MONASH University

A Mixed-Methods Study Examining the Work and Financial Burden Borne by Working-Age Adults with Arthritis

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ABSTRACT

Arthritis contributes to physical and psychological impairment, reduced work productivity, and economic strain at individual and societal levels. Results from the most recent National Health Survey (2017-2018) indicate that fifty percent of Australians with arthritis are aged between 25-64 years, challenging traditional perceptions that arthritis only affects older adults. The impacts of arthritis pertinent to younger, working-age adults (for example, impacts on work and personal finances) require exploration to better understand their lived experience and inform person-centred care.

The overarching aim of this PhD was to examine the experiences of adults aged 18-50 years living with arthritis (broadly categorised as osteoarthritis or inflammatory arthritis). The specific objectives were to:

1. Examine the work impacts of arthritis for younger, working-age adults;
2. Quantify the personal financial burden (comprising direct and indirect healthcare costs) of arthritis on younger, working-age adults;
3. Develop recommendations around work-related and financial impacts for clinicians, to support person-centred care.

The aim and objectives were addressed by conducting a sequential, exploratory, mixed-methods research program. First, a qualitative study was undertaken to explore the work and personal financial impacts of living with arthritis. The qualitative results informed a second quantitative study, which used a purpose-designed cost diary to quantify the personal financial burden of living with arthritis. These findings were triangulated to develop evidence-informed recommendations for clinicians who provide care to younger people with arthritis. A systematic review was conducted to synthesise contemporary data on work-related outcomes for working-age populations with arthritis. Finally, a supplementary social media study (due to the COVID-19 pandemic and challenges related to the collection of healthcare costs) was also undertaken.

The qualitative study revealed that working-age adults with arthritis start to experience work-related challenges before their careers even begin. For some, this included avoiding certain professions due to physical symptom burden. Other work impacts included perceptions of being burdensome to the workplace and lost productivity. The qualitative data also highlighted significant arthritis-attributable financial burden and financial distress, in relation to the costs of clinical care, medications, and reduced wages. Even within the Australian healthcare system that

provides universal care, the quantitative study showed that non-reimbursed arthritis-related healthcare costs totalled $1,635 Australian Dollars over a six-week period. Levels of financial distress were significantly associated with higher out-of-pocket costs.

The systematic review identified moderate-to-high quality evidence (from 29 studies with over 4,500 participants) that arthritis is associated with poorer work outcomes for working-age adults – specifically work limitations and higher work disability rates – relative to healthy populations. There was some evidence that the magnitude of impact may increase with age.

Taken together, this research has identified that working-age adults living with arthritis can experience substantial work and financial burden sequelae. These outcomes are detrimental for the individual and have broader impacts for their families, workplaces, the health system, and the overall economy. These PhD findings have the potential to raise awareness of the broader personal impacts of arthritis, beyond pain and stiffness, and inform positive changes to healthcare provision to ensure holistic and patient-centred care.

PUBLICATIONS ARISING FROM THIS THESIS DURING ENROLMENT

Chapter 2

Berkovic, D., Briggs, AM., Ayton, D., Parker, C., Ackerman, IN. Arthritis-related work outcomes experienced by younger to middle-aged adults: a systematic review. Occupational and Environmental Medicine. Epub ahead of print: 31 July 2020. doi: 10.1136/oemed-2020-106640.

Chapter 4

Berkovic, D., Ayton, D., Briggs, AM., Ackerman, IN. "The View From the Inside": Positionality and Insider Research. International Journal of Qualitative Methods. 2020;19:1-4. doi: 10.1177/1609406919900828.

Chapter 5

Berkovic, D., Ayton, D., Briggs, AM., Ackerman, IN. "I Would be More of a Liability than an Asset": Navigating the Workplace as a Younger Person with Arthritis. Journal of Occupational Rehabilitation. 2020;30:125-134. doi: 10.1007/s10926-019-09853-2.

Chapter 6

Berkovic, D., Ayton, D., Briggs, AM., Ackerman, IN. "The Financial impact is depressing and anxiety inducing": A qualitative exploration of the personal financial toll of arthritis among younger people. Arthritis Care and Research. Epub ahead of print: 26 February 2020. doi: 10.1002/acr.24172

Chapter 8

Berkovic, D., Ayton, D., Briggs, AM., Ackerman, IN. Tweets by People with Arthritis During the COVID-19 Pandemic: Content and Sentiment Analysis. Journal of Medical Internet Research. 2020;22(12):e24550

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Chapter 7

Berkovic, D., Ayton, D., Briggs, AM., Ademi, Z., Ackerman, IN. Personal healthcare costs borne by younger people living with arthritis: an exploratory study. Health and Social Care in the Community. *[Currently under review]*.

PUBLICATIONS ARISING FROM CONTRIBUTIONS TO OTHER RESEARCH DURING ENROLMENT

Crawford, JO., **Berkovic, D.,** Erwin, J., Copsey, SM., Davis, A., Giagloglou, E., Yazdani, A., Hartvigsen, J., Graveling, R., Woolf, A. Musculoskeletal health in the workplace. Best Pract Res Clin Rheumatol. 2020;34(5):101558

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Fulcher, BJ., Nicholson, AJ., Linke, NJ., **Berkovic, D.,** Hodgson, C. The perceived barriers and facilitators to implementation of ECMO services in acute hospitals. Intensive Care Med. 2020;46:2115-2117

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PRESENTATIONS ARISING FROM THIS THESIS

Berkovic, D., Ayton, D., Briggs, AM., Ackerman, IN. A Qualitative Exploration of the Financial Toll of Arthritis. Australian Rheumatology Association Annual Scientific Meeting. October 2020. Sydney, Australia [Oral presentation].

Berkovic, D., Ayton, D., Briggs, AM., Ackerman, IN. Work Impacts Experienced by Younger People with Arthritis: A Systematic Review. Annual European Congress of Rheumatology. June 2020. Frankfurt, Germany (online due to COVID-19) [Oral presentation].

Berkovic, D., Ayton, D., Briggs, AM., Ackerman, IN. Listening to younger people with arthritis: A qualitative study of experiences in the workplace. The 11th Health Services and Policy Research Conference. December 2019. Auckland, New Zealand [Oral presentation].

Berkovic, D., Ayton, D., Briggs, AM., Ackerman, IN. Navigating the workplace and financial burden as a younger person with inflammatory arthritis. Australian Physiotherapy Association National Conference. October 2019. Adelaide, Australia [Oral presentation – invited symposium speaker].

