shops or police stations willing to consider requests for temporary gun storage, which could reduce suicides by firearm. Similar programs have been put into place in Washington and Maryland, and could be scaled up across the U.S. during the pandemic.¹³²

While effective prevention efforts will reduce psychological distress and enhance resilience in the long term, it is necessary to address loneliness and distress as large-scale home confinement and social isolation have already and will continue to serve as potential stressors. Routine, frequent, and widespread surveillance, with potentially even daily outreach, should be administered for signs and symptoms of adverse mental and behavioral health. Screening on this scale will require engagement by healthcare providers, communities, and additional institutions to consider innovative methods for such surveillance, and prioritization of at-risk populations, including young adults, unpaid caregivers, those in quarantine or self-isolation after infection with SARS-CoV-2, and those in bereavement after losses to COVID-19 or other causes. Healthcare personnel should consider supplementary training and remain vigilant for psychological distress

among recipients of care and consider additional clinical screening tools during patient interactions to identify those at risk for mental and behavioral health symptoms. Communication strategies should increase visibility of diagnostic services (in particular telehealth services), promote early health-seeking behavior, and encourage those experiencing symptoms of adverse mental health or those who know someone experiencing adverse mental health to connect with services to help.

Correct diagnosis is critical for the development of effective treatment plans. Culturally, demographically, and linguistically appropriate mental and behavioral health screening tools should be used, and COVID-19-specific screening instruments for COVID-19-related symptoms of adjustment disorders or TSRDs should be developed and implemented to account for elements of psychological distress unique to the COVID-19 pandemic.¹³³ Early diagnosis should be coordinated with early clinical interventions to prevent progression from acute symptoms to chronic mental health conditions, which could have prolonged health consequences that outlast the pandemic.

For many with pre-existing psychiatric conditions, rapid suspension of in-person services has presented a formidable challenge.¹³⁴ In the acute phase of the pandemic, many mental and behavioral health providers pivoted to telemental and telebehavioral health to provide behavioral therapy or psychotherapy remotely. While there is robust evidence to support the efficacy of telemental health as an effective means of delivering treatment for mental health conditions, including depression, substance use disorder, and suicidal ideation,¹³⁵⁻¹³⁷ it may not be universally desirable and effective, and there are barriers to access (e.g., Internet subscriptions) in under-resourced communities. Expanding access to remote telemental and telebehavioral health services is recommended, along with safe in-person care equipped to meet the varying needs of specific populations. Alternative resources may include digital mental health interventions (especially for adolescents and young adults),¹³⁸⁻¹⁴¹ which offer potential to use data to design personalized interventions, though determining the efficacy of interventions is important.¹⁴²

Finally, emergency mental health crisis support may involve encouraging people to contact helplines, and, in the face of more urgent concerns, to go to a hospital emergency department. For the former, it is critical that communities, employers, and public health communicators ensure that these resources are adequately funded and staffed and that individuals are aware of national resources to support mental and behavioral health during a crisis (Table). However, some individuals will require treatment in an emergency department. This sometimes ends with compulsory psychiatric hospitalization, which has been associated with adverse patient outcomes.^{143,144} Possibilities to reduce potentially detrimental psychiatric hospitalization could include preventative monitoring program psychoeducation comprising accurate risk assessment and preparation of 24-hour crisis intervention programs to provide immediate psychiatric support and treatment. The former was associated with a host of better patient outcomes and experiences, including lower levels of perceived coercion and distress and higher levels of optimism.¹⁴⁵ Crisis intervention programs have been associated with a significant decrease in psychiatric hospitalizations,^{146,147} with one study finding a rebound in hospitalizations after the services of the psychiatrist were terminated.¹⁴⁷

Encouraging Signs and a Path Forward

Addressing the considerable increase in adverse mental and behavioral health during the COVID-19 pandemic serves as an opportunity

Table 34 (15.1). National Resources to Support those with Mental Health and Substance Use Disorders

Table. National Resources to Support Those With Mental Health and Substance Use Disorders.

Immediate help during a crisis	
Call 911	
Disaster Distress Helpline	https://www.samhsa.gov/disaster-preparedness 1-800-985-5990 (press 2 for Spanish), or text TalkWithUs for English or Hablanos for Spanish to 66746. Spanish speakers from Puerto Rico can text Hablanos to 1-787-339-2663.
National Suicide Prevention Lifeline	https://suicidepreventionlifeline.org/ 1-800-273-TALK (8255) for English, 1-888-628-9454 for Spanish
National Domestic Violence Hotline	https://www.thehotline.org/ 1-800-799-7233 or text LOVEIS to 22522
National Child Abuse Hotline	https://www.childhelp.org/hotline/ 1-800-4AChild (1-800-422-4453) or text 1-800-422-4453
National Sexual Assault Hotline	https://rainn.org/ 1-800-656-HOPE (4673)
The Eldercare Locator	https://eldercare.acl.gov/Public/Index.aspx 1-800-677-1116
Veteran's Crisis Line	https://www.veteranscrisisline.net/ 1-800-273-TALK (8255) or text: 8388255
Find a health care provider for substance use disorder and mental health	
SAMHSA's National Helpline	https://www.samhsa.gov/find-help/national-helpline 1-800-662-HELP (4357) and TTY 1-800-487-4889
Treatment Services Locator Website	https://findtreatment.samhsa.gov/
Interactive Map of Selected Federally Qualified Health Centers	https://data.cms.gov/Government/Map-Selected-Federally-Qualified-Health-Center-FQH/hqut-bhwm

Source: <https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/managing-stress-anxiety.html>.

to improve the accessibility, promotion, scale, and effectiveness of mental and behavioral health services that could save lives, reduce the social and economic consequences of adverse mental health, and improve health and well-being during and beyond the pandemic.^{148,149}

There are positive signs in the U.S., including \$425 million in federal funding in emergency funds to address mental and substance use disorders through SAMHSA and the presidential Executive Order on Saving Lives Through Increased Support For Mental- and Behavioral-Health Needs,¹⁵⁰ which established the Coronavirus Mental Health Working Group to facilitate an “all-of-government” response to the mental health conditions. To improve crisis support, 9-8-8 was established as a 3-digit national suicide prevention and mental health hotline through The National Suicide Hotline Designation Act,¹⁵¹ creating a mental-health-equivalent to 9-1-1. At the state level, in late September, California Governor Gavin Newsom signed Senate Bill 855 into law, which expanded mental health and substance use disorder treatment eligibility,¹⁵² a progressive move that may set the stage for additional states to follow suit. Furthermore, the National Safety Council has developed a National Plan to Address Opioid Misuse,¹⁵³ and the American Medical Association recently announced the Behavioral Health Integration (BHI) Collaborative to assist physicians working to combine mental and physical health services in their medical practices,¹⁵⁴ which could transform approaches to patient care for the better.

While these steps are an encouraging start, and there have been many parallel efforts initiated and augmented by other groups, addressing mental and behavioral health during the COVID-19 pandemic will require a comprehensive effort extending beyond cultural changes and social programs that support individuals to structural changes at the state and federal levels. If accomplished, these investments in

mental and behavioral health infrastructure could support the mental health needs of our health systems and increase economic recovery well beyond the pandemic.

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The Long Arm of Mental Health: New Urgency With the COVID-19 Pandemic

Jennifer A. Sumner, PhD¹, Karestan C. Koenen, PhD², and Laura D. Kubzansky, PhD³



The outbreak of the novel coronavirus disease 2019 (COVID-19), its high death toll and uncertainty regarding how long it will persist, the socially isolating effects of distancing, and the subsequent economic impact have contributed to dramatic increases in psychological distress.¹ Given the near universal exposure to aspects of the COVID-19 pandemic, and the many forms of psychological distress (e.g., depression, posttraumatic stress disorder [PTSD], substance misuse) that can occur in response to traumatic experiences, researchers and public health professionals have emphasized the need to intervene to offset the mental health consequences of the pandemic.² These calls to action on mental health are separate from—but parallel to—those from the infectious disease community, which is focused on mitigating the spread of COVID-19. However, the independence of these efforts perpetuates a potentially dangerous competition between investing in interventions that promote physical health (e.g., by reducing morbidity and mortality from the virus) and those that promote mental health (e.g., by treating PTSD and other mental health conditions). Indeed, given the reality of limited resources, this framing creates a false dichotomy, implying we must attend to and choose between preserving either physical or mental health but not both. With the recent tremendous increase in methodologically rigorous research demonstrating that poor mental health—including in the context of traumatic stress—precedes and predicts chronic disease onset and premature mortality, such a dichotomy is no longer tenable. However, the pandemic throws into sharp relief the persistence of this dichotomization and the costs of continuing to view mental and physical health as competing for resources required to improve the public's health.

We and others have shown that experiencing high levels of psychological distress after a traumatic or severely stressful event increases risk of developing a range of physical health conditions, including several of the leading causes of mortality: heart disease, stroke, diabetes, and dementia.³ PTSD is the most well-studied form of psychological distress occurring as a consequence of trauma, but extensive research has shown parallel findings for depression, loneliness, and anxiety predicting adverse physical health.⁴ Longitudinal research has also linked high psychological distress levels to drivers of chronic disease, including unhealthy behaviors like physical inactivity and poor diet and physiological factors like chronic inflammation.^{3,4} This work has further suggested that even psychological distress occurring below clinically relevant thresholds can substantially impact physical health. Thus, mental health matters in its own right, but also because it serves as the “canary in the coal mine”—an early warning signal that physical health is at risk. If we take these findings

seriously, the increases in psychological distress as a result of COVID-19 have sobering implications for chronic disease trends in upcoming decades.

Although it is generally accepted that the diagnosis and management of a chronic disease requires psychological adjustment, the idea that mental health influences physical health has long been debated, and significant skepticism remains. *We believe that we ignore the evidence that mental health is fundamentally intertwined with—and can serve as a foundation of—physical health at our peril.* It is time to take this idea seriously and allocate resources accordingly. First, we as a community—researchers and practitioners—need to stop viewing and treating mental and physical health as if they are completely independent of one another. The disease-focused institute structure of the National Institutes of Health, which sets funding priorities for much U.S. health research, contributes to this false dichotomy. Although some institutes have supported specific research projects at the intersection of mental and physical health, such work is often orphaned, considered outside the purview of any one institute and therefore not taken up for funding. More funding opportunities targeted at the intersection of mental health and chronic disease are needed.

Second, we need to advance research on whether effectively reducing psychological distress improves physical health outcomes. We found a cardioprotective effect of PTSD remission in a large community-based sample of women; women with remitted PTSD symptoms did not exhibit the elevated cardiovascular disease rates of those with ongoing elevated PTSD symptoms.⁵ Another study showed veterans with PTSD who exhibited clinically meaningful decreases in symptoms subsequently had a lower risk of incident type 2 diabetes compared to veterans with minimal or no PTSD symptom improvement.⁶ However, these results are based on observational data rather than randomized controlled trials examining effects of successful treatment

¹ Department of Psychology, University of California, Los Angeles, CA, USA

² Department of Epidemiology, Harvard T.H. Chan School of Public Health, Boston, MA, USA

³ Department of Social and Behavioral Sciences, Harvard T.H. Chan School of Public Health, Boston, MA, USA

Corresponding Author:

Jennifer A. Sumner, University of California, Los Angeles, Department of Psychology, Psychology Building 1285, Box 951563, Los Angeles, CA 90095, USA.

Email: jsumner@psych.ucla.edu

15.2.3. SUMMARY OF RESEARCH FINDINGS FROM SURVEILLANCE OF SPECIFIC POPULATIONS

The remaining chapters of this thesis built upon population-level mental health surveillance by focusing on evaluation of behavioural changes during the pandemic associated with adverse mental health symptoms, identification of potential modifiable risk factors for adverse mental health, or characterisation of factors associated with adverse mental health symptoms and substance use among disproportionately affected populations.

The Original Investigations presented in [Chapter Four](#) and in [Chapter Ten](#) provided evidence of profound lifestyle changes, at least acutely, during multiple phases of the pandemic. As of April 2020, three-quarters of surveyed adults in the US and Australia reported moderate to extreme disruption of their social lives, and more than two-fifths reported similar levels of disruption to their work or studies, physical activity, and sleep patterns (Czeisler, Howard, et al., 2021). Respondents reported perceived changes to sleep, including more time in bed (31%), more trouble sleeping (24%), and less regular sleep-wake schedules (16%). Short sleep duration, insomnia symptoms, and maintaining a less regular sleep-wake schedule were associated with higher prevalence ratios for adverse mental health symptoms (Czeisler et al., 2021), consistent with other surveillance studies during the pandemic (Killgore et al., 2020; Meaklim et al., 2021) and further supporting investigation of sleep as a potential modifiable risk factor for adverse mental health and for poor health in general (Grandner, 2020).

The Original Investigation in [Chapter Eleven](#) provided more substantial evidence to support the hypothesis that lifestyle factors, in particular sleep-wake behaviours, might serve as modifiable risk factors for adverse mental health symptoms. Specifically, this longitudinal study of sleep-wake behaviour with objective sleep data collected using the WHOOP wearable device (Miller et al.,

2020) worn for months both before and during the pandemic revealed that respondents with persistently short sleep duration or low consistency of sleep timing had significantly higher odds of adverse mental health symptoms and substance use compared with adults who had persistently long sleep duration or high sleep consistency (Czeisler et al., 2021). The findings on the relationship between sleep consistency and mental health resiliency adds to emerging literature supporting the importance of this measure (Fang et al., 2021; Fischer et al., 2020; Lyall et al., 2018; Phillips et al., 2017), and to the value of a broad view of sleep health (DeSantis et al., 2019) and to the public health implications of sleep health (Hale et al., 2020).

Regarding disproportionately affected populations, young adults, unpaid caregivers, and people with disabilities were among the groups that had the largest mental health disparities. Age-related differences in mental health were a major focus of mental health researchers (Barcellos et al., 2021; Bruine de Bruin, 2021; Bulloch et al., 2021; Vahia, 2020; Vahia et al., 2020; Wilson et al., 2021). Fewer studies had investigated mental health and substance use among unpaid caregivers and people with disabilities.

Unpaid caregivers of adults were of heightened interest given the unexpectedly large magnitude of mental health disparities found in [Chapter Six](#), with two-thirds of unpaid caregivers of adults having experienced adverse mental health symptoms or substance use in June 2020, compared with one-third of adults not in this role (Czeisler, Lane, et al., 2020). The Original Investigation presented in [Chapter Twelve](#), which was a secondary analysis of the data presented in [Chapter Six](#), revealed that adverse mental health symptoms were more common among unpaid caregivers who had been in caregiving roles for less than one year compared with those who had been in caregiving roles for one or more years (for one or more adverse mental health symptoms or substance use, adjusted prevalence ratio = 1.25 [95% confidence interval = 1.12 to 1.40]), and among those who

reported feelings of unpreparedness (for one or more adverse mental health symptoms or substance use, Spearman's $\rho = 0.44$, $P < 0.0001$), caregiving-related family disagreements ($\rho = 0.40$, $P < 0.0001$), having to cut down on living expenses ($\rho = 0.39$, $P < 0.0001$), and increased employee absenteeism ($\rho = 0.42$, $P < 0.0001$).

The Original Investigation in [Chapter Thirteen](#) built upon the findings of [Chapter Twelve](#) by also evaluating associations based on the role of providing unpaid care to children or adolescents aged under 18 years (i.e., parenting roles) (Czeisler, Rohan, et al., 2021). Unpaid caregivers of children and unpaid caregivers of adults had significantly higher odds of adverse mental health symptoms compared with adults in neither of these roles and were especially high for adults in the role of caring for people in both age groups. Unpaid caregivers of adults with mental health or substance use conditions or active COVID-19 had the highest odds of adverse mental health symptoms, though having someone to turn to for support was protective for mental health.

Finally, [Chapter Fourteen](#) described mental health and substance use among people with disabilities (Czeisler et al., 2021). This population has been under-researched during the pandemic (Lebrasseur et al., 2021) despite evidence of considerably higher risk of SARS-CoV-2 infection and COVID-19 morbidity and mortality (England - Office for National Statistics, 2021; Gleason et al., 2021; Landes et al., 2020; Shakespeare et al., 2021), and documentations of heightened adverse mental health symptoms before (Cree et al., 2020) and in the early months of the pandemic (Okoro et al., 2021; Steptoe & Di Gessa, 2021). The Original Investigation in [Chapter Fourteen](#) further identified a disproportionate increase in adverse mental health symptoms among people with disabilities during a later stage of the COVID-19 pandemic (February to March of 2021), including one-and-one-half times the odds of adverse mental health symptoms, two-and-one-half times the odds of suicidal ideation, twice the prevalence of methamphetamine use, nonopioid prescription

drug misuse, and polysubstance use, and thrice the prevalence of cocaine use and prescription or illicit opioid use. Furthermore, people with disabilities and diagnosed mental health or substance use more commonly reported that the pandemic had disrupted access to related treatment, furthering pre-pandemic disparities in access to care (Okoro et al., 2018).

15.2.4. MENTAL HEALTH AND SUBSTANCE USE OUTCOMES IN THE UNITED STATES, AUSTRALIA, AND AROUND THE WORLD

The COPE Initiative findings of high levels of adverse mental health symptoms in the general US and Australian adult populations were consistent with those from other surveys in these regions, both in the early months of the pandemic (Batterham et al., 2021; Biddle et al., 2020a; Daly, Sutin, et al., 2021; Dawel et al., 2020; Ettman et al., 2020; Giuntella et al., 2021; Holman et al., 2020; McKnight-Eily et al., 2021; Meaklim et al., 2021; Pollard et al., 2020; Varma et al., 2021) and near the end of 2020 and into 2021 (Biddle et al., 2020b; Centers for Disease Control and Prevention, 2020b; Vahratian et al., 2021). Prominent levels of adverse mental health symptoms were also observed in regions around the world, including the UK (Fancourt et al., 2021; Jia et al., 2020; M. Pierce, Hope, et al., 2020; M. Pierce et al., 2021), China (Zhou et al., 2020), multinational studies (Lieberoth et al., 2021; Meaklim et al., 2021; Varma et al., 2021), and reviews (Hossain et al., 2020; Rajkumar, 2020; Ren et al., 2020; J. Xiong et al., 2020). Limited mental health research in the lower-middle-income countries located in Africa and Asia also pointed to considerable mental health challenges in these regions (Kar et al., 2020).

Data from other sources provide alternative methods of quantifying increases in adverse mental health and substance use during the COVID-19 pandemic that we and others reported from public health surveillance data. In the US, during mid-March through October 2020 as compared with the same interval in 2019, weekly adult emergency department visits increased for all mental health

conditions, drug overdoses, and suicide attempts (**Holland et al., 2021**). Provisional mortality data from 2020 indicate that although US deaths classified as suicides declined by 2,677 as compared with 2019 (**Ahmad et al., 2021; Ahmad & Anderson, 2021**), consistent with a decrease found based on an analysis from data during March through August of 2020 (**Faust et al., 2021**). However, deaths classified as unintentional injuries rose by 19,136 during the same intervals—largely driven by a record increase in drug overdose deaths (**Ahmad et al., 2021; Ahmad & Anderson, 2021; Centers for Disease Control and Prevention, 2020i**). The CDC announced that from June of 2019 through May of 2020 as compared with the 12 prior months, more than 81 thousand drug overdose deaths occurred in the US, the highest number ever recorded (**Centers for Disease Control and Prevention, 2020i**). Overall, 37 of 38 jurisdictions with available data reported increases in synthetic opioid-involved overdose deaths, and 10 western states reported near or above 100% increases in such deaths; emergency department visits for nonfatal opioid overdoses increased (**Soares et al., 2021**), and San Francisco experienced a 50% increase in weekly overdose deaths (**Appa et al., 2021**). Overdose deaths were increasing before the pandemic in the US but have accelerated. Thus, deaths of despair (**Case & Deaton, 2015**) rose considerably during 2020. Moreover, CDC surveillance of emergency departments in February to March of 2021 revealed that visits for suspected suicide attempts were 51% higher among adolescent girls as compared to the same interval in 2019 (**Yard et al., 2021**). Furthermore, population-level statistics may mask demographic trends within these figures. For example, deaths by suicide in Maryland doubled among Black residents but decreased among White residents (**Bray et al., 2021**), consistent with concerning pre-pandemic trends of increasing suicide mortality among Black persons in the US over the past two decades (**Ramchand et al., 2021**).

Elsewhere, studies of suicide attempts in France (**Olié et al., 2021**) and in 21 countries or regions of countries (16 high-income and five upper-middle-income) with real-time suicide data

(Pirkis et al., 2021) did not find evidence of significantly increased risk of suicide since the pandemic began, consistent with findings from a review of suicide and self-harm during prior infectious disease outbreaks (Rogers et al., 2021). However, two studies from Japan revealed increased deaths by suicide in 2020 as compared with 2019 (Sakamoto et al., 2021; Tanaka & Okamoto, 2021). Following a 14% decline in deaths by suicide during the first five months of the pandemic in Japan, monthly suicide rates increased by 16% during July through October 2020, with particularly high increases among adolescents (49%) and female persons (37%) (Tanaka & Okamoto, 2021). These studies highlight the importance of remaining vigilant about suicide during and beyond the pandemic (Botchway & Fazel, 2021), and, together with findings of a 51% increase in suicide attempts among female adolescents in the US (Yard et al., 2021) and evidence of disproportionate worsening of mental health among female adolescents in Iceland (Thorisdottir et al., 2021), indicate that monitoring mental health may be particularly important among young, female persons.

Lost in population-level evidence of directional changes to behaviours and mental health is the marked heterogeneity observed among subpopulations. For example, as shown in Figure 20 (11.2), which is part of the investigation of sleep and mental health among WHOOP users reported in Chapter Eleven, multiple measures of early- versus pre-pandemic measures of sleep differed considerably (Czeisler et al., 2021). Amidst a sample-wide mean lengthening of sleep duration by approximately 15 minutes, the 10 percent of participants with the highest-magnitude changes in sleep duration recorded lengthening and shortening of 46.1 minutes (95% CI = 44.5 to 47.7) and 29.8 minutes (95% CI = 28.2 to 31.3), respectively. Heterogeneity in changes to sleep during the pandemic were also reported by Ong *et al.* among city-dwelling, working adults in Singapore (Ong et al., 2021) and by Robillard *et al.*, who identified three profiles of change among Canadian adults: Reduced Time in Bed, Delayed Sleep, and Extended Time in Bed (Robillard et al., 2021).

Heterogeneous changes in physical activity were also observed, including by Bu *et al.*, who identified six classes of growth trajectories among adults in The UK between March and August 2020 **(Bu et al., 2021)**. Three of these trajectories, comprising 62.4% of adult respondents, showed little change in physical activity over time, whereas three differed, with either decreasing physical activity (two trajectories totalling 28.6% of respondents) or increasing physical activity (9.0%) over time.

Differing mental health trajectories were also documented **(Ellwardt & Präg, 2021; M. Pierce et al., 2021)**. In an analysis of mental health during late April through early October 2020 among nearly 20 thousand adult residents of The UK, Pierce *et al.* employed latent class analysis to identify five discrete mental health trajectories: consistently good (39.3%), consistently very good (37.5%), recovering (12.0%), consistently poor (4.1%), or deteriorating, with a steady and sustained decline over the study interval (7.0%). This important finding reflects that mental health trajectories identified through longitudinal assessment are informative beyond sample-wide prevalence estimates over time.

Finally, while older age was associated with comparatively better pre- and mid-pandemic mental health **(Centers for Disease Control and Prevention, 2020b; Czeisler et al., 2021, 2021; Dawel et al., 2020; Ettman et al., 2020; Fancourt et al., 2021; M. Pierce, Hope, et al., 2020; Rajkumar, 2020; J. Xiong et al., 2020)**, significantly increased levels of depression, loneliness, and poor quality of life was found among older adults **(Zaninotto et al., 2021)**, highlighting the broad needs for mental health services to support people of all ages. While populations demonstrated heterogeneous behavioural changes and experiences with mental health and substance use, some characteristics and behavioural changes were associated with changes in adverse mental health.

Our data reveal that adverse mental health symptoms were associated with spending most of the time at home or being in quarantine **(Czeisler, Howard, et al., 2021)**, consistent with findings from

prior infectious disease outbreaks (**Hawryluck et al., 2004; Robertson et al., 2004**) and supportive of predictions regarding potential indirect mental health effects of the pandemic related to social isolation and fears about the disease (**S. K. Brooks et al., 2020; Galea et al., 2020**). Evidence also highlights the negative mental health associations of loss of employment (**Posel et al., 2021**), bereavement from COVID-19 kin loss (**Borghi & Menichetti, 2021; Verdery et al., 2020**), housing environment and insecurity (**Amerio et al., 2020; Bushman & Mehdipanah, 2021**), managing unpaid caregiving responsibilities (**Czeisler et al., 2021; Czeisler, Lane, et al., 2020; Czeisler, Rohan, et al., 2021**), and working on the frontline of the pandemic as essential workers (**Czeisler, Lane, et al., 2021**), healthcare workers (**Di Tella et al., 2020**) or public health employees (**Bryant-Genevier et al., 2021**).

In addition to demographic or employment characteristics, adverse mental health symptoms and substance use were associated with chronically insufficient or irregular sleep (**Czeisler et al., 2021**) and unhealthy changes to sleep during the pandemic (reduced sleep duration, less regular sleep timing) (**Czeisler et al., 2021**), consistent with evidence from other studies (**Khader et al., 2020; Killgore et al., 2020; Meaklim et al., 2021; Varma et al., 2021**). Additionally, high levels of consumption of media about COVID-19 was associated with adverse mental health symptoms, as was increase time on screens and reduced time outdoors (**Czeisler et al., 2021; Silver et al., 2021**). To complement indirect mental health effects of the pandemic, emerging evidence also provides increasing evidence of potential direct mental health sequelae of COVID-19, which might not correlate with the severity of other COVID-19 symptoms. Large-scale electronic health record cohort studies have revealed significantly increased risk of psychiatric or neurologic diagnoses among COVID-19 patients within three or six months of diagnosis compared with patients with other health conditions (**Taquet, Geddes, et al., 2021; Taquet, Luciano, et al., 2021**). Mental health surveillance studies have also found associations between COVID-19 diagnoses or SARS-

CoV-2 infections and symptoms of post-traumatic stress disorder (**Chamberlain et al., 2021; Janiri et al., 2021; Tarsitani et al., 2021**) and depression (**Perlis et al., 2021; Speth et al., 2020**).

Mechanistic studies provide evidence of neuropsychiatric consequences following SARS-CoV-2 infection, which may occur due to neuronal or astrocytic infection, or through microvascular or inflammatory mechanisms (**Boldrini et al., 2021; Solomon, 2021**). Regarding direct neuronal infection, SARS-CoV-2 ribonucleic acid (RNA) and associated proteins have been detected in the olfactory mucosa (**Meinhardt et al., 2021**) and human brain organoids (**Ramani et al., 2020**), providing evidence of central nervous system (CNS) involvement. However, direct viral neuronal infection with SARS-CoV-2 is unlikely to be the primary cause of neuropsychiatric sequelae given that SARS-CoV-2 rarely appears in the cerebrospinal fluid (CSF) of COVID-19 patients with neurological symptoms (**Lewis et al., 2021; Solomon, 2021**). Evidence of vascular damage and inflammation have also been reported (**Bryce et al., 2021; Varatharaj et al., 2020**).

Most currently published investigations of post-acute neuropsychiatric sequelae of COVID-19 lack pre-infection data and have relied exclusively on persons tested for SARS-CoV-2 or use hospitalised controls, which subjects the studies to collider bias (**Griffith et al., 2020**). Recently, however, a preprint was posted based on 782 brain scans collected from participants of the UK Biobank COVID-19 reimagining study, approximately half of whom had a history of SARS-CoV-2 infection (**Douaud et al., 2021**). Structural and functional brain scans revealed significant loss of grey matter in COVID-19 patients in the limbic cortical areas linked to the olfactory and gustatory systems. Given the high prevalence of altered smell and taste as symptoms of COVID-19 (**Struyf et al., 2021**), this grey matter loss may be a hallmark of the spread of SARS-CoV-2 via the olfactory and gustatory pathways.

While this thesis did not distinguish between direct and indirect mental health consequences, population-level surveillance studies such as The COPE Initiative could consider using altered smell or taste to screen for COVID-19 with potential direct mental health sequelae. This screening approach could be important because altered smell or taste is a common **(Lechien et al., 2021)** and highly distinctive (pooled specificity = 90.5% [95% confidence interval = 81.2% to 95.4%]) **(Struyf et al., 2021)** symptom of COVID-19, and because the vast majority of SARS-CoV-2 infections are undetected **(Reese et al., 2020)**. Otherwise, studies that rely on hospitalised patients or persons with SARS-CoV-2 infections might be subject to collider bias **(Griffith et al., 2020)** and have persons with an undetected history of SARS-CoV-2 infection or COVID-19 in control groups.

Given evidence of considerable mental health morbidity resulting from indirect effects of the pandemic and its mitigation, there is an urgent need to return to pre-pandemic social and economic behaviours. Simultaneously, with potential serious post-acute neuropsychiatric sequelae as direct effects of SARS-CoV-2 infection, minimising the number of SARS-CoV-2 infections is imperative. Section 15.3 of this thesis describes outcomes from the development and distribution of COVID-19 vaccines, which could represent the means of controlling the pandemic.

To comprehend some of the factors associated with COVID-19 vaccine hesitancy (e.g., concern that the approval process was rushed), it is useful to understand the nature of the COVID-19 vaccine development relative to prior vaccines. Additionally, to understand the potential for COVID-19 vaccines to reduce SARS-CoV-2 infections and COVID-19 morbidity and mortality, it is critical to review data on the effectiveness of the vaccines. Therefore, while the vaccine-related work presented in this thesis is focused on vaccine intentions rather than the development of vaccines or evaluation of vaccine effectiveness, subsections 15.3.1. through 15.3.3. provide a brief review of these aspects of the COVID-19 vaccine era.

15.3. COVID-19 VACCINES: A NEW ERA OF THE COVID-19 PANDEMIC

During the early months of the COVID-19 pandemic, vaccines were heralded as the tools to end the pandemic. Indeed, while NPIs present as the best infection control practices in the absence of a vaccine, vaccines designed specifically to induce population-level immunity against SARS-CoV-2 infection have greater potential to (1) prevent infection through vaccine-induced immunity and (2) protect against severe illness when there are breakthrough infections. The impact of the vaccine on the pandemic course is dependent on several parameters, including vaccine efficacy, vaccine coverage, and post-infection immunity. Although these numbers are dynamic and highly variable across countries, findings from a modelling study indicate that to reduce the SARS-CoV-2 peak by more than 99%, with vaccine efficacy (infection prevention) estimates of 60%, 70%, and 80%, vaccine coverage requisites were estimated at 100%, 75%, and 60% (**Bartsch et al., 2020**). With the vaccine efficacy variable across vaccines and SARS-CoV-2 strains, enhancing vaccine coverage is a controllable way to reduce SARS-CoV-2 transmission. Understanding public attitudes and intentions regarding immunisations is important for achieving this target.

15.3.1. COVID-19 VACCINE DEVELOPMENT

In May 2020, the US government-initiated Operation Warp Speed to facilitate the development, manufacturing, and distribution of COVID-19 vaccines (**The White House, 2020a, 2020c**). At the time, no vaccine had been developed to combat an infectious disease within four years (the mumps vaccine in the 1960s) (**University of California Los Angeles Health, 2020**). As of August 2020, eight companies received USD\$11 billion in funding for research and development of COVID-19 vaccines (Johnson & Johnson [Janssen Pharmaceutical]; AstraZeneca—University of Oxford; Vaccitech; Moderna; Novavax; Merck; Sanofi; and GlaxoSmithKline). Outside of Operation Warp

Speed, Pfizer-BioNTech initiated research and development for a COVID-19 vaccine (**Higgins-Dunn, 2020; Slaoui & Hepburn, 2020**). Additional COVID-19 vaccine development efforts included Sputnik V (**Jones & Roy, 2021; Logunov et al., 2021**)—developed by the Gamaleya Research Institute of Epidemiology and Microbiology in Russia, COVAX (**World Health Organization, 2020a**)—which was co-developed by Gavi, the Coalition for Epidemic Preparedness Innovations, and the WHO, several vaccines developed in China—including by Sinopharm, Sinovac, CanSino, and Anhui Zhifei Longcom (**Mallapaty, 2021**), among others candidates.

On 11 August 2020, the Sputnik V COVID-19 vaccine was registered by the Russian Ministry of Health as Gam-COVID-Vac (**Logunov et al., 2021**). On 11 December 2020, the Pfizer—BioNTech messenger RNA (mRNA) COVID-19 vaccine became the first to receive FDA Emergency Use Authorization (EUA) for administration to people aged 16 years and older (**Food and Drug Administration, 2021c**). One week later, the Moderna mRNA COVID-19 vaccine received an FDA EUA for administration to people aged 18 years and older (**Food and Drug Administration, 2021b**). Both of these vaccines followed two-dose regimens. On 27 February 2021, the FDA issued an EUA for use among people aged 18 years and older for the first single-dose COVID-19 vaccine available in the US, developed by the Janssen Pharmaceutical Companies of Johnson & Johnson (**Food and Drug Administration, 2021d**).

15.3.2. COVID-19 VACCINE EFFICACY: PHASE 3 CLINICAL TRIAL DATA

Phase 3 clinical trial results published in February 2021 indicated over 90% efficacy against SARS-CoV-2 without unusual side effects for the heterologous recombinant adenovirus (rAd)-based vaccine, Gam-COVID-Vac (Sputnik V), which was the first COVID-19 vaccine approved in any country (**Jones & Roy, 2021; Logunov et al., 2021**). Two-dose regimens both the BNT162b2

mRNA vaccine (Pfizer-BioNTech) and mRNA-1273 vaccine (Moderna) yielded approximately 95% protection against COVID-19 illness in adults (**Baden et al., 2021; Gonzalez-Reiche et al., 2020**), and a single-dose regimens of the recombinant, replication-incompetent human adenovirus type 26 vector Ad26.COV2.S vaccine (Janssen [Johnson & Johnson]) was 67% effective against moderate to severe-critical COVID-19 at least 14 days after administration, with higher efficacy against severe-critical COVID-19 and reduced efficacy against the 20H/501Y.V2 variant (**Sadoff et al., 2021**). Finally, a two-dose regimen of the ChAdOx1 nCoV-19 (Oxford/AstraZeneca) was estimated at 70% effective against symptomatic COVID-19 based on four randomised controlled trials (RCTs) in Brazil, South Africa, and the UK (**Voysey et al., 2021**).

Overall, several COVID-19 vaccines produced encouraging data in clinical trials and were eventually approved in regions around the globe. With the subsequent mass inoculation, there was a need to understand the real-world effectiveness of these vaccines against SARS-CoV-2 infection and COVID-19 morbidity and mortality.

15.3.3. COVID-19 VACCINE EFFECTIVENESS: REAL-WORLD SETTINGS

Early estimates of nationwide COVID-19 vaccine effectiveness came from Israel, which was among the world leaders in early vaccine distribution. A case-control study of 1.2 million persons in Israel estimated Pfizer-BioNTech mRNA COVID-19 vaccine effectiveness with full immunisation to be 92% (95% confidence interval = 88% to 95%) for documented infection, 94% (95% confidence interval = 87% to 98%) for symptomatic COVID-19, and 92% (95% confidence interval = 75% to 100%) for severe COVID-19 (**Dagan et al., 2021**). Full immunization was highly effective across all eligible age groups (**Chodick, Tene, Patalon, et al., 2021; Chodick, Tene, Rotem, et al., 2021; Haas et al., 2021**), and the number of patients requiring mechanical

ventilation also decreased considerably in Israel following widespread vaccination (**Rinott et al., 2021**).

Data also provide strong evidence for vaccines in populations at high risk for severe COVID-19, and for people in high-risk occupations. An evaluation of 24 hospitals revealed estimates for partial and full COVID-19 vaccine effectiveness against COVID-19 hospitalisation among older adults—who are at higher risk of severe COVID-19—of 64% (95% confidence interval = 28% to 82%) and 94% (95% confidence interval = 49% to 99%), respectively (**Tenforde et al., 2021**). High estimates of efficacy for the Pfizer-BioNTech and Oxford/AstraZeneca vaccines were also documented among older adults in England (**Lopez Bernal et al., 2021**). Indeed, by May 2021, 82% of US adults aged 65 years or older had received one or more COVID-19 vaccine doses; comparing the first two weeks of December 2020 with the last two weeks of April 2021, rate ratios for COVID-19 incidence declined by 40%, and rate ratios for COVID-19 emergency department visits, hospitalisations, and deaths decreased by 59% to 66% (**Christie et al., 2021**). Assessment of the Pfizer-BioNTech and Moderna vaccines among 3,950 health care personnel, first responder, and other essential and frontline workers in the US led to estimates of mRNA vaccine effectiveness against SARS-CoV-2 infection at 90% for full immunization and 80% for partial immunization (**M. G. Thompson et al., 2021**). During the study interval from mid-December 2020 to mid-March 2021, unvaccinated participants reported 1.38 SARS-CoV-2 infections per one thousand person-days, whereas fully immunised persons reported 0.04 infections per one thousand person-days. Similar vaccine efficacy data against SARS-CoV-2 infection were found among 6,423 health care workers in Italy (**Fabiani et al., 2021**). A test-negative case-control study for symptomatic COVID-19 among health care personnel across 25 US states found 82% mRNA vaccine efficacy with a single dose and 94% efficacy for complete two-dose regimens (**Pilishvili et al., 2021**).

These data demonstrated the potential for most approved COVID-19 vaccines to curb SARS-CoV-2 infections and considerably reduce COVID-19 hospitalisations and deaths. With this promising potential, ensuring maximal COVID-19 vaccine coverage has been a priority. The next Section describes the myriad barriers to COVID-19 vaccine distribution, including willingness to vaccinate among the public—a focus of The COPE Initiative described in [Chapter Five](#) of this thesis.

15.3.4. COVID-19 VACCINE BARRIERS TO DISTRIBUTION

High vaccine effectiveness data are encouraging, though reaching population-level immunity is dependent upon a high percentage of combined post-infection and post-vaccination immunity against SARS-CoV-2. There are several barriers to the attainment of sufficient vaccine coverage.

First, the global demand for COVID-19 vaccines far outweighs the supply. Premarket purchase agreements revealed that high-income countries (representing 14% of the global population) had reserved more than half of the available vaccine stock as of November 2020 **(So & Woo, 2020)**. The US, which has a population of approximately 330 million persons, had accumulated 800 million COVID-19 vaccine doses—enough to vaccinate 400 million people **(Kuehn, 2021; So & Woo, 2020)**. As of early April 2021, WHO Director-General announced that over 87% of available vaccine doses had gone to high income or upper middle-income countries, while low income countries had received just 0.2% of vaccines **(World Health Organization, 2021)**. Differences in access and vaccine coverage also exist within high-income countries. For example, the CDC found that counties with high social vulnerability and in rural areas had lower vaccine coverage compared with other US counties, furthering health inequities in these areas **(V. Barry et al., 2021)**.

Second, in regions with ample vaccine supplies, vaccine hesitancy and apathy have emerged as barriers to vaccine coverage. Vaccine hesitancy has rightly garnered considerable attention.

Consistent with findings reported in [Chapter Five](#) of this thesis, surveillance of vaccine intentions in the US (Daly, Jones, et al., 2021; Fisher, Bloomstone, et al., 2020; Grumbach et al., 2021; Kreps et al., 2020; Largent et al., 2020; Meyer et al., 2021; Nguyen et al., 2021; Szilagyi et al., 2020) revealed dynamic demographic differences in COVID-19 vaccine intentions. In general, vaccine refusal among US adults was associated with younger age, refusal of other vaccines, less frequent engagement in COVID-19 prevention measures, Black race, higher levels of medical mistrust, and more conservative political ideology. Global surveys of vaccine intentions have found comparable demographic relationships (de Figueiredo et al., 2020; Lazarus et al., 2021), and considerable regional heterogeneity (de Figueiredo et al., 2020; Sallam, 2021). Additionally, vaccine sentiment monitoring by the Australian Government Department of Health revealed intent to vaccinate trending with public concern about COVID-19 in general, and that COVID-19 outbreaks in late 2021 resulted in 23% of respondents considering vaccination and 12% booking vaccination appointments (Australian Government Department of Health, 2021f).

Real-time health and safety monitoring and reporting can also affect vaccine intentions, particularly regarding adverse events. Monitoring of COVID-19 adverse events is critical as the vaccine is rolled out globally, and transparency might help to alleviate the medical mistrust identified in [Chapter Five](#) of this thesis as a driver of vaccine hesitancy (Czeisler, Rajaratnam, Howard, et al., 2021). Most observed adverse events or side effects have been minor and are commonly observed following inoculation with routine recommended vaccines (e.g., localised soreness, fatigue, soreness, chills, headache, nausea) (Bae et al., 2021; Kadali, Janagama, Peruru, Gajula, et al., 2021; Kadali, Janagama, Peruru, & Malayala, 2021). However, more recently, evidence of rare presentations of venous thrombosis with thrombocytopenia syndrome (TTS) and thrombocytopenia have been reported following inoculation with the Oxford/AstraZeneca vaccine (Greinacher et al., 2021; Schultz et al., 2021) and the Janssen vaccine (See et al., 2021), which constitute serious

adverse events. These reports, which were disproportionately observed among women aged 18 to 49 years, led the CDC and FDA to pause administration of Janssen vaccine on 13 April 2021 **(Food and Drug Administration, 2021a)** to review safety monitoring data **(Shay et al., 2021)**.

In Australia, where Oxford/AstraZeneca was initially the most available vaccine, such observations led the Australian Technical Advisory Group on Immunisation (ATAGI) to recommend in mid-April that the Pfizer vaccine be administered to adults aged under 50 years **(Australian Government Department of Health, 2021a)**, and updated the advisory to include persons with conditions associated with increased risk for thrombosis **(Australian Government Department of Health, 2021c)**. On 17 June 2021, the ATAGI expanded the upper age limit for which Pfizer (the available mRNA vaccine in Australia) was the preferred vaccine to 60 years based on increased observed severity of TTS in Australia among persons aged 50 to 59 years compared with initial estimates **(Australian Government Department of Health, 2021d)**. On 13 July 2021, the ATAGI released a statement on the use of COVID-19 vaccines in outbreak settings, which indicated that during COVID-19 outbreaks, in the absence of sufficient Pfizer COVID-19 vaccine supply, vaccination with the Oxford/AstraZeneca COVID-19 vaccine was recommended given that the COVID-19-related benefits far outweighed TTS risks **(Australian Government Department of Health, 2021e)**.

In the US, the CDC and FDA ultimately elected to resume administration of the Janssen vaccine on 23 April 2021 **(MacNeil et al., 2021)**, but not without consequence. Ironically, though the pause demonstrated the careful safety monitoring and transparency of the CDC and FDA, the pause was associated with a 15% decline in belief that the Janssen COVID-19 vaccine was safe (down to 37%) **(Frankovic, 2021)**, willingness to obtain the Janssen vaccine declined from 49% to 19% **(SurveyMonkey Research, 2021)**, and approximately half of surveyed unvaccinated US adults

reported that they were less likely to get *any* COVID-19 vaccine after the Janssen pause (**MacNeil et al., 2021**). This reaction might reflect perceived realisations of concerns reported by potential COVID-19 vaccine refusers in the Original Investigation in [Chapter Five](#), including that the approval process was rush (41.7% to 48.7%) or that all vaccines are dangerous (14.3% to 14.7%) (**Czeisler, Rajaratnam, Howard, et al., 2021**). The observed decline in vaccine intentions following media coverage of adverse events is also consistent with pre-pandemic evidence that media representations of vaccine side effects can impact uptake (**B. X. Tran et al., 2018**). More recently, case reports have identified rare occurrences of paediatric acute myocarditis following receipt of the Pfizer-BioNTech or Moderna mRNA vaccines (**Abu Mouch et al., 2021; Albert et al., 2021; Marshall et al., 2021**).

The population-level influence of rare serious adverse events on vaccine hesitancy is difficult to quantify, though most scientists and public health officials have largely concluded that the benefits of COVID-19 vaccination outweighs associated risks (**Hunter, 2021; MacNeil et al., 2021**). Regarding use of the Janssen COVID-19 vaccine after reports of TTS, a benefit-harm analysis estimated that, per one million US adults received Janssen COVID-19 vaccines, expected COVID-19 hospitalisations and deaths would decrease by approximately 400 to 900 and by approximately 60 to 140, respectively, while such coverage would be associated with two to three TTS cases (**MacNeil et al., 2021**). Regarding use of mRNA COVID-19 vaccines after reports of myocarditis, a similar analysis estimated that, per one million US persons aged 12 to 29 years who received mRNA COVID-19 vaccines, expected COVID-19 hospitalisations and deaths would decrease by 560 and 6, respectively, with about 39 to 47 myocarditis cases in this age group (**Gargano et al., 2021**). In contrast, per one million US persons aged 30-plus years who received mRNA vaccines, expected COVID-19 hospitalisations and deaths would decrease by 4,600 and 700, respectively, with about three to four myocarditis cases in this age group.

Additional factors in vaccine hesitancy, which are sometimes related to the above phenomena, include misinformation and disinformation. Robust evidence for the impact of misinformation on COVID-19 vaccine intentions is provided by a randomised controlled trial conducted by Loomba *et al.* among adults in The UK and the US (**Loomba et al., 2021**). The pre-post-exposure questionnaires used to estimate the causal impact of exposure to online COVID-19 vaccine information relative to factual information found that among 8,001 total respondents, misinformation induced a decline in intent to vaccinate of 6.2% (95% CI = 3.9% to 8.5%) in The UK and 6.4% (95% CI = 4.0% to 8.8%) in the US. Investigations of information channels and demographic characteristics associated with susceptibility to COVID-19 vaccine information found that higher such levels were associated with social media versus traditional media (e.g., national television, national newspapers, local newspapers) (**Piltch-Loeb et al., 2021**), and with lower trust in scientists (**Roozenbeek et al., 2020**).

Encouragingly, there are some evidence-based interventions to counteract misinformation, including empathetic engagement, motivational interviewing, leveraging trusted sourcing, and pairing rebuttals with alternative explanations (**Scales et al., 2021**). Unfortunately, however, if ineffective, attempts to correct vaccine misinformation can reinforce misinformed beliefs about vaccination, thereby strengthening positions against vaccination (**Pluviano et al., 2017**).

Additional strategies to combat COVID-19 vaccine hesitancy can be gleaned from evidence on vaccine opposition dating back to the 19th century, which was largely fuelled by transmission of syphilis through vaccines (**Rusnock, 2016**). At the time, such opposition was sometimes countered by government mandates. In 1902, acting under the authority of a statute in the Revised Laws of the Commonwealth of Massachusetts, the Board of Health of the US city of Cambridge, Massachusetts enacted a requirement of all residents to obtain vaccination against smallpox. The city imposed a

USD\$5 fine for failure to comply with the regulation. While the authority of the Cambridge Board of Health to impose such a vaccination requirement was ultimately upheld by the Supreme Court of the United States (SCOTUS) (*Jacobson v Massachusetts*, 1905), over the ensuing century, concerns about preserving personal liberty have precluded government-imposed compulsory vaccinations in the US (Gostin, 2005; Mariner et al., 2005). While some private businesses and schools can and have legally enforced COVID-19 vaccination requirements on their customers, students and employees, in most cases, vaccine hesitancy must be addressed through persuasion, which why it is critical to understand the factors underlying such hesitancy.

Modern vaccine hesitancy is driven by cognitive, cultural, and social factors related to lack of experience with vaccine-preventable diseases, misinformation, and denialism (Callender, 2016; Jacobson et al., 2015). Recommended practices to overcome vaccine hesitancy include multicomponent interventions (Jarrett et al., 2015) and might include unified messaging from medical providers, popular figures, and public figures (Callender, 2016), identifying and better understanding drivers of vaccine hesitancy in local clusters (Salmon et al., 2015), promoting rapid, independent, and transparent vaccine safety systems (Salmon et al., 2015), and maximising the opportunities afforded by clinical encounters to educate and vaccinate patients (Jacobson et al., 2015).

In addition to vaccine hesitancy (active decisions to not obtain vaccines), emerging evidence suggests vaccine apathy (indifference towards vaccine obtainment) has also slowed vaccine distributions in regions with plentiful supply (D. L. Mann, 2021; Wood & Schulman, 2021b). Vaccine barrier reduction and incentivization could help to surmount such apathy.

15.3.5. BREAKTHROUGH INFECTIONS AND SARS-CoV-2 VARIANTS

Amidst tremendous optimism about vaccines and their potential to end widespread community transmission of SARS-CoV-2 and COVID-19 morbidity and mortality, vaccines do not eliminate risk of SARS-CoV-2 transmission **(Teran et al., 2021)**, and by the end of April 2021, more than 10 thousand COVID-19 vaccine breakthrough infections had been reported to the CDC, with 160 deaths **(CDC COVID-19 Vaccine Breakthrough Case Investigations Team, 2021)**. This number likely underestimates breakthrough infections, because as of July 2021, SARS-CoV-2 testing is not recommended among fully vaccinated persons following an exposure. Furthermore, vaccine-evasive variants may threaten the efficacy of vaccines **(JAMA, 2021; Mascola et al., 2021; Moore & Offit, 2021; R. Rubin, 2021)**.

As of 8 July 2021, the CDC and FDA have maintained that fully vaccinated individuals do not need a COVID-19 vaccine booster at this time **(CDC and FDA, 2021)**, a position also held by WHO Director-General Ghebreyesus **(Branswell, 2021)**—although his perspective is primarily based on the global shortage of COVID-19 vaccine supply. However, the COVID-19 vaccine supplier Pfizer will seek an EUA from the FDA for a third COVID-19 booster dose within 12 months **(Neergard, 2021)**. The company stated that a booster could considerably increase immunity and protect against variants, with early evidence suggesting a 5- to 10-fold increase in SARS-CoV-2 antibody levels compared with the second dose. Moderna has also initiated clinical trials for a booster **(Garde & Herper, 2021)**.

While the need for a booster remains to be seen, our findings from [Chapter Five](#) indicate that COVID-19 vaccine booster intentions will largely mirror those for the original dose or doses. Of respondents who were willing to receive COVID-19 vaccine boosters, 95.2% had indicated they were eager to obtain the original COVID-19 vaccine **(Czeisler, Rajaratnam, Howard, et al., 2021)**. These findings indicate that COVID-19 vaccine boosters could further divide the protection

of vaccinated persons compared with unvaccinated persons and highlight the importance of progress in addressing vaccine hesitancy.

15.4. REFLECTIONS ON THE COVID-19 PANDEMIC AND IMPLICATIONS FOR FUTURE PUBLIC HEALTH EMERGENCIES

The following subsections of this thesis offer reflections on engagement in the practice of NPIs and on anticipated and unanticipated consequences of the pandemic and its mitigation.

15.4.1. MAXIMISING IMPACT OF NONPHARMACEUTICAL INTERVENTIONS

The diversity of approaches employed to enhance COVID-19 nonpharmaceutical intervention adherence across regions, together with literature from pre-pandemic experiences, offer insights as to key factors for community engagement in NPIs to control an infectious disease outbreak. First, enforcement of NPIs through fines was associated with higher levels of mask usage, even in regions with lower SARS-CoV-2 prevalence (**MacIntyre et al., 2021**). In the US, even during mask mandates, local law enforcement officers were largely reluctant to resort to legal remedies for non-adherence with mandates (**Jacobs & Ohinmaa, 2020**), which might limit the efficacy of such directives. Moreover, there are debates about the ethics and legality of various levels of enforcement of NPIs (**Gostin et al., 2020; Parmet & Sinha, 2020**), and public perceptions on more stringent interventions vary widely (**Doogan et al., 2020**).

Particularly in regions without enforcement, there were substantial demographic differences in levels of adherence with NPIs. For example, as reviewed in Chapters [Two](#), [Three](#), and [Four](#) of this thesis, in the US, adherence with stay-at-home orders, mask usage, physical distance recommendations, gathering bans, and hand hygiene practices was generally less common among

younger adults, men, and people with lower COVID-19 risk perception. Tailored public health communication to reach these groups and address risk perception is one key measure to improve adherence with these measures, especially among younger adults **(Yang et al., 2020)**. Previous literature highlights that behavioural changes require a combination of verbal communication, legislation, and environmental interventions, with an example of the latter being providing handwashing stations or hand sanitiser in highly visible areas within public settings (rather than solely encouraging people to practice hand hygiene) **(Finset et al., 2020)**. Concurrently, principles of the Self-Determination Theory **(Deci & Ryan, 2000; Ryan & Deci, 2000)** suggest that providing choice, creating solidarity, and acknowledging uncertainty might be key features of effective public health communication for NPIs **(Porat et al., 2020)**.

To further efforts tailored toward groups with low levels of adherence and the general public, there are advantages to partnering foundational community engagement actors, namely local leaders, community and faith-based organisations, community groups, health facility committees, individuals, and key interested parties **(Gilmore et al., 2020)**. Based on experiences with the Ebola, Zika, SARS, Middle East respiratory syndrome and H1N1 epidemics, engagement of a combination of these actors facilitated trust building, communication about recommended social and behavioural changes, and risk communication, among other important aspects of the rollout of NPIs. For example, regarding the engagement of local leaders, in the US, federal and state agencies have at times provided conflicting messages, which can complicate critical health communications during a pandemic **(Huberfeld et al., 2020; D. K. D. Kim & Kreps, 2020)**. In contrast, a newly established National Cabinet in Australia convened to coordinate a nonpartisan collaboration between state and federal governments has been credited with creating a more unified national response **(Child et al., 2020)**.

To summarise, as with past pandemics (**Soper, 1919**), navigating communication during the response to the COVID-19 pandemic has been particularly challenging. This was especially true during the early stages amidst uncertainty surrounding its origins, transmission dynamics, symptoms, and treatments. These challenges are exacerbated by modern pressure for real-time and peer-to-peer sharing despite the commonality of poor health media literacy. The immediacy of media and the Internet have made it easier to promote all types of information, including disinformation (**Gottlieb & Dyer, 2020**). Nevertheless, clear and effective communication between governments, health professionals, scientists, the media, and the public is a key component of the pandemic response (**H. Wang et al., 2020**), and while the ethics can be debated, enforcement of NPIs improves adherence.

15.4.2. MAXIMISING THE IMPACT OF VACCINES

Multiple safe and effective COVID-19 vaccines were developed, trialled, and authorised for widespread use less than one year after SARS-CoV-2 was first sequenced (**F. Wu et al., 2020**)—an unprecedented achievement. This is a testament to basic science, particularly with mRNA vaccines, an emerging technology that had never been used in vaccines before (**Garde, 2020**). In Israel, most US states, and other regions with high vaccine coverage, SARS-CoV-2 prevalence and COVID-19 hospitalisations and deaths declined rapidly (**Dong et al., 2020**), providing optimism about an eventual end to the pandemic.

However, vaccines are not vaccinations. Even within the US, geographic heterogeneity in vaccine coverage—driven largely by difference in acceptance (**Malik et al., 2020**)—limits optimism about the attainment of population-level immunity (**Mandavilli, 2021**). These data highlight the importance of monitoring vaccine intentions and identifying groups with high levels of vaccine hesitancy (**Czeisler, Rajaratnam, Howard, et al., 2021**), as such surveillance can inform group-specific interventions (**Loomba et al., 2021**). More significant inequities to vaccine access globally,

which disproportionately affect low-income and middle-income countries, will likely prolong the pandemic in these regions. This delay has the potential to further limit social and economic growth opportunities and restrict opportunities for travel to and from these countries and create stigmatisation against countries with low vaccine coverage. Moreover, an extended interval of partial vaccine coverage increases opportunities for selectivity of vaccine-evasive variants, which could in turn threaten both the vaccinated and unvaccinated populations **(R. Rubin, 2021)**.

Reflecting on the past 18 months and looking ahead, the experience with vaccines during the COVID-19 pandemic has equally demonstrated the value of basic science and the importance of scaling up infrastructure for supply chains and distribution. Longstanding inequities have been magnified during the rollout, with high-income countries determining the locations and pace of vaccine allocation. Moreover, vaccines should not be considered in isolation. Australia has received criticism for a slow COVID-19 vaccine rollout, particularly given suggestions by leadership that the rollout is “not a race” **(Murphy, 2021)** shortly before new lockdowns were announced in late May 2021 in Victoria **(Khalil, 2021)** and late June 2021 in New South Wales **(Swanston, 2021)** over a small cluster of new infections. Given the widespread consequences of lockdowns, epidemiologists have cautioned against excessive use of lockdowns **(Maiden, 2021)** and emphasised that the purpose of short-term lockdowns is not to completely eliminate infections, but rather to maximise the efficacy and reduce the load on contact tracers working to cease infection paths **(Bennett, 2021)**. Encouragingly, the lockdown in Victoria was associated with a revitalised sense of urgency about vaccine uptake **(Taylor, 2021)**, though global vaccine hesitancy continues to present as a barrier to coverage and reduction of SARS-CoV-2 transmission (Section 15.3.4).

Overall, the focus on vaccine development rather than NPIs in the US came at an enormous human cost—including 600 thousand COVID-19 deaths and counting, plus the ripple effect of

these deaths. Vaccines can play a vital role in containing pandemics, but they should be considered as part of a larger, multicomponent solution.

15.4.3. MENTAL AND BEHAVIOURAL HEALTH

Quantifying the mental health impact of COVID-19 and the COVID-19 pandemic is challenging, because the global burden of mental health has increased over the past few decades **(Rehm & Shield, 2019)**, and it will be difficult to distinguish between direct and indirect effects of the pandemic compared with non-pandemic effects. Before the pandemic, Vigo, Thornicroft, and Atun estimated that the global disease burden of mental illness accounted for nearly one-third of years lived with disability and 13% of disability-adjusted life-years (DALYs)—which positions mental illness as accounting for more than twice the second-place illness for years lived with disabilities **(Vigo et al., 2016)**. Pre-pandemic evidence also highlights the global burden of alcohol use disorders, which accounted for 4.2% of DALYs **(Global Burden of Disease 2016 Alcohol and Drug Use Collaborators, 2018)**. Most of the burden of alcohol use was related to the effect of alcohol use on other health outcomes. Illicit drug dependence is also a significant contributor to disability-adjusted life years, with opioid dependence the primary actor along with amphetamine and cocaine dependence **(Degenhardt et al., 2013)**. Estimates for the economic cost of mental illness were considerable and, on the rise, up to USD\$16 trillion during 2010 through 2030 (an average of USD\$800 billion annually) **(Patel, Saxena, Lund, Thornicroft, Baingana, Bolton, Chisholm, Collins, Cooper, Eaton, Herrman, Herzallah, Huang, Jordans, Kleinman, Medina-Mora, Morgan, Niaz, Omigbodun, Prince, Rahman, Saraceno, Sarkar, Silva, et al., 2018)** from approximately USD\$100 billion in 1985 **(Rice et al., 1992)** (which likely represents a combination of increased detection and burden). Despite these staggering figures, approximately 2.8% of total

global government health spending was allocated for mental health, and just 0.5% of national health budgets in low-income countries **(Vigo et al., 2016)**.

While adverse mental health symptoms do not necessarily reflect diagnosable mental health or substance use conditions, and the extent to which these symptoms persist beyond the pandemic remains to be seen, several-fold increased prevalence estimates for adverse mental health symptoms suggest that these figures may have increased in response to the pandemic. The disproportionate impact on mental health of young persons **(Czeisler, Lane, et al., 2020, 2021; Czeisler et al., 2021; Ettman et al., 2020; Holman et al., 2020; M. Pierce, Hope, et al., 2020; Yard et al., 2021)** is of particular concern, as approximately half of all lifetime mental health conditions start by the mid-teen years of age, and three-quarters start by the mid-twenties **(Kessler et al., 2007)**. While predictions of a lost generation might be premature **(Bass, 2021; Cowie & Myers, 2020; Hafstad & Augusti, 2021; Harrop et al., 2021)**, enhanced efforts are warranted to ensure sufficient mental health supports and services are available—particularly for children, adolescents, and young adults. After all, the young age of onset and life-course of illness and its impact on workforce participation and productivity is a large reason for the staggering economic cost of mental illness **(Patel, Saxena, Lund, Thornicroft, Baingana, Bolton, Chisholm, Collins, Cooper, Eaton, Herrman, Herzallah, Huang, Jordans, Kleinman, Medina-Mora, Morgan, Niaz, Omigbodun, Prince, Rahman, Saraceno, Sarkar, De Silva, et al., 2018)**.

Given the scale of mental health challenges, in addition to individualised prevention and intervention resources, evidence-based mental health promotion efforts are also warranted at the organisational, community, and societal levels **(Victoria State Department of Health & Human Services, 2011)**. Specifically, organisations (e.g., employers, institutions) might prioritise positive working environments that are inclusive and supportive, and that are responsive to the mental health

and wellbeing needs of their staff. Communities could strive to enhance community cohesion and civic engagement while endorsing the value of mental health, while societies could ensure that there are strong legislative platforms and resources to support policies and programs for mental health promotion.

Amidst troubling observations of adverse mental and behavioural health during the COVID-19 pandemic, there are reasons for optimism pertaining to increased investment in mental and behavioural health care systems globally, new initiatives for mental health promotion, and innovations in technology and advances in treatment methods that could have benefits that outlast the pandemic. For example, in the US, a Presidential Executive Order that included USD\$425 million in emergency funds to address mental and substance use disorders cited The COPE Initiative findings **(Czeisler, Lane, et al., 2020)** as reflective of the need to increase support for mental and behavioural health needs **(The White House, 2020e)**. Community health centres have received USD\$4 billion (approximately USD\$1.3 billion over 2020 funding levels), and legislation was introduced to allow for Medicare reimbursement for telemedicine for new patients **(American Psychiatric Association, 2021)**. Furthermore, the US Congress has allocated USD\$1.15 billion to study post-acute sequelae of COVID-19, including neuropsychiatric symptoms **(National Institute of Health, 2021)**. In Australia, AUD\$2.3 billion was recently announced in the National Mental Health and Suicide Prevention Plan, which will include reform to prioritise person-centred treatment **(Australian Government Department of Health, 2021b)**. Overall, estimated government mental health spending in Australia has increased by 90% within the last decade. Gains in mental health funding and support services are not limited to high-income countries, as many low-income and middle-income countries launched national mental health response plans during the pandemic **(Kola et al., 2021)**.

In addition to increased financial support and infrastructure, reducing person-to-person contact necessitated rapid expansion of contactless mental health support and services, including telepsychiatry and other virtual platforms. For example, Victorian psychiatry consultations increased by 19% during April through September 2020 compared with the same interval in 2019, with telehealth representing 73% of consultations—more than half of which were video (**Looi et al., 2021**). Similarly, odds of completing a telepsychiatry visit were more than six times higher than the odds of completing an in-person psychiatry visit in the US during the pandemic (**Avalone et al., 2021**). While the shift proceeded with rapidity and strain, it has set the stage for some lasting changes (**Kannarkat et al., 2020; D. M. Mann et al., 2020**). Finding a balance between in-person and remote care will take time, and some demographic disparities in healthcare access have been exacerbated by telehealth during the pandemic (**Gmunder et al., 2021; Y. Zhai, 2021**), though it has increased access to and accessibility of care for many (**J. A. Chen, Chung, et al., 2020**)—as evidenced by a higher rate of visit completion compared with in-person visits during and prior to the pandemic (**Avalone et al., 2021**). Indeed, surveyed US psychiatrists estimated they would continue to perform 35% of their clinical work via telepsychology after the pandemic (**B. S. Pierce et al., 2021**). Comparing the effectiveness of telehealth and in-person visits, a randomised crossover study of feasibility, cost, and satisfaction of care among multiple sclerosis patients found no difference in the number of completed telehealth versus in-person visits, and the telehealth visits were both time- and cost-saving, with 97% of participants recommending telehealth visits to others (**Robb et al., 2019**). However, a narrative review of telehealth in the US during the pandemic reported potential challenges related to lack of available technological resources in disadvantaged communities, issues with patient data security, and challenges in performing traditional patient examinations (**Kichloo et al., 2020**). That said, new and future technologies (e.g., electronic stethoscopes, smartphone

applications) will continue to offer opportunities to address some of the limitations of remote physical examinations.

To summarise, while some level of elevation in adverse mental health symptoms was anticipated and difficult to avoid during a global magnitude of historic proportions, shortcomings of mental health support and services already existed and were made worse by increased need for services during the pandemic (**Auerbach & Miller, 2020**). Indeed, historic underinvestment and lack of legislative support for community mental health promotion programs, combined with underfunding in mental and behavioural health care services and systems, resulted in global mental health care systems strained in the best of times—and unprepared for the scale of mental health needs during the pandemic. On the other hand, amplification of the mental health crisis, which was worsening before and accelerated during the pandemic, has led to increased global funding and new initiatives that can have a lasting positive impact. Meantime, the rapid scaling up of telemental health services during the pandemic has created infrastructure that will continue to be improved as innovations in the methods for the delivery of care continue to be presented.

15.4.4. OTHER UNINTENDED CONSEQUENCES

Adverse impacts of the pandemic extend beyond the impact of COVID-19 on physical health and the pandemic on mental health. Though outside the scope of this thesis, delay or avoidance of medical care has been widely observed during the COVID-19 pandemic and evaluated as part of The COPE Initiative. For example, during April 2020 compared with April 2019, emergency department visits in the US were down 42% (**Hartnett et al., 2020**), with variations in reductions by region and type of care (**Jeffery et al., 2020; Kaufman et al., 2020; Lange et al., 2020a, 2020b**). In addition to declines in urgent or emergency care-seeking, electronic health record data showed that preventive cancer screenings for breast, colon, and cervical cancer were 86% to 94% lower than

recent years (**Epic Health Research Network, 2020**), and paediatric vaccine coverage declined rapidly in March 2020 (**Santoli et al., 2020**) and remained below pre-pandemic levels as of September 2020 (**Patel Murthy et al., 2021**). While healthcare provider cancellations likely contributed to reduced presentations for elective procedures and primary care early during the pandemic, findings from The COPE Initiative included in Appendix 1 suggest that up to 40% of US adults delayed care due to concerns about COVID-19 (**Czeisler, Marynak, et al., 2020**), consistent with evidence that patients with higher COVID-19 risk perception were at greater risk of missing follow-up care appointments (**Lindeke-Myers et al., 2021**).

Similar observations of forgone medical care were observed in other countries (**Czeisler et al., 2021; Kam et al., 2020; Mansfield et al., 2021; Wyatt et al., 2021**), including regions with relatively low prevalence of COVID-19. For example, in Australia, the number of emergency department presentations in New South Wales decreased by 25% during the first two months of the pandemic (**Kam et al., 2020**), and in September 2020, findings from The COPE Initiative in Appendix 2 include that approximately one-third of surveyed adults in Victoria reported delay or avoidance of medical care (**Czeisler et al., 2021**). Delay or avoidance of medical care can have short-term and long-term health consequences. In the short term, delay or avoidance of urgent or emergency care can be life-threatening, which may be reflected by regions with higher COVID-19 prevalence experiencing large proportional increases in non-COVID-19 deaths—primarily diabetes (96%) and heart diseases (89%)—with exceptional increases of 398% and 356%, respectively, in an early US COVID-19 epicentre of New York City (**Woolf, Chapman, Sabo, Weinberger, & Hill, 2020**). In the long term, missed routine care can make it more difficult to manage chronic conditions and reduces opportunities for early diagnoses. Based on a national population-based modelling study, Mirange *et al.* estimate approximately three-and-one-half thousand avoidable cancer deaths in the

UK are to be expected over the next five years due to diagnostic delays during the pandemic, corresponding to about sixty thousand years of life lost (**Maringe et al., 2020**).

Outside of health-related impacts, the COVID-19 pandemic has been associated with an exacerbation of gender inequalities, disproportionate socioeconomic impact on marginalised communities, and rise in anti-Asian hate crimes. For example, surveillance of academic medicine faculty members found that women more commonly reported having reduced employment to part time, considered leaving employment, and turned down leadership opportunities since the onset of the pandemic, a difference that was also found among faculty members with children (**Matulevicius et al., 2021**). The gender gap in publishing on *medRxiv* also increased during the pandemic, from 23% in January 2020 to 55% in April 2020 (**Wehner et al., 2020**). Both of these phenomena could have long-term consequences for gender equity in academia (**Gewin, 2020; Viglione, 2020**).

Regarding socioeconomic impacts of the pandemic, persons of LatinX ethnicity are historically overrepresented as grocery store employees, many of whom have limited vertical mobility and found themselves employed in precarious positions during the pandemic—yet still carried out essential services despite a median pay of approximately USD\$11 hourly (**Kantamneni, 2020**). There were also disparities in unemployment. During a time of historic rises in unemployment, LatinX, Black, and women workers' employment was more disrupted (**Groshen, 2020**). In April 2020, Black workers' unemployment rate was 16.7%, compared with 14.2% for White workers (**Williams, 2020**). The differential increased as businesses started to reopen, as unemployment rates among White workers fell rapidly and was reduced to 7.3% (a 49% reduction) by August 2020, compared with Black workers, who experienced a 22% reduction to a 13.0% unemployment rate.

Finally, anti-Asian and anti-Black stigmatisation, discrimination, and hate incidents or crimes increased, particularly in the US, following the onset of the COVID-19 pandemic. Anti-Asian

rhetoric was partially fuelled by the belief that the coronavirus originated in Wuhan, China, leading some—including community leaders and influencers—to use potentially harmful terms, including “China virus,” “Chinese virus,” “Wuhan virus,” and “kung flu” for the virus and disease, rather than WHO official nomenclature of COVID-19 and SARS-CoV-2 (**Gover et al., 2020**). The group Stop Asian Americans and Pacific Islanders (AAPI) Hate documented approximately 6,600 incidents during the calendar year from March 2020 to March 2021, with the number increasing over time (**Jeung et al., 2021**). Overall, verbal harassment (65%), shunning (18%), and physical assault (13%) were the most common incident types, with 65% of incidents reported by women. Anti-Black hate crimes and violence reportedly increased in response to the Black Lives Matter movement (**Buchanan et al., 2020**) and in the wake of protests following the death of George Floyd (**Philimon, 2020**). Longitudinal analyses revealed that publicised incidents of anti-Black racial violence was associated with poor mental health days among Black persons in the US (**Curtis et al., 2021**). While national estimates are not yet available, the California Department of Justice recently reported that 2020 attacks on Asian people were up 107% compared with 2019, while hate crimes against Black people were up by 88% (**Bonta, 2021**). Furthermore, hate crime reports likely underestimate the true prevalence, as immigrant victims with limited English or who are worried about their immigration status less frequently report incidents (**A. Do, 2021**). Stigma and discrimination can have adverse psychological impacts (**Misra et al., 2020**). The extents to which these exist and can be mitigated during and beyond the COVID-19 pandemic, for example with unifying and just rather than divisive and discriminatory leadership (**Shultz et al., 2019**), merit attention.

On the other hand, there have been a few silver linings of the pandemic, some of which were transient and some that may outlast the pandemic. Global carbon dioxide (CO₂) emissions decreased by 17% (95% confidence interval = -11% to -25%) in early April 2020 compared with mean 2019

levels (**Le Quéré et al., 2020**), with an approximately 9% decrease sustained over the first half of 2020 compared with the same interval in 2019 (**Z. Liu et al., 2020**). As these decreased emissions data were closely tied with the intensity of COVID-19 mitigation policies, the decreases began to diminish as restrictions eased globally (**Le Quéré et al., 2020; Z. Liu et al., 2020**). While employers were forced to adapt rapidly to remote work instructions, success has led some major companies to offer greater workplace flexibility to employees, including the option to work remotely indefinitely (**Brownlee, 2020**). Additionally, enhanced investment and improvements in technology to support remote meeting platforms (e.g., Zoom, Skype, Microsoft Teams, Google Meet) has increased opportunities for global connectivity and facilitated collaborations.

To summarise, the COVID-19 pandemic was associated with profound changes to morbidity, mortality, and mental health, among other phenomena. Disparities in health and opportunities among advantaged versus historically oppressed and marginalised populations widened, consistent with observations during the 1918 influenza pandemic (**Grantz et al., 2016; Pearce et al., 2011**). Finally, early names for a disease and beliefs about its origin and transmission can cause harmful and lasting stigmatisation, as in the cases of the 1918 influenza pandemic (colloquially known as the “Spanish flu”) (**Barrett & Brown, 2008; Hoppe, 2018; Parmet & Rothstein, 2018**), the 2009 H1N1 influenza pandemic (“swine flu”) (**Earnshaw & Quinn, 2013; McCauley et al., 2013; Schoch-Spana et al., 2010**), and human immunodeficiency virus, acquired immunodeficiency syndrome (HIV/AIDS) epidemic (**Mahajan et al., 2008; Turan et al., 2017**).

15.5. REFLECTIONS ON THE METHODS

Following the onset of the COVID-19 pandemic, in response to calls for research such as that by Holmes *et al.* (**Holmes et al., 2020**), the scientific, medical, and public health communities devoted considerable effort to research on COVID-19 and the pandemic. In 2020, approximately four

percent of the global research output focused on COVID-19 (**Else, 2020**). Journals, publishers, and preprint servers reported record-setting increases in submission volumes (**Bauchner et al., 2020; Else, 2020**), and COVID-19 papers received considerably more views than non-COVID-19 papers (**Giustini et al., 2021**). Sections 15.5.1. and 15.5.2. discuss strengths and limitations of The COPE Initiative in view of the global research effort on COVID-19 and the pandemic, while Section 15.5.3. considers future directions.

15.5.1. STRENGTHS

Strengths of The COPE Initiative include the rapid design and development of the public health surveillance activity, assembly of a multinational and diverse team of collaborators, administration of surveys in regions of SARS-CoV-2 prevalence ranging from extremely high (the US) to extremely low (Australia), and inclusion of mixed methodologies with largescale surveillance.

The first wave of data collection for The COPE Initiative began on 2 April 2020 following Monash University Human Research Ethics review and approval. This was fewer than two weeks after the declaration of the COVID-19 by the WHO (**World Health Organization, 2020d**). At the time, there had been fewer than 900 thousand laboratory-confirmed SARS-CoV-2 infections globally (compared with more than 3.2 million one month later), with approximately 183 thousand in the US and approximately five thousand in Australia (**World Health Organization, 2020f**). Initiating The COPE Initiative near the onset of the pandemic enabled a long-term view of public attitudes, behaviours, and beliefs about the pandemic, as well as mental and behavioural health.

Additionally, the recruitment methodology and access to the large Qualtrics respondent pools enabled The COPE Initiative to rapidly assemble large samples that often exceeded 5,000 respondents with approximately 60% response rates over the course of one to three weeks. Collecting surveys within a short timeframe was a priority during the pandemic given the dynamic

natures of SARS-CoV-2 case trajectories, infection control measures, and other contextual factors that could influence or systematically bias responses if surveys were administered over a prolonged duration on the order of months or years.

The COPE Initiative benefited from collaboration with researchers at 11 institutions across Australia and the US, including academic medical and research centres, the CDC, and two health-focused companies (**The COPE Initiative, 2020**). Importantly, this collaboration supported an expanded scope of the surveillance and brought in unique perspectives, including the idea to assess unpaid caregiver status—which ended up consistently yielding some of the strongest associations with outcomes and was the focus of two publications. Working with the CDC COVID-19 Response Team also facilitated a more direct avenue for public health impact of the surveillance, which was a priority of The COPE Initiative that was accomplished through developing reports for the CDC and responding to inquiries from local and state health departments to inform public health decisions and messaging. It also allowed for advocacy for the inclusion of topics within the CDC response to the pandemic, which ultimately resulted in the publication of the first paper on mental health by the CDC’s *MMWR* as part of the COVID-19 response (**Czeisler, Lane, et al., 2020**), as well as the first papers focused on unpaid caregivers and on people with disabilities (**Czeisler et al., 2021; Czeisler, Rohan, et al., 2021**). Responding to the urgent need for timely information, we published two papers within 60 days of data collection (**Czeisler, Lane, et al., 2020; Czeisler, Tynan, et al., 2020**) despite extensive rounds of reviews for CDC Clearance as part of the *MMWR* publication process (**Cono & Jaffe, 2015; Rasmussen et al., 2020**), which has at times been criticised for its intensity (**Blank & Jemmott, 2015; Hagopian et al., 2015**).

Inclusion of the US and Australia in surveillance activities allowed for insights in regions with mixed implementation of COVID-19 prevention measures despite widespread community SARS-

CoV-2 transmission and with strictly enforced COVID-19 prevention measures despite low SARS-CoV-2 prevalence, respectively. Finally, while most data were collected through Internet-based surveys—which allowed for the rapid collection of largescale samples without potential SARS-CoV-2 exposures—a complementary dataset with longitudinal, objective sleep-wake data provided unique opportunities for the assessment of relationships between sleep and mental health. Overall, during April 2020 through June 2021, approximately 61 thousand adults participated in The COPE Initiative (Qualtrics in the US = 30 thousand; Qualtrics in Australia = 4 thousand; WHOOP in the US, Australia, Ireland, Canada, and the UK = 27 thousand). The standard size of datasets was approximately five thousand well-characterised participants, which allowed for well-powered subgroup and multivariable analyses that would not have been possible with smaller datasets.

15.5.2. LIMITATIONS

In addition to the limitations specified within each of the Original Investigations included in this thesis, the methodologies employed by The COPE Initiative were subject to some general limitations: the lack of pre-pandemic data, use of non-probability-based sampling methods, largely cross-sectional samples, and primarily self-reported data.

A principal limitation is the lack of pre-pandemic data (except for WHOOP sleep-wake data), which precluded comparisons of outcomes before and during the pandemic. For some measures, such as anxiety and depression symptoms, the administration of the validated and widely administered four-item Patient Health Questionnaire (PHQ-4) provided opportunities to more directly compare The COPE Initiative findings with pre-pandemic data from other sources (Ettman et al., 2020; Terlizzi & Schiller, 2021). However, these comparisons may be limited by unknown differences in sampling bias, as well as other biases from differences in survey design (e.g., survivorship bias, in the case of cross-sectional versus longitudinal studies).

A second limitation of The COPE Initiative public health surveillance was the potential for limited representativeness of the samples compared with the populations from which they were sampled. There were three central factors that could limit the generalisability of samples. First, the reliance on non-probability-based sampling methods for most surveys subject the sample to biases (**M. Pierce, McManus, et al., 2020**). Demographic quota sampling and survey weighting can eliminate demographic differences in response rates; however, these strategies might not address residual, inherent sampling biases, and it is difficult to characterise the way in and degree to which the sample differs from the population (**Tyrer & Heyman, 2016**). Second, Internet-based surveys have advantages and disadvantages compared with more traditional survey methods (**Ball, 2019; Heiervang & Goodman, 2011**), as by nature, Internet-based surveys may underrepresent people without Internet access. While this limitation is increasingly attenuated by increasing Internet access in the US and Australia, as of 2018, the US Census Bureau estimated that 85% of households had a broadband internet access (**US Census Bureau, 2021**)—indicating that as much as 15% of US households could be unable to participate in such surveys. Importantly, rural residents, renters, households with lower income, lower educational attainment, and limited English-language proficiency were more commonly without Internet access. Third, The COPE Initiative surveys were administered in English-language only, which could be another source of bias toward individuals with higher English-language proficiency. The decision to field in English-language only was pragmatic, as questions were frequently finalised close to the fielding date, making it infeasible to translate the surveys to additional languages.

A related limitation was the exclusion of individuals aged under 18 years from the study. Though outside the scope of this study, given strong relationships found in data from The COPE Initiative and other data sources between age and, for example, adherence with NPIs (**Czeisler, Howard, et al., 2021; Czeisler, Tynan, et al., 2020; Fisher, Barile, et al., 2020**) and mental health (**Czeisler,**

Lane, et al., 2020; Ettman et al., 2020; Holman et al., 2020), extended the lower bound of the age range of respondents could have been informative.

The use of primarily cross-sectional samples limited the potential for causal analyses and left open the question of directionality of associations. However, the decision to switch from a combination of longitudinal and cross-sectional respondents to entirely cross-sectional was informed by an assessment of survivorship bias described in [Chapter Eight](#) and [Chapter Nine](#) (**Czeisler, Wiley, Czeisler, et al., 2021c**), which revealed that participants with worse mental health had higher longitudinal dropout rates, which limited cross-sectional comparisons of adherence with COVID-19 prevention behaviours and mental health over time—which were primary aims of the surveillance.