Berkovic, D., Ayton, D., Briggs, AM., Ackerman, IN. Insider Research: Advantages, Disadvantages, and Lessons Learned. Qualitative Methods Conference. May 2019. Brisbane, Australia [Oral presentation].

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 five original papers published in peer reviewed journals and one submitted publication. The core theme of the thesis is arthritis. 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 Public Health and Preventive Medicine under the supervision of Associate Professor Ilana Ackerman, Doctor Darshini Ayton, and Professor Andrew Briggs.

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 chapters 2, 4, 5, 6, 7, and 8, my contribution to the work involved the following:

Thesis chapter	Publication title	Status	Nature and % of student contribution	Co-author names. Nature and % of co-author contribution	Co-authors Monash student
2	Arthritis-related work outcomes experienced by younger to middle-aged adults: a systematic review	Published	Development of search strategy, screening of titles and abstracts, data extraction, risk of bias assessment, data analysis, data interpretation, preparation of manuscript and revision. 60%.	Ilana Ackerman: development of search strategy, data interpretation, input into manuscript; 10% Andrew Briggs: development of search strategy, data interpretation, input into manuscript; 10% Darshini Ayton: data interpretation, input into manuscript; 10% Catriona Parker: screening of titles and abstracts, data extraction, input into manuscript; 10%	Y
4	"The View From the Inside": Positionality and Insider Research	Published	Manuscript preparation and revision. 80%	Darshini Ayton: input into manuscript; 8% Ilana Ackerman: input into manuscript; 8% Andrew Briggs: input into manuscript; 4%	N
5	"I Would be More of a Liability than an Asset": Navigating the Workplace as a Younger Person with Arthritis	Published	Study design, data collection, data analysis, interpretation, manuscript preparation and revision. 70%	Ilana Ackerman: study design, interpretation, input into manuscript; 11% Darshini Ayton: study design, interpretation, input into manuscript; 11% Andrew Briggs: interpretation, input into manuscript; 8%	N
6	"The Financial impact is depressing and anxiety inducing": A qualitative exploration of the personal financial toll of arthritis among younger people	Published	Study design, data collection, data analysis, interpretation, manuscript preparation and revision. 70%	Ilana Ackerman: study design, interpretation, input into manuscript; 11% Darshini Ayton: study design, interpretation, input into manuscript; 11% Andrew Briggs: interpretation, input into manuscript; 8%	N
7	Personal healthcare costs borne by younger people living with arthritis: an exploratory study	Submitted	Study design, data collection, data analysis, interpretation, manuscript preparation. 60%	Ilana Ackerman: study design, interpretation, input into manuscript; 11% Andrew Briggs: study design, interpretation, input into manuscript, 11% Darshini Ayton: study design, interpretation, input into manuscript; 10% Zanfina Ademi: interpretation, input into manuscript; 8%	N
8	Tweets by People with Arthritis During the COVID-19 Pandemic: Content and Sentiment Analysis	Published	Study design, data collection, data analysis, interpretation, manuscript preparation and revision. 70%	Darshini Ayton: study design, interpretation, input into manuscript; 14% Ilana Ackerman: interpretation, input into manuscript; 10% Andrew Briggs: interpretation, input into manuscript; 6%	N

I have added page numbers to the published and submitted papers in order to generate a consistent presentation within the thesis.

Student name: Danielle Berkovic

Student Signature: **Date:**

I 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.

Main Supervisor name: Ilana Ackerman

Main Supervisor signature: **Date:**

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Finally, to my Dad, who would have been so proud to have a doctor in the family. This one's for you.

ABBREVIATIONS

ACPA	Anti-citrullinated protein antibodies
ACR	American College of Rheumatology
ACSQHC	Australian Commission on Safety and Quality in Health Care
ADL	Activities of daily living
AS	Ankylosing spondylitis
ASAS	Assessment of Spondyloarthritis International Society
AUD	Australian dollars
CRP	C-reactive protein
CT	Computed tomography
DASH	Disabilities of the Arm, Shoulder and Hand Questionnaire
DALY	Disability-adjusted life year
DMARD	Disease-modifying anti-rheumatic drug
ESCEO	European Society for Clinical and Economic Aspects of Osteoporosis, Osteoarthritis and Musculoskeletal Diseases
ESR	Erythrocyte sedimentation rate
EULAR	European League Against Rheumatism
GP	General practitioner
GBD	Global Burden of Disease
HLA-B27	Human leukocyte antigen B27
HR	Hazard ratio
IFDFW	InCharge Financial Distress/Financial Well-Being
IA	Inflammatory arthritis
ICF	International Classification of Functioning, Disability, and Health
ILAR	International League of Associations for Rheumatology
JIA	Juvenile idiopathic arthritis
MBS	Medicare Benefits Schedule
MRI	Magnetic resonance imaging
NICE	National Institute for Health and Care Excellence
NSAPA	Australia's National Strategic Action Plan for Arthritis
OA	Osteoarthritis

OARSI	Osteoarthritis Research Society International
OECD	Organisation for Economic Cooperation and Development
OMERACT	Outcome Measures in Rheumatology
OOP	Out of pocket
OR	Odds ratio
PBS	Pharmaceutical Benefits Scheme
PROM	Patient-reported outcome measure
PsA	Psoriatic arthritis
QoL	Quality of life
RA	Rheumatoid arthritis
RACGP	Royal Australian College of General Practitioners
RF	Rheumatoid factor
ROM	Range of motion
RTW	Return to work
SD	Standard deviation
SLE	Systemic lupus erythematosus
SpA	Spondyloarthritis
UK	United Kingdom
WALS	Workplace Activity Limitations Scale
WHO	World Health Organization
WPAI	Work Productivity Activity Impairment
YLD	Years lived with disability

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List of Tables

This list excludes tables published articles (Chapters 2, 4-8).

THESIS OVERVIEW

The structure of this thesis, including each chapter number and title, is summarised in Figure 1.

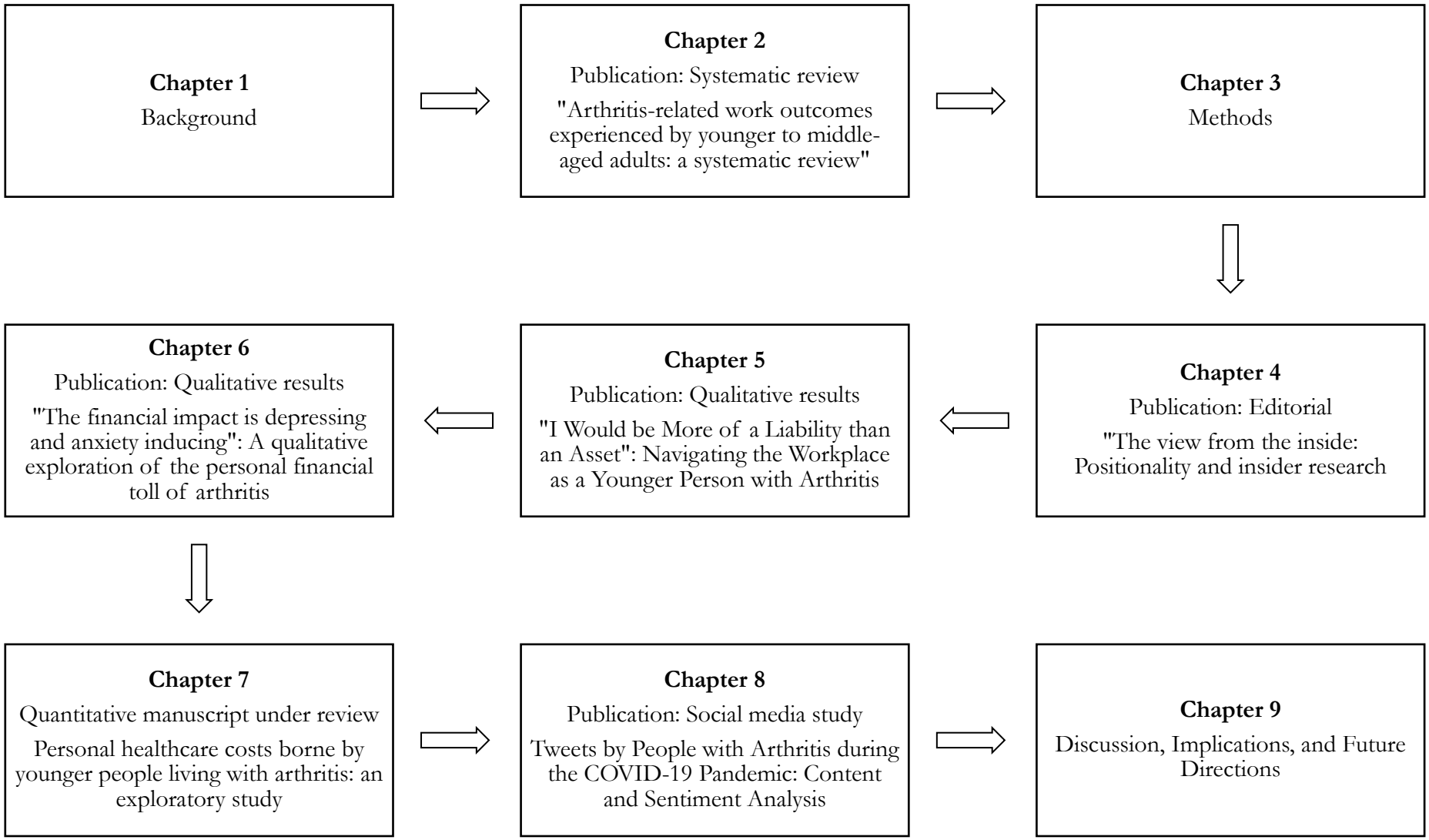

Figure 1: Structure of the Thesis

CHAPTER 1: BACKGROUND

1.1 Musculoskeletal Conditions

Musculoskeletal conditions commonly affect bones, muscles, joints and connective tissues, and can affect multiple body areas or bodily systems (1). Prevalent musculoskeletal conditions include different forms of arthritis, neck and back pain, and osteoporosis (2). The most recent Global Burden of Disease Study data show that in 2017, there were over one billion prevalent cases of musculoskeletal conditions worldwide (3). Musculoskeletal conditions are the second leading cause (after mental health) of non-fatal disease burden in adolescents and younger, working-age populations (4). According to the most recent Global Burden of Disease study, when measured across the life course, musculoskeletal conditions are the leading cause of non-fatal disease burden worldwide (5). Within a local context, musculoskeletal conditions affect seven million Australians (30% of the national population) (6), represent 23% of Australia's non-fatal disease burden, and comprise almost 12% of the total burden of disease in this country (7).

When considering 'disease burden', musculoskeletal conditions make up 20% of all years lived with disability (YLDs) for both men and women globally (8). In 2017, there were 138.7 million disability-adjusted life years (DALYs) due to musculoskeletal conditions globally (3), yet this figure is likely an underestimation given additional DALYs that relate to musculoskeletal injury and trauma (9). According to the most recent Survey of Disability, Ageing and Carers, musculoskeletal conditions account for 31% of disability in Australia, and over 50% of pain in Australia (7). It is also known that people with musculoskeletal conditions experience lower work participation rates (10-12), and indeed, they account for the greatest proportion of lost productivity in the workplace (9, 13, 14). At an individual level, having a musculoskeletal condition can also reduce one's capacity to earn steady income (15), and is a risk factor for falling into poverty (16-18).

Importantly, musculoskeletal conditions are prevalent across the lifespan. In Australia, 1 in 1,000 children aged 0 – 15 years has juvenile idiopathic arthritis (1), over half the population (58%) diagnosed with a musculoskeletal condition are aged between 25 – 64 years (19), and 29% of people aged 65 – 79 years, and 65% of people aged 80 years or over, live with osteoarthritis (20).

1.2 Definition, Physiology, and Aetiology of Arthritis

Arthritis is an umbrella term for a range of musculoskeletal, autoimmune, inflammatory and/or degenerative conditions affecting structures including but not limited to the articular and peri-articular structures. Arthritis can be broadly categorised into the two key sub-types of 'inflammatory arthritis' and 'osteoarthritis', although some arthritic conditions (for example, gout and scleroderma) sit outside these classifications (6). Osteoarthritis is a largely degenerative disease associated with structural changes and inflammation of the joints (21). Osteoarthritis has also been described as 'joint failure', akin to the failure of any other bodily part (22). Inflammatory arthritis is a title that encompasses over 100 chronic, autoimmune, and inflammatory diseases.