Finally, self-reported data can be subject to biases due to social desirability, cognitive processes, and survey conditions (**Althubaiti, 2016; Bauhoff, 2014**). In practice, self-report biases are challenging to overcome in population-level surveillance activities and can influence a range of measures. For example, adherence with NPIs (e.g., mask usage, physical distancing) is difficult to monitor in a national sample, and hand hygiene is frequently over-reported (**Contzen et al., 2015**). Smaller studies that quantify these biases using objective measurements [e.g., through covert observation, mobile phone mobility data (**S. Chang et al., 2021; Y. Liu et al., 2021; Nouvellet et al., 2021; C. Xiong et al., 2020**), assessment of soap or hand sanitizer use (**Zivich et al., 2021**)] could be used to calibrate self-report data and estimate factors that could be applied to largescale surveillance to aid the interpretation of self-report data.

15.5.3. FUTURE DIRECTIONS FOR THE COPE INITIATIVE

The COPE Initiative was launched to collect data and disseminate findings rapidly to inform the public health response to the COVID-19 pandemic. Future directions for The COPE Initiative can be categorised as methodological or analytic.

Methodological choices were made balancing the need for rapidly assembled, largescale samples with the robustness of sampling methods, which led to the decision of using Internet-based surveys using demographic quota sampling. That said, for the reasons outlined in Sections 15.5.1. and 15.5.2., probability-based sampling methods are subject to fewer sampling biases and might have greater generalisability compared with non-probability-based quota sampling methods. Moreover, during the first year of The COPE Initiative, surveys were administered in English-language only. With the added time to acquire specific funding to support this work, and greater stability of the pandemic with the infrastructure developed over the past 18 months, The COPE Initiative has started to incorporate probability-based sampling methods and made the survey available in both English and Spanish.

In addition to expanding data collection methodologies, study designs to examine mechanisms underlying the disparities observed in adherence with NPIs, vaccine uptake, and mental health more comprehensively could inform the design of tailored interventions. For example, findings from the randomised controlled trial by Loomba *et al.* to quantify the impact of online misinformation on vaccine intentions (**Loomba et al., 2021**), including that individuals of female gender were more likely than were those of male gender to lower their intent to vaccinate following exposure to vaccine misinformation, could be used for the design of group-specific interventions.

Analytic choices during the first year of The COPE Initiative were largely driven by evolving priorities within the public health response to the pandemic. Going forward, analyses of data over

multiple cross-sectional waves for trends and responses from longitudinal subsamples with sampling and analytic methods that address survivorship bias (e.g., planned missing data designs with multiple imputation) (**Rioux et al., 2020**) may provide valuable insights about support for and adherence with NPIs, or about mental health. Additionally, with the increasing number of datasets published, there may be opportunities to crosswalk datasets (e.g., COVID-19 prevention policies or recommendations, COVID-19 metrics, vaccine coverage).

As of the submission of this thesis, the pandemic is still ongoing and new data are constantly emerging. Indeed, by the end of January 2022, of the approximately 375 million confirmed cases since the beginning of the pandemic, 83 million (22%) occurred in January, largely driven by the Omicron variant (**Dong et al., 2020**). While the pandemic phase marked by Omicron has been associated with a lower case-fatality rate due to a combination of factors (possibly related to the virulence of the Omicron variant and vaccine- and infection-induced immunity) (**Imperial College London, 2021; Iuliano et al., 2022; Wolter et al., 2021**), the high case load has strained healthcare systems and inequitable distribution has left some under-resourced. As a result, 215 thousand of the 5.6 million cumulative global deaths (3.8%) have occurred within January 2022—despite advancements over the past 22 months with effective vaccines and treatments. The Omicron variant has been particularly impactful in the two countries that were the focus of The COPE Initiative. Despite decreased testing in some areas, and incomplete reporting of at-home rapid antigen tests to national databases, the US recorded 19.3 million of the 74.2 million (26.0%) cumulative confirmed cases and 56 thousand of the 884 thousand (6.3%) cumulative deaths in January 2022. After having largely contained COVID-19 for much of the pandemic prior to the Omicron variant, Australia recorded 2.1 million of the 2.6 million (80.8%) cumulative confirmed cases and 1.5 thousand of the 3.7 thousand (40.5%) cumulative deaths in the same interval. Both recent and cumulative infection

and death counts are substantial undercounts (**Centers for Disease Control and Prevention, 2020a; Noh & Danuser, 2021; Reese et al., 2020**).

These figures demonstrate not just the presence but the vitality of the pandemic, which continue to be associated with consequences for societies globally. Continued monitoring of direct and indirect effects of the pandemic on all aspects of life and the environment are essential as we prepare for a post-pandemic era, whenever that may begin.

15.6. THE LESSONS OF THE (COVID-19) PANDEMIC

Writing in 1919, US Army Major and sanitation engineer George Soper II, PhD published his observations during the 1918 influenza pandemic in *Science*: “The Lessons of the Pandemic” (**Soper, 1919**). Many of the sentiments shared by Major Soper about the 1918 pandemic resonate with the COVID-19 pandemic, including the mystery surrounding its origins and the universal span of its consequences. Soper asserts that failure to contain the 1918 pandemic came down to several factors: public indifference, the difficulty in ascertaining high levels of adherence to prevention measures—especially among those with low risk perception, the highly infectious nature of respiratory infections, and the perils of asymptomatic transmission. He later stated, “It would not be surprising if there should be another pandemic in the US”^(p505), and that “The great lesson of the pandemic is to call attention to the prevalence of respiratory diseases in ordinary times, to the indifference with which they are ordinarily regarded and to our present inability to protect ourselves against them”^(p505) (**Soper, 1919**). Finally, Soper offered 12 condensed Lessons of the Pandemic.

1. Avoid needless crowding—influenza is a crowd disease.
2. Smother your coughs and sneezes—others do not want the germs which you would throw away.

3. Your nose, not your mouth was made to breathe through—get the habit.
4. Remember the three C's—a clean mouth, clean skin, and clean clothes.
5. Try to keep cool when you walk and warm when you ride and sleep.
6. Open the windows—always at home at night; at the office when practicable.
7. Food will win the war if you give it a chance—help by choosing and chewing your food well.
8. Your fate may be in your own hands—wash your hands before eating.
9. Don't let the waste products of digestion accumulate—drink a glass or two of water on getting up.
- 10 Don't use a napkin, towel, spoon, fork, glass or cup which has been used by another person and not washed.
11. Avoid tight clothes, tight shoes, tight gloves—seek to make nature your ally not your prisoner.
12. When the air is pure breathe all of it you can—breathe deeply.

George A. Soper

Sanitary Corps US

(Soper, 1919)

Just as Soper remarked he was “still too close to the [1918 pandemic] to fully measure it”^(p502)
(Soper, 1919), so too am I too close to the current pandemic to fully measure it—not least the date

or year of its conclusion. However, I propose 12 condensed Lessons of the Great Pandemic of Coronavirus Disease 2019 based on learnings from The COPE Initiative.

1. Historical records from prior pandemics offer insights to prepare and respond to emerging infectious diseases.
2. However simplistic, nonpharmaceutical interventions (e.g., masking, physical distancing, practicing hand hygiene, avoiding large gatherings) remain our first line of defence against infection and can reduce the incidence of other infectious viruses or pathogens.
3. Vaccines can save lives.
4. Prolonged implementation of stringent prevention measures is unpopular—and difficult to maintain if not enforced.
5. Politicization of public health and medical guidance can be divisive and limit adherence with recommended community prevention efforts and should be avoided if possible.
6. Social factors predispose historically marginalised populations to higher risk of exposure and disproportionate morbidity and mortality.
7. Pandemics can exacerbate existing inequities—domestically and internationally.
8. Resource availability and medical capacity do not themselves ensure an effective pandemic response; effective leadership is needed to coordinate and mobilise efforts.
9. Chronic underinvestment in public health and mental health is difficult to rectify during a public health emergency.
10. Direct and indirect mental health effects of infectious diseases have precedence and warrant scientific investigation and a public health response.
11. Acute mental health effects are not always transient and may not depend solely on local prevalence of the disease.
12. This pandemic will not be the last.

Mark É. Czeisler

The COPE Initiative.

2020 to 2021 Australian-American Fulbright Scholar.

Turner Institute for Brain and Mental Health and School of Psychological Sciences, Monash University, Melbourne, Victoria, Australia.

Institute for Breathing and Sleep, Austin Health, Melbourne, Victoria, Australia.

Department of Psychiatry, Brigham and Women's Hospital, Boston, Massachusetts, US.

Francis Weld Peabody Society, Harvard Medical School, Boston, Massachusetts, US.

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The capitalisation style of each reference is preserved as listed in the US National Library of Medicine at the National Institutes of Health database or alternative original source.

Appendix 1. Delay or Avoidance of Medical Care Because of COVID-19-Related Concerns - United States, June 2020

Czeisler MÉ, Marynak K, Clarke KEN, Salah Z, Shakya I, Thierry JM, Ali N, McMillan H, Wiley JF, Weaver MD, Czeisler CA, Rajaratnam SMW, Howard ME. Delay or Avoidance of Medical Care Because of COVID-19-Related Concerns - United States, June 2020. *MMWR Morb Mortal Wkly Rep.* 2020 Sep 11;69(36):1250-1257. digital object identifier (doi): 10.15585/mmwr.mm6936a4. PubMed reference number (PMID): 32915166; PubMed Central reference number (PMCID): PMC7499838.

Delay or Avoidance of Medical Care Because of COVID-19–Related Concerns — United States, June 2020

Mark É. Czeisler^{1,2}; Kristy Marynak, MPP^{3,4}; Kristie E.N. Clarke, MD³; Zainab Salah, MPH³; Iju Shakya, MPH³; JoAnn M. Thierry, PhD³; Nida Ali, PhD³; Hannah McMillan, MPH³; Joshua F. Wiley, PhD¹; Matthew D. Weaver, PhD^{1,5,6}; Charles A. Czeisler, PhD, MD^{1,5,6}; Shantha M.W. Rajaratnam, PhD^{1,2,5,6}; Mark E. Howard, MBBS, PhD^{1,2,7}

Temporary disruptions in routine and nonemergency medical care access and delivery have been observed during periods of considerable community transmission of SARS-CoV-2, the virus that causes coronavirus disease 2019 (COVID-19) (1). However, medical care delay or avoidance might increase morbidity and mortality risk associated with treatable and preventable health conditions and might contribute to reported excess deaths directly or indirectly related to COVID-19 (2). To assess delay or avoidance of urgent or emergency and routine medical care because of concerns about COVID-19, a web-based survey was administered by Qualtrics, LLC, during June 24–30, 2020, to a nationwide representative sample of U.S. adults aged ≥18 years. Overall, an estimated 40.9% of U.S. adults have avoided medical care during the pandemic because of concerns about COVID-19, including 12.0% who avoided urgent or emergency care and 31.5% who avoided routine care. The estimated prevalence of urgent or emergency care avoidance was significantly higher among the following groups: unpaid caregivers for adults* versus noncaregivers (adjusted prevalence ratio [aPR] = 2.9); persons with two or more selected underlying medical conditions† versus those without those conditions (aPR = 1.9); persons with health insurance versus those without health insurance (aPR = 1.8); non-Hispanic Black (Black) adults (aPR = 1.6) and Hispanic or Latino (Hispanic) adults (aPR = 1.5) versus non-Hispanic White (White) adults; young adults aged

18–24 years versus adults aged 25–44 years (aPR = 1.5); and persons with disabilities§ versus those without disabilities (aPR = 1.3). Given this widespread reporting of medical care avoidance because of COVID-19 concerns, especially among persons at increased risk for severe COVID-19, urgent efforts are warranted to ensure delivery of services that, if deferred, could result in patient harm. Even during the COVID-19 pandemic, persons experiencing a medical emergency should seek and be provided care without delay (3).

During June 24–30, 2020, a total of 5,412 (54.7%) of 9,896 eligible adults¶ completed web-based COVID-19 Outbreak Public Evaluation Initiative surveys administered by Qualtrics, LLC.** The Human Research Ethics Committee of Monash University (Melbourne, Australia) reviewed and approved the study protocol on human subjects research.

§ Persons who had a disability were defined as such based on a qualifying response to either one of two questions: “Are you limited in any way in any activities because of physical, mental, or emotional condition?” and “Do you have any health conditions that require you to use special equipment, such as a cane, wheelchair, special bed, or special telephone?” <https://www.cdc.gov/brfss/questionnaires/pdf-ques/2015-brfss-questionnaire-12-29-14.pdf>.

¶ Eligibility to complete a survey during June 24–30, 2020, was determined following electronic contact of potential participants based on a minimum age of 18 years and residence within the United States. Age and residence were assessed using screening questions without indication of eligibility criteria before commencement of the earliest survey (recontacted respondents: April 2–8, 2020; first-time respondents: June 24–30, 2020). Residence was reassessed among recontacted respondents during June 24–30, and one respondent whose primary residence had changed to outside of the United States was excluded from the analysis. Country-specific geolocation verification via IP address mapping was used to ensure respondents were responding from the United States. Informed consent was obtained electronically during June 24–30, 2020, before enrollment into the study as a participant. All surveys underwent Qualtrics, LLC data quality screening procedures, including algorithmic and keystroke analysis for attention patterns, click-through behavior, duplicate responses, machine responses, and inattentiveness. Respondents who failed an attention or speed check, along with any responses that failed data quality screening procedures, were excluded from the analysis (6.6%).

** The COVID-19 Outbreak Public Evaluation (COPE) Initiative (www.thecopeinitiative.org) is designed to assess public attitudes, behaviors, and beliefs related to the coronavirus disease 2019 (COVID-19) pandemic, and to evaluate the mental and physical health consequences of the pandemic. The COPE Initiative surveys included in this analysis were administered by Qualtrics, LLC (<https://www.qualtrics.com/>), a commercial survey company with a network of participant pools comprising hundreds of suppliers and with varying recruitment methodologies that include digital advertisements and promotions, word-of-mouth and membership referrals, social networks, television and radio advertisements, and offline mail-based approaches.

* Unpaid caregiver status was self-reported. The definition of an unpaid caregiver for adults was having provided unpaid care to a relative or friend aged ≥18 years to help them take care of themselves at any time in the last 3 months. Examples provided to survey respondents included helping with personal needs, household chores, health care tasks, managing a person’s finances, taking them to a doctor’s appointment, arranging for outside services, and visiting regularly to see how they are doing.

† Selected underlying medical conditions known to increase the risk for severe COVID-19 included in this analysis were obesity (body mass index [BMI] ≥30 kg/m²), diabetes, high blood pressure, cardiovascular disease, and any type of cancer. BMI was calculated from self-reported height and weight as BMI = weight (lb)/[height (in)]² × 703 (https://www.cdc.gov/healthyweight/assessing/bmi/adult_bmi/index.html). The remaining conditions were assessed using the following question: “Have you ever been diagnosed with any of the following conditions?” with the following four response options: 1) “Never”; 2) “Yes, I have in the past, but don’t have it now”; 3) “Yes I have, but I do not regularly take medications or receive treatment”; and 4) “Yes I have, and I am regularly taking medications or receiving treatment.” Respondents who answered that they have been diagnosed and chose either response 3 or 4 were considered as having the specified medical condition.

This activity was also reviewed by CDC and was conducted consistent with applicable federal law and CDC policy.^{††} Respondents were informed of the study purposes and provided electronic consent before commencement, and investigators received anonymized responses. The 5,412 participants included 3,683 (68.1%) first-time respondents and 1,729 (31.9%) persons who had completed a related survey^{§§} during April 2–8, 2020. Among the 5,412 participants, 4,975 (91.9%) provided complete data for all variables in this analysis. Quota sampling and survey weighting^{¶¶} were employed to improve cohort representativeness of the U.S. population by gender, age, and race/ethnicity.

Respondents were asked “Have you delayed or avoided medical care due to concerns related to COVID-19?” Delay or avoidance was evaluated for emergency (e.g., care for immediate life-threatening conditions), urgent (e.g., care for immediate non-life-threatening conditions), and routine (e.g., annual check-ups) medical care. Given the potential for variation in interpretation of whether conditions were life-threatening, responses for urgent and emergency care delay or avoidance were combined for analysis. Covariates included gender; age; race/ethnicity; disability status; presence of one or more selected underlying medical conditions known to increase risk for severe COVID-19; education; essential worker status^{***}; unpaid adult caregiver status; U.S. census region; urban/rural classification^{†††}; health insurance status; whether respondents knew someone who had received a positive SARS-CoV-2 test result or had died from COVID-19; and whether the respondents believed they were at high risk for severe COVID-19. Comparisons within all these subgroups were evaluated using multivariable Poisson regression models^{§§§} with robust standard errors to estimate prevalence ratios adjusted for all covariates, 95% confidence intervals, and p-values to evaluate statistical significance ($\alpha = 0.05$) using the R survey package (version 3.29) and R software (version 4.0.2; The R Foundation).

As of June 30, 2020, among 4,975 U.S. adult respondents, 40.9% reported having delayed or avoided any medical care, including urgent or emergency care (12.0%) and routine care (31.5%), because of concerns about COVID-19 (Table 1). Groups of persons among whom urgent or emergency care avoidance exceeded 20% and among whom any care avoidance exceeded 50% included adults aged 18–24 years (30.9% for urgent or emergency care; 57.2% for any care), unpaid caregivers for adults (29.8%; 64.3%), Hispanic adults (24.6%; 55.5%), persons with disabilities (22.8%; 60.3%), persons with two or more selected underlying medical conditions (22.7%; 54.7%), and students (22.7%; 50.3%). One in four unpaid caregivers reported caring for adults who were at increased risk for severe COVID-19.

In the multivariable Poisson regression models, differences within groups were observed for urgent or emergency care avoidance (Figure) and any care avoidance (Table 2). Adjusted prevalence of urgent or emergency care avoidance was significantly higher among unpaid caregivers for adults versus noncaregivers (2.9; 2.3–3.6); persons with two or more selected underlying medical conditions versus those without those conditions (1.9; 1.5–2.4); persons with health insurance versus those without health insurance (1.8; 1.2–2.8); Black adults (1.6; 1.3–2.1) and Hispanic adults (1.5; 1.2–2.0) versus White adults; young adults aged 18–24 years versus adults aged 25–44 years (1.5; 1.2–1.8); and persons with disabilities versus those without disabilities (1.3; 1.1–1.5). Avoidance of urgent or emergency care was significantly lower among adults aged ≥ 45 years than among younger adults.

Discussion

As of June 30, 2020, an estimated 41% of U.S. adults reported having delayed or avoided medical care during the pandemic because of concerns about COVID-19, including 12% who reported having avoided urgent or emergency care. These findings align with recent reports that hospital admissions, overall emergency department (ED) visits, and the number of ED visits for heart attack, stroke, and hyperglycemic crisis have declined since the start of the pandemic (3–5), and that excess deaths directly or indirectly related to COVID-19 have increased in 2020 versus prior years (2). Nearly one third of adult respondents reported having delayed or avoided routine medical care, which might reflect adherence to community mitigation efforts such as stay-at-home orders, temporary closures of health facilities, or additional factors. However, if routine care avoidance were to be sustained, adults could miss opportunities for management of chronic conditions, receipt of routine vaccinations, or early detection of new conditions, which might worsen outcomes.

^{††} 45 C.F.R. part 46, 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d); 5 U.S.C. Sect. 552a; 44 U.S.C. Sect. 3501 et seq.

^{§§} <https://www.medrxiv.org/content/10.1101/2020.04.22.20076141v1>.

^{¶¶} Statistical raking and weight trimming were employed to improve the cross-sectional June cohort representativeness of the U.S. population by gender, age, and race/ethnicity according to the 2010 U.S. Census.

^{***} Essential worker status was self-reported. For the aPRs, essential workers were compared with all other respondents (including those who were nonessential workers, retired, unemployed, and students).

^{†††} Rural-urban classification was determined by using self-reported ZIP codes according to the Federal Office of Rural Health Policy definition of rurality. <https://www.hrsa.gov/rural-health/about-us/definition/datafiles.html>.

^{§§§} Reference groups were chosen for ease of interpretation. For example, the household income level of \$50,000–\$99,999 was selected as the reference group because the median household income was \$61,937 in the United States in 2018. <https://www.census.gov/content/dam/Census/library/publications/2019/acs/acsbr18-01.pdf>.

TABLE 1. Estimated prevalence of delay or avoidance of medical care because of concerns related to COVID-19, by type of care and respondent characteristics — United States, June 30, 2020

Characteristic	No. (%) [†]	Type of medical care delayed or avoided*					
		Urgent or emergency		Routine		Any	
		% [‡]	P-value [§]	% [‡]	P-value [§]	% [‡]	P-value [§]
All respondents	4,975 (100)	12.0	—	31.5	—	40.9	—
Gender							
Female	2,528 (50.8)	11.7	0.598	35.8	<0.001	44.9	<0.001
Male	2,447 (49.2)	12.3		27.0		36.7	
Age group, yrs							
18–24	650 (13.1)	30.9	<0.001	29.6	0.072	57.2	<0.001
25–44	1,740 (35.0)	14.9		34.2		44.8	
45–64	1,727 (34.7)	5.7		30.0		34.5	
≥65	858 (17.3)	4.4		30.3		33.5	
Race/Ethnicity							
White, non-Hispanic	3,168 (63.7)	6.7	<0.001	30.9	0.020	36.2	<0.001
Black, non-Hispanic	607 (12.2)	23.3		29.7		48.1	
Asian, non-Hispanic	238 (4.8)	8.6		31.3		37.7	
Other race or multiple races, non-Hispanic [¶]	150 (3.0)	15.5		23.9		37.3	
Hispanic, any race or races	813 (16.3)	24.6		36.4		55.5	
Disability**							
Yes	1,108 (22.3)	22.8	<0.001	42.9	<0.001	60.3	<0.001
No	3,867 (77.7)	8.9		28.2		35.3	
Underlying medical condition^{††}							
No	2,537 (51.0)	8.2	<0.001	27.9	<0.001	34.7	<0.001
One	1,328 (26.7)	10.4		33.0		41.2	
Two or more	1,110 (22.3)	22.7		37.7		54.7	
2019 household income, USD							
<25,000	665 (13.4)	13.9	0.416	31.2	0.554	42.8	0.454
25,000–49,999	1,038 (20.9)	11.1		30.9		38.6	
50,000–99,999	1,720 (34.6)	12.5		30.5		41.1	
≥100,000	1,552 (31.2)	11.2		33.0		41.4	
Education							
Less than high school diploma	65 (1.3)	15.6	0.442	24.7	0.019	37.9	0.170
High school diploma	833 (16.7)	12.3		28.1		38.1	
Some college	1,302 (26.2)	13.6		29.7		40.3	
Bachelor's degree	1,755 (35.3)	11.2		34.8		43.6	
Professional degree	1,020 (20.5)	10.9		31.2		39.5	
Employment status							
Employed	3,049 (61.3)	14.6	<0.001	31.5	0.407	43.3	<0.001
Unemployed	630 (12.7)	8.7		34.4		39.5	
Retired	1,129 (22.7)	5.3		29.9		33.8	
Student	166 (3.3)	22.7		30.5		50.3	
Essential worker status^{§§}							
Essential worker	1,707 (34.3)	19.5	<0.001	32.4	0.293	48.0	<0.001
Nonessential worker	1,342 (27.0)	8.4		30.3		37.3	
Unpaid caregiver status^{¶¶}							
Unpaid caregiver for adults	1,344 (27.0)	29.8	<0.001	41.0	<0.001	64.3	<0.001
Not unpaid caregiver for adults	3,631 (73.0)	5.4		27.9		32.2	
U.S. Census region^{***}							
Northeast	1,122 (22.6)	11.0	0.008	33.9	0.203	42.5	0.460
Midwest	936 (18.8)	8.5		32.0		38.7	
South	1,736 (34.9)	13.9		29.6		40.7	
West	1,181 (23.7)	13.0		31.5		41.5	
Rural/Urban classification^{†††}							
Urban	4,411 (88.7)	12.3	0.103	31.5	0.763	41.2	0.216
Rural	564 (11.3)	9.4		30.9		38.2	
Health insurance status							
Yes	4,577 (92.0)	12.4	0.036	32.6	<0.001	42.3	<0.001
No	398 (8.0)	7.8		18.4		24.8	
Know someone with positive test results for SARS-CoV-2^{§§§}							
Yes	989 (19.9)	8.8	0.004	40.7	<0.001	46.6	<0.001
No	3,986 (80.1)	12.8		29.2		39.5	

See table footnotes on the next page.

TABLE 1. (Continued) Estimated prevalence of delay or avoidance of medical care because of concerns related to COVID-19, by type of care and respondent characteristics — United States, June 30, 2020

Characteristic	No. (%) [†]	Type of medical care delayed or avoided*					
		Urgent or emergency		Routine		Any	
		% [†]	P-value [§]	% [†]	P-value [§]	% [†]	P-value [§]
Knew someone who died from COVID-19							
Yes	364 (7.3)	10.1	0.348	41.4	<0.001	46.3	0.048
No	4,611 (92.7)	12.2		30.7		40.5	
Believed to be in group at high risk for severe COVID-19							
Yes	981 (19.7)	10.0	0.050	42.5	<0.001	49.4	<0.001
No	3,994 (80.3)	12.5		28.8		38.8	

Abbreviations: CI = confidence interval; COVID-19 = coronavirus disease 2019; USD = U.S. dollars.

* The types of medical care avoidance are not mutually exclusive; respondents had the option to indicate that they had delayed or avoided more than one type of medical care (i.e., routine medical care and urgent/emergency medical care).

[†] Statistical raking and weight trimming were employed to improve the cross-sectional June cohort representativeness of the U.S. population by gender, age, and race/ethnicity according to the 2010 U.S. Census.

[§] The Rao-Scott adjusted Pearson chi-squared test was used to test for differences in observed and expected frequencies among groups by characteristic for avoidance of each type of medical care (e.g., whether avoidance of routine medical care differs significantly by gender). Statistical significance was evaluated at a threshold of $\alpha = 0.05$.

[¶] "Other" race includes American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or Other.

** Persons who had a disability were defined as such based on a qualifying response to either one of two questions: "Are you limited in any way in any activities because of physical, mental, or emotional condition?" and "Do you have any health conditions that require you to use special equipment, such as a cane, wheelchair, special bed, or special telephone?" <https://www.cdc.gov/brfss/questionnaires/pdf-ques/2015-brfss-questionnaire-12-29-14.pdf>.

†† Selected underlying medical conditions known to increase the risk for severe COVID-19 included in this analysis were obesity, diabetes, high blood pressure, cardiovascular disease, and any type of cancer. Obesity is defined as body mass index ≥ 30 kg/m² and was calculated from self-reported height and weight (https://www.cdc.gov/healthyweight/assessing/bmi/adult_bmi/index.html). The remaining conditions were assessed using the question "Have you ever been diagnosed with any of the following conditions?" with response options of 1) "Never"; 2) "Yes, I have in the past, but don't have it now"; 3) "Yes I have, but I do not regularly take medications or receive treatment"; and 4) "Yes I have, and I am regularly taking medications or receiving treatment." Respondents who answered that they have been diagnosed and chose either response 3 or 4 were considered as having the specified medical condition.

^{§§} Essential worker status was self-reported.

^{¶¶} Unpaid caregiver status was self-reported. Unpaid caregivers for adults were defined as having provided unpaid care to a relative or friend aged ≥ 18 years at any time in the last 3 months. Examples provided to survey respondents included helping with personal needs, household chores, health care tasks, managing a person's finances, taking them to a doctor's appointment, arranging for outside services, and visiting regularly to see how they are doing.

*** Region classification was determined by using the U.S. Census Bureau's Census Regions and Divisions. https://www2.census.gov/geo/pdfs/maps-data/maps/reference/us_regdiv.pdf.

††† Rural-urban classification was determined by using self-reported ZIP codes according to the Federal Office of Rural Health Policy definition of rurality. <https://www.hrsa.gov/rural-health/about-us/definition/datafiles.html>.

^{§§§} For this question, respondents were asked to select the following statement, if applicable: "I know someone who has tested positive for COVID-19."

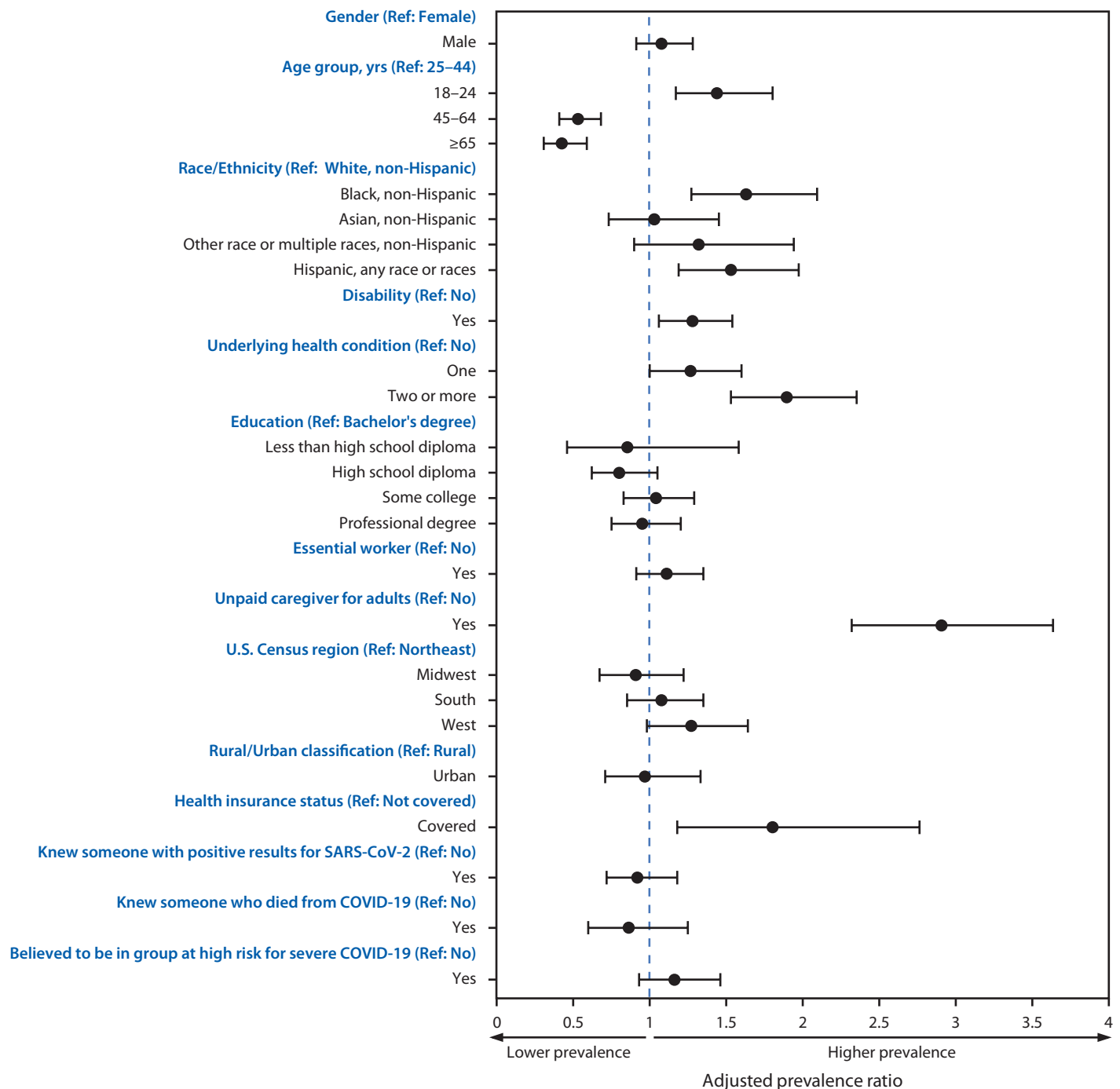
Avoidance of both urgent or emergency and routine medical care because of COVID-19 concerns was highly prevalent among unpaid caregivers for adults, respondents with two or more underlying medical conditions, and persons with disabilities. For caregivers who reported caring for adults at increased risk for severe COVID-19, concern about exposure of care recipients might contribute to care avoidance. Persons with underlying medical conditions that increase their risk for severe COVID-19 (6) are more likely to require care to monitor and treat these conditions, potentially contributing to their more frequent report of avoidance. Moreover, persons at increased risk for severe COVID-19 might have avoided health care facilities because of perceived or actual increased risk of exposure to SARS-CoV-2, particularly at the onset of the pandemic. However, health care facilities are implementing important safety precautions to reduce the risk of SARS-CoV-2 infection among patients and personnel. In contrast, delay or avoidance of care might increase risk for life-threatening medical emergencies. In a recent study, states with large numbers of COVID-19-associated deaths also experienced large proportional increases in deaths from other underlying causes, including diabetes and cardiovascular disease (7). For persons

with disabilities, accessing medical services might be challenging because of disruptions in essential support services, which can result in adverse health outcomes. Medical services for persons with disabilities might also be disrupted because of reduced availability of accessible transportation, reduced communication in accessible formats, perceptions of SARS-CoV-2 exposure risk, and specialized needs that are difficult to address with routine telehealth delivery during the pandemic response. Increasing accessibility of medical and telehealth services^{§§§} might help prevent delay of needed care.

Increased prevalences of reported urgent or emergency care avoidance among Black adults and Hispanic adults compared with White adults are especially concerning given increased COVID-19-associated mortality among Black adults and Hispanic adults (8). In the United States, the age-adjusted COVID-19 hospitalization rates are approximately five times higher among Black persons and four times higher among Hispanic persons than are those among White

^{§§§} <https://www.cdc.gov/coronavirus/2019-ncov/hcp/telehealth.html>.

FIGURE. Adjusted prevalence ratios^{*,†} for characteristics^{§,¶,,††} associated with delay or avoidance of urgent or emergency medical care because of concerns related to COVID-19 — United States, June 30, 2020**



Abbreviation: COVID-19 = coronavirus disease 2019.

* Comparisons within subgroups were evaluated using Poisson regressions used to calculate a prevalence ratio adjusted for all characteristics shown in figure.

† 95% confidence intervals indicated with error bars.

§ "Other" race includes American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or Other.

¶ Selected underlying medical conditions known to increase the risk for severe COVID-19 were obesity, diabetes, high blood pressure, cardiovascular disease, and any type of cancer. Obesity is defined as body mass index ≥ 30 kg/m² and was calculated from self-reported height and weight (https://www.cdc.gov/healthyweight/assessing/bmi/adult_bmi/index.html). The remaining conditions were assessed using the question "Have you ever been diagnosed with any of the following conditions?" with response options of 1) "Never"; 2) "Yes, I have in the past, but don't have it now"; 3) "Yes I have, but I do not regularly take medications or receive treatment"; and 4) "Yes I have, and I am regularly taking medications or receiving treatment." Respondents who answered that they have been diagnosed and chose either response 3 or 4 were considered as having the specified medical condition.

** Essential worker status was self-reported. For the adjusted prevalence ratios, essential workers were compared with all other respondents (including those who were nonessential workers, retired, unemployed, and students).

†† Unpaid caregiver status was self-reported. Unpaid caregivers for adults were defined as having provided unpaid care to a relative or friend aged ≥ 18 years to help them take care of themselves at any time in the last 3 months.

TABLE 2. Characteristics associated with delay or avoidance of any medical care because of concerns related to COVID-19 — United States, June 30, 2020

Characteristic	Weighted* no.	Avoided or delayed any medical care		
		aPR [†]	(95% CI [†])	P-value [†]
All respondents	4,975	—	—	—
Gender				
Female	2,528	Referent	—	—
Male	2,447	0.81	(0.75–0.87) [§]	<0.001
Age group, yrs				
18–24	650	1.12	(1.01–1.25) [§]	0.035
25–44	1,740	Referent	—	—
45–64	1,727	0.80	(0.72–0.88) [§]	<0.001
≥65	858	0.72	(0.64–0.81) [§]	<0.001
Race/Ethnicity				
White, non-Hispanic	3,168	Referent	—	—
Black, non-Hispanic	607	1.07	(0.96–1.19)	0.235
Asian, non-Hispanic	238	1.04	(0.91–1.18)	0.567
Other race or multiple races, non-Hispanic [¶]	150	0.87	(0.71–1.07)	0.196
Hispanic, any race or races	813	1.15	(1.03–1.27) [§]	0.012
Disability**				
Yes	1,108	1.33	(1.23–1.43) [§]	<0.001
No	3,867	Referent	—	—
Underlying medical condition^{††}				
No	2,537	Referent	—	—
One	1,328	1.15	(1.05–1.25) [§]	0.004
Two or more	1,110	1.31	(1.20–1.42) [§]	<0.001
Education				
Less than high school diploma	65	0.72	(0.53–0.98) [§]	0.037
High school diploma	833	0.79	(0.71–0.89) [§]	<0.001
Some college	1,302	0.85	(0.78–0.93) [§]	0.001
Bachelor's degree	1,755	Referent	—	—
Professional degree	1,020	0.90	(0.82–0.98) [§]	0.019
Essential workers vs others^{§§}				
Essential workers	1,707	1.00	(0.92–1.09)	0.960
Other respondents (nonessential workers, retired persons, unemployed persons, and students)	3,268	Referent	—	—
Unpaid caregiver status^{¶¶}				
Unpaid caregiver for adults	1,344	1.64	(1.52–1.78) [§]	<0.001
Not unpaid caregiver for adults	3,631	Referent	—	—
U.S. Census region^{***}				
Northeast	1,122	Referent	—	—
Midwest	936	0.93	(0.83–1.04)	0.214
South	1,736	0.90	(0.82–0.99) [§]	0.028
West	1,181	0.99	(0.89–1.09)	0.808

See table footnotes on the next page.

persons (9). Factors contributing to racial and ethnic disparities in SARS-CoV-2 exposure, illness, and mortality might include long-standing structural inequities that influence life expectancy, including prevalence and underlying medical conditions, health insurance status, and health care access and utilization, as well as work and living circumstances, including use of public transportation and essential worker status. Communities, health care systems, and public health agencies can foster equity by working together to ensure access to information, testing, and care to assure maintenance and management of physical and mental health.

The higher prevalence of medical care delay or avoidance among respondents with health insurance versus those without

insurance might reflect differences in medical care-seeking behaviors. Before the pandemic, persons without insurance sought medical care much less frequently than did those with insurance (10), resulting in fewer opportunities for medical care delay or avoidance.

The findings in this report are subject to at least five limitations. First, self-reported data are subject to recall, response, and social desirability biases. Second, the survey did not assess reasons for COVID-19–associated care avoidance, such as adherence to public health recommendations; closure of health care provider facilities; reduced availability of public transportation; fear of exposure to infection with SARS-CoV-2; or availability, accessibility, and acceptance or recognition of

TABLE 2. (Continued) Characteristics associated with delay or avoidance of any medical care because of concerns related to COVID-19 — United States, June 30, 2020

Characteristic	Weighted* no.	Avoided or delayed any medical care		
		aPR [†]	(95% CI [†])	P-value [‡]
Rural/Urban classification^{†††}				
Urban	4,411	1.00	(0.89–1.12)	0.993
Rural	564	Referent	—	—
Health insurance status				
Yes	4,577	1.61	(1.31–1.98) [§]	<0.001
No	398	Referent	—	—
Know someone with positive test results for SARS-CoV-2^{§§§}				
Yes	989	1.22	(1.12–1.33) [§]	<0.001
No	3,986	Referent	—	—
Knew someone who died from COVID-19				
Yes	364	0.99	(0.88–1.12)	0.860
No	4,611	Referent	—	—
Believed to be in a group at high risk for severe COVID-19				
Yes	981	1.33	(1.23–1.44) [§]	<0.001
No	3,994	Referent	—	—

Abbreviations: aPR = adjusted prevalence ratio; CI = confidence interval; COVID-19 = coronavirus disease 2019.

* Statistical raking and weight trimming were employed to improve the cross-sectional June cohort representativeness of the U.S. population by gender, age, and race/ethnicity according to the 2010 U.S. Census.

† Comparisons within subgroups were evaluated using Poisson regressions used to calculate a prevalence ratio adjusted for all characteristics listed, as well as a 95% CI and p-value. Statistical significance was evaluated at a threshold of $\alpha = 0.05$.

§ P-value calculated using Poisson regression among respondents within a characteristic is statistically significant at levels of $p < 0.05$.

¶ "Other" race includes American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or Other.

** Persons who had a disability were defined based on a qualifying response to either one of two questions: "Are you limited in any way in any activities because of physical, mental, or emotional condition?" and "Do you have any health conditions that require you to use special equipment, such as a cane, wheelchair, special bed, or special telephone?" <https://www.cdc.gov/brfss/questionnaires/pdf-ques/2015-brfss-questionnaire-12-29-14.pdf>.