1.2.1 Osteoarthritis

Osteoarthritis is classified into two groups: primary (idiopathic or non-traumatic) and secondary (usually occurring following trauma) (23). Osteoarthritis can be diagnosed either radiographically or clinically. There have been many attempts to consistently diagnose and grade radiographic disease severity in osteoarthritis, but it is most widely assessed using the Kellgren-Lawrence score (24). Kellgren-Lawrence scores range from 0 (mild) to 4 (severe disease), and are graded based on pathological changes seen on imaging (25). The World Health Organization (WHO) has adopted the Kellgren-Lawrence scores as the standard for epidemiological studies on osteoarthritis (26). However, this is not always possible for pragmatic reasons (for example, costs and access to imaging), so in practice many large-scale epidemiological studies rely on self-reported, 'doctor-diagnosed osteoarthritis'. Additionally, radiographic disease severity often correlates poorly with symptom severity (25). For this reason, clinical diagnosis is preferred for adults aged over 45 years (27). This is outlined in the National Institute for Health and Care Excellence (NICE) clinical osteoarthritis guidelines and in the Australian Clinical Care Standards for osteoarthritis (28, 29)

Consistent with current Australian Clinical Care Standards, osteoarthritis can be diagnosed clinically by patient history and physical examination (28). A clinical diagnosis of osteoarthritis usually requires the presence of joint pain and stiffness. At an international level, two of the most well recognised standards for the diagnosis of clinical osteoarthritis are the NICE osteoarthritis guidelines (29)and the American College of Rheumatology (ACR) criteria (30, 31).

The knee is the most common site of osteoarthritis, followed by the hip, wrist and hand (32, 33). Pathological changes seen in joints affected by osteoarthritis include progressive destruction and

loss of cartilage, subchondral bone thickening, formation of osteophytes, degeneration of ligaments, inflammation of the synovium, and hypertrophy of the joint (34).

1.2.2 Inflammatory Arthritis

The most common types of inflammatory arthritis include rheumatoid arthritis and spondyloarthritis (7). Spondyloarthritis itself has several distinguishable subtypes, including ankylosing spondylitis and psoriatic arthritis. According to the most recent criteria published by the ACR and European League Against Rheumatism (EULAR) Collaborative Initiative (35), classification of rheumatoid arthritis (Appendix A) is based on the presence of at least one joint with definite clinical synovitis (swelling), where the symptom cannot be better explained by another diagnosis. In addition, new diagnoses must come with a score of $\geq$6/10 for the following criteria:

(a) Joint involvement (referring to swelling or tenderness on physical examination); where one large joint is scored zero, 2 – 10 large joints are scored one, 1 – 3 small joints (with or without involvement of large joints) are scored two, 4 – 10 small joints (with or without involvement of large joints) are scored three, and >10 joints (at least one small joint) are scored five.
(b) Serology, where negative rheumatoid factor (RF) and negative anti-citrullinated protein antibodies (ACPA) are scored zero, low-positive RF or low-positive ACPA are scored two, and high-positive RF or high-positive ACPA are scored three.
(c) Inflammatory markers, where normal C-reactive protein (CRP) and erythrocyte sedimentation rate (ESR) levels are scored zero, and abnormal CRP or ESR levels are scored one.
(d) Duration of symptoms, where <6 weeks is scored zero, and $\geq$6 weeks is scored one.

Pathological changes seen in joints affected by rheumatoid arthritis include a thickened and inflamed synovial membrane, resulting in unwanted tissue growth (36). The small joints of the hands and feet are the most common site of rheumatoid arthritis (37).

Inflammatory arthritis sub-types vary greatly, with the clinical presentation and diagnosis processes for spondyloarthritis following different criteria to that of rheumatoid arthritis. There are many features of spondyloarthritis, including low but constant levels of inflammatory pain, psoriasis, uveitis, and high CRP levels (38). Most recently, the Assessment of SpondyloArthritis international Society (ASAS) and the Outcome Measures in Rheumatology (OMERACT) group defined benchmarks to diagnose spondyloarthritis as radiological diagnosis of sacroiliitis in addition to one

or more feature(s) of spondyloarthritis; or the presence of human leukocyte antigen B27 (HLA-B27) – a genetic marker for spondyloarthritis – combined with two or more features of spondyloarthritis (39). Pathological changes seen in joints affected by spondyloarthritis include ossification of ligaments and ankyloses of the sacroiliac and apophyseal joints (40). The spine, followed by the hips, are the most common sites of spondyloarthritis (41).

In addition to rheumatoid arthritis and spondyloarthritis, juvenile idiopathic arthritis is a separate inflammatory arthritis sub-type, describing a clinically heterogeneous group of arthritis conditions of unknown origin presenting in children before 16 years of age (42). Clinically, juvenile idiopathic arthritis is difficult to diagnose as there are few biomarkers for the disease, and CRP and ESR levels often remain unchanged (43). There are seven juvenile idiopathic arthritis categories according to the International League of Associations for Rheumatology (ILAR) Classification of Juvenile Idiopathic Arthritis. Each is characterised by varying symptoms including but not limited to: fever, dactylitis, enthesitis, sacroiliac joint tenderness, and symptomatic anterior uveitis (44).

To date, there are no accurate or reliable scoring systems for diagnosing juvenile idiopathic arthritis. Magnetic resonance imaging (MRI) is currently the only diagnostic tool that can assess all relevant anatomical structures in joint inflammation, however, differentiating between normal findings and pathology can be challenging in this population (45). The knees and ankles, followed by the hips, are the most common sites of juvenile idiopathic arthritis (46).

1.3 Global and Australian Prevalence of Arthritis

Arthritis (of any diagnostic category) affects an estimated 3.6 million Australians or 15% of the population (19). One in seven Australians have some form of arthritis (6). Forecasting estimates based on projections of population growth and ageing indicate that the number of people with arthritis in Australia is expected to increase to 5.4 million by the year 2030, representing 18% of the population (47).

Osteoarthritis is the most common form of arthritis. The most recent Global Burden of Disease study showed that there were approximately 303.1 million prevalent cases (95% uncertainty interval 273.3 – 338.6 million) of hip and knee osteoarthritis worldwide (48). In 2017, the annual incidence rate of osteoarthritis was 181.2 per 100,000 population (95% uncertainty interval 162.6 – 202.4) (48). According to the most recent National Health Survey data, an estimated 2.2 million Australians (9.3% of the population) currently have osteoarthritis (62% of the population with arthritis) (19), affecting 12% of females and 7% of males (21).