†† Underlying medical conditions were obesity, diabetes, high blood pressure, cardiovascular disease, and any type of cancer. Obesity is defined as body mass index ≥ 30 kg/m² and was calculated from self-reported height and weight (https://www.cdc.gov/healthyweight/assessing/bmi/adult_bmi/index.html). The remaining conditions were assessed using the question "Have you ever been diagnosed with any of the following conditions?" with response options of 1) "Never"; 2) "Yes, I have in the past, but don't have it now"; 3) "Yes I have, but I do not regularly take medications or receive treatment"; and 4) "Yes I have, and I am regularly taking medications or receiving treatment." Respondents who answered that they have been diagnosed and chose either response 3 or 4 were considered as having the specified medical condition.

§§ Essential worker status was self-reported. For the adjusted prevalence ratios, essential workers were compared with all other respondents (including those who were nonessential workers, retired, unemployed, and students).

¶¶ Unpaid caregiver status was self-reported. Unpaid caregivers for adults were defined as having provided unpaid care to a relative or friend aged ≥ 18 years at any time in the last 3 months. Examples provided to survey respondents included helping with personal needs, household chores, health care tasks, managing a person's finances, taking them to a doctor's appointment, arranging for outside services, and visiting regularly to see how they are doing.

*** Region classification was determined by using the U.S. Census Bureau's Census Regions and Divisions. https://www2.census.gov/geo/pdfs/maps-data/maps/reference/us_regdiv.pdf.

††† Rural/urban classification was determined by using self-reported ZIP codes according to the Federal Office of Rural Health Policy definition of rurality. <https://www.hrsa.gov/rural-health/about-us/definition/datafiles.html>.

§§§ For this question, respondents were asked to select the following statement, if applicable: "I know someone who has tested positive for COVID-19."

telemedicine as a means of providing care in lieu of in-person services. Third, the survey did not assess baseline patterns of care-seeking or timing or duration of care avoidance. Fourth, perceptions of whether a condition was life-threatening might vary among respondents. Finally, although quota sampling methods and survey weighting were employed to improve cohort representativeness, this web-based survey might not be fully representative of the U.S. population for income, educational attainment, and access to technology. However, the findings are consistent with reported declines in hospital admissions and ED visits during the pandemic (3–5).

CDC has issued guidance to assist persons at increased risk for severe COVID-19 in staying healthy and safely following

treatment plans**** and to prepare health care facilities to safely deliver care during the pandemic.†††† Additional public outreach in accessible formats tailored for diverse audiences might encourage these persons to seek necessary care. Messages could highlight the risks of delaying needed care, especially among persons with underlying medical conditions, and the importance of timely emergency care. Patient concerns related to potential exposure to SARS-CoV-2 in health care settings could be addressed by describing facilities' precautions to reduce exposure risk.

**** <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>.

†††† <https://www.cdc.gov/coronavirus/2019-ncov/hcp/us-healthcare-facilities.html>.

Summary**What is already known about this topic?**

Delayed or avoided medical care might increase morbidity and mortality associated with both chronic and acute health conditions.

What is added by this report?

By June 30, 2020, because of concerns about COVID-19, an estimated 41% of U.S. adults had delayed or avoided medical care including urgent or emergency care (12%) and routine care (32%). Avoidance of urgent or emergency care was more prevalent among unpaid caregivers for adults, persons with underlying medical conditions, Black adults, Hispanic adults, young adults, and persons with disabilities.

What are the implications for public health practice?

Understanding factors associated with medical care avoidance can inform targeted care delivery approaches and communication efforts encouraging persons to safely seek timely routine, urgent, and emergency care.

Further exploration of underlying reasons for medical care avoidance is needed, including among persons with disabilities, persons with underlying health conditions, unpaid caregivers for adults, and those who face structural inequities. If care were avoided because of concern about SARS-CoV-2 exposure or if there were closures or limited options for in-person services, providing accessible telehealth or in-home health care could address some care needs. Even during the COVID-19 pandemic, persons experiencing a medical emergency should seek and be provided care without delay (3).

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Corresponding author: Kristy Marynak, KMarynak@cdc.gov.

¹Turner Institute for Brain and Mental Health, Monash University, Melbourne, Australia; ²Austin Health, Melbourne, Australia; ³CDC COVID-19 Response Team; ⁴Johns Hopkins University Bloomberg School of Public Health, Baltimore, Maryland; ⁵Brigham and Women's Hospital, Boston, Massachusetts; ⁶Harvard Medical School, Boston, Massachusetts; ⁷University of Melbourne, Melbourne, Australia.

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4 in 10 U.S. adults

reported avoiding medical care because of concerns related to COVID-19*

Delaying or avoiding urgent or emergency care
was more common among:



People with disabilities



People with two or more
underlying conditions

Telehealth may
help people get the
care they need

*Web-based survey of a representative sample of U.S. adults aged ≥18 years during June 24–30, 2020

Even during the COVID-19 pandemic, people who experience a medical
emergency should seek care **without delay**

Appendix 2. Delay or avoidance of routine, urgent and emergency medical care due to concerns about COVID-19 in a region with low COVID-19 prevalence: Victoria, Australia

Czeisler MÉ*, Kennedy JL*, Wiley JF, Facer-Childs ER, Robbins R, Barger LK, Czeisler CA, Rajaratnam SMW, Howard ME. Delay or avoidance of routine, urgent and emergency medical care due to concerns about COVID-19 in a region with low COVID-19 prevalence: Victoria, Australia. *Respirology*. 2021 Jul;26(7):707-712. doi: 10.1111/resp.14094. Epub 2021 Jun 3. PMID: 34081819.

* indicates equal contribution

Delay or avoidance of routine, urgent and emergency medical care due to concerns about COVID-19 in a region with low COVID-19 prevalence: Victoria, Australia

To the Editors:

In August 2020, the World Health Organization reported that 89% of 105 surveyed countries reported disruption to essential health services during the coronavirus disease 2019 (COVID-19) pandemic.¹ In late June 2020, when there were 2.5 million cumulative confirmed severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infections in the United States,² 40.9% of 4977 surveyed US adults reported having delayed or avoided medical care due to COVID-19 concerns.³

Given the potential short- and long-term consequences of medical care delay or avoidance, we sought to determine whether similar care avoidance was observed in a region with low SARS-CoV-2 prevalence. As of mid-September 2020, the Australian state of Victoria reported fewer than 20,000 cumulative SARS-CoV-2 cases with a low positivity rate⁴ in a population of approximately 6.7 million people. Cross-sectional Internet-based surveys were therefore administered to respondent panellists aged ≥ 18 years residing in Victoria by Qualtrics using quota sampling in the third Australian wave of The COVID-19 Outbreak Public Evaluation (COPE) Initiative (www.thecopeinitiative.org). To assess medical care avoidance cross-sectionally while minimizing potential confounders of varying mitigation measures or SARS-CoV-2 prevalence, surveys were administered during 15–24 September 2020, when peak COVID-19 prevention measures were in place.

Participants were asked, 'In the past month, have you delayed or avoided medical care due to concerns related to COVID-19?' Delay or avoidance was evaluated for emergency (e.g., immediate life-threatening conditions), urgent (e.g., immediate non-life-threatening conditions) and routine (e.g., annual check-ups) medical care. Urgent and emergency care avoidance were combined for analysis (urgent or emergency care) due to potential variance in perception of level of care needed, and a variable representing any care avoidance was created. Demographic and health information were collected as covariates, including sex, age, ancestry, regional versus metropolitan postcode, education attainment, employment status, unpaid caregiver status (providing unpaid care for children only, for adults only, for both age groups [multigenerational] or not an unpaid caregiver), disability status and support through the National Disabilities Insurance Scheme (NDIS) and presence of underlying

conditions known to increase the risk of severe COVID-19, including: obesity (BMI > 30 kg/m²), diabetes, hypertension, cardiovascular disease, chronic kidney disease, liver disease, chronic obstructive pulmonary disease and cancer.

Surveys underwent Qualtrics data-quality screening procedures, including algorithmic and keystroke analysis for click-through behaviour, duplicate responses, machine responses and inattentiveness. The investigators conducted secondary cleaning for missing sex and age, invalid postcodes and BMI below 14 or above 100 kg/m². Iterative proportional fitting (raking) and weight trimming ($[1/3] \leq \text{weight} \leq [3]$) were employed to improve sample representativeness by age and sex according to Victorian population estimates from the Australian Bureau of Statistics 2016 Census of Population and Housing.

Rao–Scott adjusted Pearson chi-square tests with a Bonferroni adjustment (10 comparisons) were used to test for differences in delay or avoidance of routine, urgent or emergency, and any medical care by demographic subgroups. Adjusted prevalence ratios (aPRs) and 95% CIs for delay or avoidance of any medical care were estimated using Poisson regressions with robust SEs among respondents who had complete data for the following variables: sex, age, ancestry, regional or metropolitan residence, education attainment, employment status and unpaid caregiver status. Additional models including these variables plus either disability status or presence of underlying medical conditions were used to estimate aPRs for these collinear variables. Statistical analyses were conducted with Python (version 3.7.8; Python Software Foundation) and R version 4.0.2 (The R Project for Statistical Computing) using the R survey package version 3.29; $p < 0.05$ were deemed statistically significant.

During 15–24 September 2020, 1260 of 4900 (25.7%) eligible invited Victorian adults completed surveys, including 1168 (92.7%) first-time respondents and 92 (7.3%) re-contacted respondents. Overall, 414 (32.9%) adults reported having delayed or avoided any medical care due to concerns about COVID-19, including routine medical care (333 [26.4%]) and urgent or emergency care (128 [10.1%]) (Table 1).

Populations that most commonly reported delay or avoidance of any medical care were those with disabilities with NDIS support (40 of 48 [83.9%]), multigenerational unpaid caregivers (128 of 189 [67.8%]), adults with higher education degrees (83 of 156 [53.4%]), adults with multiple

TABLE 1 Prevalence of and aPRs for having delayed or avoided medical care, by select respondent characteristics

	All respondents		Avoid or delay routine medical care		Avoid or delay urgent or emergency care		Avoid or delay any type of care	
	n	% ^a	n	% ^a	n	% ^a	n	% ^a aPR ^b (95% CI) p
Total respondents	1260	100	333	26.4	128	10.1	414	32.9 —
Sex								
Female	649	51.5	184	28.3	53	8.2	220	33.9 1.30 (1.09, 1.55) 0.0036
Male	611	48.5	149	24.4	74	12.2	194	31.8 1 (Ref)
Age group in years								
18–24	153	12.1	38	24.7	23	15.1	53	34.6 1.31 (0.79, 2.17) 0.30
25–44	460	36.5	165	35.9	65	14.1	205	44.5 1.39 (0.95, 2.02) 0.089
45–64	396	31.4	89	22.5	30	7.6	109	27.6 1.11 (0.77, 1.61) 0.57
≥65	251	19.9	40	16.2	9	3.7	47	18.6 1 (Ref)
Ancestry ^d								
Oceanian	307	24.4	81	26.2	46	14.9	110	35.9 1 (Ref)
North-West European	371	29.5	87	23.3	23	6.1	106	28.6 0.91 (0.73, 1.13) 0.38
Southern and Eastern European	118	9.3	23	19.4	7	5.8	28	23.8 0.79 (0.56, 1.12) 0.19
South-East Asian	55	4.3	13	23.7	3	6.3	13	23.7 0.71 (0.44, 1.15) 0.16
North-East Asian	84	6.7	23	27.2	8	9.6	29	34.7 1.10 (0.78, 1.54) 0.59
Southern and Central Asian	97	7.7	33	33.7	13	13.5	41	41.9 1.14 (0.85, 1.53) 0.39
North-West European, Oceanian	103	8.2	37	36.2	17	16.1	44	42.2 1.19 (0.90, 1.56) 0.23
Other ancestry or other combination	110	8.7	30	27.6	8	7.2	35	32.3 No estimate
Unknown	15	1.2	6	42.2	3	22.0	8	51.9 No estimate
Disability								
No	1091	86.6	271	24.9	94	8.6	333	30.6 1 (Ref)
Yes, with support from the NDIS	48	3.8	31	63.8	18	36.8	40	83.9 1.46 (1.21, 1.75) 0.0001
Yes, without support from the NDIS	101	8.0	26	26.0	14	14.2	34	33.9 1.44 (1.06, 1.95) 0.018
Prefer not to say	20	1.6	4	21.0	2	9.3	6	30.3 No estimate
Health conditions known to increase risk for severe COVID-19 ^e								
No	664	52.7	150	22.6	41	6.1	177	26.6 1 (Ref)
One	317	25.2	80	25.1	35	11.0	101	31.7 1.45 (1.14, 1.83) 0.0022
Two or more	278	22.1	103	36.8	52	18.7	137	49.0 2.02 (1.60, 2.54) <0.0001
Residence and COVID-19 restrictions level ^f								
Regional (Stage 3 lockdowns)	256	20.3	63	24.7	26	10.1	80	31.2 1 (Ref)
Metropolitan (Stage 4 lockdowns)	1004	79.7	269	26.8	102	10.2	334	33.3 0.91 (0.74, 1.13) 0.40
Education attainment								

(Continues)

TABLE 1 (Continued)

	All respondents		Avoid or delay routine medical care		Avoid or delay urgent or emergency care		Avoid or delay any type of care	
	n	% ^a	n	% ^a	n	% ^a	n	aPR ^b (95% CI) p
Secondary school diploma or less	398	31.6	84	21.1	24	5.9	97	24.4 0.87 (0.68, 1.10) 0.24
Some university	204	16.2	43	21.0	18	8.9	57	27.8 0.91 (0.68, 1.23) 0.55
Bachelor's degree or equivalent	492	39.1	135	27.5	54	11.0	173	35.1 1 (Ref)
Doctoral or professional degree	156	12.4	68	43.2	31	19.7	83	53.4 1.21 (1.00, 1.47) 0.046
Unknown	9	0.7	3	31.7	1	11.1	4	42.7 No estimate
Employment status								
Employed non-essential	339	26.9	89	26.3	28	8.4	108	31.8 1 (Ref)
Employed essential	410	32.5	124	30.2	69	16.9	174	42.4 1.10 (0.90, 1.34) 0.36
Retired	269	21.3	47	17.5	7	2.5	50	18.5 0.87 (0.59, 1.28) 0.47
Unemployed	191	15.2	60	31.1	19	9.8	68	35.3 1.13 (0.86, 1.49) 0.37
Student	51	4.1	13	25.5	5	9.2	15	29.9 0.86 (0.47, 1.55) 0.60
Unpaid caregiver status								
Not unpaid caregiver	759	60.2	160	21.1	45	5.9	180	23.7 1 (Ref)
Unpaid caregiver for adults	172	13.6	52	30.3	18	10.8	65	37.8 1.52 (1.17, 1.98) 0.0017
Unpaid caregiver for children	140	11.1	30	21.5	10	7.4	41	29.0 1.08 (0.79, 1.48) 0.64
Multigenerational unpaid caregiver (i.e., for both age groups)	189	15.0	90	47.7	54	28.6	128	67.8 2.42 (1.98, 2.97) <0.0001

Abbreviations: aPR, adjusted prevalence ratio; COVID-19, coronavirus disease 2019; NDIS, National Disabilities Insurance Scheme.

^aFor all respondents (Columns 2 and 3), percentages are based on the number of respondents in a demographic group out of all respondents ($n = 1260$). For type of care avoided or delayed (Columns 4 through 9), percentages are reported based on the number of respondents who delayed or avoided care within that demographic group.^bMultivariable Poisson regression models include all variables listed in table, except for disability status and health conditions, which were run in separate models that also included all demographic variables to avoid collinearity between these two variables. The primary demographic model included 1260 respondents. The model including disability status included 1112 respondents, and the model including health conditions included 1127 respondents.^cBonferroni-adjusted Rao-Scott adjusted Pearson chi-square test result was statistically significant ($p < 0.05$) for the demographic subgroup below the marker. Chi-square tests excluded 'Unknown' and 'Other ancestry or other combination' categories.^dThe 'Other ancestry or other combination' category included persons who were North African and Middle Eastern, Sub-Saharan African, People of the Americas or a combination of ancestries other than North-West European and Oceanian. Estimates were not provided for Other or Unknown due to small counts and the inability to meaningfully characterize the ancestry off these respondents.^eObesity (BMI > 30 kg/m²), diabetes, hypertension, cardiovascular disease, chronic kidney disease, liver disease, sickle cell disease, chronic obstructive pulmonary disease and/or cancer.^fRegional-metropolitan classification and COVID-19 restriction levels were determined using self-reported postal codes according to the Victorian Department of Health and Human Services COVID-19 local regional restrictions map (<https://www.dhhs.vic.gov.au/victorias-restriction-levels-covid-19>).

medical conditions that increase the risk of severe COVID-19 (137 of 278 [49.0%]) and essential workers (174 of 410 [42.4%]). Avoidance of any care did not differ significantly by sex; however, routine care avoidance was more common among female compared to male respondents (184 of 649 [28.3%] vs. 149 of 611 [24.4%], respectively), and urgent or emergency care avoidance was more common among male compared to female respondents (74 [12.2%] vs. 53 [8.2%], respectively).

Multivariate Poisson regression revealed that avoidance of any medical care was more common among multigenerational unpaid caregivers and unpaid caregivers for adults compared to those who were not unpaid caregivers (e.g., multigenerational, aPR = 2.42, 95% CI = 1.98–2.97, $p < 0.0001$); in those with multiple medical conditions compared to those without (one health condition, aPR = 1.45, 95% CI = 1.14–1.83, $p = 0.0022$; two or more health conditions, aPR = 2.02, 95% CI = 1.60–2.54, $p < 0.0001$); those with disabilities compared to those without disabilities (with NDIS support, aPR = 1.46, 95% CI = 1.21–1.75, $p = 0.0001$; without NDIS support, aPR = 1.44, 95% CI = 1.06–1.95, $p = 0.018$); females compared to males (aPR = 1.30, 95% CI = 1.09–1.55, $p = 0.0036$); and those with a doctoral or professional degree versus a bachelor's degree (aPR = 1.21, 95% CI = 1.00–1.47, $p = 0.046$).

These findings provide important insights regarding healthcare-seeking behaviour during the COVID-19 pandemic in a region with relatively low SARS-CoV-2 prevalence. Intentional medical care avoidance may have contributed to the observed 22% decrease in Victorian emergency department (ED) presentations during September 2020 compared to September 2019.⁵

Individuals with multiple medical conditions associated with an increased risk of severe COVID-19 more commonly avoided or delayed urgent or emergency care, a finding also observed in the United States.³ This is particularly concerning, as in addition to higher risk of severe COVID-19, these conditions put individuals at greater risk of other acute medical conditions for which time-critical interventions can reduce morbidity and mortality. Decreased presentations of stroke and myocardial infarction occurred during July and August 2020 in Victoria, Australia,⁵ and symptom-to-door-time for patients with acute coronary syndrome requiring revascularization increased four-fold during March and April 2020, whilst overall case presentations remained unchanged.⁶ These observations suggest that people delayed seeking urgent care.

Early evidence of consequences of disrupted routine care during the COVID-19 pandemic have been reported, particularly in relation to cancer screening and diagnoses. Reduced screening, referrals and presentations for lung and colorectal cancers in the UK have led to projections of 4.8% and 16.5% increased deaths, respectively, within 5 years of diagnosis.^{7,8} In Victoria, on 11 September 2020, the Premier urged Victorians to stop delaying hospital visits and health check-ups due to the pandemic, as not only had ED visits

reduced, diagnoses for common cancers had reduced by approximately one-third.⁹ Findings from this study suggest that strategies to reduce COVID-19-related care avoidance may be warranted, with enhanced efforts among at-risk groups.

Although quota sampling and survey weighting were employed to improve sample representatives of the Victorian population by age and sex, the sample may not be fully representative of the 2020 Victorian population. Furthermore, self-reported data may be subject to recall and response biases, and this study did not assess reasons for COVID-19 care avoidance or baseline patterns of care-seeking or avoidance in this population; however, the results are consistent with trends in Victorian hospital and ED admissions data. Finally, although the survey items specified that the reason for delay or avoidance of medical care was COVID-19 concerns, respondents did not detail sources of these concerns (e.g., fear of SARS-CoV-2 infection or spreading SARS-CoV-2 to others at the healthcare facility, during transportation to or from the facilities). Future research could identify such sources of COVID-19-related concerns, and what measures may lead to their alleviation.

Given that considerable portions of adults reported having delayed or avoided medical care due to COVID-19 concerns in regions with minimal (Victoria) and substantial (United States) community transmission of SARS-CoV-2, determining the extent to which similar behaviour has continued in these regions and may be occurring in other regions is warranted. To that end, the World Health Organization has recently developed a population health surveillance tool to monitor delay or avoidance of medical care among the wider effects of the COVID-19 pandemic.¹⁰

Proactive public health messaging and targeted services to minimize healthcare avoidance—particularly for individuals with chronic medical conditions, people with disabilities and unpaid caregivers—may be critical to avoid preventable increases in all-cause morbidity and mortality during and beyond the COVID-19 pandemic.

KEYWORDS

Australia, COVID-19, emergency medical services, SARS-CoV-2, coronavirus disease

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AUTHOR CONTRIBUTIONS

Mark Czeisler: Conceptualization; data curation; formal analysis; investigation; methodology; writing-original draft; writing-review & editing. **Jessica Kennedy:** Conceptualization; formal analysis; investigation; writing-original draft; writing-review & editing. **Joshua Wiley:** Formal analysis; methodology; writing-review & editing. **Elise Facer-Childs:** Conceptualization; writing-review & editing. **Rebecca Robbins:** Conceptualization; writing-review & editing. **Laura Barger:** Conceptualization; writing-review & editing. **Charles Czeisler:** Conceptualization; funding acquisition; methodology; writing-review & editing. **Shantha Rajaratnam:** Conceptualization; funding acquisition; investigation; methodology; supervision; writing-review & editing. **Mark Howard:** Conceptualization; funding acquisition; investigation; methodology; supervision; writing-original draft; writing-review & editing.

CONFLICT OF INTEREST


Mark É. Czeisler, Charles A. Czeisler, Shantha M. W. Rajaratnam and Mark E. Howard report grants from the CDC Foundation with funding from BNY Mellon, and grants from WHOOP and Hopelab, outside the submitted work. Mark É. Czeisler reported receiving personal fees from Vanda Pharmaceuticals outside the submitted work. Rebecca Robbins reports personal fees from Denihan Hospitality, Rituals Cosmetics, SleepCycle, Dagmejan and byNacht. Laura K. Barger reports a grant from the National Institute for Occupational Safety and Health and personal fees from the University of Pittsburgh, CurAegis, Casis, Puget Sound Pilots and Boston Children's Hospital. Charles A. Czeisler reported receiving grants to support. The COVID-19 Outbreak Public Evaluation (COPE) Initiative and grants from Brigham and Women's Physician's Organization during the conduct of the study; being a paid consultant to or speaker for Ganésco, Institute of Digital Media and Child Development, Klarman Family Foundation, M. Davis and Co, Physician's Seal, Samsung Group, State of Washington Board of Pilotage Commissioners, Tencent Holdings, Teva Pharma Australia and Vanda Pharmaceuticals, in which Charles A Czeisler holds an equity interest; receiving travel support from Aspen Brain Institute, Bloomage International Investment Group, UK Biotechnology and Biological Sciences Research Council, Bouley Botanical, Dr Stanley Ho Medical Development Foundation, Illuminating Engineering Society, National Safety Council, Tencent Holdings and The Wonderful Co; receiving institutional research and/or education support from Cephalon, Mary Ann and Stanley Snider via Combined Jewish Philanthropies, Harmony Biosciences, Jazz Pharmaceuticals PLC, Johnson and Johnson, Neurocare, Peter Brown and


Margaret Hamburg, Philips Respironics, Regeneron Pharmaceuticals, Regional Home Care, Teva Pharmaceuticals Industries, Sanofi S.A., Optum, ResMed, San Francisco Bar Pilots, Schneider National, Serta, Simmons Betting, Sysco and Vanda Pharmaceuticals; being or having been an expert witness in legal cases, including those involving Advanced Power Technologies, Aegis Chemical Solutions, Amtrak, Casper Sleep, C and J Energy Services, Complete General Construction, Dallas Police Association, Enterprise Rent-A-Car, Steel Warehouse Co, FedEx, Greyhound Lines, Palomar Health District, PAR Electrical, Product, and Logistics Services, Puckett Emergency Medical Services, South Carolina Central Railroad Co, Union Pacific Railroad, UPS and Vanda Pharmaceuticals; serving as the incumbent of an endowed professorship provided to Harvard University by Cephalon; and receiving royalties from McGraw Hill and Philips Respironics for the Actiwatch-2 and Actiwatch Spectrum devices. Charles A. Czeisler's interests were reviewed and are managed by the Brigham and Women's Hospital and Mass General Brigham in accordance with their conflict of interest policies. Shantha M. W. Rajaratnam reported receiving institutional consulting fees from CRC for Alertness, Safety, and Productivity, Teva Pharmaceuticals, Vanda Pharmaceuticals, Circadian Therapeutics, BHP Billiton and Herbert Smith Freehills; receiving grants from Teva Pharmaceuticals and Vanda Pharmaceuticals; and serving as chair for the Sleep Health Foundation outside the submitted work. No other disclosures were reported.


HUMAN ETHICS APPROVAL DECLARATION


The Monash University Human Research Ethics Committee (Melbourne, Australia) approved the study (24036). The participants provided informed electronic consent prior to data collection.


Mark É. Czeisler^{1,2,3} 

Jessica L. Kennedy^{2,4} 


Joshua F. Wiley¹ 

Elise R. Facer-Childs¹ 

Rebecca Robbins^{5,6,7} 

Laura K. Barger^{5,6,7} 

Charles A. Czeisler^{1,5,6,7} 

Shantha M. W. Rajaratnam^{1,2,5,6,7} 

Mark E. Howard^{1,2,4} 

¹Turner Institute for Brain and Mental Health and School of Psychological Sciences, Monash University, Melbourne, Victoria, Australia

²Institute for Breathing and Sleep, Austin Health, Melbourne, Victoria, Australia

³Department of Psychiatry, Brigham and Women's Hospital, Boston, Massachusetts, USA

⁴Department of Medicine, The University of Melbourne, Melbourne, Victoria, Australia

⁵Division of Sleep and Circadian Disorders, Department of Medicine, Brigham and Women's Hospital, Boston, Massachusetts, USA

⁶*Division of Sleep and Circadian Disorders, Department of Neurology, Brigham and Women's Hospital, Boston, Massachusetts, USA*

⁷*Division of Sleep Medicine, Harvard Medical School, Boston, Massachusetts, USA*

Correspondence

Mark É. Czeisler, Turner Institute for Brain and Mental Health and School of Psychological Sciences, Monash University, 18 Innovation Walk, Clayton, Melbourne, VIC 3800, Australia.

Email: mark.czeisler@fulbrightmail.org; mark.czeisler@monash.edu

Mark É Czeisler and Jessica L Kennedy contributed equally to this study.

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ORCID

Mark É. Czeisler  <https://orcid.org/0000-0003-3100-7347>

Jessica L. Kennedy  <https://orcid.org/0000-0003-2086-743X>

Joshua F. Wiley  <https://orcid.org/0000-0002-0271-6702>

Elise R. Facer-Childs  <https://orcid.org/0000-0003-4549-9266>

Rebecca Robbins  <https://orcid.org/0000-0003-0288-2505>

Laura K. Barger  <https://orcid.org/0000-0001-8547-7331>

Charles A. Czeisler  <https://orcid.org/0000-0002-7408-1849>

Shantha M. W. Rajaratnam  <https://orcid.org/0000-0001-7527-8558>

Mark E. Howard  <https://orcid.org/0000-0001-7772-1496>

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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Delay or avoidance of medical care due to COVID-19 concerns in a region with low COVID-19 prevalence

Of 1260 surveyed adults in Victoria, Australia (Sept 2020), delay or avoidance was reported by:

33%

Any care

26%

Routine care

10%

Urgent or emergency care

Any care avoidance was more common among...



People with chronic conditions

aPR [95%CI] = 2.0 [1.6-2.5]

People with disabilities

aPR [95%CI] = 1.5 [1.2-1.8]



Multigenerational unpaid caregivers

aPR [95%CI] = 2.4 [2.0-3.0]

*aPR = adjusted prevalence ratio

Appendix 3. Health Care Access and Use Among Adults with Diabetes During the COVID-19 Pandemic - United States, February-March 2021

Czeisler MÉ*, Barrett CE*, Siegel KR, Weaver MD, Czeisler CA, Rajaratnam SMW, Howard ME, Bullard KM. Health Care Access and Use Among Adults with Diabetes During the COVID-19 Pandemic - United States, February-March 2021. MMWR Morb Mortal Wkly Rep. 2021 Nov 19;70(46):1597-1602. doi: 10.15585/mmwr.mm7046a2. PMID: 34793416; PMCID: PMC8601412.

* indicates equal contribution

Health Care Access and Use Among Adults with Diabetes During the COVID-19 Pandemic — United States, February–March 2021

Mark É. Czeisler^{1,2,3,*}; Catherine E. Barrett^{4,*}; Karen R. Siegel⁴; Matthew D. Weaver^{1,3,5}; Charles A. Czeisler^{1,4,5}; Shantha M.W. Rajaratnam^{1,2,3,5}; Mark E. Howard^{1,2,6}; Kai McKeever Bullard⁴

Diabetes affects approximately one in 10 persons in the United States[†] and is a risk factor for severe COVID-19 (1), especially when a patient's diabetes is not well managed (2). The extent to which the COVID-19 pandemic has affected diabetes care and management, and whether this varies across age groups, is currently unknown. To evaluate access to and use of health care, as well as experiences, attitudes, and behaviors about COVID-19 prevention and vaccination, a nonprobability, Internet-based survey was administered to 5,261 U.S. adults aged ≥18 years during February–March 2021. Among respondents, 760 (14%) adults who reported having diabetes currently managed with medication were included in the analysis. Younger adults (aged 18–29 years) with diabetes were more likely to report having missed medical care during the past 3 months (87%; 79) than were those aged 30–59 years (63%; 372) or ≥60 years (26%; 309) ($p < 0.001$). Overall, 44% of younger adults reported difficulty accessing diabetes medications. Younger adults with diabetes also reported lower intention to receive COVID-19 vaccination (66%) compared with adults aged ≥60 years[§] (85%; $p = 0.001$). During the COVID-19 pandemic, efforts to enhance access to diabetes care for adults with diabetes and deliver public health messages emphasizing the importance of diabetes management and COVID-19 prevention, including vaccination, are warranted, especially in younger adults.

During February–March 2021, among 8,475 eligible U.S. adults, 5,261 (62.1%) completed the COVID-19 Outbreak Public Evaluation Initiative nonprobability, Internet-based survey administered by Qualtrics LLC.[¶] Respondents answered questions on demographic characteristics, attitudes and beliefs about COVID-19, and access to and use of medical care (including health care or telemedicine visits, delayed care,

and loss of health insurance) since March 2020. The Human Research Ethics Committee of Monash University (Melbourne, Australia) reviewed and approved the study protocol on human participants research. This activity was also reviewed by CDC and was conducted consistent with applicable federal law and CDC policy.^{**}

Among the 5,261 respondents, 760 (14%) who reported having diabetes currently managed by regular medications or treatment were included in the analyses.^{††} Demographic characteristics, experiences, attitudes, and behaviors related to the pandemic and health care access and use were assessed among these 760 persons. Demographic variables included age, sex, race/ethnicity, household income, education attainment, employment status, U.S. Census region,^{§§} urban/rural classification,^{¶¶} and health insurance status. Experiences, attitudes, and behaviors related to the pandemic included knowing someone who had received a positive test result for SARS-CoV-2 or who had died from COVID-19, perception of being at risk for severe COVID-19, vaccination intention, and composite measures of support for^{***} and adherence to recommended COVID-19 prevention behaviors^{†††} (e.g., wearing a mask, physical distancing, avoiding gatherings, and practicing hand

^{**} 45 C.F.R. part 46, 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d); 5 U.S.C. Sect. 552a; 44 U.S.C. Sect. 3501 et seq.

^{††} Diabetes diagnosis was ascertained by responses to the following question: "Have you ever been diagnosed with any of the following conditions?" with the response options 1) "Never"; 2) "Yes, I have in the past, but don't have it now"; 3) "Yes I have, but I do not regularly take medications or receive treatment"; and 4) "Yes I have, and I am regularly taking medications or receiving treatment." Respondents who chose response 4 regarding diabetes were considered to have diabetes.

^{§§} https://www2.census.gov/geo/pdfs/maps-data/maps/reference/us_regdiv.pdf

^{¶¶} Rural-urban classification was determined using self-reported zip codes according to the Federal Office of Rural Health Policy definition of rurality. <https://www.hrsa.gov/rural-health/about-us/definition/datafiles.html>

^{***} A COVID-19 Prevention Support Index represents summed responses to questions on whether participants believed nonessential workers should stay home, believed persons should always keep ≥6 ft of physical distance, believed groups of 10 or more persons should not be allowed, or believed dining inside restaurants should not be allowed. Respondents reported whether they strongly disagreed, disagreed, neither agreed nor disagreed, agreed, or strongly agreed to each statement. Summed responses were three-way split into high, medium, and low categories.

^{†††} A COVID-19 Prevention Behavior Index represents summed responses to questions on whether participants kept ≥6 ft apart from others, avoided groups of 10 or more persons, wore a cloth face covering when in public, and washed hands or used sanitizer after touching high-touch public surfaces. Respondents reported the frequency (never, rarely, sometimes, often, or always) of each behavior in the last week. Summed responses were three-way split into high, medium, and low categories.

*These authors contributed equally to this report.

[†] <https://www.cdc.gov/diabetes/data/statistics-report/index.html>

[§] On December 20, 2020, the Advisory Committee on Immunization Practices recommended that persons with high-risk medical conditions, including type 2 diabetes, should be offered a COVID-19 vaccine in Phase 1C (<https://www.cdc.gov/mmwr/volumes/69/wr/mm695152e2.htm>). CDC classified type 1 and type 2 diabetes at the same risk level for severe COVID-19 on March 29, 2021; however, many states had previously categorized both types at the same level.

[¶] The COVID-19 Outbreak Public Evaluation Initiative surveys included in this analysis were administered by Qualtrics, LLC (<https://www.qualtrics.com>), a commercial survey company with a network of participant pools with varying recruitment methodologies that include digital advertisements and promotions, word-of-mouth and membership referrals, social networks, television and radio advertisements, and offline mail-based approaches.

hygiene). Regarding health care access and use, respondents reported whether they had delayed or avoided medical care because of concerns related to COVID-19,^{§§§} and whether their ability to access care or medications for diabetes was easier, harder, or unaffected as a consequence of the pandemic.

Weighted percentages and 95% CIs were calculated by age group (18–29, 30–59, and ≥60 years). CIs were calculated using a logit model. Significant differences (defined as p -values < 0.05) among age groups were assessed using chi-square tests; statistical differences between groups were determined by nonoverlapping CIs only where chi-square tests were significant. Quota sampling and survey weighting were employed to match the U.S. Census Bureau's 2019 American Community Survey population estimates for sex, age, and race/ethnicity of the general population. Analyses were conducted using the R survey package (version 3.29) and R software (version 4.0.2; R Foundation).

By age group, respondent characteristics varied by income, education, employment status, U.S. Census region, urban/rural classification, health insurance status, and diagnosed mental health conditions (all p < 0.05) (Table 1). Adults aged 18–29 years (younger adults) less commonly reported having health insurance (77%), compared with those aged 30–59 years (91%) and ≥60 years (97%; p < 0.001). Diagnosed mental health conditions, including depression, anxiety, and posttraumatic stress disorder, were more commonly reported among younger adults (86%) and adults aged 30–59 years (64%) than among adults aged ≥60 years (32%) (p < 0.001).

A larger proportion of younger adults with diabetes reported not knowing someone who had received a positive SARS-CoV-2 test result (90%) than did adults aged 30–59 years (69%) or ≥60 years (57%) (p < 0.001) (Table 2). Both groups of adults aged < 60 years were more likely to believe they were not at high risk for severe COVID-19 (94% [18–29 years], 76% [30–59 years]) than were adults aged ≥60 years (52%) (p < 0.001). Younger adults reported the lowest support for COVID-19 prevention guidelines (28%) and COVID-19 prevention behaviors (30%), compared with adults aged 30–59 years (62% and 64%, respectively; p < 0.001) and ≥60 years (51% and 72%, respectively; p < 0.001). A lower proportion of younger adults reported that they intended to be vaccinated (66%) than did those aged ≥60 years (85%) (p < 0.001).

Younger adults with diabetes reported having the lowest percentage of in-person health care appointments (53%), compared with those aged 30–59 years (76%) and ≥60 years

(85%) (p < 0.001) (Table 3). Both groups of adults aged < 60 years were more likely to report delayed health care (87% [18–29 years], 63% [30–59 years]) than were adults aged ≥60 years (26%) (p < 0.001). Approximately two thirds of adults aged 18–29 years (66%) and 30–59 years (69%) with diabetes reported that their access to diabetes care was unaffected, whereas 91% of older adults reported that their access to diabetes care was unaffected (p < 0.001). Adults with diabetes aged < 60 years were less likely to report unaffected access to diabetes medications (44% [18–29 years], 72% [30–59 years]), than were adults aged ≥60 years (96%) (p < 0.001).

Among all respondents with diabetes, 28%, 33%, and 17% of those aged 18–29 years, 30–59 years, ≥60 years, respectively, reported that their health care was disrupted because of personal concerns that the health care system might be overwhelmed (p = 0.001). The most common reason for disruption in care among younger adults was concern about becoming infected with SARS-CoV-2 (44%), which did not significantly differ from that of adults aged ≥30 years (31% [30–59 years], 27% [≥60 years]; p = 0.151). Concerns about the cost of medical care did not differ significantly across the three age groups.

Discussion

In this convenience sample of adults with diabetes, nearly nine in 10 (87%) younger adults (aged 18–29 years) reported delayed receipt of health care. In a previous survey (June 2020), 45% of adults aged 18–24 years, irrespective of diabetes status, reported delayed care or avoided health care.^{¶¶¶} Younger adults with diabetes largely did not consider themselves at risk for severe COVID-19 and reported the lowest engagement in preventive behaviors. Younger adults might be unaware of their own risk for severe COVID-19. Significantly fewer younger adults with diabetes reported health insurance coverage compared with older adults; thus, health policy interventions that increase access to health insurance coverage among younger adults with diabetes might be warranted.

Routine diabetes management is essential to mitigating risk for adverse health outcomes and severe COVID-19 in these patients (3); however, the pandemic might have contributed to disruptions in diabetes management, worsening of glycemic control, and increasing rates of severe diabetic ketoacidosis (4–7). Approximately 60% of patients with newly diagnosed type 1 diabetes experienced diabetic ketoacidosis as their first sign or symptom during April–August 2020, roughly twice as many as during previous years, suggesting delays in care-seeking behavior and diagnosis among persons with diabetes (4). Significant reductions in testing for hemoglobin A1c, an

^{§§§} Delayed or avoided medical care was determined by response to the question, “Have you delayed or avoided medical care because of concerns related to COVID-19?” Delay or avoidance was evaluated for emergency (e.g., care for immediate life-threatening conditions), urgent (e.g., care for immediate non-life-threatening conditions), and routine (e.g., annual checkups) medical care.