Osteoarthritis has traditionally been considered a disease affecting only older people, however, diagnoses are increasing amongst working-age populations. International data show that the prevalence of knee osteoarthritis now peaks at around 50 years of age (49). Since 1990 there has been a steady growth in osteoarthritis amongst people aged 15 – 49 years, with the greatest burden evident for females (5). In Australia, the number of people with osteoarthritis aged less than 55 years is projected to increase by 20% over the next 15 years (47). Younger, working-age adults with osteoarthritis are four times more likely to experience high levels of psychological distress than the general population, and individuals aged 40 – 49 years with osteoarthritis have reported a 35% reduction in health-related quality of life (HRQoL) compared with population norms (50). Younger populations with osteoarthritis represent a new public health issue, given that these individuals will likely live with osteoarthritis for a period of time (51).

Inflammatory arthritis is currently the most prevalent form of arthritis in younger and working-age individuals. Rheumatoid arthritis is the most common inflammatory arthritis type: the most recent Global Burden of Disease study showed that there was close to 20 million prevalent cases (19,965,115; 95% uncertainty interval 17,990,489 – 21,955,673) of rheumatoid arthritis worldwide (52). In 2017, the annual incidence rate of rheumatoid arthritis was 14.9 per 100,000 population (95% uncertainty interval 13.3 – 16.4) (52). According to the most recent National Health Survey data, an estimated 457,000 Australians (1.9% of the population) currently have rheumatoid arthritis (12.7% of the population with arthritis) (19). It affects 2.3% of females and 1.5% of males (6).

Due to different reporting standards across countries, the estimated global prevalence of other inflammatory arthritis sub-types such as spondyloarthritis are less clear. One report estimates that the global prevalence of spondyloarthritis is one percent (53). It is estimated that the prevalence of spondyloarthritis in the United States (US) is 1.35% (95% confidence interval 0.44 – 2.79), with a lower prevalence reported for Europe: 0.54% (95% confidence interval 0.36 – 0.78) (54). The global prevalence of spondyloarthritis subtypes also vary: for psoriatic arthritis, prevalence rates range from 20 per 100,000 people in Sweden, to 670 per 100,000 people in Norway (55). For ankylosing spondylitis, prevalence rates range from 30 per 100,000 people in the Philippines, to 320 per 100,000 people in the US, to 370 per 100,000 people in Italy (56).

There are limited data on the prevalence of spondyloarthritis and its subtypes in Australia. It has been estimated that ankylosing spondylitis affects 1-2% of Australians (57), and that between 6-41% of Australians with psoriasis (estimated Australian prevalence 2.3-6.6%) will develop psoriatic arthritis (58). Psoriatic arthritis affects Australian men and women equally (59), however, Australian men are three times more likely to be diagnosed with ankylosing spondylitis than women (60).

1.4 Risk Factors for the Development of Osteoarthritis and Inflammatory Arthritis

Table 1 provides a summary of the known risk factors for the development of arthritis, including biological, lifestyle/behavioural and environmental risk factors.

Table 1: Summary of Known Risk Factors for the Development of Arthritis

	Osteoarthritis	**Inflammatory Arthritis**	**Brief Description of Risk Factor**
Biological Risk Factors			
Age	✓	✓	In joints affected by osteoarthritis there is destruction and loss of cartilage accompanied by osteophyte formation and subchondral bone thickening, a process which develops through cumulative effects of mechanical load across the lifespan, typically presenting in older adulthood (61). Rheumatoid arthritis is most frequently diagnosed between the ages of 30 and 50, however, the disease can present at any age (62). Psoriatic arthritis is positively associated with a younger age of onset (63), and spondyloarthritis diagnoses are most frequent amongst populations under 45 years of age (64). There is no consensus in the literature on why younger population are more susceptible to inflammatory arthritis (65).
Sex	✓	✓	Research suggests that female hormones and reproductive factors play a role in the pathogenesis of knee osteoarthritis in women over 50 years of age (66). Anatomic difference may also contribute to osteoarthritis development: increased pelvis width in females is recognised as a risk factor for hip osteoarthritis in middle-aged and older women (67). Rheumatoid arthritis is more common amongst females than males. Incidence rates of rheumatoid arthritis appear to be increased one to two years post-partum (68, 69). There is also an increased concentration of oestrogen observed in rheumatoid arthritis of both sexes (70). The inverse is true

	Osteoarthritis	Inflammatory Arthritis	Brief Description of Risk Factor
			for ankylosing spondylitis, which is more common amongst males than females. No specific risk factors have been identified that may predispose men to the disease (71-73).
Genetics	✓	✓	There are currently 90 genome-wide significant risk loci that are related to osteoarthritis (74). Heritability estimates range between 40-65%, but appear to be stronger overall for hand and hip osteoarthritis than for knee osteoarthritis (75). There are more than 100 genome-wide significant risk loci related to rheumatoid arthritis (76). Heritability contributes to the majority of ankylosing spondylitis susceptibility (77, 78): up to 90% of people with ankylosing spondylitis have the HLA-B27 gene (79). There are currently 20 genome-wide significant risk loci in relation to psoriatic arthritis, accounting for one fifth of heritability (78).
Lifestyle/Behavioural Risk Factors			
Overweight and Obesity	✓	✓	Obesity is widely acknowledged as a major risk factor for the development of osteoarthritis (80, 81), yet the mechanism by which weight influences osteoarthritis onset is unclear. Increased biomechanical load across cartilage has been traditionally theorised as a disease-related mechanism (82). Recent findings have revealed that obesity is a strong risk factor for hand osteoarthritis (83), suggesting that adipose tissue may be a more targeted osteoarthritis risk factor (84), and that the effect of obesity on joints may be metabolically driven and influenced by the pro-inflammatory effects of adipose tissue (85, 86).

	Osteoarthritis	Inflammatory Arthritis	Brief Description of Risk Factor
			Initial evidence suggests that women who are overweight (hazard ratio 1.45, 95% CI 1.03-2.03) or obese (hazard ratio 1.65, 95% CI 1.34-2.05) are at higher risk of receiving a rheumatoid arthritis diagnosis at a younger age (87), although more research is required to understand the mechanisms of how overweight and obesity affects rheumatoid arthritis (88). Being overweight at diagnosis has also been found to decrease the chance of achieving good disease control during the early stages of rheumatoid arthritis (89).
Exercise and sedentariness	✓		Participation in professional sport at an elite level is associated with increased risk of developing knee osteoarthritis (90-92), but this may relate to overuse injuries. At the same time, cartilage requires cyclic movement to remain healthy, for example through recreational walking and participation in activities of daily living. People who spend more time participating in sedentary behaviours, such as sitting, are also at increased risk of developing knee osteoarthritis (93, 94).
Joint injury	✓		The rupture of the anterior cruciate ligament (ACL) leads to early-onset knee osteoarthritis in 13% of cases after 10 – 15 years; this increases to up to 48% with additional meniscal injury (95). Hence, for a young adult playing sport, joint injury could be a pivotal life event that leads to the development of osteoarthritis by 30 years of age (96).
Tobacco		✓	Multiple studies have found a more than doubling of the likelihood of rheumatoid arthritis among smokers compared with non-smokers (97, 98), with further estimates that exposure to smoking accounts for 20-30% of the environmental risk for rheumatoid arthritis (99).

	Osteoarthritis	Inflammatory Arthritis	Brief Description of Risk Factor
Low vitamin D intake and levels		✓	Recent evidence found that people with rheumatoid arthritis treated with vitamin D as a complementary therapy experienced beneficial effects on disease activity, tender joint count, and ESR, but still experienced high levels of pain, joint swelling, and CRP (100).
Dietary intake		✓	Some studies have found that certain foods promote rheumatoid arthritis onset. Evidence suggests that consumption of dietary items, including potatoes and non-citrus fruits, are independent risk factors for rheumatoid arthritis development (101). Regular consumption of sugar-sweetened beverages is associated with increased risk of rheumatoid arthritis in women, and this risk increases with age (102). There is little evidence that dietary aspects influence any part of spondyloarthritis aetiology (103, 104).
Environmental Risk Factors			
Occupational loading and injury	✓		A recent investigation of the association between predominant lifetime occupation and prevalent osteoarthritis (from five international community-based cohorts) identified a more than two-fold increase in the odds of knee osteoarthritis amongst heavy manual workers compared to workers in sedentary occupations (105). Professions with repetitive thumb use (for example, typing work), and jobs with repetitive hand bending and twisting are associated with the development of hand and wrist osteoarthritis (106, 107). Cumulative physical workloads from before 16 years of age and into young adulthood are also associated with more frequent knee, hip, or hand osteoarthritis diagnoses (108).
Viral infection		✓	A recent systematic review found that the human Parvovirus B19, and hepatitis C, are associated with rheumatoid arthritis development (109). Parainfluenza and some coronaviruses have also been found

	Osteoarthritis	Inflammatory Arthritis	Brief Description of Risk Factor
			to be associated with increased rheumatoid arthritis incidence (110). The relationship between the Epstein-Barr virus and rheumatoid arthritis is under investigation (111, 112).

1.5 Physical and Psychological Impacts of Arthritis

Arthritis is associated with a range of physical and psychological impacts that likely stem from pain and other symptoms, decreased functional capacity, and a reduced ability to participate in activities of daily living (ADLs), work and social roles. For people with osteoarthritis or inflammatory arthritis, these limitations can be contextualised within the WHO's International Classification of Functioning, Disability and Health (ICF) framework (51, 113-117). This framework is shown in Figure 2.

The ICF is a framework for the description of health and health-related states, where functioning is viewed as an outcome of interactions between the health condition of an individual, and their contextual factors (117).

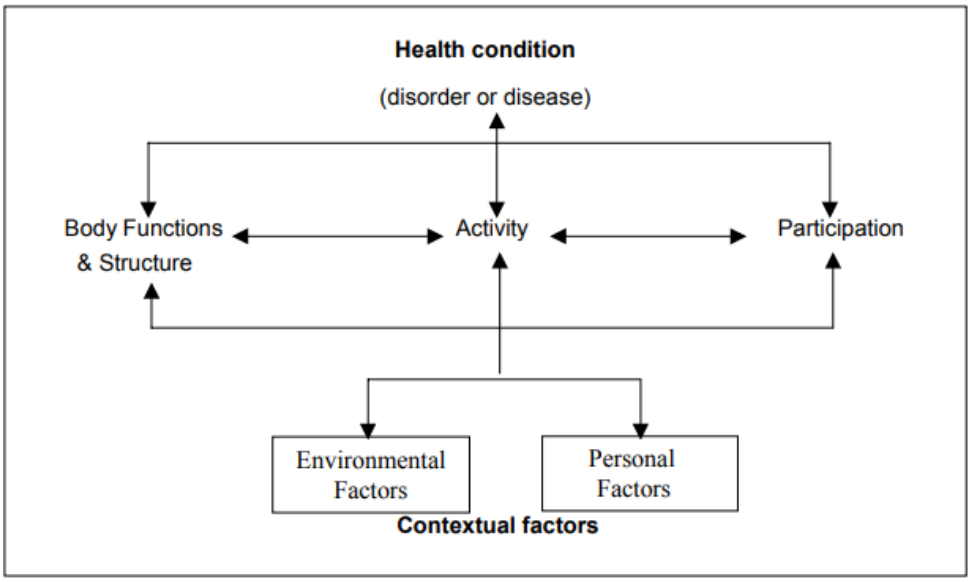

Figure 2: Diagram of the WHO ICF; reproduced from the World Health Organization (117)

As seen in Figure 2, the ICF contains five domains:

1. Body Functions and Structures: Physiological and psychological functioning, as well as anatomical parts of the body such as organs, limbs, and their components;
2. Activity: The execution of a task or action by an individual, and problems an individual with a specific health condition may have executing the activity;
3. Participation: Involvement in a life situation and problems an individual may experience partaking in everyday life;
4. Environmental Factors: Make up the physical, social, attitudinal, and legal structures in which people conduct their lives;

5. Personal Factors: Features of the individual, for example, age, gender, and profession.

The ICF offers a useful framework for considering the range of functional and participation restrictions that individuals with osteoarthritis or inflammatory arthritis may experience. As both diagnostic categories share common symptoms, there is likely an overlap in limitations experienced by people with either osteoarthritis or inflammatory arthritis. For people with arthritis, the literature identifies that these primarily relate to body function (for example, general movement and mental health), activity limitations (for example, carrying out ADLs and specific work-related tasks), participation restrictions (for example, going to work and contributing to family roles), and environmental factors (for example, disease awareness and perceptions) (113).

Table 2 summarises the physical and psychological symptom burden of osteoarthritis and inflammatory arthritis, mapped to the ICF framework. Where possible, supporting evidence has been drawn from younger populations with arthritis.