^{¶¶¶} <https://www.cdc.gov/mmwr/volumes/69/wr/mm6936a4.htm>

TABLE 1. Demographic characteristics of adults with self-reported diabetes, by age — COVID-19 Outbreak Public Evaluation Initiative Survey, United States, February–March 2021

Characteristic	Age group, yrs						p-value
	18–29 (n = 79)		30–59 (n = 372)		≥60 (n = 309)		
	Weighted no.	% (95% CI)*	Weighted no.	% (95% CI)	Weighted no.	% (95% CI)	
Sex							
Male	45	57 (42–71)	224	60 (54–66)	180	58 (51–65)	0.941
Female	34	43 (29–58)	144	39 (33–44)	128	42 (34–49)	
Mean age (95% CI), yrs	23 (22–24)		45 (44–46)		70 (70–71)		
Race/Ethnicity							
White, non-Hispanic	31	40 (25–57)	211	57 (51–63)	168	55 (46.3–62.5)	0.144
Black, non-Hispanic	16	21 (13–32)	48	13 (9–18)	44	14 (9–21)	
Asian, non-Hispanic	6	8 (2–20)	18	—*	33	11 (6–17)	
Hispanic, any race	22	28 (17–43)	90	24 (19–31)	54	17 (10–28)	
2019 household income, USD							
<25,000	12	16 (9–27)	81	22 (17–28)	63	20 (14–29)	<0.001
25,000–49,999	37	48 (32–64)	51	14 (10–19)	75	24 (19–31)	
50,000–99,999	15	20 (11–33)	68	18 (14–24)	101	33 (25–41)	
≥100,000	10	—	158	42 (37–48)	58	19 (13–26)	
Education							
High school diploma or less	33	41 (26–58)	71	19 (14–25)	42	14 (9–19)	<0.001
College or some college	36	46 (31–62)	193	52 (46–58)	212	69 (61–75)	
After bachelor's degree	10	—	108	29 (24–34)	55	18 (13–25)	
Employed	55	70 (5–24)	258	70 (24–34)	35	11 (13–25)	<0.001
U.S. Census region†							
Northeast	8	—	93	25 (20–31)	38	12 (8–18)	0.006
Midwest	24	30 (18–47)	68	18 (14–24)	57	18 (13–25)	
South	39	50 (34–66)	148	40 (34–46)	148	48 (40–56)	
West	8	—	63	17 (13–22)	66	22 (15–30)	
Rural/Urban residence§							
Rural	26	33 (17–52)	53	14 (11–19)	55	18 (12–25)	0.015
Urban	53	67 (49–81)	318	86 (81–89)	253	82 (75–88)	
Health insurance status							
Yes	61	77 (60–89)	338	91 (85–94)	299	97 (93–98)	<0.001
No	13	—	33	9 (5–14)	4	—	
Medical conditions¶							
Mental health	67	86 (67–96)	236	64 (57–69)	100	32 (25–41)	<0.001
Cardiovascular	61	77 (60–88)	277	75 (69–80)	256	83 (75–89)	0.190
Other	53	67 (48–83)	191	51 (45–58)	154	50 (11–25)	0.172

Abbreviation: USD = U.S. dollars.

* Data are weighted percentages, rounded to the nearest whole number. Rounded counts might not sum to expected values. Dashes represent percentages that are suppressed because relative SE>30%.

† Region classification was determined by using the U.S. Census Bureau's Census Regions and Divisions. https://www2.census.gov/geo/pdfs/maps-data/maps/reference/us_regdiv.pdf

‡ Rural-urban classification was determined by using self-reported zip codes according to the Federal Office of Rural Health Policy definition of rurality. <https://www.hrsa.gov/rural-health/about-us/definition/datafiles.html>

¶ Selected underlying medical conditions included mental health (e.g., depression, anxiety, or posttraumatic stress disorder), cardiovascular (e.g., hypertension, cardiovascular disease, or high cholesterol), and other (e.g., any type of cancer or gastrointestinal disorder). Conditions were assessed using the question, "Have you ever been diagnosed with any of the following conditions?" with the response options: 1) "Never"; 2) "Yes, I have in the past, but don't have it now"; 3) "Yes I have, but I do not regularly take medications or receive treatment"; and 4) "Yes I have, and I am regularly taking medications or receiving treatment." Respondents who answered that they have received a diagnosis and chose either response 3 or 4 were considered to have the specified medical condition.

indicator of average blood glucose levels over the previous 2–3 months, were reported in 2020 (5). Use of telemedicine (8) or continuous glucose monitoring (9) might help improve glycemic control during the COVID-19 pandemic. However, others have reported worsening of glucose control through telehealth (10) and lower satisfaction with telehealth visits among persons with diabetes (6). It is also possible that use of telehealth might have led to missed diagnosis of diabetes in

cases in which patients sought treatment for symptoms that were less severe than diabetic ketoacidosis. Increased accessibility of in-person medical services and improved telehealth services might help to maintain required diabetes care.**** Health care providers can follow CDC guidance for maintaining safe operations.††††

**** <https://www.cdc.gov/coronavirus/2019-ncov/hcp/telehealth.html>

†††† <https://www.cdc.gov/coronavirus/2019-ncov/hcp/us-healthcare-facilities.html>

TABLE 2. COVID-19 experiences, attitudes, and behaviors among adults with self-reported diabetes, by age — COVID-19 Outbreak Public Evaluation Initiative Survey, United States, February–March 2021

Characteristic	Age group, yrs						p-value
	18–29 (n = 79)		30–59 (n = 372)		≥60 (n = 309)		
	Weighted no.	% (95% CI)*	Weighted no.	% (95% CI)	Weighted no.	% (95% CI)	
Know someone with a positive SARS-CoV-2 test result[†]							
Yes	8	—*	117	31 (26–37)	134	43 (35–52)	<0.001
No	70	90 (81–95)	255	69 (63–74)	175	57 (48–65)	
Know someone who died from COVID-19							
Yes	8	—	57	15 (11–20)	69	22 (16–30)	0.048
No	71	90 (79–96)	315	85 (80–89)	240	78 (70–84)	
Believe to be at high risk for severe COVID-19							
Yes	4	—	90	24 (19–30)	148	48 (40–56)	<0.001
No	74	94 (86–99)	282	76 (70–81)	161	52 (44–60)	
Total COVID-19 Prevention Support Index[§]							
High	22	28 (17–41)	229	62 (55–67)	158	51 (43–59)	<0.001
Medium	31	40 (25–56)	102	27 (22–33)	100	32 (25–40)	
Low	26	—	41	11 (8–15)	51	17 (12–23)	
Total COVID-19 Prevention Behavior Index[¶]							
High	24	30 (19–45)	236	64 (58–69)	223	72 (64–79)	<0.001
Medium	32	41 (26–58)	91	25 (20–30)	74	24 (17–32)	
Low	23	—	44	12 (9–16)	12	4 (2–6)	
Would get vaccinated with COVID-19 vaccine							
Yes	52	66 (50–79)	284	77 (71–81)	261	85 (79–89)	0.001
Not sure	6	—	49	13 (8–14)	30	10 (6–15)	
No	21	26 (4–15)	39	11 (9–18)	18	6 (3–9)	

* Data are weighted percentages, rounded to the nearest whole number. Rounded counts might not sum to expected values. Dashes represent percentages that are suppressed because relative SE>30%.

† Respondents were asked to select the following statement, if applicable: "I know someone who has tested positive for COVID-19."

§ A COVID-19 Prevention Support Index represents summed responses to questions on whether participants believed nonessential workers should stay home, believed persons should always keep ≥6 ft of physical distance, believed groups of 10 or more persons should not be allowed, or believed dining inside restaurants should not be allowed. Respondents reported whether they strongly disagreed, disagreed, neither agreed nor disagreed, agreed, or strongly agreed to each individual statement. Summed responses were three-way split into high, medium, and low categories.

¶ A COVID-19 Prevention Behavior Index represents summed responses to questions on whether participants kept ≥6 ft apart from others, avoided groups of 10 or more persons, wore cloth face covering when in public, and washed hands or used sanitizer after touching high-touch public surfaces. Respondents reported the frequency (i.e., never, rarely, sometimes, often, or always) of each behavior during the last week. Summed responses were three-way split into high, medium, and low categories.

Persons with diabetes reported higher general and diabetes-related stress during the pandemic, which was associated with negative impacts on disease management, difficulty accessing diabetes care, and not adhering to COVID-19 precautions (6,7). Persons with diabetes are at increased risk for mental health issues.^{§§§§} In the present study, mental health conditions were approximately 2.5 times as likely in adults with diabetes aged 18–29 years (86%) as in adults aged ≥60 years (32%). Future research that assesses the impact of COVID-19 on mental health among persons with diabetes could further inform public health strategies in this population.

The findings in this report are subject to at least five limitations. First, quota sampling and survey weighting might not have eliminated inherent biases in this Internet-based convenience sample; thus, results might not be generalizable to all U.S. adults, including those with diabetes. Second, determination of diabetes was through self-report, and to increase specificity for diabetes, only respondents who reported having diabetes managed with medication were included; therefore,

the findings are not representative of all persons with diabetes. Prevalence of diabetes managed with medication in this sample might be higher than would be expected in the larger U.S. population, potentially reflecting a higher diabetes prevalence and survey completion among older adults. Third, this survey is cross-sectional and causality between measures cannot be inferred. Fourth, participants were asked about their behavior during the preceding year, and responses are subject to recall bias. Similarly, temporal changes in participants' access to medical care and attitudes around COVID-19 prevention were not assessed before or throughout the COVID-19 pandemic. This survey was conducted before emergence of the highly contagious SARS-CoV-2 B.1.617.2 (Delta) variant in the United States.^{¶¶¶¶} It is possible that younger adults might know more people who received positive test results since the Delta variant became prevalent in the United States, resulting in changing attitudes and behaviors not captured here. Finally, the small sample of adults aged 18–29 years with diabetes led to unreliable estimates for some measures and precluded multivariable analyses.

^{§§§§} <https://www.cdc.gov/diabetes/managing/mental-health.html>

^{¶¶¶¶} <https://www.cdc.gov/coronavirus/2019-ncov/variants/delta-variant.html>

TABLE 3. Reported health care experiences, attitudes, and behaviors in adults with self-reported diabetes, by age — COVID-19 Outbreak Public Evaluation Initiative Survey, United States, February–March 2021

Characteristic	Age group, yrs						p-value
	18–29 (n = 79)		30–59 (n = 372)		≥60 (n = 309)		
	Weighted no.	% (95% CI)*	Weighted no.	% (95% CI)	Weighted no.	% (95% CI)	
Health services received since Mar 2020							
In-person [†]	41	53 (37–68)	281	76 (70–81)	262	85 (79–89)	<0.001
Telehealth [†]	32	40 (26–57)	192	52 (45–58)	158	51 (43–60)	0.416
Disruption in health care because of COVID-19							
Delayed or avoided care because of COVID-19–related concerns[§]							
Any	69	87 (78–93)	232	63 (56–68)	80	26 (20–33)	<0.001
Urgent or emergency	37	47 (32–63)	90	24 (19–30)	12	—*	<0.001
Routine medical care	37	47 (31–63)	183	49 (43–55)	75	24 (18–32)	<0.001
No	10	—	139	38 (32–44)	229	74 (67–80)	<0.001
Affected ability to access care for diabetes[¶]							
Harder to access	19	—	102	28 (24–34)	24	8 (4–13)	<0.001
Not harder to access	52	66 (55–86)	255	69 (66–76)	282	91 (87–96)	
Affected ability to access medication for diabetes[¶]							
Harder to access	35	44 (33–67)	95	26 (21–32)	10	—	<0.001
Not harder to access	35	44 (33–67)	269	72 (68–79)	297	96 (94–98)	
Reasons for disruption							
Disruption of transportation to health care facility	7	—	34	9 (6–13)	15	5 (2–13)	0.335
Personal concerns about receiving health care							
Health care system may be overwhelmed	22	28 (17–42)	124	33 (28–39)	53	17 (12–24)	0.001
Me spreading SARS-CoV-2 at health care facility	22	28 (17–42)	73	20 (15–25)	11	—	<0.001
Becoming infected with SARS-CoV-2 at the health care facility	34	44 (28–61)	114	31 (25–36)	85	27 (21–35)	0.151
Becoming infected and infecting my household	15	—	95	26 (21–31)	60	20 (14–27)	0.406
Concerns about the cost of the medical care	5	6 (3–13)	33	9 (6–13)	17	6 (3–9)	0.280

* Data are weighted percentages, rounded to the nearest whole number. Rounded counts might not sum to expected values. Dashes represent percentages that are suppressed because relative SE>30%.

† Health services for physical health, mental health, or substance abuse.

§ Respondents reported disrupted care in the past 3 months.

¶ Respondents were asked, “Has the pandemic affected your ability to access care and medication for diabetes?”

Summary

What is already known about this topic?

Persons with diabetes are at high risk for severe COVID-19, and the COVID-19 pandemic has affected diabetes care and management in the United States.

What is added by this report?

Among adults with diabetes, those aged 18–29 years reported the most disruption in access to and use of medical care and the least engagement in prevention of COVID-19, including vaccination intent.

What are the implications for public health practice?

Efforts are warranted to enhance access to diabetes care during the COVID-19 pandemic, and to deliver public health messages emphasizing the importance of diabetes management and COVID-19 prevention, including vaccination, especially among younger adults with diabetes.

Adherence to diabetes care, including receiving COVID-19 vaccination, is important for managing risk for severe COVID-19 among persons with diabetes, including younger adults.***** Health care providers should recommend

***** <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>

COVID-19 vaccination to all eligible persons, especially those at increased risk for severe COVID-19. Maintenance of diabetes management and promotion of health care-seeking behavior are essential for lifetime diabetes care. Future studies that assess factors affecting access to and use of care during the pandemic, particularly among younger persons with diabetes, could help inform tailored prevention strategies.

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Corresponding author: Catherine E. Barrett, ohi6@cdc.gov.

¹Turner Institute for Brain and Mental Health, Monash University, Melbourne, Australia; ²Austin Health, Melbourne, Australia; ³Harvard Medical School, Boston, Massachusetts; ⁴Division of Diabetes Translation, National Center for Chronic Disease Prevention and Health Promotion, CDC; ⁵Brigham and Women's Hospital, Boston, Massachusetts; ⁶University of Melbourne, Melbourne, Australia.

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Almost 9 in 10 younger adults with diabetes delayed health care during the pandemic

Maintain diabetes care to prevent serious illness:

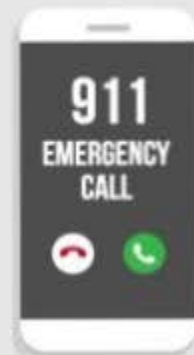
Keep routine appointments



Take prescribed medications



Seek care for urgent medical issues



Get a COVID-19 vaccine



bit.ly/MMWR7046a2

MMWR

Appendix 4. Accommodating vaccine preferences among women of childbearing age

Czeisler MÉ, Rajaratnam SMW, Howard ME, Czeisler CA. Accommodating vaccine preferences among women of childbearing age. *Am J Obstet Gynecol.* 2021 Dec;225(6):697-699. doi: 10.1016/j.ajog.2021.07.017. Epub 2021 Jul 31. PMID: 34343503; PMCID: PMC8372432.

Accommodating vaccine preferences among women of childbearing age

TO THE EDITORS: After pregnant persons were excluded from the initial trials leading to emergency use authorizations for COVID-19 vaccines in the United States, Gray et al¹ demonstrated robust vaccine-induced immune responses among pregnant women following COVID-19 messenger RNA (mRNA) vaccination (Pfizer-BioNTech and Moderna), with placental and breastmilk immune transfer to neonates. Unfortunately, rare clotting events following Janssen and AstraZeneca COVID-19 vaccination, which have been disproportionately experienced by women of childbearing age, have dampened the enthusiasm for these vaccines. At present, tailored education and vaccine deployment efforts should prioritize pregnant persons to mitigate newly recognized maternal and neonatal health risks following SARS-CoV-2 infection.² Moreover, given the fundamental principles of self-determination, personhood, and patient autonomy that underlie informed consent, respecting patients' right to make voluntary and informed healthcare decisions requires that all individuals should be fully informed about the risks and benefits of each vaccine, and—if feasible—provided a choice among the available COVID-19 vaccines.

Improving vaccine uptake among pregnant women is of heightened importance given recent evidence that pregnant women with SARS-CoV-2 infection have a considerably elevated risk of adverse maternal and neonatal health outcomes, including 22 times the risk of maternal mortality and twice the risk of both severe neonatal morbidity and perinatal morbidity and mortality than do pregnant women without SARS-CoV-2 infection.² Reassuringly, we found that 70% of surveyed pregnant women in the United States would definitely or most likely obtain a COVID-19 vaccine as soon as possible.³ Understandably, the initial phase of the US vaccine rollout did not accommodate personal preferences among COVID-19 vaccines. However, in contrast to other countries with inadequate vaccine supplies or only 1 available vaccine, in the United States, 3 different COVID-19 vaccines are currently in supply that now exceeds demand because of vaccine hesitancy and apathy. With newfound evidence of maternal and neonatal protection conferred by mRNA vaccines,¹ increased risk of adverse health outcomes associated with SARS-CoV-2 infection among pregnant women,² and disproportionate Janssen and AstraZeneca vaccine side effects among women of childbearing age, we strongly disagree with the recent suggestion that “health systems . . . should communicate to patients that they will receive, and only really need, one choice of vaccine.”⁴ We believe that amid this public health crisis, these considerations necessitate that women of childbearing age be afforded a choice among COVID-19 vaccines to

reduce elevated adverse vaccination side effects experienced by women of childbearing age, vaccine hesitancy, and the serious risks COVID-19 poses for pregnant women and their children.² ■

Mark É. Czeisler, AB
Turner Institute for Brain and Mental Health
Monash University
Level 5, 18 Innovation Walk
Clayton Campus
Melbourne
Victoria 3800
Australia
Institute for Breathing and Sleep
Austin Health
Heidelberg, Victoria
Australia
Department of Psychiatry
Brigham and Women's Hospital
Boston, MA
Brigham and Women's Hospital
Harvard Medical School
Boston, MA
mark.czeisler@fulbrightmail.org

Shantha M. W. Rajaratnam, PhD
Turner Institute for Brain and Mental Health
Monash University
Melbourne, Victoria
Australia
Institute for Breathing and Sleep
Austin Health
Heidelberg, Victoria
Australia
Division of Sleep and Circadian Disorders
Department of Medicine
Brigham and Women's Hospital
Boston, MA
Department of Neurology
Brigham and Women's Hospital
Boston, MA
Division of Sleep Medicine
Harvard Medical School
Boston, MA

Mark E. Howard, MBBS, PhD
Turner Institute for Brain and Mental Health
Monash University
Melbourne, Victoria
Australia
Institute for Breathing and Sleep
Austin Health
Heidelberg, Victoria
Australia
Department of Medicine

University of Melbourne
Melbourne, Victoria
Australia

Charles A. Czeisler, PhD, MD
Turner Institute for Brain and Mental Health
Monash University
Melbourne, Victoria
Australia
Division of Sleep and Circadian Disorders
Department of Medicine
Brigham and Women's Hospital
Boston, MA
Department of Neurology
Brigham and Women's Hospital
Boston, MA
Division of Sleep Medicine
Harvard Medical School
Boston, MA

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Appendix 5. Occupational burnout, associated demographic, sleep and employment factors, and adherence with mask usage and other recommended COVID-19 prevention behaviors

Czeisler MÉ, Wolkow AP, Czeisler CA, Howard ME, Rajaratnam SMW, Lane RI. Occupational burnout, associated demographic, sleep and employment factors, and adherence with mask usage and other recommended COVID-19 prevention behaviors. Submitted manuscript under review.

Appendix Five Original Investigation: Czeisler *et al.* Occupational burnout, associated demographic, sleep and employment factors, and adherence with mask usage and other recommended COVID-19 prevention behaviors.

Title

Occupational burnout, associated demographic, sleep and employment factors, and adherence with mask usage and other recommended COVID-19 prevention behaviors

Short Title

Burnout and COVID-19 prevention behaviors

Authors

Mark É. Czeisler, A.B.^{*1-3} Alexander P. Wolkow, Ph.D.¹ Charles A. Czeisler, Ph.D., M.D.^{1,4,5} Mark E. Howard, M.B.B.S., Ph.D.^{1,2,6} Shantha M.W. Rajaratnam, Ph.D.^{1,2,4,5} Rashon I. Lane, Ph.D.⁷

* Corresponding author

Affiliations

¹Turner Institute for Brain and Mental Health, Monash University, Melbourne, Victoria, Australia

²Institute for Breathing and Sleep, Austin Health, Melbourne, Victoria, Australia

³Department of Psychiatry, Brigham & Women's Hospital, Boston, Massachusetts, USA

⁴Division of Sleep and Circadian Disorders, Departments of Medicine and Neurology, Brigham & Women's Hospital, Boston, Massachusetts, USA

⁵Division of Sleep Medicine, Harvard Medical School, Boston, Massachusetts, USA

⁶Department of Medicine, University of Melbourne, Melbourne, Victoria, Australia

⁷Department of Social and Behavioral Sciences, University of California, San Francisco, California, USA

Corresponding author information

Mark É. Czeisler, A.B.

Appendix Five Original Investigation: Czeisler *et al.* Occupational burnout, associated demographic, sleep and employment factors, and adherence with mask usage and other recommended COVID-19 prevention behaviors.

M.D. Candidate

Harvard Medical School

107 Avenue Louis Pasteur, Box 236

Boston, MA, 02115

Email: mark.czeisler@fulbrightmail.org

Abstract

Studies have found associations between occupational burnout symptoms and reduced engagement with healthy behaviors. We characterized demographic, employment, and sleep characteristics associated with occupational burnout symptoms, and evaluated relationships between such symptoms and adherence with COVID-19 prevention behaviors (mask usage, hand hygiene, avoiding gatherings, physical distancing, obtaining COVID-19 tests if potentially infected). During December 2020, surveys were administered cross-sectionally to 5,208 U.S. adults (response rate=65.8%). Quota sampling and survey weighting were employed to improve sample representativeness of sex, age, and race/ethnicity. Among 3,026 employed respondents, logistic regression models examined associations between burnout symptoms and demographic, employment, and sleep characteristics. Similar models were conducted to estimate associations between burnout and non-adherence with COVID-19 prevention behaviors. Women, younger adults, unpaid caregivers, those working more onsite versus remotely, and those with insufficient or impaired sleep had higher odds of occupational burnout symptoms. Burnout symptoms were associated with less frequent mask usage (adjusted odds ratio [aOR]=1.7, 95% confidence interval [CI]=1.3-2.1), hand hygiene

Appendix Five Original Investigation: Czeisler *et al.* Occupational burnout, associated demographic, sleep and employment factors, and adherence with mask usage and other recommended COVID-19 prevention behaviors.

(aOR=2.1, 95% CI=1.7-2.7), physical distancing (aOR=1.3, 95% CI=1.1-1.6), avoiding gatherings (aOR=1.4, 95% CI=1.1-1.7), and obtaining COVID-19 tests (aOR=1.4, 95% CI=1.1-1.8). The cross-sectional design of this study limits the ability to infer causality. Additionally, use of self-report data may be subject to recall, response, and social desirability biases. Disparities in occupational burnout symptoms exist by gender, age, caregiving, employment, and sleep health. Employees experiencing occupational burnout symptoms might exhibit reduced adherence with COVID-19 prevention behaviors. Employers can support employee health by implementing strategies to address occupational burnout symptoms.

Keywords

SARS-CoV-2; public health; health disparities; nonpharmaceutical interventions

Introduction

Burnout, a psychological syndrome resulting from chronic work-related stress (Norlund et al. 2010, World Health Organization 2019), is experienced across occupations and characterized by emotional exhaustion, depersonalization, and reduced professional efficacy. Many employed U.S. adults experienced work-related changes in 2020 in response to the coronavirus disease 2019 (COVID-19) pandemic. Approximately one-third transitioned from in-person to remote work (Brynjolfsson et al. 2020), and many have experienced layoffs or furloughs (U.S. Bureau of Labor Statistics 2020). To provide essential services or manage staff reductions, others are working extended-duration shifts and long work-weeks (DeFilippis et al. 2020), potentially contributing to sleep deficiency and circadian disruption, which are factors associated

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with burnout (Peterson et al. 2019, Wolkow et al. 2019). Insufficient sleep is common, as one-third of U.S. adults report insufficient sleep (Liu et al. 2016) and many live with undiagnosed and untreated sleep disorders (Lee et al. 2008). Some recent worksite and employment changes could alleviate burnout (e.g., reduced commute time, affording increased opportunity for sleep), while others may exacerbate burnout (e.g., reduced work-and-home separation). Indeed, a growing body of evidence reports sleep and occupational factors associated with burnout among healthcare professionals during the COVID-19 pandemic (Amanullah and Ramesh Shankar 2020, Bradley and Chahar 2020, Shreffler et al. 2020, Sharifi et al. 2021); however little research has focused on burnout across occupational sectors. Furthermore, studies conducted during the COVID-19 pandemic have found unpaid caregivers for children and adults, young adults, women, and essential workers have disproportionately experienced adverse mental health symptoms (Czeisler et al. 2020, Ettman et al. 2020, Pierce et al. 2020, Czeisler et al. 2021a, Czeisler et al. 2021c, Varma et al. 2021), but our understanding of how these and other demographic factors relate to burnout risk during the pandemic is limited.

Burnout can negatively influence individual workers and the people with whom they interact (Maslach and Leiter 2016). For example, if an individual is affected by burnout, evidence suggests they are less likely to seek medical care for health concerns, such as a serious emotional problem (Dyrbye et al. 2015, Arnhart et al. 2019, Dyrbye et al. 2020). Pre-pandemic studies have also found negative associations of burnout with hand hygiene among nurses (Manomenidis et al. 2019), and with adherence with

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personal protective equipment utilization and work-safety practices among firefighters (Smith et al. 2019). Such findings linking lower adherence with safety measures and burnout are particularly relevant during the COVID-19 pandemic, especially among unvaccinated individuals. Together, these highlight the need to investigate the impact of burnout on health behaviors in response to the COVID-19 pandemic, alongside identifying key factors associated with burnout to inform targeted workplace strategies. Therefore, we examined burnout symptoms, associated sleep, demographic and occupational factors, and adherence with recommended COVID-19 health behaviors in a representative sample of employed U.S. adults.

Methods

Study Sample

To assess occupational burnout symptoms in December 2020, Internet-based surveys were administered by Qualtrics to U.S. adults aged ≥ 18 years as part of The COVID-19 Outbreak Public Evaluation (COPE) Initiative. The COPE Initiative (<https://www.thecopeinitiative.org/>) is designed to assess public attitudes, behaviors, and beliefs related to the COVID-19 pandemic and to evaluate the mental and behavioral health consequences of the pandemic. The COPE Initiative surveys included in this analysis were administered by Qualtrics, LLC. Quota sampling and survey weighting were employed to improve sample representativeness of the U.S. population by sex, age, and race/ethnicity. Surveys were administered cross-sectionally to eliminate potential for survivorship bias (Czeisler et al. 2021b), a source of selection bias in which survey respondents who consistently participate in longitudinal studies

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have better baseline mental health and mental health trajectories compared with those who attrite.

A minimum age of 18 years and residence within the United States were required for eligibility to complete a survey in December 2020. All surveys underwent data quality screening procedures including algorithmic and keystroke analysis for attention patterns, click-through behavior, duplicate responses, machine responses, and inattentiveness. Country-specific geolocation verification via IP address mapping was used to ensure respondents were from the United States. Respondents who failed an attention or speed check, along with any responses identified by the data-scrubbing algorithms, were excluded from analysis.

Measures

Burnout was assessed using the single-item Mini-Z, a non-proprietary measure of the emotional exhaustion dimension of burnout across occupations (Dolan et al. 2015). The Mini-Z has been validated using the emotional exhaustion subscale of the widely administered, proprietary Maslach Burnout Inventory (Worley et al. 2008), with a 0.79 correlation, 83.2% sensitivity, 87.4% specificity, and 0.93 area under the receiver operator curve (Dolan et al. 2015). Higher Mini-Z scores from 1 through 5 reflect progressively more severe burnout symptoms. Respondents who scored ≥ 3 out of 5 screened positive for burnout symptoms (Dolan et al. 2015).

Demographic variables included gender, age, race/ethnicity, disability status as assessed as a positive response to Items 7.22 or 7.23 of the Behavioral Risk Factor Surveillance System Questionnaire (Centers for Disease Control and Prevention 2021),

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education attainment, U.S. Census region, and urbanicity. Employment-related characteristics included employment status, paid work hours per week, percentage of work hours completed remotely (i.e., not in-person), and job sector. Unpaid caregiver status was assessed, both for adults aged ≥ 18 years and for children or adolescents aged < 18 years. Sleep characteristics included self-reported sleep duration, insomnia symptoms assessed using the clinically validated 2-item Sleep Condition Indicator (Espie et al. 2014), and history of diagnosed sleep or circadian disorders and whether or not respondents were receiving treatment or taking medication for these conditions.

Frequency of adhering with recommended COVID-19 protective behaviors was assessed using a five-item Likert scale with Never, Rarely, Sometimes, Often, and Always as response options. The question “In the last week, how frequently did you...” was asked with the following behaviors: avoid gatherings for ≥ 10 persons; avoid going to places where you could not stay 6 feet away from people outside your household unit; wear a mask or cloth face covering when in public; wash your hands with soap and water after touching high-touch surfaces in public (e.g., shopping carts, gas pumps, ATMs); and use hand sanitizer after touching high-touch surfaces in public (e.g., shopping carts, gas pumps, ATMs). Hand hygiene was considered as frequency of either washing hands or using hand sanitizer, with the higher frequency designated. Mask usage and hand hygiene were only assessed among respondents who indicated they had been in public in the prior week. Odds ratios were estimated with Rarely and Never collapsed into a single response option given the similar public health implications for both scenarios.

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Likelihood of obtaining a COVID-19 test if potentially infected with SARS-CoV-2 was assessed using a three-item Likert scale with Not at all likely, Somewhat likely, and Very likely as response options. Respondents could also select “Don’t know/Not sure” or “I do this anyway.” The question “If you thought you might have COVID-19, how likely would you be to do the following?” was asked with the following specified as getting tested for COVID-19. Odds ratios were estimated among respondents who did not select “Don’t know/Not sure” or “I do this anyway.”

Statistical Analysis

Survey weighting (iterative proportional fitting, trimmed with $1/3 \leq \text{weight} \leq 3$) was employed to improve sample representativeness of the U.S. adult population by sex, age, and race/ethnicity using 2010 U.S. Census estimates. Sex and gender were assessed separately. Sex was used to weight based on population estimates. Gender was used as a demographic variable in the analysis.

To evaluate potential associations with demographic, employment, and sleep characteristics and occupational burnout, weighted ordinal logistic regressions were used to estimate adjusted odds ratios (aORs) for Mini-Z burnout scores. All adjusted models for potential associations between demographic, employment, and sleep-related characteristics and burnout symptoms included gender, age, race/ethnicity, disability status, education attainment, U.S. Census region, rural/urban residence, unpaid caregiver status, paid weekly work hours, and remote-work percentage. Separate models were used to evaluate potential associations with other employment-related variables and sleep-related variables.

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To evaluate potential associations with recommended COVID-19 health behaviors, weighted ordinal logistic regressions with occupational burnout as explanatory variables were used to estimate aORs for lower frequency of mask-wearing, hand hygiene, avoiding gatherings of ≥ 10 persons, and physical-distancing from others, and for lower likelihood of the following behaviors if the respondent believed they had COVID-19: obtaining a SARS-CoV-2 test, staying home from work, and staying home from social gatherings. All adjusted models for potential associations between burnout symptoms and non-adherence with COVID-19 health behaviors included these previously listed variables, plus job sector.

Statistical significance was assessed as $p < 0.05$. Rounded, weighted values are reported. Analyses were conducted in R version 4.0.2 (The R Project for Statistical Computing) with the R survey package using version 3.29 and Python version 3.7.8 (Python Software Foundation). The Monash University Human Research Ethics Committee approved this study. All participants provided informed electronic consent prior to enrollment in the survey.

Results

During December 6-27, 2020, 5,208 of 7,909 (65.8%) eligible invited adults completed surveys. Complete survey data for analyzed variables were obtained from 5,185 (99.6%) respondents, 3,026 (58.4%) of whom were employed. Of these 3,026 employed respondents, 1,235 (40.8%) were women and 1,835 (60.6%) were non-Hispanic White (Table 1). Overall, 1,762 (58.2%) reported sufficient sleep duration (> 7 hours per day), while 701 (23.2%) reported an average of 6-7 hours and 562 (18.6%)

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reported sleeping <6 hours (Table 2).

Overall, 762 of the 3,026 (25.2%) employed respondents scored ≥ 3 out of 5 on the single-item Mini-Z in December 2020, qualifying as positive screens for occupational burnout symptoms. The prevalence of positive burnout symptom screens was common across occupational sectors (11.2-58.7%) (Table 1). Demographic characteristics associated with greater odds of more severe occupational burnout included younger compared with older age (e.g., aged 18-24 versus ≥ 65 years, burnout symptoms prevalence=37.6%, 5.7%, respectively; aOR=3.3, 95% CI=2.1-5.3), women compared with men (30.9%, 21.3%; aOR=1.6, 95% CI=1.4-1.9), and Hispanic or Latino adults compared with non-Hispanic White adults (33.1%, 22.4%; aOR=1.7, 95% CI=1.3-2.3) (Tables 1,3). Employment characteristics associated with increased odds of more severe occupational burnout included evening or night shifts compared with day shifts (e.g., evening versus day shift, 42.9%, 22.3%; aOR=1.6, 95% CI=1.1-2.4) and lesser remote-work (e.g., 11-49% versus 90-100%, 30.6%, 17.9%; aOR=1.4, 95% CI=1.1-1.8). Unpaid caregivers for children also had greater odds of burnout than non-caregivers (37.1%, 19.0%; aOR=1.9, 95% CI=1.4-2.5).

Sleep characteristics associated with increased odds of more severe occupational burnout included insufficient sleep duration and impaired sleep, as increased odds were found for those with daily sleep duration <7-hours compared with >7-hours (e.g., <6-hours, 36.5%, 22.0%; aOR=1.9, 95% CI=1.5-2.4) and for those who screened positive for insomnia symptoms (38.5%, 22.2%, aOR=1.8, 95% CI=1.4-2.3) (Tables 2,3). Additionally, odds of more severe burnout symptoms were higher among individuals

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who had diagnosed sleep or circadian disorders (insomnia, obstructive sleep apnea, shift work disorder) who were not receiving treatment or taking medication compared to individuals who were not diagnosed with these disorders, but not among those with these diagnosed sleep or circadian disorders who were receiving treatment or taking medication (Tables 2,3).

Employed U.S. adults who were experiencing burnout symptoms had greater odds of less frequently adhering with recommended COVID-19 health behaviors (Table 4). Adjusting for demographic and employment characteristics, those who were experiencing burnout symptoms had greater odds of having less frequently worn a mask when in public (aOR=1.7, 95% CI=1.3-2.1), practiced hand hygiene (aOR=2.1, 95% CI=1.7-2.7), avoided gatherings of ≥ 10 persons (aOR=1.4, 95% CI=1.1-1.7), or maintained a six-foot physical distance from others (aOR=1.3, 95% CI=1.1-1.6); all $p < 0.05$. Individuals with burnout symptoms also had higher odds of being less likely to obtain a COVID-19 test if they thought they may be infected with SARS-CoV-2 (aOR=1.4, 95% CI=1.1-1.8, $p=0.0096$).

Discussion

More than one-quarter of 3,026 employed U.S. adult respondents were experiencing occupational burnout symptoms in December 2020. Occupational burnout was associated with less frequent practice of recommended COVID-19 prevention behaviors, including mask usage. Women, younger adults, unpaid caregivers, Hispanic or Latino adults, and those working more onsite versus remotely more commonly experienced burnout symptoms. Working night and evening shifts, short sleep duration,

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and insomnia symptoms were also associated with burnout symptoms. Finally, individuals with untreated sleep or circadian disorders had greater odds of burnout symptoms than those without these disorders, whereas those receiving treatment did not.

Burnout symptoms were associated with reduced engagement in personal COVID-19 protective behaviors, as employees experiencing occupational burnout symptoms had greater odds of less frequent practice of behaviors recommended to protect against COVID-19, including mask usage, practice of hand hygiene, avoidance of in-person gatherings, and maintenance of a physical distance between persons. These findings persisted after adjusting for demographic and employment characteristics that may influence these behaviors. To our knowledge, this study is the first to highlight the negative association between burnout symptoms and COVID-19-recommended health behaviors in a general occupational sample, revealing associations that align with pre-pandemic burnout and safety practice research (Manomenidis et al. 2019, Smith et al. 2019). Moreover, reduced healthcare-seeking behaviors and increased perceived barriers to seeking medical care are further concerns commonly reported among individuals with burnout (Dyrbye et al. 2015, Dyrbye et al. 2020). Our findings add to this area of the literature by demonstrating that if affected by burnout, employees were less likely to obtain a COVID-19 test if potentially infected. Community- and employer-supported programs targeted toward reducing occupational burnout may improve adherence with COVID-19 health behaviors among employees, which could benefit both employees and those with whom they interact.

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Occupational burnout symptoms were disproportionately experienced by specific populations, including women, younger adults, and unpaid caregivers, which is consistent with pre-pandemic data (Norlund et al. 2010) and evidence from Germany during the COVID-19 pandemic (Meyer et al. 2021). Importantly, Meyer et al. (2021) found that female employees with job autonomy and partner support had better psychological health during the pandemic, highlighting value in protective factors. Our findings of burnout among young persons and unpaid caregivers closely align with broader mental health research that has revealed that these populations have disproportionately experienced adverse mental health symptoms, including depression and anxiety symptoms (Czeisler et al. 2020, Ettman et al. 2020, Pierce et al. 2020, Czeisler et al. 2021a, Czeisler et al. 2021c, Varma et al. 2021). Occupational burnout symptoms may be another area of concern for these populations. There is debate regarding the extent to which burnout symptoms may overlap with depression and anxiety symptoms (Maslach and Leiter 2016), yet recent findings show these conditions to be distinct (Koutsimani et al. 2019, Fischer et al. 2020), and, to our knowledge, there is no evidence of this overlap using the Mini-Z burnout measure administered in the current study.

Further research is needed to understand and alleviate contributors to burnout within disproportionately affected populations in the workforce (e.g., women, caregivers, young adults). Intervention efforts could focus on restructuring economic systems to reduce gender and racial pay gaps (Moore and Continelli 2016, Litman et al. 2020, Chen et al. 2021), which create inequitable opportunities for these populations to have living wages.

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Concurrent efforts could focus on developing support systems for additional factors that might more broadly contribute to occupational burnout, including essential work in low-wage jobs and economic insecurities for younger persons, increased need for daytime childcare for those in virtual-learning environments, and disruptions to the provision of care for adults.

Compared with day shift workers, employees working evening and night shifts had higher odds of burnout symptoms. These results are consistent with pre-pandemic data (Cheng and Cheng 2017, Peterson et al. 2019), and with recent research conducted during COVID-19 in frontline healthcare workers (Liu et al. 2020). Shift work is becoming increasingly common across occupations, including those outside of healthcare and other frontline professions (McMenamin 2007). Therefore, by including employees from a range of job sectors, our findings highlight the association between burnout symptoms and night or evening shift work among the general working population during the pandemic. Of further relevance to the general working population is the potential impact of working remotely on burnout symptoms, given over a third of employed adults transitioned to this type of work during the pandemic (Brynjolfsson et al. 2020, Eurofound 2020). Working remotely only a small amount of time with most of their work completed onsite, less extensive remote work has been shown to result in lower job satisfaction and higher work-family conflict (Gajendran and Harrison 2007, Allen et al. 2015), which are factors shown to increase the risk of burnout (Molero Jurado et al. 2019, Terry and Woo 2021). Considering 30% of our sample reported combined onsite and remote work arrangements, our findings may have implications for

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monitoring burnout symptoms in these sectors of the workforce.

Beyond demographic and employment characteristics, employed adults with sleep deficiency or insomnia symptoms had higher odds of more severe burnout symptoms. Untreated or potentially undiagnosed sleep or circadian disorders (i.e., insomnia, obstructive sleep apnea, shift work disorder) were associated with more severe burnout symptoms but treated diagnosed sleep and circadian disorders were not. Pre-pandemic research has reported similar relationships between untreated and undiagnosed sleep disorders and burnout symptoms in healthcare workers (Weaver et al. 2020), which, together with our findings, highlight the potential protective role that treatment of sleep and circadian disorders may have in reducing burnout symptoms. With sleep deficiency and undiagnosed and untreated sleep disorders common among U.S. adults (Liu et al. 2016), these findings suggest that employers may address burnout by sponsoring sleep disorder and sleep enhancement or fatigue reduction workplace health promotion programs, which were offered by less than 10% of U.S. worksites in 2017 (Robbins et al. 2021). Improving sleep health may also reduce the economic impact of sleep deficiency, which was estimated to cost U.S. businesses USD\$411 billion annually (Hafner et al. 2017).

Strengths of this study include assessment of burnout in a demographically representative sample of more than 3000 employed U.S. adults spanning across occupations, use of a validated instrument to assess burnout symptoms, and application of measures to reduce non-response bias during (demographic quota sampling) and after (survey weighting) data collection. Moreover, demographic, employment, and

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sleep characteristics were comprehensively characterized and adjusted for in multivariable analyses, and multiple COVID-19 prevention behaviors were assessed and included in this analysis. Finally, a cross-sectional study design was used to eliminate potential for survivorship bias to influence relationships (Czeisler et al. 2021b). Limitations of this study include the use of self-report data, which are subject to recall, response, and social desirability biases, especially for COVID-19 health behaviors. Additionally, the single-item Mini-Z is validated to assess the emotional exhaustion dimension of occupational burnout; future studies could focus on the depersonalization and reduced personal accomplishment dimensions. Moreover, cross-sectional findings do not demonstrate causality. While a comprehensive set of variables was included in multivariable analyses, confounding factors might partially account for relationships reported in this analysis. Finally, although quota sampling methods and survey weighting were employed to improve representativeness, this Internet-based sample may not be fully representative of the 2020 employed adult U.S. population.