Table 2: Symptoms of Arthritis in Relation to the World Health Organization International Classification of Functioning, Disability, and Health Framework

Symptoms				
	Osteoarthritis	**Inflammatory Arthritis**	**Brief Description of Symptom**	**Mapping to the WHO ICF**
Physical Symptoms				
Joint pain and joint stiffness	✓	✓	*Osteoarthritis* There are two major types of pain in people with hip or knee osteoarthritis: one is intermittent but severe, and the other is constant background pain or aching (age range of study participants: 47-92 years) (118, 119). Osteoarthritis pain mainly occurs during the day and typically during movement or physical activities, but many individuals can exhibit resting pain at night (120). Some individuals with hip and knee osteoarthritis also experience neuropathic pain (mean age of study participants 66 years) (121), most likely arising from structural changes in joint innervation (122). People with osteoarthritis commonly also experience stiffness around the affected joint/s (mean age of study participants >40 years) (123). Stiffness most commonly occurs in the morning, after sitting, or after prolonged	*Osteoarthritis* • *Body Function and Structure:* In Australia, over half the population with osteoarthritis (58%) experience self-reported moderate to very severe pain associated with osteoarthritis, and are 2.9 times as likely to experience very severe pain (4.9%) compared with those without the disease (1.7%) (21). • *Participation:* Severe pain intensity is also associated with work participation restrictions in the form of productivity loss (odds ratio 2.5, 95% CI 1.3 – 4.8) (mean age of study participants >50 years) (125).

Symptoms				
	Osteoarthritis	**Inflammatory Arthritis**	**Brief Description of Symptom**	**Mapping to the WHO ICF**
			periods of rest (mean age of study participants >65 years) (124).	
			Inflammatory Arthritis Morning stiffness in particular is a prominent symptom for people living with inflammatory arthritis (126). Stiffness may not be isolated to the joints, but may be more widespread and felt over the whole body (age range of study participants 29-75 years) (127). Recent data suggests that stiffness is not just restricted to morning periods or post-rest, but so too after movement, after consuming certain medications, and can be influenced by the weather (age range of study participants 33-78 years) (128-130). Alongside stiffness, people with inflammatory arthritis consistently rate pain as one of their highest priorities (131). Pain associated with inflammatory arthritis is often chronic, in that individuals living with the disease may need to constantly manage pain throughout their	*Inflammatory Arthritis* • *Body Function and Structure:* From Australian research, morning stiffness is strongly associated with poor psychological coping (correlation 0.78 – 0.89, $p<0.001$) (mean age of study participants 57 years) (138). • *Activity:* Across 11 European countries, 47% of 1,061 adults with rheumatoid arthritis (mean age of study participants 55 years) reported that morning stiffness affected their work performance (139). • *Participation:* Across the US and Europe, 32% of 3,426 adults with psoriatic arthritis (mean age of study participants 56 years) reported missing work due to the disease (140).

Symptoms				
	Osteoarthritis	**Inflammatory Arthritis**	**Brief Description of Symptom**	**Mapping to the WHO ICF**
			day or over long periods of time (132). Inflammatory arthritis-related pain typically arises from synovitis, bone erosion, and inflammation (133). Rheumatoid arthritis related pain most commonly presents in the wrist and hand (mean age of study participants 60 years) but can also present in the neck and feet (37, 134). Spondyloarthritis pain most commonly presents in the lower back (135-137).	
Reduced joint range of motion	✓	✓	*Osteoarthritis* Reduced range of motion (ROM) is an indicator of the presence of osteoarthritis at the majority of joint sites, particularly the reduction or loss of rotation movement for the hip. Evidence of reduced ROM is part of two of the 10 EULAR recommendations for the diagnosis of knee osteoarthritis in people aged ≥50 years (141).	*Osteoarthritis* • *Activity:* People with osteoarthritis (mean age of study participants 63 years) report that reduced ROM impacts their ability to complete common ADLs such as wringing out washed clothes, opening jars and bottles, and washing floors (142).
			Inflammatory Arthritis Reduced spinal ROM is a key indicator of ankylosing spondylitis (143), and reduced wrist ROM due to progressive joint deformity is one of the symptoms of	*Inflammatory Arthritis* • *Body Function and Structure:* There is a strong and significant association (r^2=0.75,

Symptoms				
	Osteoarthritis	**Inflammatory Arthritis**	**Brief Description of Symptom**	**Mapping to the WHO ICF**
			rheumatoid arthritis (mean age of study participants 55 years) (144).	p=0.002) between reduced dorsal flexion ROM and walking velocity and stride length in people with rheumatoid arthritis (age range of study participants 51-72 years) (145).
Muscle weakness around the joint	✓	✓	*Osteoarthritis* The progressive loss of periarticular muscle mass and muscle function has consequences on joint stability and health (146). Muscle weakness is often precipitated by arthrogenic muscle inhibition, which is found to significantly affect the quadriceps of people with knee osteoarthritis (147). People with hip osteoarthritis (age range of study participants 45-80 years) also display poorer lower knee and hip flexor strength, and hip extensor and abductor strength compared to people without osteoarthritis (148).	*Osteoarthritis* • *Body Function and Structure:* There are demonstrable associations between osteoarthritis-related muscle weakness and increased risk of falls (age ≥45 years, mean age of study participants 67 years) (149, 150).
			Inflammatory Arthritis A 25-70% reduced in muscle strength has been observed in people with rheumatoid arthritis when	*Inflammatory Arthritis* • *Activity:* People with rheumatoid arthritis report significant activity limitations related

Symptoms				
	Osteoarthritis	**Inflammatory Arthritis**	**Brief Description of Symptom**	**Mapping to the WHO ICF**
			compared with age-matched controls without rheumatoid arthritis (151). Computed tomography (CT) scans have also showed decreased muscle mass in the quadriceps of people with ankylosing spondylitis, likely stemming from reduced activity due to decreased spinal mobility (152)	to reduced shoulder muscle weakness according to the Disabilities of the Arm, Shoulder and Hand (DASH) questionnaire, for example, placing an object on a shelf above head height, or using a knife to cut food (153).
Fatigue		✓	From an international sample of 6,120 participants with inflammatory arthritis, half of all participants (mean age of study participants 47 years) experienced severe fatigue (154). In rheumatoid arthritis, research has established that fatigue is present on most days for most people (age range of study participants 18-75 years), with more than 70% of individuals with the disease reporting fatigue levels equal to those seen in myalgic encephalomyelitis (chronic fatigue syndrome) (155). It is estimated that more than half (53%) of people with ankylosing spondylitis (mean age of study participants 45 years) experienced fatigue (156), although more recent research determined that prevalence of fatigue	• *Participation:* A systematic review of qualitative studies found that people with rheumatoid arthritis were unable to participate fully at work mostly due to fatigue and energy loss (159). • *Body Function and Structure:* People with psoriatic arthritis experience far reaching fatigue, which is linked to patient-reported outcomes of lack of motivation, loss of appetite, and bodily pain (160).