Conclusion

In this demographically diverse sample of 3,026 employed U.S. adults, occupational burnout symptoms were more common among respondents who were of younger age or female gender, those with lesser remote-work or with unpaid caregiver roles, and those with insufficient or impaired sleep. In turn, occupational burnout symptoms were associated with non-adherence with key COVID-19 prevention behaviors, including hand hygiene, mask usage, physical distancing, avoiding gatherings, and obtaining COVID-19 tests if potentially infected. Future studies should explore the extent to which

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employers can support the health of their employees by implementing strategies to address occupational burnout, such as promotion of work-life balance and sponsorship of sleep enhancement programs and other wellness promotion programs. Addressing burnout symptoms and providing resources to reduce burnout among employees could reduce non-adherence with recommended COVID-19 health behaviors.

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Tables

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Table 1. Employed U.S. adult respondent characteristics and prevalence of burnout symptoms – December 6-27, 2020

	Number of respondents		Positive screen for burnout symptoms	
	n	%	n	%
Total	3026	(100)	762	(25.2)
Single-item Mini Z burnout response				
No symptoms	1304	(43.1)	0	(0)
Occasional stress, no burnout symptoms	960	(31.7)	0	(0)
Definite burnout, physical and emotional exhaustion	480	(15.9)	480	(100)
Burnout symptoms won't go away	124	(4.1)	124	(100)
Complete burnout - may need to make changes or seek help	158	(5.2)	158	(100)
Demographic characteristics				
Gender				
Male	1759	(58.2)	375	(21.3)
Female	1235	(40.8)	382	(30.9)
Transgender	28	(0.9)	4	(14.2)
None of these	3	(0.1)	1	(45.3)
Age group, yrs				
18-24	417	(13.8)	157	(37.6)
25-34	530	(17.5)	173	(32.7)
35-44	896	(29.6)	220	(24.5)
45-54	551	(18.2)	132	(24.0)
55-64	472	(15.6)	70	(14.9)
≥65	160	(5.3)	9	(5.7)
Race/ethnicity				
White, non-Hispanic	1835	(60.6)	411	(22.4)
Black, non-Hispanic	311	(10.3)	86	(27.7)
Asian, non-Hispanic	178	(5.9)	37	(21.1)
Other race(s), non-Hispanic	98	(3.3)	27	(27.9)
Hispanic or Latino	604	(20.0)	200	(33.1)
Disability status				
Yes	669	(22.1)	204	(30.4)
No	2331	(77.0)	549	(23.5)
Prefer not to say	26	(0.9)	10	(36.9)
Education attainment				
High school diploma or less	444	(14.7)	150	(33.8)
College or some college	1626	(53.7)	419	(25.8)
After bachelor's degree	956	(31.6)	193	(20.2)

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U.S. Census region				
Northeast	704	(23.3)	163	(23.2)
Midwest	544	(18.0)	171	(31.4)
South	1181	(39.0)	309	(26.2)
West	596	(19.7)	119	(19.9)
Urban-rural residence				
Urban	2715	(89.7)	654	(24.1)
Rural	311	(10.3)	108	(34.7)
Employment and unpaid caregiving characteristics				
Percent of paid work completed remotely				
0-10	945	(31.2)	221	(23.4)
11-49	910	(30.1)	278	(30.6)
50-89	491	(16.2)	141	(28.6)
90-100	680	(22.5)	122	(17.9)
Paid work hours in previous week				
≤40	1939	(64.1)	426	(21.9)
41-60	705	(23.3)	199	(28.2)
>60	382	(12.6)	137	(35.9)
Types of shifts				
Day shifts only	2280	(75.4)	510	(22.3)
Evening shifts only	251	(8.3)	107	(42.9)
Night shifts only	102	(3.4)	32	(31.5)
Multiple types of shifts	393	(13.0)	113	(28.7)
Occupational sector				
Construction	227	(7.5)	62	(27.2)
Educational services	245	(8.1)	69	(28.0)
Federal government	47	(1.5)	13	(27.3)
Financial activities	240	(7.9)	61	(25.3)
Health care and social assistance	374	(12.3)	106	(28.3)
Information	358	(11.8)	67	(18.8)
Leisure and hospitality	123	(4.1)	40	(32.5)
Manufacturing	248	(8.2)	50	(20.2)
Mining	9	(0.3)	5	(58.7)
Retail trade	211	(7.0)	58	(27.5)
State and local government	124	(4.1)	35	(28.2)
Transportation and warehouses	109	(3.6)	27	(24.9)
Utilities	44	(1.5)	9	(19.8)
Wholesale trade	66	(2.2)	7	(11.2)
Other services	601	(19.9)	153	(25.5)
Unpaid caregiver status				
No	1425	(47.1)	271	(19.0)
Caregiver for adults only	346	(11.4)	94	(27.2)

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Caregiver for children only	264	(8.7)	98	(37.1)
Caregiver for children and adults	991	(32.8)	299	(30.1)

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Table 2. Employed U.S. adult sleep characteristics and prevalence of burnout symptoms – December 6-27, 2020

	Number of respondents		Positive screen for burnout symptoms	
	n	(%)	n	(%)
Total	3026	(100)	762	(25.2)
Sleep characteristics				
Sleep duration, hrs				
>7	1762	(58.2)	388	(22.0)
6-7	701	(23.2)	169	(24.1)
<6	562	(18.6)	205	(36.5)
Insomnia symptoms				
No	2471	(81.7)	548	(22.2)
Yes	555	(18.3)	214	(38.5)
History with diagnosed insomnia				
Never	2065	(68.2)	434	(21.0)
Yes, in the past, but not now	336	(11.1)	141	(41.9)
Yes, untreated	318	(10.5)	113	(35.7)
Yes, treated	307	(10.1)	74	(24.0)
History with diagnosed obstructive sleep apnea				
Never	2120	(70.1)	464	(21.9)
Yes, in the past, but not now	218	(7.2)	88	(40.4)
Yes, untreated	421	(13.9)	138	(32.9)
Yes, treated	266	(8.8)	71	(26.7)
History with diagnosed shift work disorder				
Never	2297	(75.9)	508	(22.1)
Yes, in the past, but not now	184	(6.1)	70	(38.0)
Yes, untreated	317	(10.5)	122	(38.4)
Yes, treated	227	(7.5)	62	(27.2)

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Table 3. Demographic, employment, and sleep factors associated with burnout symptoms among U.S. adults– December 6-27, 2020

	Weighted ordered unadjusted odds ratios		Weighted ordered adjusted odds ratios	
	OR (95% CI)	P	aOR (95% CI)	P
Demographic characteristics				
Gender (reference: Male)				
Female	1.63, (1.37, 1.94)	<0.0001	1.61, (1.35, 1.91)	<0.0001
Age group, yrs (reference: ≥65)				
18-24	4.28, (2.76, 6.62)	<0.0001	3.33, (2.09, 5.29)	<0.0001
25-34	3.00, (2.14, 4.22)	<0.0001	2.25, (1.52, 3.32)	<0.0001
35-44	1.97, (1.43, 2.71)	<0.0001	1.71, (1.19, 2.45)	0.0034
45-54	2.42, (1.68, 3.47)	<0.0001	2.13, (1.45, 3.13)	0.0001
55-64	1.64, (1.15, 2.33)	0.0064	1.52, (1.04, 2.23)	0.030
Race/ethnicity (reference: non-Hispanic White)				
Black, non-Hispanic	1.33, (1.02, 1.72)	0.035	1.16, (0.89, 1.52)	0.27
Asian, non-Hispanic	1.23, (0.97, 1.55)	0.091	1.47, (1.12, 1.91)	0.0048
Other race(s), non-Hispanic	1.39, (0.90, 2.13)	0.13	1.33, (0.95, 2.10)	0.21
Hispanic or Latino	1.70, (1.28, 2.26)	0.0003	1.69, (1.26, 2.27)	0.0005
Education attainment (reference: After bachelor's degree)				
High school diploma or less	1.80, (1.32, 2.44)	0.0002	1.30, (0.94, 1.79)	0.11
College or some college	1.44, (1.19, 1.73)	0.0001	1.23, (1.01, 1.51)	0.044
Employment and unpaid caregiving characteristics				
Percent of paid work completed remotely (reference: 90-100%)				
0-10	1.39, (1.11, 1.74)	0.0044	1.28, (1.00, 1.65)	0.054
11-49	1.55, (1.21, 1.99)	0.0005	1.36, (1.05, 1.76)	0.018
50-89	1.38, (1.02, 1.86)	0.038	1.18, (0.87, 1.62)	0.29
Types of shifts (reference: Day shifts only)				
Evening shifts only	2.05, (1.38, 3.04)	0.0003	1.64, (1.12, 2.41)	0.011
Night shifts only	1.64, (1.14, 2.36)	0.0072	1.50, (1.05, 2.13)	0.024
Multiple types of shifts	1.26, (0.98, 1.62)	0.068	1.10, (0.85, 1.43)	0.47
Unpaid caregiver status (reference: No)				
Caregiver for adults only	1.45, (1.11, 1.88)	0.0056	1.26, (0.95, 1.66)	0.11
Caregiver for children only	2.07, (1.54, 2.80)	<0.0001	1.87, (1.39, 2.51)	<0.0001
Caregiver for children and adults	1.30, (1.05, 1.61)	0.014	1.30, (0.98, 1.73)	0.068
Sleep duration, hrs (reference: >7)				
6-7	1.33, (1.09, 1.63)	<0.0001	1.45, (1.18, 1.79)	0.0005

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<6	1.94, (1.53, 2.46)	0.0058	1.91, (1.51, 2.40)	<0.0001
Insomnia symptoms (reference: No)				
Yes	1.82, (1.43, 2.32)	<0.0001	1.75, (1.36, 2.25)	<0.0001
History of diagnosed insomnia (reference: Never)				
Yes, in the past, but not now	2.17, (1.57, 2.98)	<0.0001	1.99, (1.44, 2.77)	<0.0001
Yes, untreated	2.02, (1.51, 2.69)	<0.0001	2.05, (1.49, 2.83)	<0.0001
Yes, treated	0.83, (0.58, 1.19)	0.31	0.90, (0.62, 1.30)	0.56
History of diagnosed obstructive sleep apnea (reference: Never)				
Yes, in the past, but not now	1.69, (1.14, 2.51)	0.0094	1.68, (1.11, 2.55)	0.015
Yes, untreated	1.57, (1.22, 2.02)	0.0005	1.56, (1.16, 2.10)	0.0035
Yes, treated	1.09, (0.75, 1.58)	0.65	1.20, (0.83, 1.74)	0.34
History of diagnosed shift work disorder (reference: Never)				
Yes, in the past, but not now	1.61, (1.12, 2.32)	0.010	1.50, (1.01, 2.23)	0.043
Yes, untreated	1.79, (1.31, 2.45)	0.0003	1.81, (1.24, 2.62)	0.0019
Yes, treated	0.99, (0.66, 1.48)	0.95	0.98, (0.65, 1.47)	0.91

Boldface indicates statistical significance (p<0.05).

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Table 4. Associations of burnout symptoms and non-adherence with recommended COVID-19 prevention behaviors among employed U.S. adults – December 6-27, 2020

Less frequently having:										Less likely to have:	
	Worn a mask in public		Practiced hand hygiene		Avoided gatherings of ≥10 persons		Maintained physical distance		Obtained a COVID-19 test if potentially infected		
	OR	<i>P</i>	OR	<i>P</i>	OR	<i>P</i>	OR	<i>P</i>	OR	<i>P</i>	
	95% CI		95% CI		95% CI		95% CI		95% CI		
Unadjusted											
Burnout symptoms	2.05	<0.0001	2.20	<0.0001	1.72	<0.0001	1.51	<0.0001	1.70	<0.0001	
	(1.64, 2.58)		(1.77, 2.74)		(1.40, 2.12)		(1.24, 1.83)		(1.32, 2.20)		
Adjusted											
Burnout symptoms	1.67	<0.0001	2.14	<0.0001	1.41	0.0014	1.29	0.014	1.41	0.0096	
	(1.33, 2.09)		(1.71, 2.67)		(1.14, 1.73)		(1.05, 1.58)		(1.09, 1.83)		

Boldface indicates statistical significance (p<0.05).

Appendix 6. Supplement to Chapter Four: Early public adherence with and support for stay-at-home COVID-19 mitigation strategies despite adverse life impact: a transnational cross-sectional survey study in the United States and Australia

US Census Bureau Nationwide Population Place of Residence: July 2019			US Sample Respondent Place of Residence: September to December 2019			Comparison
State or Territory	Population	% of US Population	State or Territory	Respondents	% of US Sample	Difference in % of US Population
Alabama	4903185	1.49%	Alabama	41	1.36%	-0.13%
Alaska	731545	0.22%	Alaska	9	0.30%	0.08%
Arizona	7278717	2.22%	Arizona	100	3.32%	1.10%
Arkansas	3017804	0.92%	Arkansas	10	0.33%	-0.59%
California	39512223	12.04%	California	241	8.01%	-4.03%
Colorado	5758736	1.75%	Colorado	65	2.16%	0.41%
Connecticut	3565287	1.09%	Connecticut	43	1.43%	0.34%
Delaware	973764	0.30%	Delaware	15	0.50%	0.20%
District of Columbia	705749	0.22%	District of Columbia	6	0.20%	-0.02%
Florida	21477737	6.54%	Florida	294	9.77%	3.22%
Georgia	10617423	3.23%	Georgia	105	3.49%	0.25%
Hawaii	1415872	0.43%	Hawaii	27	0.90%	0.47%
Idaho	1787065	0.54%	Idaho	19	0.63%	0.09%
Illinois	12671821	3.86%	Illinois	115	3.82%	-0.04%
Indiana	6732219	2.05%	Indiana	49	1.63%	-0.42%
Iowa	3155070	0.96%	Iowa	36	1.20%	0.23%
Kansas	2913314	0.89%	Kansas	22	0.73%	-0.16%
Kentucky	4467673	1.36%	Kentucky	40	1.33%	-0.03%
Louisiana	4648794	1.42%	Louisiana	28	0.93%	-0.49%
Maine	1344212	0.41%	Maine	17	0.56%	0.16%
Maryland	6045680	1.84%	Maryland	46	1.53%	-0.31%
Massachusetts	6892503	2.10%	Massachusetts	85	2.82%	0.72%
Michigan	9986857	3.04%	Michigan	96	3.19%	0.15%
Minnesota	5639632	1.72%	Minnesota	50	1.66%	-0.06%
Mississippi	2976149	0.91%	Mississippi	17	0.56%	-0.34%
Missouri	6137428	1.87%	Missouri	51	1.69%	-0.18%
Montana	1068778	0.33%	Montana	7	0.23%	-0.09%
Nebraska	1934408	0.59%	Nebraska	20	0.66%	0.08%
Nevada	3080156	0.94%	Nevada	57	1.89%	0.96%
New Hampshire	1359711	0.41%	New Hampshire	16	0.53%	0.12%
New Jersey	8882190	2.71%	New Jersey	27	0.90%	-1.81%
New Mexico	2096829	0.64%	New Mexico	19	0.63%	-0.01%
New York	19453561	5.93%	New York	110	3.65%	-2.27%
North Carolina	10488084	3.20%	North Carolina	92	3.06%	-0.14%
North Dakota	762062	0.23%	North Dakota	5	0.17%	-0.07%
Ohio	11689100	3.56%	Ohio	114	3.79%	0.23%
Oklahoma	3956971	1.21%	Oklahoma	28	0.93%	-0.28%
Oregon	4217737	1.28%	Oregon	59	1.96%	0.68%
Pennsylvania	12801989	3.90%	Pennsylvania	190	6.31%	2.41%
Rhode Island	1059361	0.32%	Rhode Island	13	0.43%	0.11%
South Carolina	5148714	1.57%	South Carolina	51	1.69%	0.13%
South Dakota	884659	0.27%	South Dakota	7	0.23%	-0.04%

State or Territory	Population	% of US Population	State or Territory	Respondents	% of US Sample	Difference in % of US Population
Tennessee	6829174	2.08%	Tennessee	58	1.93%	-0.15%
Texas	28995881	8.83%	Texas	198	6.58%	-2.26%
Utah	3205958	0.98%	Utah	29	0.96%	-0.01%
Vermont	623989	0.19%	Vermont	6	0.20%	0.01%
Virginia	8535519	2.60%	Virginia	75	2.49%	-0.11%
Washington	7614893	2.32%	Washington	90	2.99%	0.67%
West Virginia	1792147	0.55%	West Virginia	14	0.47%	-0.08%
Wisconsin	5822434	1.77%	Wisconsin	75	2.49%	0.72%
Wyoming	578759	0.18%	Wyoming	3	0.10%	-0.08%
			Outside US in Sept to Dec 2019 (currently in US)	20	0.66%	
Total US population	328239523		Total US Sample Size	3010		

AU Bureau of Statistics Nationwide Population Place of Residence: September 2019			AU Sample Respondent Place of Residence: September to December 2019			Comparison
State or Territory	Population	% of AU Population	State or Territory	Population	% of AU Sample	Difference in % of AU Population
New South Wales	8118000	31.89%	New South Wales	379	24.76%	-7.13%
Queensland	5115500	20.09%	Queensland	278	18.16%	-1.93%
South Australia	1756500	6.90%	South Australia	201	13.13%	6.23%
Tasmania	535500	2.10%	Tasmania	58	3.79%	1.69%
Victoria	6629900	26.04%	Victoria	335	21.88%	-4.16%
Western Australia	2630600	10.33%	Western Australia	212	13.85%	3.51%
Northern Territory	245600	0.96%	Northern Territory	33	2.16%	1.19%
Australian Capital Territory	428100	1.68%	Australian Capital Territory	11	0.72%	-0.96%
			Outside AU Sept to Dec 2019 (currently in AU)	24	1.57%	
Total AU population	25459700		Total AU Sample Size	1531		

**Appendix 7. Supplement to Chapter Seven: Follow-up Survey
of US Adult Reports of Mental Health, Substance Use, and
Suicidal Ideation During the COVID-19 Pandemic,
September 2020**

Supplemental Online Content

Czeisler MÉ, Lane RI, Wiley JF, Czeisler CA, Howard ME, Rajaratnam SMW. Follow-up survey of US adult reports of mental health, substance use, and suicidal ideation during the COVID-19 pandemic, September 2020. *JAMA Netw Open*. 2021;4(2):e2037665. doi:10.1001/jamanetworkopen.2020.37665

eAppendix. Supplementary Methods

eReferences.

This supplemental material has been provided by the authors to give readers additional information about their work.

eAppendix. Supplementary Methods

Study review and approval

This activity was reviewed by US Centers for Disease Control and Prevention (CDC) and was conducted consistent with applicable federal law and CDC policy (i.e., 45 C.F.R. part 46, 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d); 5 U.S.C. Sect. 552a; 44 U.S.C. Sect. 3501 et seq.).

Recruitment Methodologies

Qualtrics recruitment methodologies include digital advertisements and promotions, word of mouth, and membership referrals, social networks, television and radio advertisements, and offline, mail-based approaches. Potential respondents received invitations and could opt to participate by activating a survey link directing them to the participation information and consent page preceding the survey. Ineligible respondents who did not meet inclusion criteria (eg, aged below 18 years, or exceeded pre-specified demographic quotas) were disempaneled from the survey.

Screening tools

Symptoms of anxiety and depression were assessed via the 4-item Patient Health Questionnaire (PHQ-4).¹ Those who scored at least 3 of 6 on the Generalized Anxiety Disorder (GAD-2) or the Patient Health Questionnaire (PHQ-2) subscales were considered symptomatic of an anxiety or depression. Symptoms of a COVID-19 trauma- and stressor-related disorder (TSRD) were assessed via the 6-item Impact-of-Event Scale to screen for overlapping symptoms of posttraumatic stress disorder, acute stress disorder, and adjustment disorders (IES-6).² For this survey, the COVID-19 pandemic

was specified as the traumatic exposure to record peri- and posttraumatic symptoms associated with the range of stressors introduced by the COVID-19 pandemic. Those who scored at least 1.75 of 4 were considered symptomatic. Trauma- and stressor-related symptoms assessed were common to multiple TSRDs, including posttraumatic stress disorder (PTSD), acute stress disorder (ASD), and adjustment disorders (ADs) to capture COVID-19–specific trauma and stress symptoms responsive to prolonged exposures that do not meet diagnostic criteria for PTSD.^{3,4} Symptoms of insomnia were assessed via the 2-item Sleep Condition Indicator (SCI-02).⁵ Those who scored less than or equal to 2 of 8 were considered symptomatic. Persons who had disabilities were defined as such based on a response indicating limitations of activities because of physical, mental, or emotional conditions, or health conditions that require special equipment, based on the CDC Behavioral Risk Factor Surveillance System. Substance use was defined as use of “alcohol, legal or illegal drugs, or prescriptions drugs that are taken in a way not recommended by your doctor,” and respondents were given the opportunity to respond “Yes”, “No”, or “Prefer not to say.” Suicidal ideation was indicated by responses to the question: “At any time in the past 30 days, did you seriously think about trying to kill yourself?”

Reporting Race/Ethnicity

Race and ethnicity were assessed among survey respondents with separate questions and options defined by the investigators based on US Census classifications. The race and ethnicity questions follow.

1. What is your race? (Select all that apply)
 - a. American Indian or Alaskan Native

- b. Asian
- c. Black or African American
- d. Native Hawaiian or other Pacific Islander
- e. White
- f. Other

Please use the categories that most reflect your recognition in the community for purposes of reporting mixed racial and/or ethnic origins.

American Indian or Alaskan Native: a person having origins in any of the original peoples of North, Central, or South America, and maintains tribal affiliations or community attachment.

Asian: A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

Black or African American: A person having origins in any of the black racial groups of Africa.

Native Hawaiian or Pacific Islander: A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

White: A person having origins in any of the original peoples of Europe, North Africa, or the Middle East.

2. What is your ethnicity? (Select one)

- a. Hispanic or Latino
- b. Not Hispanic or Latino

Hispanic or Latino: A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race.

For this analysis, race and ethnicity were combined into the following categories: White, non-Hispanic; Black, non-Hispanic; Asian, non-Hispanic; Multiple races or Other race, non-Hispanic; and Hispanic, any race or races.

Race and ethnicity were assessed in this study given mental health disparities documented during the COVID-19 pandemic.

Secondary screening criteria

Following Qualtrics standard screening procedures, the investigators conducted a secondary screening, including removal of duplicate respondents, those who reported

invalid US ZIP codes according to the US Department of Housing and Urban Development United States Postal Service ZIP Code Crosswalk Files, recontacts who had moved outside of the US, and those with missing or uncharacterizable responses to demographic questions used for weighting (sex, age, race/ethnicity).

Survey Weighting

Survey weights were trimmed ($0.3 \leq \text{weight} \leq 3.0$).

Longitudinal analysis, June 2020 and September 2020

Participants who completed June 2020 surveys, including first-time June 2020 respondents and those recontacted from April 2020, were reweighted for longitudinal analyses. McNemar χ^2 test with continuity correction was used to test for changes in prevalence of all 5 mental or behavioral health measures between June 2020 and September 2020.

September 2020 regressions

For regression models, respondents who did not provide characterizable responses to variables included in the model were excluded, including the following: sexual orientation (“Something else,” “I don’t know the answer,” and “Prefer not to say”; total n = 174 [3.4%]) and disability status (“Prefer not to say”; n = 216 [4.2%]).

Additional information

Methods were further detailed elsewhere.⁶

eReferences

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3. Shevlin M, Hyland P, Karatzias T. Is posttraumatic stress disorder meaningful in the context of the COVID-19 pandemic: response to Van Overmeire's commentary on Karatzias et al. (2020). *J Trauma Stress*. 2020;3(5):866-868. doi:10.1002/jts.22592
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6. Czeisler MÉ, Lane RI, Petrosky E, et al. Mental health, substance use, and suicidal ideation during the COVID-19 pandemic. *MMWR Morb Mortal Wkly Rep*. 2020;69(32):1049-1057. doi:10.15585/mmwr.mm6932a1

Appendix 8. Supplement to Chapter Ten: Mental health, substance use, and suicidal ideation during a prolonged COVID-19-related lockdown in a region with low SARS-CoV-2 prevalence

Supplementary Methods

Mental health, substance use, and suicidal ideation during a prolonged COVID-19–related lockdown in a region with low SARS-CoV-2 prevalence

Mark É. Czeisler, Joshua F. Wiley, Elise R. Facer-Childs, Rebecca Robbins, Matthew D. Weaver, Laura K. Barger, Charles A. Czeisler, Mark E. Howard, Shantha M.W. Rajaratnam

Corresponding author: Mark É. Czeisler, mark.czeisler@fulbrightmail.org

The COVID-19 Outbreak Public Evaluation (COPE) Initiative

The mission of The COPE Initiative is to assess public attitudes, behaviours, and beliefs related to the COVID-19 pandemic, and to evaluate mental and behavioural health during the pandemic. Our goal is to provide the public a voice through the collection and dissemination of findings that help shape the design and delivery of targeted communication and intervention strategies to improve public health efforts and save lives.

More information about The COPE Initiative can be found at www.thecopeinitiative.org.

Qualtrics, LLC – Recruitment methodology

In this section, we provide more details about the Qualtrics, LLC (Provo, Utah, and Seattle, Washington, USA), the data source, and about its advantages and limitations. Qualtrics partners with sample partners that employ various recruitment methodologies, with most samples come from traditional, actively managed, double-opt-in market research panels, through which sample partners randomly select respondents for surveys where respondents are likely to qualify. Most survey invitations are sent via email, in-mobile-application notifications, and Short Message Service (SMS) notifications, and do not include information about the contents of the survey to reduce self-selection bias. Respondents receive incentives, which vary and may include cash, airline miles, gift cards, redeemable points, charitable donations, sweepstakes entrance, and vouchers, with the level of incentive based on a number of factors, including the length of the survey.

For additional information, ESOMAR (www.esomar.org) provides a Guideline for Online Research that provides further detail for how Qualtrics aims for best practices in the handling of ethical, methodological, and regulatory issues, as well as the legalities regarding technology in research.¹

For this study, Qualtrics was selected based on its demonstrated ability to recruit more demographically representative samples compared with alternative online survey companies (eg, Facebook, Amazon Mechanical Turk).²

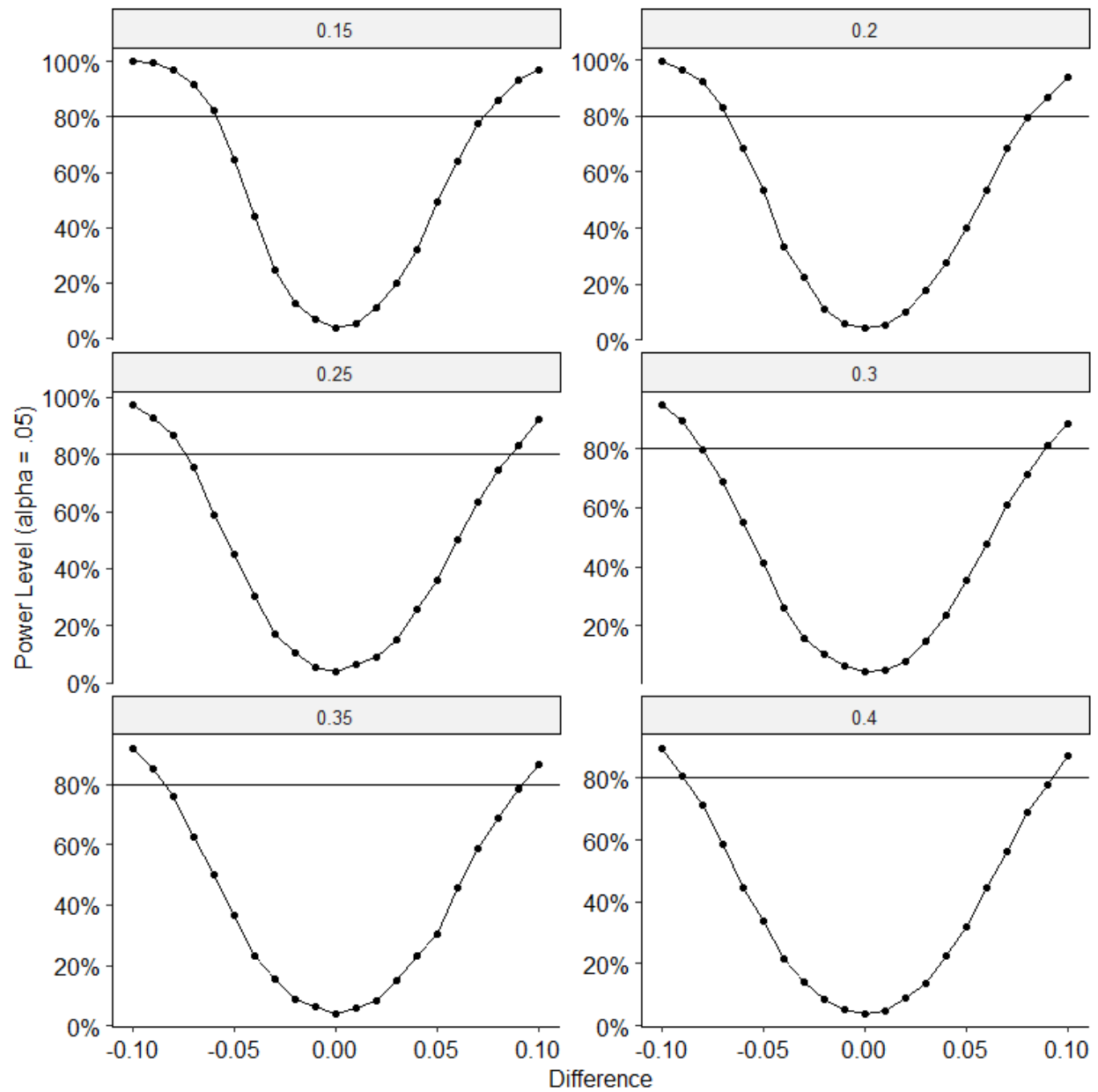
Qualtrics LLC response screening

Qualtrics employs multiple algorithmic analyses of survey responses to improve the quality of responses through the identification of click thru behaviour, duplicate responses, machine responses (ie, bots), inattentiveness, and through geolocation verification via country-level Internet Protocol (IP) address mapping. For this analysis, geolocation verification was employed to confirm that respondents who self-reported residence within the US were responding to the survey from within the US.

Secondary response screening and inclusion criteria

All surveys underwent Qualtrics, LLC data quality screening procedures, including algorithmic and keystroke analysis for attention patterns, click-through behaviour, duplicate responses, machine responses, and inattentiveness. In addition to the Qualtrics standard measures for quality control, given the encoding of postal codes as variables in this analysis, supplementary cleaning of postal codes was conducted to ensure all manually entered values were valid Victorian postal codes.

Power analysis



Output from Monte Carlo simulation power analyses.³

Definition and encoding of outcome measures

1. **Symptoms of an anxiety disorder** encoded as one categorical variable: Yes and No. Anxiety disorder symptoms were assessed via the 2-item Generalized Anxiety Disorder (GAD-2) subscale of the 4-item Patient Health Questionnaire.⁴ Respondents who scored ≥ 3 out of 6 on the GAD-2 were considered symptomatic for an anxiety disorder.
2. **Symptoms of a depressive disorder** encoded as one categorical variable: Yes and No. Depressive disorder symptoms were assessed via the 2-item Patient Health Questionnaire (PHQ-2) subscale of the 4-item Patient Health Questionnaire.⁴ Respondents who scored ≥ 3 out of 6 on the PHQ-2 were considered symptomatic for an anxiety disorder.
3. **Symptoms of an anxiety or depressive disorder** encoded as one categorical variable: Yes and No. Anxiety or depressive disorder symptoms were classified if a respondent screened positive for symptoms of an anxiety disorder (Item 1), symptoms of a depressive disorder (Item 2), or both.
4. **Symptoms of a COVID-19 trauma- and stressor-related disorder (COVID-19 TSRD) (September)** encoded as one categorical variable: Yes and No. Symptoms of a COVID-19 TSRD were assessed via the six-item Impact of Event Scale (IES-6)⁵ to screen for overlapping symptoms of post-traumatic stress disorder (PTSD), acute stress disorder (ASD), and adjustment disorders (ADs). For this survey, the COVID-19 pandemic was specified as the traumatic exposure to record peri- and posttraumatic symptoms associated with the range of stressors introduced by the COVID-19 pandemic. Those who scored ≥ 1.75 out of 4 were considered symptomatic.
5. **Symptoms of burnout** encoded as one categorical variable: Yes and No. Symptoms of burnout were assessed via a single-item burnout measure.⁶
6. **World Health Organization Well-Being Index Quartile (September)** encoded as one categorical variable: 0–25%, 26–50%, 51–75%, and 76–100%, based on percentile score. Well-being was assessed using the WHO-5.⁷
7. **Having started or increased substance use to cope with stress or emotions related to COVID-19 (September)** encoded as one categorical variable: Yes and No. For this survey, substance use was defined as use of “alcohol, legal or illegal drugs, or prescriptions drugs that are taken in a way not recommended by your doctor.”
8. **Seriously thought of trying to kill themselves in the prior 30 days (September)** encoded as one categorical variable: Yes and No. Respondents were categorised based on their response to the following question: “At any time in the past 30 days, did you seriously think about trying to kill yourself?”

Participants were informed that responses were deidentified and that direct support could not be provided to those who reported substance use behaviour or suicidal ideation. Participants were provided with resources for adverse mental health symptoms, substance use, suicidal ideation.

9. **Passive suicidal ideation in the prior 30 days (September)** encoded as one categorical variable: Yes and No. This was assessed using a modified item from the Columbia-Suicide Severity Rating Scale (C-SSRS),⁸ as follows: “At any time in the past 30 days, have you wished you were dead or wished you could go to sleep and not wake up?”
10. **Any suicidal ideation in the prior 30 days (September)** encoded as one categorical variable: Yes and No. If respondents answered “Yes” to the questions in Items 8 or 9, they were categorised as having experienced suicidal ideation in the prior 30 days.

Definition and encoding of explanatory measures

Covariates for the analysis can be categorised as demographic characteristics, medical history, sleep measures, and behavioural changes. Covariates assessed in the September wave only are indicated as such.

11. **Age group in years** encoded as one categorical variable: 18–24, 25–44, 45–64, ≥ 65 . Responses were collected on a continuous scale and later categorised.

12. **Sex** encoded as one categorical variable: Female and Male. For April-2020, gender was collected, and sex was not collected. Given that the Census did not assess gender, population estimates were reported by sex.
13. **Sexual orientation (September)** encoded as one categorical variable: Heterosexual, Lesbian or gay, Bisexual, Something else, I don't know the answer, and Prefer not to say.
14. **Ancestry** encoded as one categorical variable: Oceanian, North-West European, South-East European, North-East Asian, South-East Asian, South and Central Asian, North African and Middle Eastern, Sub-Saharan African, Peoples of the Americas, North-West European, North-West European & Oceanian, Other combination, and Unknown. Ancestry was assessed via the ancestry question on the 2016 Australian Census Household Form (Question 18), with respondents able to provide up to two ancestries. Responses were manually encoded into broad groups according to the Australian Standard Classification of Cultural and Ethnic Groups (ASCCEG), 2016 (cat. no. 1249.0) to classify responses given to the ancestry question. Respondents who reported multiple ancestries other than North-West European & Oceanian were classified as due to a low number of responses, and those who did not provide an answer or who did not provide enough information for classification were categorised as Unknown.
15. **Disability status (September)** encoded as one categorical variable: Not living with disability, Living with a disability and receive support from the 2013 National Disability Insurance Scheme,⁹ Living with a disability and receive support from the 2013 National Disability Insurance Scheme, Prefer not to say. Respondents were asked whether they had an intellectual, physical, sensory, cognitive, or psychosocial disability.
16. **Highest education attainment** encoded as one categorical variable: Secondary diploma or less, More than secondary diploma, less than bachelor's degree, and Bachelor's degree or more. Education was re-categorised based on survey responses: Secondary diploma or less (Less than secondary school, Secondary school or equivalent), More than secondary diploma, less than bachelor's degree (Some university), and Bachelor's degree or more [Bachelor's degree or equivalent, Doctoral or professional degree (PhD, MD, JD, MBA, etc.)]. This re-categorisation was done for weighting purposes, so responses could be matched with Census data: Secondary diploma or less (Secondary Education - Years 10 and above, Certificate I & II Level, Secondary Education - Years 9 and below), More than secondary diploma, less than bachelor's degree (Advanced Diploma and Diploma Level, Certificate III & IV Level), and Bachelor's degree or more (Postgraduate Degree Level, Bachelor Degree Level, Graduate Diploma and Graduate Certificate Level)
17. **Regional versus metropolitan postal code (September)** encoded as one categorical variable: Regional and Metropolitan. Regional versus metropolitan postal code classification was determined using self-reported postal codes according to the Victorian Department of Health and Human Services COVID-19 local regional restrictions map (<https://www.dhhs.vic.gov.au/victorias-restriction-levels-covid-19>).
18. **Employment status** encoded as one categorical variable: Employed, Unemployed, Retired, and Student. Employed respondents included those who indicated they were employed part-time, employed full-time, and self-employed. Students who were also employed were classified as Employed.
19. **Essential worker status (September)** encoded as one categorical variable: Essential and Nonessential. Self-reported essential worker status was only assessed among respondents who were employed.
20. **Unpaid caregiver status (September)** encoded as one categorical variable: Not an unpaid caregiver, Unpaid caregiver for adults only, Unpaid caregiver for children or adolescents only, and Multigenerational unpaid caregivers (unpaid caregivers for both adults and children or adolescents). For this survey, caregiver status was self-reported. The definition of an unpaid caregiver for adults was a person who had provided unpaid care to a relative or friend aged ≥ 18 years to help them take care of themselves at any time in the last 3 months. Examples provided included helping with personal needs, household chores, health care tasks, managing a person's finances, taking them to a doctor's appointment, arranging for outside services, and visiting regularly to see how they are doing. The definition of an unpaid caregiver for children or adolescents was a person who had provided unpaid care to a child or adolescent aged < 18 years to help raise them or help them take care of themselves at any time in the last 3 months. Examples provided included helping them with schoolwork, personal needs, household chores, health care and nutrition, taking them to a doctor's appointment, arranging for outside services, visiting regularly to see how they are doing.

21. **Political ideology** encoded as one categorical variable: Far left, Slightly left, Centre, Slightly right, Far right, Apolitical and/or prefer not to answer.
22. **COVID-19 risk perception** encoded as one categorical variable: Yes and No. For this survey, COVID-19 risk perception was assessed based on whether respondents selected that they agreed with the following statement: “I believe that I am in a group at high risk of severe illness caused by COVID-19.”
23. **Diurnal preference** encoded as one categorical variable: Definite morning type, Somewhat morning type, Somewhat evening type, and Definite evening type. Diurnal preference was assessed via Item 19 of the Horne & Östberg Morningness-Eveningness Questionnaire.¹⁰

Covariates related to medical history of sleep and psychiatric conditions. Medical history of sleep and psychiatric conditions were also considered and included as covariates in separate models given potential collinearity with each other. Respondents reported whether they had ever been diagnosed with each condition, with the response options of “Never”, “Yes, I have in the past, but don’t have it now”, “Yes I have, and I am regularly taking medications or receiving treatment”, and “Yes I have, but I do not regularly take medications or receive treatment”. Respondents who indicated they had every been diagnosed with a given condition (ie, selected a response other than “Never”) were classified as having previously been diagnosed with the condition.

24. **Anxiety disorder** encoded as one categorical variable: Yes and No.
25. **Depression** encoded as one categorical variable: Yes and No.
26. **Post-traumatic stress disorder** encoded as one categorical variable: Yes and No.
27. **Substance use disorder (September)** encoded as one categorical variable: Yes and No.
28. **Psychiatric condition** encoded as one categorical variable: Yes and No. Respondents were classified as having previously been diagnosed with a psychiatric condition if they were classified as “Yes” for any of Items 24–26 (April) or Items 24–27 (September).
29. **Insomnia** encoded as one categorical variable: Yes and No.
30. **Obstructive sleep apnoea** encoded as one categorical variable: Yes and No.
31. **Narcolepsy** encoded as one categorical variable: Yes and No.
32. **Restless leg syndrome** encoded as one categorical variable: Yes and No.
33. **Shift work disorder** encoded as one categorical variable: Yes and No.
34. **Periodic limb movement disorder** encoded as one categorical variable: Yes and No.
35. **Sleep condition** encoded as one categorical variable: Yes and No. Respondents were classified as having previously been diagnosed with a sleep condition if they were classified as “Yes” for any of Items 29–34.

Covariates that were sleep measures follow.

36. **Sleep duration per 24-hour period in hours** encoded as one ordinal variable: <6, 6–7, >7. Responses were collected on a continuous scale and later categorised.
37. **Symptoms of insomnia** encoded as one categorical variable: Yes and No. Symptoms of insomnia were assessed via the two-item Sleep Condition Indicator (SCI-02: nights per week having a sleep problem, extent troubled by poor sleep).¹¹
38. **More time in bed compared to before the COVID-19 pandemic** encoded as a categorical variable: Yes and No.
39. **Less time in bed compared to before the COVID-19 pandemic** encoded as a categorical variable: Yes and No.
40. **More trouble falling asleep compared to before the COVID-19 pandemic** encoded as a categorical variable: Yes and No.
41. **Less trouble falling asleep compared to before the COVID-19 pandemic** encoded as a categorical variable: Yes and No.
42. **More regular sleep-wake schedule compared to before the COVID-19 pandemic** encoded as a categorical variable: Yes and No.
43. **Less regular sleep-wake schedule compared to before the COVID-19 pandemic** encoded as a categorical variable: Yes and No.

44. **Daytime sleepiness (September)** encoded as one categorical variable: Normal, Mild to Moderate, Excessive. Daytime sleepiness was assessed via the Epworth Sleepiness Scale, with scores 0–10 categorised as Normal, 11–15 Mild to Moderate, and ≥ 16 Excessive.^{12,13}

Covariates that were behavioural changes to before the COVID-19 pandemic follow.

45. **Daily time outdoors during daylight hours compared to before the COVID-19 pandemic** encoded as one categorical variable: Reduced by >1 hour, Reduced by ≤ 1 hour, About the same, Increased by ≤ 1 hour, Increased by >1 hour.
46. **Daily time on screens compared to before the COVID-19 pandemic** encoded as one categorical variable: Reduced by >1 hour, Reduced by ≤ 1 hour, About the same, Increased by ≤ 1 hour, Increased by >1 hour.
47. **Daily time spent following COVID-19 in hours** encoded as one ordinal variable: 0, 1, 2–3, ≥ 4 . For this variable, respondents were asked whether they had discussed, attended meetings, and/or followed news and announcements about COVID-19 in the two weeks prior to the survey. Respondents who indicated that they had done so were then asked to estimate the number of hours per day that respondents' spent following COVID-19. Those who indicated they were not following COVID-19 were designated as having spent 0 hours. Other responses were collected on a continuous scale and later categorised.

Statistical Analysis

Poisson regression models

For the Poisson regression models used to estimate adjusted prevalence ratios for adverse mental and behavioural health symptoms, respondents who did not provide complete questions for demographic variables included in a model were excluded. Those with incomplete demographics were excluded because it would be illogical to interpret findings for the “unknown” characteristic of a given variable. Groups within the sexual orientation and ancestry demographic characteristics were combined for estimating adjusted prevalence ratios in cases where small size could lead to unstable and inaccurate estimates. For sexual orientation, respondents were re-categorized as Heterosexual (Heterosexual) or Other (Lesbian or gay, Bisexual, Something else), with those who responded as “I don't know the answer” or “Prefer not to say” excluded from the Poisson regression models. For ancestry, respondents were re-categorised as Oceanian (Oceanian), South-East European (South-East European), North-West European (North-West European), Southern and Central Asian (Southern and Central Asian), North-East Asian (North-East Asian), South-East Asian (South-East Asian), North-West European, Oceanian (North-West European, Oceanian), and Other or Other Combination (Other or Other Combination, North African and Middle Eastern, Peoples of the Americas, and Sub-Saharan African), with those with unknown ancestry excluded from the Poisson regression models.

Longitudinal analysis

Incidence and remission of symptoms of anxiety or depressive disorder, burnout, and insomnia, along with sleep duration <6 hours and spending time following COVID-19, were assessed in the Victorian-Longitudinal sample. Continuity-corrected McNemar's Chi-squared tests were used to test for within-participant differences in the prevalence of these conditions between April-2020 and September-2020.

Supplementary Results

Table 1 – Characteristics of the April samples before and after weighting

Table 2 – Characteristics of the September samples before and after weighting

Table 3 – Prevalence of adverse mental and behavioural health symptoms among Victorian adults, by demographic characteristics, September 2020

Table 4 – Prevalence of adverse mental and behavioural health symptoms among Victorian adults, by medical history, sleep, and behavioural changes, September 2020

Table 5 – Adjusted prevalence ratios for having experienced at least one adverse mental or behavioural health symptoms condition Victorian adults, by demographic characteristics, medical history, sleep, and behavioural changes, September 2020

Table 6 – Adjusted prevalence ratios for adverse mental and behavioural health symptoms among Victorian adults, by select sleep and psychiatric conditions, September 2020

Table 7 – Longitudinal incidence and remission of adverse mental and behavioural health symptoms – Victoria, April & September 2020

Table 1 – Characteristics of the April samples before and after weighting

	April non-Victorian Australian				April Victorian			
	unweighted		weighted		unweighted		weighted	
	n	(%)	n	(%)	n	(%)	n	(%)
Demographics	1164	(100)	1164	(100)	331	(100)	331	(100)
Sex								
Male	517	(44.4)	536	(46.1)	159	(48.0)	171	(51.7)
Female	647	(55.6)	628	(53.9)	172	(52.0)	160	(48.3)
Age group, years								
18-24	151	(13.0)	141	(12.1)	58	(17.5)	42	(12.8)
25-44	404	(34.7)	423	(36.4)	116	(35.0)	123	(37.2)
45-64	379	(32.6)	389	(33.4)	98	(29.6)	105	(31.7)
≥65	230	(19.8)	211	(18.1)	59	(17.8)	61	(18.4)
Ancestry								
Oceanian	304	(26.1)	297	(25.5)	77	(23.3)	86	(26.1)
North-West European	368	(31.6)	375	(32.2)	75	(22.7)	82	(24.8)
South-East European	78	(6.7)	74	(6.4)	38	(11.5)	32	(9.6)
North-East Asian	58	(5.0)	54	(4.6)	23	(6.9)	19	(5.8)
South-East Asian	41	(3.5)	37	(3.2)	16	(4.8)	16	(4.8)
South and Central Asian	43	(3.7)	40	(3.4)	27	(8.2)	22	(6.7)
North African and Middle Eastern	12	(1.0)	15	(1.3)	9	(2.7)	9	(2.8)
Sub-Saharan African	6	(0.5)	3	(0.3)	1	(0.3)	0	(0.1)
Peoples of the Americas	12	(1.0)	12	(1.0)	5	(1.5)	4	(1.1)
North-West European, Oceanian	146	(12.5)	153	(13.1)	29	(8.8)	34	(10.4)
Other combination	90	(7.7)	98	(8.4)	30	(9.1)	25	(7.6)
Unknown	6	(0.5)	6	(0.5)	1	(0.3)	1	(0.2)
Highest education attainment								
Secondary diploma or less	518	(44.5)	541	(46.5)	105	(31.7)	147	(44.4)
More than secondary diploma, less than bachelor's degree	192	(16.5)	311	(26.7)	58	(17.5)	90	(27.2)
Bachelor's degree or more	454	(39.0)	312	(26.8)	168	(50.8)	94	(28.4)
Employment status								
Employed	641	(55.1)	650	(55.8)	199	(60.1)	183	(55.4)
Unemployed	178	(15.3)	191	(16.4)	42	(12.7)	47	(14.2)
Retired	259	(22.3)	242	(20.8)	60	(18.1)	70	(21.2)
Student	86	(7.4)	81	(7.0)	30	(9.1)	31	(9.2)
Political ideology								
Far left	79	(6.8)	80	(6.9)	18	(5.4)	14	(4.4)
Slightly left	230	(19.8)	217	(18.6)	66	(19.9)	69	(20.8)
Centre	369	(31.7)	391	(33.6)	105	(31.7)	106	(32.0)
Slightly right	236	(20.3)	225	(19.4)	73	(22.1)	70	(21.2)
Far right	81	(7.0)	82	(7.1)	18	(5.4)	19	(5.7)
Apolitical and/or prefer not to answer	169	(14.5)	168	(14.5)	51	(15.4)	53	(16.0)
COVID-19 risk perception								
Believe to be at high risk for severe COVID-19 illness	234	(20.1)	217	(18.7)	67	(20.2)	64	(19.3)
Do not believe to be at high risk for severe COVID-19 illness	930	(79.9)	947	(81.3)	264	(79.8)	267	(80.7)
Diurnal preference								
Definite morning type	314	(27.0)	328	(28.2)	87	(26.3)	90	(27.1)
Rather more of a morning type than evening type	279	(24.0)	274	(23.6)	74	(22.4)	67	(20.4)
Rather more of an evening type than morning type	334	(28.7)	325	(27.9)	93	(28.1)	98	(29.7)
Definite evening type	237	(20.4)	236	(20.3)	77	(23.3)	75	(22.8)
History of diagnosed sleep condition								
Yes	371	(31.9)	371	(31.8)	94	(28.4)	91	(27.5)
No	793	(68.1)	793	(68.2)	237	(71.6)	240	(72.5)
History of diagnosed psychiatric condition								
Yes	497	(42.7)	521	(44.8)	124	(37.5)	123	(37.1)
No	667	(57.3)	643	(55.2)	207	(62.5)	208	(62.9)
State or territory of residence								
Victoria (VIC)	0	(0.0)	0	(0.0)	331	(100)	331	(100)
New South Wales (NSW)	374	(32.1)	498	(42.8)	0	(0.0)	0	(0.0)
Queensland (QLD)	276	(23.7)	314	(27.0)	0	(0.0)	0	(0.0)
South Australia (SA)	199	(17.1)	115	(9.9)	0	(0.0)	0	(0.0)
West Australia (WA)	212	(18.2)	162	(14.0)	0	(0.0)	0	(0.0)
Tasmania (TAS)	59	(5.1)	35	(3.0)	0	(0.0)	0	(0.0)

Australian Capital Territory (ACT)	33	(2.8)	26	(2.2)	0	(0.0)	0	(0.0)
Northern Territory (NT)	11	(0.9)	14	(1.2)	0	(0.0)	0	(0.0)

Table 2 – Characteristics of the September samples before and after weighting

	Victorian September				Victorian Longitudinal			
	unweighted		weighted		unweighted		weighted	
	n	(%)	n	(%)	n	(%)	n	(%)
Demographics	1249	(100)	1249	(100)	92	(100)	92	(100)
Sex								
Male	596	(47.7)	589	(47.2)	52	(56.5)	46	(49.5)
Female	653	(52.3)	660	(52.8)	40	(43.5)	46	(50.5)
Age group, years								
18-24	84	(6.7)	134	(10.7)	6	(6.5)	11	(12.3)
25-44	487	(39.0)	470	(37.6)	29	(31.5)	34	(36.5)
45-64	443	(35.5)	408	(32.7)	32	(34.8)	29	(31.1)
≥65	235	(18.8)	236	(18.9)	25	(27.2)	19	(20.2)
Sexual Orientation								
Heterosexual	1110	(88.9)	1114	(89.2)	86	(93.5)	82	(88.9)
Lesbian or gay	47	(3.8)	47	(3.8)	2	(2.2)	3	(3.3)
Bisexual	51	(4.1)	45	(3.6)	2	(2.2)	2	(1.9)
Something else	10	(0.8)	9	(0.7)	1	(1.1)	3	(2.7)
I don't know the answer	8	(0.6)	14	(1.1)	1	(1.1)	3	(3.2)
Prefer not to say	23	(1.8)	20	(1.6)	0	(0.0)	0	(0.0)
Ancestry								
Oceanian	305	(24.4)	319	(25.6)	27	(29.3)	29	(32.0)
North-West European	369	(29.5)	406	(32.5)	21	(22.8)	22	(23.7)
South-East European	124	(9.9)	120	(9.6)	14	(15.2)	12	(12.9)
North-East Asian	85	(6.8)	56	(4.5)	7	(7.6)	8	(8.5)
South-East Asian	47	(3.8)	46	(3.7)	3	(3.3)	5	(5.0)
South and Central Asian	98	(7.8)	77	(6.2)	9	(9.8)	6	(6.2)
North African and Middle Eastern	20	(1.6)	15	(1.2)	1	(1.1)	1	(0.9)
Sub-Saharan African	2	(0.2)	2	(0.2)	0	(0.0)	0	(0.0)
Peoples of the Americas	12	(1.0)	12	(0.9)	3	(3.3)	2	(1.7)
North-West European, Oceanian	99	(7.9)	106	(8.5)	6	(6.5)	6	(6.5)
Other combination	74	(5.9)	80	(6.4)	1	(1.1)	3	(2.7)
Unknown	14	(1.1)	10	(0.8)	0	(0.0)	0	(0.0)
Disability status								
None	1083	(86.7)	1071	(85.7)	79	(85.9)	79	(85.4)
Yes, qualify for NDIS	50	(4.0)	39	(3.1)	2	(2.2)	1	(1.2)
Yes, do not qualify for NDIS	100	(8.0)	123	(9.8)	11	(12.0)	12	(13.4)
Unknown	16	(1.3)	17	(1.3)	0	(0.0)	0	(0.0)
Highest education attainment								
Secondary diploma or less	394	(31.5)	543	(43.5)	32	(34.8)	40	(43.6)
More than secondary diploma, less than bachelor's degree	187	(15.0)	337	(27.0)	14	(15.2)	25	(27.0)
Bachelor's degree or more	668	(53.5)	369	(29.5)	46	(50.0)	27	(29.5)
Regional vs metropolitan postal code								
Regional	255	(20.4)	278	(22.3)	22	(23.9)	23	(25.1)
Metropolitan	994	(79.6)	971	(77.7)	70	(76.1)	69	(74.9)
Employment status								
Employed	751	(60.1)	695	(55.7)	48	(52.2)	46	(50.3)
Unemployed	192	(15.4)	227	(18.2)	14	(15.2)	17	(18.4)
Retired	266	(21.3)	273	(21.9)	26	(28.3)	22	(23.5)
Student	40	(3.2)	53	(4.3)	4	(4.3)	7	(7.8)
Essential worker status (among employed)								
Essential	401	(53.4)	384	(55.3)	21	(43.8)	24	(51.1)
Nonessential	350	(46.6)	311	(44.7)	27	(56.3)	23	(48.9)
Unpaid caregiver status								
None	751	(60.1)	782	(62.6)	56	(60.9)	56	(61.1)
Unpaid caregiver for adults	168	(13.5)	164	(13.1)	8	(8.7)	8	(9.0)
Unpaid caregiver for children or adolescents	147	(11.8)	141	(11.3)	19	(20.7)	17	(18.1)
Multigenerational unpaid caregiver	183	(14.7)	163	(13.1)	9	(9.8)	11	(11.8)
Political ideology								
Far left	65	(5.2)	72	(5.8)	8	(8.7)	8	(9.2)
Slightly left	255	(20.4)	236	(18.9)	15	(16.3)	15	(16.0)
Centre	408	(32.7)	432	(34.5)	29	(31.5)	33	(36.1)
Slightly right	208	(16.7)	188	(15.1)	20	(21.7)	16	(17.7)
Far right	121	(9.7)	117	(9.3)	7	(7.6)	5	(5.9)

Apolitical and/or prefer not to answer	192	(15.4)	205	(16.4)	13	(14.1)	14	(15.2)
COVID-19 risk perception								
Believe to be at high risk for severe COVID-19 illness	219	(17.5)	209	(16.7)	22	(23.9)	16	(17.0)
Do not believe to be at high risk for severe COVID-19 illness	1030	(82.5)	1040	(83.3)	70	(76.1)	76	(83.0)
Diurnal preference								
Definite morning type	342	(27.4)	334	(26.7)	24	(26.1)	20	(21.8)
Rather more of a morning type than evening type	332	(26.6)	317	(25.4)	23	(25.0)	24	(26.0)
Rather more of an evening type than morning type	348	(27.9)	355	(28.4)	24	(26.1)	23	(25.1)
Definite evening type	227	(18.2)	243	(19.4)	21	(22.8)	25	(27.1)
History of diagnosed sleep condition								
Yes	390	(31.2)	379	(30.4)	31	(33.7)	29	(31.5)
No	859	(68.8)	870	(69.6)	61	(66.3)	63	(68.5)
History of diagnosed psychiatric condition								
Yes	456	(36.5)	474	(38.0)	31	(33.7)	38	(41.4)
No	793	(63.5)	775	(62.0)	61	(66.3)	54	(58.6)

Table 3 – Prevalence of adverse mental and behavioural health symptoms among Victorian adults, by demographic characteristics, September 2020

Mental or Behavioural Health Condition				Symptoms of Anxiety or Depressive Disorder		P	Symptoms of a COVID-19 TSRD		P	Started or Increased Substance Use		P	Suicidal ideation		P
Demographic	n	%	n	%	-	n	%	-	n	%	-	n	%	-	
Total Respondents	1249	(100)	427	(34.2)		379	(30.3)		154	(12.3)		220	(17.6)		
Sex															
Female	660	(52.8)	239	(36.2)	1.00	202	(30.6)	1.00	77	(11.6)	1.00	106	(16.1)	1.00	
Male	589	(47.2)	189	(32.0)		177	(30.0)		77	(13.0)		113	(19.2)		
Age Group, years															
18–24	134	(10.7)	68	(51.0)	<0.0001	70	(52.3)	<0.0001	12	(8.8)	<0.0001	42	(31.6)	<0.0001	
25–44	470	(37.6)	214	(45.4)		187	(39.7)		90	(19.1)		109	(23.1)		
45–64	408	(32.7)	114	(28.0)		96	(23.4)		41	(10.1)		52	(12.6)		
≥65	236	(18.9)	31	(13.1)		26	(11.1)		11	(4.6)		17	(7.2)		
Sexual Orientation															
Heterosexual	1114	(89.2)	368	(33.0)	1.00	324	(29.1)	1.00	126	(11.3)	1.00	187	(16.8)	1.00	
Lesbian or gay	47	(3.8)	15	(32.7)		10	(20.4)		7	(14.2)		9	(18.5)		
Bisexual	45	(3.6)	20	(45.0)		24	(52.6)		14	(31.4)		14	(31.1)		
Something else	9	(0.7)	6	(69.2)		3	(40.6)		2	(27.7)		3	(34.3)		
I don't know the answer	14	(1.1)	6	(42.9)		6	(42.9)		1	(3.8)		1	(3.8)		
Prefer not to say	20	(1.6)	12	(58.0)		12	(57.6)		4	(21.4)		6	(31.7)		
Ancestry															
Oceanian	319	(25.6)	107	(33.7)	1.00	106	(33.3)	1.00	44	(13.9)	0.0010	58	(18.1)	1.00	
North-West European	406	(32.5)	149	(36.6)		116	(28.6)		66	(16.3)		86	(21.1)		
South-East European	120	(9.6)	38	(31.7)		28	(23.7)		9	(7.8)		16	(13.8)		
North-East Asian	56	(4.5)	17	(30.1)		14	(24.5)		4	(6.3)		9	(16.6)		
South-East Asian	46	(3.7)	11	(24.9)		15	(32.5)		2	(5.0)		10	(22.6)		
South and Central Asian	77	(6.2)	27	(34.7)		27	(35.0)		5	(6.2)		6	(8.0)		
North African and Middle Eastern	15	(1.2)	6	(43.0)		5	(34.3)		0	(3.3)		2	(14.1)		
Sub-Saharan African	2	(0.2)	2	(65.7)		2	(65.7)		0	(0.0)		2	(65.7)		
Peoples of the Americas	12	(0.9)	1	(8.2)		0	(0.0)		0	(0.0)		1	(8.2)		
North-West European, Oceanian	106	(8.5)	33	(30.7)		29	(27.6)		13	(12.3)		21	(20.2)		
Other combination	80	(6.4)	34	(42.7)		34	(42.7)		10	(12.1)		7	(9.1)		
Unknown	10	(0.8)	2	(24.7)		2	(19.9)		0	(0.0)		0	(4.8)		
Disability Status															
None	1071	(85.7)	329	(30.7)	<0.0001	306	(28.6)	<0.0001	109	(10.2)	<0.0001	141	(13.1)	<0.0001	
Disability, and qualify for the NDIS	39	(3.1)	30	(77.1)		31	(78.8)		28	(72.4)		33	(84.8)		
Disability, but do not qualify for the NDIS	123	(9.8)	62	(50.3)		39	(32.1)		15	(11.9)		39	(31.5)		
Prefer not to say	17	(1.3)	7	(39.8)		3	(15.6)		2	(9.9)		7	(44.0)		
Highest education attainment															
Secondary diploma or less	543	(43.5)	157	(28.9)	0.40	147	(27.0)	1.00	33	(6.0)	<0.0001	86	(15.8)	0.59	
More than secondary diploma, less than bachelor's degree	337	(27.0)	128	(38.1)		102	(30.1)		48	(14.1)		49	(14.4)		
Bachelor's degree or more	369	(29.5)	142	(38.4)		130	(35.3)		73	(19.8)		85	(23.1)		
Regional vs metropolitan postal code															
Regional	278	(22.3)	98	(35.4)	1.00	75	(26.9)	1.00	28	(10.2)	1.00	63	(22.7)	0.91	
Metropolitan	971	(77.7)	329	(33.9)		304	(31.3)		125	(12.9)		157	(16.1)		
Employment Status															
Employed nonessential	311	(24.9)	88	(28.2)	<0.0001	81	(26.2)	<0.0001	38	(12.3)	0.0068	36	(11.7)	0.0010	
Employed essential	384	(30.8)	163	(42.4)		158	(41.0)		76	(19.7)		96	(24.9)		
Unemployed	227	(18.2)	107	(47.0)		84	(37.1)		22	(9.7)		52	(22.9)		
Student	53	(4.3)	22	(40.5)		23	(43.9)		4	(7.0)		9	(16.5)		
Retired	273	(21.9)	48	(17.7)		32	(11.7)		14	(5.1)		27	(9.8)		
Unpaid Caregiver Status															
None	782	(62.6)	221	(28.2)	<0.0001	177	(22.7)	<0.0001	41	(5.3)	<0.0001	92	(11.7)	<0.0001	
Unpaid caregiver for adults	164	(13.1)	64	(39.1)		57	(35.1)		16	(10.1)		29	(17.5)		
Unpaid caregiver for children or adolescents	141	(11.3)	44	(31.6)		32	(22.8)		27	(19.0)		16	(11.5)		

Multigenerational unpaid caregiver	163	(13.1)	98	(60.1)		112	(68.5)		69	(42.3)		83	(51.0)	
Political Ideology														
Far left	72	(5.8)	32	(44.4)	0.49	26	(36.5)	0.014	7	(9.6)	0.0075	23	(32.3)	0.049
Slightly left	236	(18.9)	76	(32.2)		57	(24.1)		38	(16.1)		32	(13.7)	
Centre	432	(34.5)	125	(28.9)		123	(28.4)		38	(8.9)		62	(14.4)	
Slightly right	188	(15.1)	59	(31.2)		53	(28.2)		24	(12.5)		34	(18.2)	
Far right	117	(9.3)	49	(42.1)		60	(51.5)		31	(26.6)		34	(28.8)	
Apolitical and/or prefer not to answer	205	(16.4)	87	(42.4)		60	(29.3)		16	(7.7)		34	(16.6)	
Believed high risk for severe COVID-19														
Yes	209	(16.7)	71	(34.0)	1.00	55	(26.2)	1.00	26	(12.6)	1.00	40	(18.9)	1.00
No	1040	(83.3)	356	(34.2)		324	(31.1)		127	(12.2)		180	(17.3)	

Table 4 – Prevalence of adverse mental and behavioural health symptoms among Victorian adults, by medical history, sleep, and behavioural changes, September 2020

Mental or Behavioural Health Condition			Symptoms of Anxiety or Depressive Disorder		P	Symptoms of a COVID-19 TSRD		P	Started or Increased Substance Use		P	Suicidal ideation		P
	n	(%)	n	(%)	-	n	(%)	-	n	(%)	-	n	(%)	-
Total Respondents	1249	(100)	427	(34.2)		379	(30.3)		154	(12.3)		220	(17.6)	
MEDICAL CONDITIONS														
Diagnosed with a sleep condition														
Yes	379	(30.4)	190	(50.0)	<0.0001	157	(41.3)	0.0001	79	(20.9)	0.0001	117	(30.8)	<0.0001
No	870	(69.6)	238	(27.3)		222	(25.5)		74	(8.6)		103	(11.8)	
Diagnosed with a psychiatric condition														
Yes	474	(38.0)	262	(55.2)	<0.0001	227	(47.9)	<0.0001	98	(20.6)	<0.0001	161	(33.9)	<0.0001
No	775	(62.0)	166	(21.4)		151	(19.6)		56	(7.2)		59	(7.6)	
SLEEP MEASURES														
Diurnal preference														
Definite morning type	317	(25.4)	90	(28.4)	1.00	94	(29.6)	1.00	48	(15.0)	1.00	57	(18.0)	1.00
Rather morning type	334	(26.7)	124	(37.0)		115	(34.3)		42	(12.6)		70	(20.8)	
Rather evening type	355	(28.4)	128	(36.1)		104	(29.4)		47	(13.2)		57	(16.0)	
Definite evening type	243	(19.4)	85	(35.1)		66	(27.1)		17	(7.1)		36	(15.0)	
Sleep Duration, hours														
<6	219	(17.5)	105	(47.9)	0.0021	89	(40.6)	0.0020	35	(15.8)	1.00	56	(25.5)	0.088
6-7	322	(25.8)	84	(25.9)		65	(20.1)		31	(9.7)		38	(11.8)	
>7	707	(56.6)	239	(33.8)		225	(31.8)		88	(12.4)		126	(17.7)	
Symptoms of insomnia														
Yes	257	(20.6)	157	(60.9)	<0.0001	143	(55.4)	<0.0001	57	(22.1)	<0.0001	81	(31.4)	<0.0001
No	992	(79.4)	271	(27.3)		236	(23.8)		97	(9.8)		139	(14.0)	
Sleep compared with October through December 2019...														
More time in bed														
Yes	381	(30.5)	178	(46.7)	<0.0001	168	(44.3)	<0.0001	63	(16.5)	1.00	96	(25.1)	0.0032
No	868	(69.5)	250	(28.8)		210	(24.2)		91	(10.5)		124	(14.3)	
Less time in bed														
Yes	74	(5.9)	30	(40.9)	1.00	32	(43.2)	0.63	18	(23.9)	1.00	22	(29.5)	0.32
No	1175	(94.1)	397	(33.8)		347	(29.5)		136	(11.6)		198	(16.8)	
More trouble falling asleep														
Yes	302	(24.2)	179	(59.3)	<0.0001	148	(49.0)	<0.0001	60	(19.9)	0.0023	78	(25.9)	0.0053
No	947	(75.8)	248	(26.2)		230	(24.3)		93	(9.9)		141	(14.9)	
Less trouble falling asleep														
Yes	71	(5.7)	31	(44.4)	1.00	29	(40.3)	1.00	16	(21.9)	0.89	19	(26.2)	1.00
No	1178	(94.3)	396	(33.6)		350	(29.7)		138	(11.7)		201	(17.1)	
More regular sleep schedule														
Yes	161	(12.9)	41	(25.4)	0.50	49	(30.3)	1.00	22	(13.6)	1.00	22	(13.9)	1.00
No	1088	(87.1)	386	(35.5)		330	(30.3)		132	(12.1)		197	(18.1)	
Less regular sleep schedule														
Yes	198	(15.9)	99	(50.0)	0.0011	91	(45.7)	0.0008	34	(17.0)	1.00	48	(24.0)	0.88
No	1051	(84.1)	328	(31.2)		288	(27.4)		120	(11.4)		172	(16.4)	
Daytime Sleepiness														
Normal	907	(72.6)	256	(28.2)	<0.0001	217	(24.0)	<0.0001	94	(10.4)	0.0001	120	(13.2)	<0.0001
Mild to moderate	168	(13.4)	95	(57.0)		84	(50.3)		27	(15.8)		43	(25.8)	
Excessive	174	(14.0)	76	(43.6)		77	(44.1)		33	(18.8)		57	(32.5)	
BEHAVIOURAL CHANGES														
Compared with October through December 2019...														
Time Spent Outdoors														
Reduced by more than 1 hour	631	(50.5)	257	(40.7)	<0.0001	214	(34.0)	0.0011	88	(14.0)	0.19	127	(20.1)	0.0013
Reduced by less than 1 hour	82	(6.6)	42	(51.3)		41	(49.7)		17	(20.5)		28	(34.5)	
About the same	387	(31)	88	(22.7)		81	(20.9)		25	(6.4)		43	(11.1)	
Increased by less than 1 hour	50	(4)	13	(26.6)		17	(33.0)		11	(21.0)		7	(13.7)	
Increased by more than 1 hour	98	(7.9)	27	(27.2)		26	(26.3)		13	(13.7)		15	(14.8)	
Time Spent on Screens														
Reduced by more than 1 hour	101	(8.1)	58	(57.2)	<0.0001	50	(50.0)	<0.0001	25	(24.7)	<0.0001	35	(34.8)	<0.0001
Reduced by less than 1 hour	48	(3.9)	24	(50.6)		28	(57.8)		18	(37.0)		23	(47.7)	
About the same	435	(34.8)	107	(24.6)		91	(20.9)		27	(6.2)		65	(14.9)	
Increased by less than 1 hour	96	(7.7)	29	(30.8)		27	(28.7)		9	(9.1)		23	(24.3)	
Increased by more than 1 hour	570	(45.6)	209	(36.6)		182	(32.0)		75	(13.2)		74	(12.9)	

Hours spent following COVID-19														
0	920	(73.7)	299	(32.5)	0.0012	273	(29.7)	<0.0001	104	(11.3)	<0.0001	152	(16.5)	<0.0001
1	199	(15.9)	59	(29.9)		39	(19.6)		15	(7.3)		27	(13.5)	
2-3	75	(6)	31	(41.6)		26	(34.4)		8	(10.8)		12	(15.8)	
≥4	52	(4.2)	35	(68.2)		39	(74.6)		24	(46.8)		27	(52.5)	

Table 5 – Adjusted prevalence ratios for having experienced at least one adverse mental or behavioural health symptoms condition Victorian adults, by demographic characteristics, medical history, sleep, and behavioural changes, September 2020

Mental or Behavioural Health Condition	At least one adverse mental or behavioural health condition		P
	aPR	[95% CI]	-
Demographic			
Sex (reference: Female)			
Male	0.91	[0.79, 1.05]	0.20
Age Group, years (reference: ≥65)			
18-24	3.25	[2.11, 5.00]	<0.0001
25-44	3.04	[2.05, 4.52]	<0.0001
45-64	2.08	[1.43, 3.00]	0.0001
Sexual orientation (reference: Not Heterosexual)			
Heterosexual	1.01	[0.82, 1.25]	0.92
Ancestry (reference: North-West European)			
Oceanian	0.90	[0.76, 1.08]	0.25
South-East European	0.90	[0.68, 1.18]	0.43
North-East Asian	0.99	[0.76, 1.29]	0.96
South-East Asian	0.75	[0.51, 1.11]	0.15
South and Central Asian	0.94	[0.69, 1.26]	0.66
North-West European, Oceanian	0.77	[0.58, 1.03]	0.084
Other or other combination	1.05	[0.82, 1.34]	0.70
Disability Status (reference: None)			
Disabled, with support from NDIS	1.31	[1.09, 1.57]	0.0034
Disabled, without support from NDIS	1.52	[1.24, 1.87]	0.0001
Regional vs metropolitan postal code (reference: Regional)			
Metropolitan (Stage 4)	0.90	[0.76, 1.06]	0.19
Employment Status (reference: Employed nonessential)			
Employed essential	1.00	[0.84, 1.20]	0.96
Unemployed	1.07	[0.87, 1.32]	0.51
Student	0.82	[0.52, 1.29]	0.39
Retired	0.84	[0.61, 1.16]	0.29
Unpaid Caregiver Status (reference: No)			
Unpaid caregiver for adults	1.26	[1.04, 1.52]	0.018
Unpaid caregiver for children or adolescents	1.05	[0.83, 1.34]	0.67
Multigenerational unpaid caregiver	1.55	[1.30, 1.84]	<0.0001
Political Ideology (reference: Centre)			
Far left	1.05	[0.78, 1.41]	0.74
Slightly left	1.14	[0.93, 1.40]	0.21
Slightly right	1.09	[0.88, 1.34]	0.42
Far right	1.39	[1.14, 1.71]	0.0016
Apolitical and/or prefer not to answer	1.12	[0.91, 1.39]	0.29
Believed high risk for severe COVID-19 (reference: No)			
Yes	1.21	[1.01, 1.46]	0.039
Diurnal preference (reference: Definite morning)			
Somewhat morning	1.14	[0.95, 1.36]	0.17
Somewhat evening	1.14	[0.94, 1.39]	0.18
Definite evening	1.04	[0.82, 1.31]	0.75
Medical history, sleep measures, and behavioural changes	aPR	[95% CI]	-
MEDICAL HISTORY			
Previous diagnosis with psychiatric condition (reference: No)			
Yes	1.73	[1.50, 2.01]	<0.0001
Previous diagnosis with sleep condition (reference: No)			
Yes	1.28	[1.11, 1.48]	0.0007
SLEEP MEASURES			

Sleep Duration, hours (reference: >7)			
<6	1.39	[1.18, 1.63]	0.0001
6-7	0.88	[0.74, 1.06]	0.18
Symptoms of insomnia (reference: No)			
Yes	1.78	[1.55, 2.05]	<0.0001
<i>Compared with October through December 2019...</i>			
More time in bed (reference: No)			
Yes	1.24	[1.08, 1.43]	0.0019
Less time in bed (reference: No)			
Yes	1.12	[0.91, 1.38]	0.28
More trouble falling asleep (reference: No)			
Yes	1.71	[1.50, 1.95]	<0.0001
Less trouble falling asleep (reference: No)			
Yes	0.90	[0.71, 1.14]	0.39
More regular sleep schedule (reference: No)			
Yes	0.89	[0.74, 1.07]	0.22
Less regular sleep schedule (reference: No)			
Yes	1.35	[1.14, 1.59]	0.0005
Daytime Sleepiness (reference: Normal)			
Mild to moderate	1.36	[1.15, 1.62]	0.0005
Excessive	1.10	[0.92, 1.33]	0.30
BEHAVIOURAL CHANGES			
<i>Compared with October through December 2019...</i>			
Time Spent Outdoors (reference: About the same)			
Reduced by more than 1 hour	1.36	[1.14, 1.63]	0.0007
Reduced by less than 1 hour	1.39	[1.09, 1.77]	0.0087
Increased by less than 1 hour	1.16	[0.78, 1.73]	0.46
Increased by more than 1 hour	1.09	[0.79, 1.50]	0.60
Time Spent on Screens (reference: About the same)			
Reduced by more than 1 hour	1.20	[0.94, 1.54]	0.15
Reduced by less than 1 hour	1.38	[1.09, 1.75]	0.0072
Increased by less than 1 hour	1.13	[0.86, 1.50]	0.38
Increased by more than 1 hour	1.30	[1.09, 1.56]	0.0038
Hours spent following COVID-19 (reference: 0)			
1	0.95	[0.76, 1.18]	0.65
2-3	1.18	[0.94, 1.48]	0.17
≥4	1.34	[1.13, 1.60]	0.0010

Table 6 – Adjusted prevalence ratios for adverse mental and behavioural health symptoms among Victorian adults, by select sleep and psychiatric conditions, September 2020

Mental or Behavioural Health Condition	Symptoms of Anxiety or Depressive Disorder		<i>P</i>	Symptoms of a COVID-19 TSRD		<i>P</i>	Started or Increased Substance Use		<i>P</i>	Suicidal ideation		<i>P</i>
	aPR	[95% CI]	-	aPR	[95% CI]	-	aPR	[95% CI]	-	aPR	[95% CI]	-
Diagnosed with an anxiety disorder (reference: No)												
Yes	2.05	[1.69, 2.48]	<0.0001	1.84	[1.49, 2.28]	<0.0001	1.72	[1.22, 2.43]	0.0019	2.77	[2.03, 3.78]	<0.0001
Diagnosed with a depressive disorder (reference: No)												
Yes	2.36	[1.95, 2.86]	<0.0001	2.06	[1.67, 2.55]	<0.0001	2.12	[1.48, 3.04]	<0.0001	3.14	[2.30, 4.28]	<0.0001
Diagnosed with post-traumatic stress disorder (reference: No)												
Yes	1.95	[1.58, 2.41]	<0.0001	2.06	[1.65, 2.58]	<0.0001	2.50	[1.63, 3.83]	<0.0001	2.90	[2.16, 3.90]	<0.0001
Diagnosed with a substance use disorder (reference: No)												
Yes	1.64	[1.28, 2.10]	0.0001	1.54	[1.21, 1.95]	0.0005	2.31	[1.50, 3.57]	0.0002	2.33	[1.71, 3.17]	<0.0001
Diagnosed with insomnia (reference: No)												
Yes	1.78	[1.47, 2.16]	<0.0001	1.42	[1.14, 1.76]	0.0017	1.82	[1.29, 2.56]	0.0006	1.96	[1.46, 2.62]	<0.0001
Diagnosed with obstructive sleep apnoea (reference: No)												
Yes	1.84	[1.47, 2.30]	<0.0001	1.53	[1.22, 1.93]	0.0003	1.57	[1.07, 2.30]	0.020	1.93	[1.42, 2.62]	<0.0001
Diagnosed with narcolepsy (reference: No)												
Yes	1.99	[1.53, 2.57]	<0.0001	1.85	[1.43, 2.40]	<0.0001	2.06	[1.33, 3.21]	0.0013	2.26	[1.61, 3.17]	<0.0001
Diagnosed with restless leg syndrome (reference: No)												
Yes	1.89	[1.55, 2.30]	<0.0001	1.65	[1.33, 2.04]	<0.0001	1.87	[1.29, 2.70]	0.0009	1.79	[1.35, 2.37]	0.0001
Diagnosed with shift work disorder (reference: No)												
Yes	1.69	[1.33, 2.15]	<0.0001	1.53	[1.21, 1.94]	0.0003	2.46	[1.62, 3.75]	<0.0001	2.11	[1.53, 2.92]	<0.0001
Diagnosed with periodic limb movement disorder (reference: No)												
Yes	2.28	[1.73, 2.99]	<0.0001	1.82	[1.40, 2.37]	<0.0001	2.52	[1.60, 3.98]	0.0001	2.29	[1.61, 3.25]	<0.0001

aPR=adjusted prevalence ratio, CI=confidence interval

Table 7 – Longitudinal incidence and remission of adverse mental and behavioural health symptoms – Victoria, April & September 2020

	Wave		April-2020		September-2020		April-2020 vs September-2020	
	n	(%)	n	(%)	n	(%)	(Δ %)	P
Total Respondents	92	(100)	92	(100)			-	-
Mental or Behavioural Health Condition								
Symptoms of anxiety or depressive disorder	30	(33.1)	39	(42.7)			(9.6)	0.020
Incidence	62		10	(16.6)				
Remission	30		1	(4.3)				
Symptoms of burnout	22	(24.3)	27	(28.8)			(4.5)	0.54
Incidence	70		15	(21.7)				
Remission	22		11	(49.0)				
Sleep Measures								
Symptoms of insomnia	16	(17.5)	17	(18.9)			(1.4)	0.93
Incidence	76		9	(11.3)				
Remission	16		7	(44.7)				
Sleep duration <6 hours	11	(11.9)	15	(16.4)			(4.5)	0.39
Incidence	81		9	(10.8)				
Remission	11		5	(41.8)				
Behaviours								
≥1 hour following COVID-19	49	(53.1)	24	(26.0)			(-27.1)	0.0001
Incidence	43		6	(13.0)				
Remission	49		31	(62.5)				

Incidence is defined as presence of the measure in September 2020 after absence of the measure in April 2020.
Remission is defined as absence of the measure in September 2020 after presence of the measure in April 2020.

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Appendix 9. Supplement to Chapter Eleven: Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic among adult users of a wearable device in the United States

Chapter Eleven Original Investigation: Czeisler *et al.* Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic.

Supplemental Online Content

Title

Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic among adult users of a wearable device in the United States

Authors

Mark É Czeisler; Emily R Capodilupo; Matthew D Weaver; Charles A Czeisler; Mark E Howard; Shantha MW Rajaratnam

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Chapter Eleven Original Investigation: Czeisler *et al.* Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic.

Supplementary Methods.

Race and ethnicity were assessed among survey respondents with separate questions and options defined by the investigators based on US Census classifications. The race and ethnicity questions follow.

1. What is your race? (Select all that apply)
 - a. American Indian or Alaskan Native
 - b. Asian
 - c. Black or African American
 - d. Native Hawaiian or other Pacific Islander
 - e. White
 - f. Other

Please use the categories that most reflect your recognition in the community for purposes of reporting mixed racial and/or ethnic origins.

American Indian or Alaskan Native: a person having origins in any of the original peoples of North, Central, or South America, and maintains tribal affiliations or community attachment.

Asian: A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

Black or African American: A person having origins in any of the black racial groups of Africa.

Native Hawaiian or Pacific Islander: A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

White: A person having origins in any of the original peoples of Europe, North Africa, or the Middle East.

2. What is your ethnicity? (Select one)
 - a. Hispanic or Latino
 - b. Not Hispanic or Latino

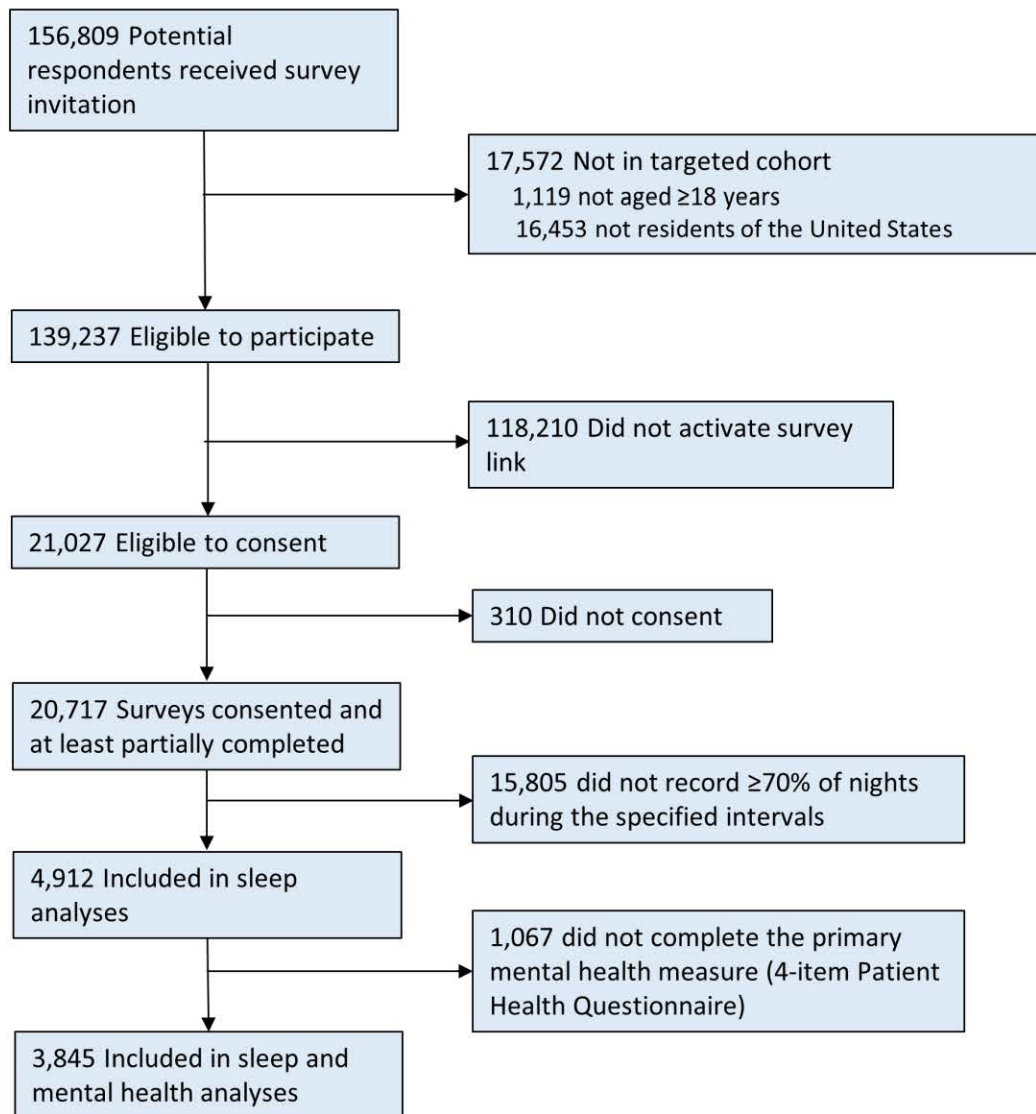
Hispanic or Latino: A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race.

For this analysis, race and ethnicity were combined into the following categories:

White, non-Hispanic; Black, non-Hispanic; Asian, non-Hispanic; Multiple races or Other race, non-Hispanic; and Hispanic, any race or races.

Chapter Eleven Original Investigation: Czeisler *et al.* Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic.

Supplementary Figure 1. Flow of the survey respondents



Chapter Eleven Original Investigation: Czeisler *et al.* Prior sleep-wake behaviors are associated with mental health outcomes during the COVID-19 pandemic.

Supplementary Table 1. Adverse mental health symptoms and sleep characteristics of the respondents

		All respondents			Did complete the PHQ-4		
MENTAL HEALTH							
	Symptoms of anxiety or depressive disorder (N=3845)-n (%)	-	-	-	755	(19.6)	-
	Started or increased substance use (N=3820)-n (%)	-	-	-	856	(22.4)	-
	Symptoms of burnout (N=3734)-n (%)	-	-	-	1208	(32.4)	-
SLEEP				p			p
Sleep duration in hrs-mean (sd)							
	Pre-pandemic	6.95	(0.687)	-	6.96	(0.687)	-
	Acute pandemic	7.20	(0.751)	-	7.21	(0.75)	-
	Early chronic pandemic	7.04	(0.705)	-	7.06	(0.702)	-
	Difference: Acute vs Pre (95% CI)	0.25	(0.237, 0.27)	<0.0001	0.25	(0.231, 0.269)	<0.0001
	Difference: Early chronic vs Pre (95% CI)	0.09	(0.076, 0.107)	<0.0001	0.09	(0.077, 0.112)	<0.0001
Sleep consistency-mean (sd)							
	Pre-pandemic	73.30	(7.179)	-	73.53	(7.222)	-
	Acute pandemic	76.81	(7.705)	-	77.00	(7.78)	-
	Early chronic pandemic	77.36	(7.259)	-	77.59	(7.33)	-
	Difference: Acute vs Pre (95% CI)	3.51	(3.295, 3.728)	<0.0001	3.47	(3.226, 3.715)	<0.0001
	Difference: Early chronic vs Pre (95% CI)	4.06	(3.856, 4.267)	<0.0001	4.07	(3.834, 4.297)	<0.0001
Wakefulness during time in bed in hrs-mean (sd)							
	Pre-pandemic	1.15	(0.576)	-	1.14	(0.527)	-
	Acute pandemic	1.10	(0.487)	-	1.10	(0.494)	-
	Early chronic pandemic	1.16	(0.662)	-	1.15	(0.668)	-
	Difference: Acute vs Pre (95% CI)	-0.05	(-0.074, -0.031)	<0.0001	-0.05	(-0.067, -0.025)	<0.0001
	Difference: Early chronic vs Pre (95% CI)	0.01	(-0.022, 0.035)	>0.99	0.01	(-0.02, 0.039)	>0.99
Sleep onset-mean (sd)							
	Pre-pandemic	22:50	(70.360)	-	22:48	(70.400)	-
	Acute pandemic	23:09	(77.306)	-	23:06	(76.401)	-
	Early chronic pandemic	23:08	(75.475)	-	23:05	(74.669)	-
	Difference: Acute vs Pre (95% CI)	0:18	(17.378, 20.045)	<0.0001	0:18	(16.663, 19.626)	<0.0001
	Difference: Early chronic vs Pre (95% CI)	0:17	(16.470, 19.289)	<0.0001	0:17	(16.029, 19.132)	<0.0001
Sleep offset-mean (sd)							
	Pre-pandemic	6:42	(69.723)	-	6:41	(69.670)	-
	Acute pandemic	7:19	(77.076)	-	7:16	(76.566)	-

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	Early chronic pandemic	7:07	(75.559)	-	7:05	(74.840)	-
	Difference: Acute vs Pre (95% CI)	0:36	(35.111, 38.106)	<0.0001	0:35	(33.997, 37.346)	<0.0001
	Difference: Early chronic vs Pre (95% CI)	0:25	(23.629, 26.714)	<0.0001	0:24	(23.234, 26.669)	<0.0001

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Supplementary Table 2. Varying trends in sleep measures during the COVID-19 pandemic

	Pre-pandemic		Pandemic		During Pandemic vs Pre-pandemic Δ		
	mean	(sd)	mean	(sd)	Δ mean	95% CI	p
Sleep Duration							
Top 10% lengthened	6.69	(0.692)	7.46	(0.674)	0.77	(0.742, 0.794)	<0.0001
Top 10% shortened	7.22	(0.706)	6.72	(0.728)	-0.50	(-0.522, -0.47)	<0.0001
Sleep Consistency							
Top 10% increased	66.26	(6.796)	79.11	(6.106)	12.85	(12.48, 13.214)	<0.0001
Top 10% decreased	74.19	(7.385)	69.78	(8.058)	-4.41	(-4.72, -4.099)	<0.0001
Wake after sleep onset							
Top 10% increased	1.00	(0.377)	1.34	(0.433)	0.34	(0.317, 0.357)	<0.0001
Top 10% decreased	1.24	(0.425)	0.99	(0.381)	-0.26	(-0.274, -0.241)	<0.0001
Sleep Onset							
Top 10% shifted earlier	23:29	(86.310)	22:55	(80.604)	-0:33	(-36.385, -30.942)	<0.0001
Top 10% shifted later	22:57	(79.021)	00:18	(89.678)	1:21	(77.284, 84.861)	<0.0001
Sleep Offset							
Top 10% shifted earlier	07:12	(94.308)	06:43	(89.100)	-0:28	(-31.358, -26.036)	<0.0001
Top 10% shifted later	06:40	(75.398)	08:19	(83.660)	1:39	(95.456, 102.811)	<0.0001

Appendix 10. Supplement to Chapter Fourteen: Mental Health and Substance Use During the COVID-19 Pandemic Among Adults with Disabilities — United States, February–March 2021

SUPPLEMENTARY TABLE. Prevalence of symptoms of anxiety or depression, substance use, and suicidal ideation among adults, by disability status — United States, February 16–March 8, 2021

Disability group	No. (%) [*]				
	All respondents	Symptoms of anxiety or depression [†]	New or increased substance use to cope [§]	Seriously considered suicide [¶]	One or more of these symptoms
Total	5,119 (100)	1,928 (37.7)	1,248 (24.4)	793 (15.5)	2,308 (45.1)
Persons with disabilities	1,648 (32.2)	932 (56.6)	640 (38.8)	504 (30.6)	1,057 (64.1)
Persons without disabilities	3,471 (67.8)	996 (28.7)	608 (17.5)	289 (8.3)	1,251 (36.0)
Chi-square p-value	—	<0.0001	<0.0001	<0.0001	<0.0001

^{*} Weighted counts and percentages might not sum to expected values because of rounding.

[†] Symptoms of anxiety and depression were assessed via the four-item Patient Health Questionnaire (PHQ-4). Those who scored ≥ 3 out of 6 on the Generalized Anxiety Disorder (GAD-2) and Patient Health Questionnaire (PHQ-2) subscales were considered symptomatic for these respective conditions.

[§] New or increased substance use was assessed using the question, “Have you started or increased using substances to help you cope with stress or emotions during the COVID-19 pandemic? Substance use includes alcohol, legal or illegal drugs, or prescription drug use in any way not directed by a doctor.”

[¶] Suicidal ideation was assessed using an item from the National Survey on Drug Use and Health adapted to refer to the preceding 30 days, “At any time in the past 30 days, did you seriously think about trying to kill yourself?”

Appendix 11. 2021 Global Partners in Disaster Behavioral Health Award from BOLANTE Threat Assessment & Disaster Behavioral Health Training and Consultation

January 12, 2021

The COPE Initiative

Mark E. Czeisler

PhD Candidate | Faculty of Medicine, Nursing and Health Sciences

School of Psychological Sciences | Monash University

Project Lead | The COPE Initiative

Mr. Mark E. Czeisler,

I am pleased to announce that **The COPE Initiative** has been chosen as this year's recipient of the **"Global Partners in Disaster Behavioral Health Award"**. This award was established to recognize an organization or professional who has made significant contributions to the field of disaster behavioral health at an international level.

In choosing the recipient, several things were considered, including the recipient's leadership in the realm of disaster behavioral health. The COPE has excelled in demonstrating the importance of partnerships, collaboration, and vision, related to disaster behavioral health. We would like to highlight the work you, Mark Czeisler, and your team contributed at the onset of the pandemic in 2020. Your spirit of collaboration towards research and resources specified in the areas of disaster behavioral health is well noted.

We would like you to attend the entire virtual conference (we will waive your registration fees) and invite you to accept this award on behalf of The COPE Initiative at our [2021 Disaster Behavioral Health Conference, February 9th and 10th, 2021](#). *Our media team will be in touch with you about the details involved.*

With gratitude for your continued support in our mutual endeavors within the field of disaster behavioral health.

Rebecca Bolante, Ph.D., CRC, CTM

Managing Director

285 Court ST NE

Salem, Oregon 97301

503.714.5499

cc: Dr. Ronald Glaus

Dr. Robert Lundblad

Jan Slick, MSW

Sarah Back

Appendix 12. The COPE Initiative website

The COVID-19 Outbreak Public Evaluation (COPE) Initiative

The mission of *The COVID-19 Outbreak Public Evaluation (COPE) Initiative* is to **assess public attitudes, behaviors, and beliefs** related to the coronavirus disease 2019 (COVID-19) pandemic, and to **evaluate the mental and behavioral health during** the pandemic.

Our goal is to provide the public a voice through the collection and dissemination of findings that help shape the design and delivery of targeted communication and intervention strategies to improve public health efforts and save lives.

The COPE Initiative

[About Us](#)

[Findings](#)

[News & Trends](#)

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Findings

During late June, 40% of U.S. adults reported struggling with mental health or substance use*

ANXIETY/DEPRESSION SYMPTOMS



STARTED OR INCREASED SUBSTANCE USE



TRAUMA/STRESSOR-RELATED DISORDER SYMPTOMS



SERIOUSLY CONSIDERED SUICIDE†



*Based on a survey of U.S. adults aged ≥18 years during June 24–30, 2020

†In the 30 days prior to survey

For stress and coping strategies: bit.ly/dailylifecoping

CDC.GOV

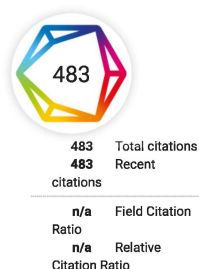
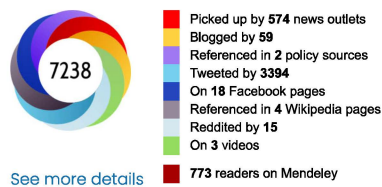
bit.ly/MMWR81320

MMWR

Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic — United States, June 24–30, 2020

The public health response to the COVID-19 pandemic should increase intervention and prevention efforts to address associated mental health conditions. Community-level efforts, including health communication strategies, should prioritize young adults, racial/ethnic minorities, essential workers, and unpaid adult caregivers.

[View Publication](#)



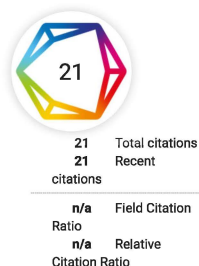
Citations	
DynaMed Plus - Clinical Citations:	2
Scopus - Citation Indexes:	328
Captures	
Mendeley - Readers:	773
Mendeley - Readers:	1
Mendeley - Readers:	1
Mentions	
Blogs:	96
News:	1840
Wikipedia - References:	4
Social Media	
Facebook - Shares, Likes & Comments:	21080
Twitter - Tweets:	3536

[PLUMX - see details](#)

Follow-up Survey of US Adult Reports of Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic, September 2020

In a later phase of the COVID-19 pandemic (September 2020), the prevalence of adverse mental health symptoms among US adults remained elevated compared with prepandemic estimates. This finding contradicts the notion that adverse mental health symptoms were transient, self-limiting responses. Despite increased COVID-19-related morbidity and mortality risk, adverse mental health symptoms among older adults remained less prevalent. Evidence of sustained adverse mental health symptoms among more than 5000 community-dwelling US adults highlights the need to promote preventive behaviors, expand mental health care access, and integrate medical and behavioral health services to mitigate the mental health effects of COVID-19.

[View Publication](#)



Citations	
CrossRef - Citation Indexes:	1
Scopus - Citation Indexes:	13
Captures	
Mendeley - Readers:	62
Mentions	
Blogs:	1
News:	32
Social Media	
Facebook - Shares, Likes & Comments:	48
Twitter - Tweets:	64

[PLUMX - see details](#)

Mental Health Among Parents of Children Aged <18 Years and Unpaid Caregivers of Adults During the COVID-19 Pandemic — United States, December 2020 and February–March 2021

Among 10,444 U.S. adults surveyed during December 6–27, 2020, and February 16–March 8, 2021, parents, unpaid caregivers of adults, and parents-caregivers (persons in both roles) had significantly worse mental health than adults not in these roles, including five times the odds of any adverse mental health symptoms (parents-caregivers). Persons who had someone to rely on for support had lower odds of experiencing any adverse mental health symptoms. Parents and unpaid caregivers of adults, and particularly those in both roles, might benefit from mental health support and services tailored to their roles.



Picked up by 44 news outlets
 Blogged by 1
 Tweeted by 120
 On 4 Facebook pages
 Reddited by 2
 24 readers on Mendeley

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1 Total citation
 1 Recent
 citation
 n/a Field Citation
 Ratio
 n/a Relative
 Citation Ratio



Citations
Scopus - Citation Indexes: 1
Captures
Mendeley - Readers: 14
Mentions
Blogs: 1 News: 9
Social Media
Twitter - Tweets: 119

PLUMX - [see details](#)

Mental health, substance use, and suicidal ideation during a prolonged COVID-19-related lockdown in a region with low SARS-CoV-2 prevalence

Investigation of mental health in a region with one of the longest lockdowns and lowest COVID-19 prevalence globally (Victoria, Australia) allowed for evaluation of mental health in the absence of substantial direct pandemic mental health consequences. In September 2020, among 1157 Victorians, one-third reported anxiety or depressive disorder symptoms, one-fifth reported suicidal ideation, and one-tenth reported having seriously considered suicide in the prior 30 days. Young adults, unpaid caregivers, people with disabilities, and people with diagnosed psychiatric or sleep conditions showed increased prevalence of adverse mental health symptoms. Persistently common experiences of adverse mental health symptoms despite low SARS-CoV-2 prevalence during prolonged lockdown highlight the urgent need for mental health support services.



Picked up by 10 news outlets
 Tweeted by 48
 Reddited by 1
 9 readers on Mendeley

[See more details](#)


1 Total citation
 1 Recent
 citation
 n/a Field Citation
 Ratio
 n/a Relative
 Citation Ratio



Captures
Mendeley - Readers: 6
Mentions
News: 3
Social Media
Twitter - Tweets: 53

PLUMX - [see details](#)

Sleep and mental health in athletes during COVID-19 lockdown

Training frequency and duration decreased during COVID-19 lockdown, which was associated with higher depression, anxiety, and stress symptoms. When presented with greater flexibility athletes shifted the times of day in which they trained, particularly avoiding evening hours. Sleep duration increased during lockdown, and sleep times became more regular (decrease in social jetlag), which was associated with better mental health symptoms. These findings suggest the need to raise awareness and education about the implications of decreased training and disrupted sleep in athlete populations. Although lockdown restrictions require social distancing, sporting organisations and teams should focus on maintaining training load, and provide remote opportunities to enhance social connectedness, motivation and support. Where possible, timing of exercise should be adapted to prevent a large discrepancy in sleep timings on work days vs free days, in an effort to increase consistency and thereby improve mental health. Finally, individual differences should be considered in health and exercise programs for athletes, especially for those with an evening chronotype.

View Publication



Picked up by 8 news outlets
Tweeted by 36
On 2 Facebook pages
104 readers on Mendeley

[See more details](#)



6	Total citations
6	Recent citations
n/a	Field Citation Ratio
n/a	Relative Citation Ratio



Citations
CrossRef - Citation Indexes: 1
Scopus - Citation Indexes: 3
Captures
Mendeley - Readers: 93
Mentions
News: 1
Social Media
Twitter - Tweets: 33

[see details](#)

In-person vs. home schooling during the COVID-19 pandemic: Differences in sleep, circadian timing, and mood in early adolescence

During COVID-19 lockdowns, adolescents around the world have been learning from home. Using objective measures of sleep and circadian timing, a longitudinal study in Melbourne, Australia showed that during remote learning, compared to pre-pandemic in-person learning, adolescents (age 12-13 years) went to sleep and woke later, had longer sleep, and woke in closer alignment with their internal body clocks. Adolescents also had less daytime sleepiness, and lower anxiety symptoms, which was related to reduced perceived stress. These results indicate a silver-lining of remote learning for teens: they slept more, and had less self-reported anxiety. Beyond the pandemic, these results suggest there should be a greater focus on delaying the timing of activities in the morning, such as school commute/start times, for secondary school students.

View Publication



Tweeted by 32

[See more details](#)



Social Media
Twitter - Tweets: 31

[see details](#)

Delay or Avoidance of Medical Care Because of COVID-19–Related Concerns — United States, June 2020

By June 30, 2020, because of concerns about COVID-19, an estimated 41% of U.S. adults had delayed or avoided medical care including urgent or emergency care (12%) and routine care (32%). Avoidance of urgent or emergency care was more prevalent among unpaid caregivers for adults, persons with underlying medical conditions, Black adults, Hispanic adults, young adults, and persons with disabilities. Even during the COVID-19 pandemic, people who experience a medical emergency should seek care **without delay**.

View Publication



Picked up by **204** news outlets
Blogged by **10**
Referenced in **2** policy sources
Tweeted by **677**
On **5** Facebook pages
Reddited by **3**
281 readers on Mendeley

[See more details](#)



157 Total citations
157 Recent citations
n/a Field Citation Ratio
n/a Relative Citation Ratio



Citations
Scopus - Citation Indexes: 95

Captures
Mendeley - Readers: 271

Mentions
Blogs: 12
News: 355

Social Media
Facebook - Shares, Likes & Comments: 357
Twitter - Tweets: 644

[PLUMX](#) - [see details](#)

Delay or avoidance of routine, urgent and emergency medical care due to concerns about COVID-19 in a region with low COVID-19 prevalence: Victoria, Australia

One-third of 1260 surveyed adults with residence in Victoria, Australia reported delay or avoidance of medical care (26% routine, 10% urgent or emergency) due to concerns about COVID-19, despite a relatively low prevalence of COVID-19 in the region. Proactive public health messaging and targeted services to minimize healthcare avoidance—particularly for individuals with chronic medical conditions, people with disabilities and unpaid caregivers—may be critical to avoid preventable increases in all-cause morbidity and mortality during and beyond the COVID-19 pandemic.

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Tweeted by **13**
Reddited by **1**
3 readers on Mendeley

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Captures
Mendeley - Readers: 3

Social Media
Twitter - Tweets: 17

[PLUMX](#) - [see details](#)

Public Attitudes, Behaviors, and Beliefs Related to COVID-19, Stay-at-Home Orders, Nonessential Business Closures, and Public Health Guidance — United States, New York City, and Los Angeles, May 5–12, 2020

Routine assessment of public priorities can guide public health decisions requiring collective action. Current levels of public support for restrictions and adherence to mitigation strategies can inform decisions about reopening and balancing duration and intensity of restrictions.

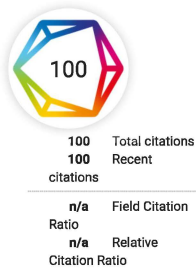
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Picked up by **132** news outlets
Blogged by **6**
Referenced in **1** policy sources
Tweeted by **393**
On **5** Facebook pages
Referenced in **2** Wikipedia pages
Reddited by **4**

See more details

264 readers on Mendeley



Citations
Scopus - Citation Indexes: 60
Captures
Mendeley - Readers: 261
Mentions
Blogs: 3 News: 110 Wikipedia - References: 2
Social Media
Facebook - Shares, Likes & Comments: 1410 Twitter - Tweets: 373

PLUMX - see details

Early public adherence with and support for stay-at-home COVID-19 mitigation strategies despite adverse life impact: a transnational cross-sectional survey study in the United States and Australia

View Publication



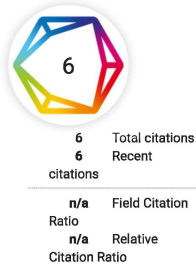
Tweeted by 11
56 readers on Mendeley

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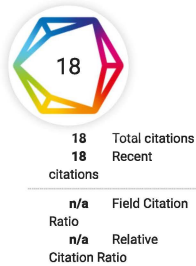
Picked up by 7 news outlets
Blogged by 3
Tweeted by 29
On 1 Facebook pages
28 readers on Mendeley

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Citations
Scopus - Citation Indexes: 3
Captures
Mendeley - Readers: 55
Social Media
Twitter - Tweets: 2

PLUMX - see details



Citations
CrossRef - Citation Indexes: 13
Captures
Mendeley - Readers: 28
Mentions
Blogs: 1
Social Media
Facebook - Shares, Likes & Comments: 20 Twitter - Tweets: 2

PLUMX - see details

Uncovering Survivorship Bias in Longitudinal Mental Health Surveys

Adjusting for demographics, individuals who completed only one or two out of four surveys had higher prevalences of anxiety and depression symptoms in April 2020 (e.g., one-survey versus four-survey, anxiety symptoms, adjusted prevalence ratio (aPR) = 1.30, 95% CI = 1.08-1.55, P = 0.0045; depression symptoms, aPR = 1.43, 95% CI = 1.17-1.75, P =

0.0005). Among respondents who completed April-2020 and May-2020 surveys, individuals who experienced incident anxiety or depression symptoms significantly higher odds of lower participation in subsequent follow-up surveys (adjusted odds ratio (aOR) = 1.68, 95% CI = 1.49-2.48, aOR = 1.56, 95% CI = 1.15-2.12, respectively, both P <0.005). These findings indicate that longitudinal mental health survey studies may be subject to survivorship bias, which could lead to overly optimistic interpretations of mental health trends.

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10

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Tweeted by 13

Reddited by 2

36 readers on Mendeley

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21 readers on Mendeley

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Citations

Scopus - Citation Indexes: 1

Captures

Mendeley - Readers: 23

PLUMX

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Citations

CrossRef - Citation Indexes: 1

Social Media

Facebook - Shares, Likes & Comments: 1

Twitter - Tweets: 2

PLUMX

see details

Demographic Characteristics, Experiences, and Beliefs Associated with Hand Hygiene Among Adults During the COVID-19 Pandemic — United States, June 24–30, 2020

Hand hygiene, including handwashing with soap and water and using hand sanitizer containing $\geq 60\%$ alcohol, is one measure recommended to prevent COVID-19 and other infectious diseases. In an Internet-based survey, approximately 85% of 4,817 U.S. adults reported frequent hand hygiene after contact with public surfaces. Males, young adults, respondents with lower concern about risk for SARS-CoV-2 infection, and respondents without personal COVID-19 experience reported less frequent hand hygiene.

COVID-19 messages should continue promoting hand hygiene, particularly among men and young adults. Messages addressing COVID-19 risk perceptions and making handwashing accessible and hand sanitizer available by facilities in public settings should be considered to encourage and facilitate hand hygiene.

View Publication

288

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Picked up by 6 news outlets

Tweeted by 300

On 1 Facebook pages

Reddited by 2

91 readers on Mendeley

11

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Citations

Scopus - Citation Indexes: 7

Captures

Mendeley - Readers: 90

Mentions

News: 2

Social Media

Facebook - Shares, Likes & Comments: 41

Twitter - Tweets: 319

PLUMX

see details

Mental Health, Substance Use, and Suicidal Ideation Among Unpaid Caregivers in the United States During the COVID-19 Pandemic: Relationships to Age, Race/Ethnicity, Employment, and Caregiver Intensity

Caregivers, who accounted for one in four US adult respondents in this demographically diverse sample, more commonly reported adverse mental health symptoms than non-caregivers. Increased visibility of and access to mental health care resources might help to address mental health challenges among unpaid caregivers.

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Social Media
Facebook - Shares, Likes & Comments: 1
Twitter - Tweets: 5

 PLUMX - [see details](#)

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Prior sleep-wake behavior predicts mental health resilience among adults in the United States during the COVID-19 pandemic

We examined objective sleep-wake data and surveyed mental health data collected among 4,912 U.S. adult users of a validated sleep wearable (WHOOP, Boston, Massachusetts) before and during the COVID-19 pandemic. Comparing the pre-pandemic (January 1 to March 12, 2020) and acute pandemic-onset intervals (March 13 to April 12, 2020), participants exhibited increased mean sleep duration (0.25h [95% CI = 0.237-0.270]), later sleep onset (18m [17.378-20.045]) and offset (36m [35.111-38.106]), and increased consistency of sleep timing (3.51 [3.295-3.728] out of 100); all $P < 0.0001$. Generally, participants with persistent sleep deficiency and low sleep consistency had higher odds of symptoms of anxiety or depression, burnout, and new or increased substance use during the pandemic. Decreases in sleep duration (adjusted odds ratio [aOR] = 1.30, 95% CI = 1.03-1.65, $P = 0.025$) and sleep consistency (2.05 [1.17-3.67], $P = 0.009$) were associated with increased anxiety and depression symptoms during the pandemic. We suggest that sleep duration and consistency may be important predictors of risk of adverse mental health outcomes during a pandemic.

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Tweeted by 5



Social Media
Twitter - Tweets: 5

 PLUMX - [see details](#)

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COVID-19 Vaccine Intentions in the United States, December 2020 to March 2021

Three-quarters of March-2021 respondents in our large, demographically diverse sample of US adults reported they would likely obtain a COVID-19 vaccine, and 60% of adults living with or caring for children plan to have them vaccinated as soon as possible. With an estimated 27% of the US population having been infected with SARS-CoV-2, once vaccines are available to children and they have been vaccinated, combined post-infection and post-vaccination immunity will approach 80% of the US population in 2021, even without further infections.

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 Tweeted by 7

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Social Media

Twitter - Tweets: 7

 **PLUMX** - [see details](#)

Peer-reviewed Publications

In-person vs. home schooling during the COVID-19 pandemic: Differences in sleep, circadian timing, and mood in early adolescence

Published 17 July 2021

Stone JE, Phillips AJK, Chachos E, Hand AJ, Lu S, Carskadon MA, Klerman EB, Lockley SW, Wiley JF, Bei B, Rajaratnam SMW; CLASS Study Team. In-person vs. home schooling during the COVID-19 pandemic: Differences in sleep, circadian timing, and mood in early adolescence. J Pineal Res. 2021 Jul 17:e12757. DOI: <https://dx.doi.org/10.1111/jpi.12757>. Epub ahead of print. PMID: [34273194](https://pubmed.ncbi.nlm.nih.gov/34273194/).

Mental Health Among Parents of Children Aged <18 Years and Unpaid Caregivers of Adults During the COVID-19 Pandemic — United States, December 2020 and February–March 2021

Published 17 June 2021

Czeisler MÉ, Rohan EA, Melillo S, Matjasko JL, DePadilla L, Patel CG, Weaver MD, Drane A, Winnay SS, Capodilupo ER, Robbins R, Wiley JF, Facer-Childs ER, Barger LK, Czeisler CA, Howard ME, Rajaratnam SMW. Mental Health Among Parents of Children Aged <18 Years and Unpaid Caregivers of Adults During the COVID-19 Pandemic — United States, December 2020 and February–March 2021. MMWR Morb Mortal Wkly Rep. 2021;70:879–887. DOI: <https://dx.doi.org/10.15585/mmwr.mm7024a3> PMID: [34138835](https://pubmed.ncbi.nlm.nih.gov/34138835/).

Mental health, substance use, and suicidal ideation during a prolonged COVID-19–related lockdown in a region with low SARS-CoV-2 prevalence

Published 4 June 2021

Czeisler MÉ, Wiley JF, Facer-Childs ER, Robbins R, Weaver MD, Barger LK, Czeisler CA, Howard ME, Rajaratnam SMW. Mental health, substance use, and suicidal ideation during a prolonged COVID-19–related lockdown in a region with low SARS-CoV-2 prevalence. J Psychiatr Res. 2021;140:533–544. Epub ahead of print June 2021. DOI: <https://doi.org/10.1016/j.jpsychires.2021.05.080>

Delay or avoidance of routine, urgent and emergency medical care due to concerns about COVID-19 in a region with low COVID-19 prevalence: Victoria, Australia

Published 3 June 2021

Czeisler MÉ, Kennedy JL, Wiley JF, Facer-Childs ER, Robbins R, Barger LK, Czeisler CA, Rajaratnam SMW, Howard ME. Delay or avoidance of routine, urgent and emergency medical care due to concerns about COVID-19 in a region with low COVID-19 prevalence: Victoria, Australia. Respirology. 2021;1–8. DOI: <https://doi.org/10.1011/resp.14084> PMID: [34081819](https://pubmed.ncbi.nlm.nih.gov/34081819/).

Uncovering Survivorship Bias in Longitudinal Mental Health Surveys During the COVID-19 Pandemic

Published 26 May 2021

Czeisler MÉ, Wiley JF, Czeisler CA, Rajaratnam SMW, Howard ME. Uncovering Survivorship Bias in Longitudinal Mental Health Surveys During the COVID-19 Pandemic. Epidemiol Psychiatr Sci. 2021;30(E45). DOI: <https://dx.doi.org/10.1017/S204579602100038X> PMID: [34036933](https://pubmed.ncbi.nlm.nih.gov/34036933/); PMCID: [PMC8207539](https://pubmed.ncbi.nlm.nih.gov/PMC8207539/).

Early public adherence with and support for stay-at-home COVID-19 mitigation strategies despite adverse life impact: a transnational cross-sectional survey study in the United States and Australia

Published 15 March 2021

Czeisler MÉ, Howard ME, Robbins R, Facer-Childs ER, Barger LK, Rajaratnam SMW, Czeisler CA. Early public adherence with and support for stay-at-home COVID-19 mitigation strategies despite adverse life impact: a transnational cross-sectional survey study in the United States and Australia. BMC Public Health. 2021;21(1):503. DOI: <https://dx.doi.org/10.1186/s12889-021-10410-x> PMID: [33722226](https://pubmed.ncbi.nlm.nih.gov/33722226/)

Follow-up Survey of US Adult Reports of Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic, September 2020

Published 19 February 2021

Czeisler MÉ, Lane RI, Wiley JF, Czeisler CA, Howard ME, Rajaratnam SMW. Follow-up Survey of US Adult Reports of Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic, September 2020. JAMA Netw Open. 2021;4(2):e2037665. DOI: <https://dx.doi.org/10.1001/jamanetworkopen.2020.37665> PMID: [33606030](https://pubmed.ncbi.nlm.nih.gov/33606030/)

Sleep and mental health in athletes during COVID-19 lockdown

Published 4 February 2021

Facer-Childs ER, Hoffman D, Tran JN, Drummond SPA, Rajaratnam SMW. Sleep and mental health in athletes during COVID-19 lockdown. Sleep. 2021;44(5):zsaa261. DOI: <https://doi.org/10.1093/sleep/zsaa261> PMID: [33535229](https://pubmed.ncbi.nlm.nih.gov/33535229/)

Demographic Characteristics, Experiences, and Beliefs Associated with Hand Hygiene Among Adults During the COVID-19 Pandemic — United States, June 24–30, 2020

Published 15 October 2020 ([Global Handwashing Day!](#))

Czeisler MÉ, García-Williams AG, Molinari N, Gharapure R, Li Y, Barrett CE, Robbins R, Facer-Childs ER, Barger LK, Czeisler CA, Rajaratnam SMW, Howard ME. Delay or Avoidance of Demographic Characteristics, Experiences, and Beliefs Associated with Hand Hygiene Among Adults During the COVID-19 Pandemic — United States, June 24–30, 2020. *MMWR Morb Mortal Wkly Rep* 2020;69:1485–1491. DOI: <http://dx.doi.org/10.15585/mmwr.mm6941a3>. PMID: [33056951](#). PMCID: [PMC7561087](#)

Delay or Avoidance of Medical Care Because of COVID-19–Related Concerns — United States, June 2020

Published 10 September 2020

Czeisler MÉ, Marynak K, Clarke KE, Salah Z, Shykya I, Thierry JM, Ali N, McMillan H, Wiley JF, Weaver MD, Czeisler CA, Rajaratnam SMW, Howard ME. Delay or Avoidance of Medical Care Because of COVID-19–Related Concerns — United States, June 2020. *MMWR Morb Mortal Wkly Rep* 2020;69:1250–1257. DOI: <http://dx.doi.org/10.15585/mmwr.mm6936a4>. PMID: [32915166](#). PMCID: [PMC7499838](#)

Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic — United States, June 24–30, 2020

Published 13 August 2020

Czeisler MÉ, Lane RI, Petrosky E, Wiley JF, Christensen A, Njai R, Weaver MD, Robbins R, Facer-Childs ER, Barger LK, Czeisler CA, Howard ME, Rajaratnam SMW. Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic — United States, June 24–30, 2020. *MMWR Morb Mortal Wkly Rep* 2020;69:1049–1057. DOI: <http://dx.doi.org/10.15585/mmwr.mm6932a1>. PMID: [32790653](#) PMCID: [PMC7440121](#)

Public Attitudes, Behaviors, and Beliefs Related to COVID-19, Stay-at-Home Orders, Nonessential Business Closures, and Public Health Guidance

Published 12 June 2020

Czeisler MÉ, Tynan MA, Howard ME, Honeycutt S, Fulmer EB, Kidder DP, Robbins R, Barger LK, Facer-Childs ER, Baldwin G, Rajaratnam SMW, Czeisler CA. Public Attitudes, Behaviors, and Beliefs Related to COVID-19, Stay-at-Home Orders, Nonessential Business Closures, and Public Health Guidance — United States, New York City, and Los Angeles, May 5–12, 2020. *MMWR Morb Mortal Wkly Rep* 2020;69:751–758. DOI: <http://dx.doi.org/10.15585/mmwr.mm6924a1>. PMID: [32555138](#). PMCID: [PMC7302477](#).

Pre-print Reports

Prior sleep-wake behavior predicts mental health resilience among adults in the United States during the COVID-19 pandemic

Posted 22 June 2021

Czeisler MÉ, Capodillupo ER, Weaver MD, Czeisler CA, Howard ME, Rajaratnam SMW. Prior sleep-wake behavior predicts mental health resilience among adults in the United States during the COVID-19 pandemic. *medRxiv*. Posted online June 2021. [Preprint Manuscript]. DOI: <https://doi.org/10.1101/2021.06.15.21258983>.

COVID-19 Vaccine Intentions in the United States, December 2020 to March 2021

Posted 17 May 2021

Czeisler MÉ, Rajaratnam SMW, Howard ME, Czeisler CA. COVID-19 Vaccine Intentions in the United States, December 2020 to March 2021. *medRxiv*. Posted online May 2021. [Preprint Manuscript]. DOI: <https://dx.doi.org/10.1101/2021.05.16.21257290>.

Uncovering Survivorship Bias in Longitudinal Mental Health Surveys

*Posted 17 February 2021 – now [published](#) in *Epidemiology and Psychiatric Sciences* ([citation above](#))*

Czeisler MÉ, Wiley JF, Czeisler CA, Rajaratnam SMW, Howard ME. Uncovering Survivorship Bias in Longitudinal Mental Health Surveys. *medRxiv*. Posted online February 2021. [Preprint Manuscript]. DOI: <https://dx.doi.org/10.1101/2021.01.28.21250694>.

Mental Health, Substance Use, and Suicidal Ideation Among Unpaid Caregivers in the United States During the COVID-19 Pandemic: Relationships to Age, Race/Ethnicity, Employment, and Caregiver Intensity

Posted 5 February 2021

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