Symptoms				
	Osteoarthritis	**Inflammatory Arthritis**	**Brief Description of Symptom**	**Mapping to the WHO ICF**
			amongst people with ankylosing spondylitis (age range of study participants 18-66 years) was as high as 85% (157). Up to half of individuals with psoriatic arthritis are estimated to be limited by fatigue (158).	
Systemic issues and elevated risk of comorbidities		✓	The most recent evidence suggests that people with rheumatoid arthritis, ankylosing spondylitis, and psoriatic arthritis (age range of study participants 30-80 years) have a higher chance of displaying cardiovascular risk factors of hypertension, elevated cholesterol, and obesity leading to a high relative risk of cardiovascular disease compared to the general population (161). Ocular manifestations are also prevalent amongst people with rheumatoid arthritis, with global prevalence of dry eye ranging from 18-90% (162-164) and global prevalence of uveitis as high as 40% (165). While some will initially have psoriasis, others with psoriatic arthritis will also develop psoriasis over their lifetime: a chronic, immune mediated inflammatory skin disease (166).	• *Activity:* In the UK, individuals with psoriasis (age range of study participants 18-65 years) are significantly less likely to partake in physical activity (p=0.04) (167).

Symptoms				
	Osteoarthritis	**Inflammatory Arthritis**	**Brief Description of Symptom**	**Mapping to the WHO ICF**
Psychological Symptoms				
Depression and anxiety	✓	✓	*Osteoarthritis* The results of a recent meta-analysis found that on a global scale, one in five adults with osteoarthritis (mean age 65 years) experience symptoms of depression and anxiety (168), possibly attributable to physical symptom burden and limitations and persistent pain. Younger people with osteoarthritis in particular have a higher comorbid presentation of psychological symptoms and conditions, including major depression (age of study participants 20-55 years) (50), bipolar disorder (169), and substance abuse (age range of study participants 18->70)(170).	*Osteoarthritis* • *Activity:* Depression is associated with increased levels of knee pain whilst performing ADLs, and is associated with worse functional knee limitations in people with osteoarthritis (age range of study participants 61-91 years) (171). • *Body Function and Structure:* Recent Australian data has found that for adults aged 18–54 years with osteoarthritis, the relative risk of experiencing high or very high psychological distress is four times that of the age-matched Australian population (4.19, 95% CI 3.53-4.98) (50).
			Inflammatory Arthritis Observational studies have described a high prevalence of depression and anxiety in people with rheumatoid	*Inflammatory Arthritis* • *Body Function and Structure:* Rheumatoid arthritis is associated with a 34% increased

Symptoms				
	Osteoarthritis	**Inflammatory Arthritis**	**Brief Description of Symptom**	**Mapping to the WHO ICF**
			arthritis (172-175). The prevalence of major depressive disorder in people with rheumatoid arthritis was between 13-42%, which is two to four times than reported for the general population (176, 177). For people in their childbearing years (age range of study participants 18-45 years) in particular, there is marked anxiety surrounding family planning (178). Women also have concerns around experiencing post-partum flares, which may negatively influence mental health at an already-stressful time (179).	risk for mental health hospitalisation (hazard ratio 1.34, 95% CI 1.22 – 1.47), and ankylosing spondylitis is associated with a 36% increased risk for mental health hospitalisation (hazard ratio 1.36, 95% CI 1.12 – 1.36) in Canada (mean age of study participants 57 years) (180). • *Body Function and Structure:* In low and middle-income countries, having arthritis (of any diagnostic category) increases the odds of depression (odds ratio 2.43, 95% CI 2.21 – 2.67), and anxiety (odds ratio 1.75, 95% CI 1.63 – 1.88) (mean age of study participants 35 years) (181).

1.6 Overview of Arthritis-Related Healthcare and Treatment

Given the symptoms and impacts of arthritis, effective arthritis management requires ongoing engagement with a range of healthcare professionals, from medical doctors, to allied health professionals, to complementary sources of care for some (for example, a naturopath) over an extended period (29, 182). However, there are different focuses of treatment for people with osteoarthritis versus inflammatory arthritis. For example, for people with osteoarthritis, a physiotherapist may oversee the exercise component of disease management, and provide education on pain management and joint protection strategies (183). Inflammatory arthritis treatment focuses more on medical management to reduce disease activity or achieve symptom remission where possible, and requires a physician (usually a rheumatologist) to both prescribe medication and monitor potential side effects (182, 184).

Inflammatory arthritis may be treated with various medications ranging from simple paracetamol, to non-steroidal anti-inflammatory drugs, to oral or injectable disease-modifying anti-rheumatic drugs (DMARDs), and biologic treatments (185). There is low–moderate levels of evidence supporting the use of supplements too, for example, omega-3 and vitamin D (186). Treatment options and plans for people with arthritis are guided by best practice evidence and the needs and preferences of the individual. In tandem with the necessary healthcare and treatment, both osteoarthritis and inflammatory arthritis should be managed within a biopsychosocial model of health, where vital aspects such as physical function and mental wellbeing remain essential (187).

1.7 Guidelines for Treatment and Management of Osteoarthritis

A range of available guidelines assist healthcare professionals in providing care to people with arthritis. These guidelines account for how to treat physical and psychological symptoms to improve quality of life (QoL), as well as empowering people with arthritis to learn more about the disease, and self-manage their symptoms as best as possible.

There is a range of guidelines to support best practice and patient-focused treatment recommendations for people with osteoarthritis. International guidelines include the Osteoarthritis Research Society International Guidelines (OARSI) (188), the American College of Rheumatology (ACR) Foundation Guideline for the Management of Osteoarthritis (189), the European Society for Clinical and Economic Aspects of Osteoporosis, Osteoarthritis and Musculoskeletal Diseases (ESCEO) (190), and the National Institute for Health and Care Excellence (NICE) guidelines for osteoarthritis care and management (29). The primary Australian guideline is the Royal Australian College of General Practitioners Guideline (RACGP) for the management of knee and hip osteoarthritis (191). These guidelines largely overlap with respect to recommended care. As an example, this section will summarise the NICE guidelines, which explicitly focus on the holistic assessment of a person with osteoarthritis (Figure 3).

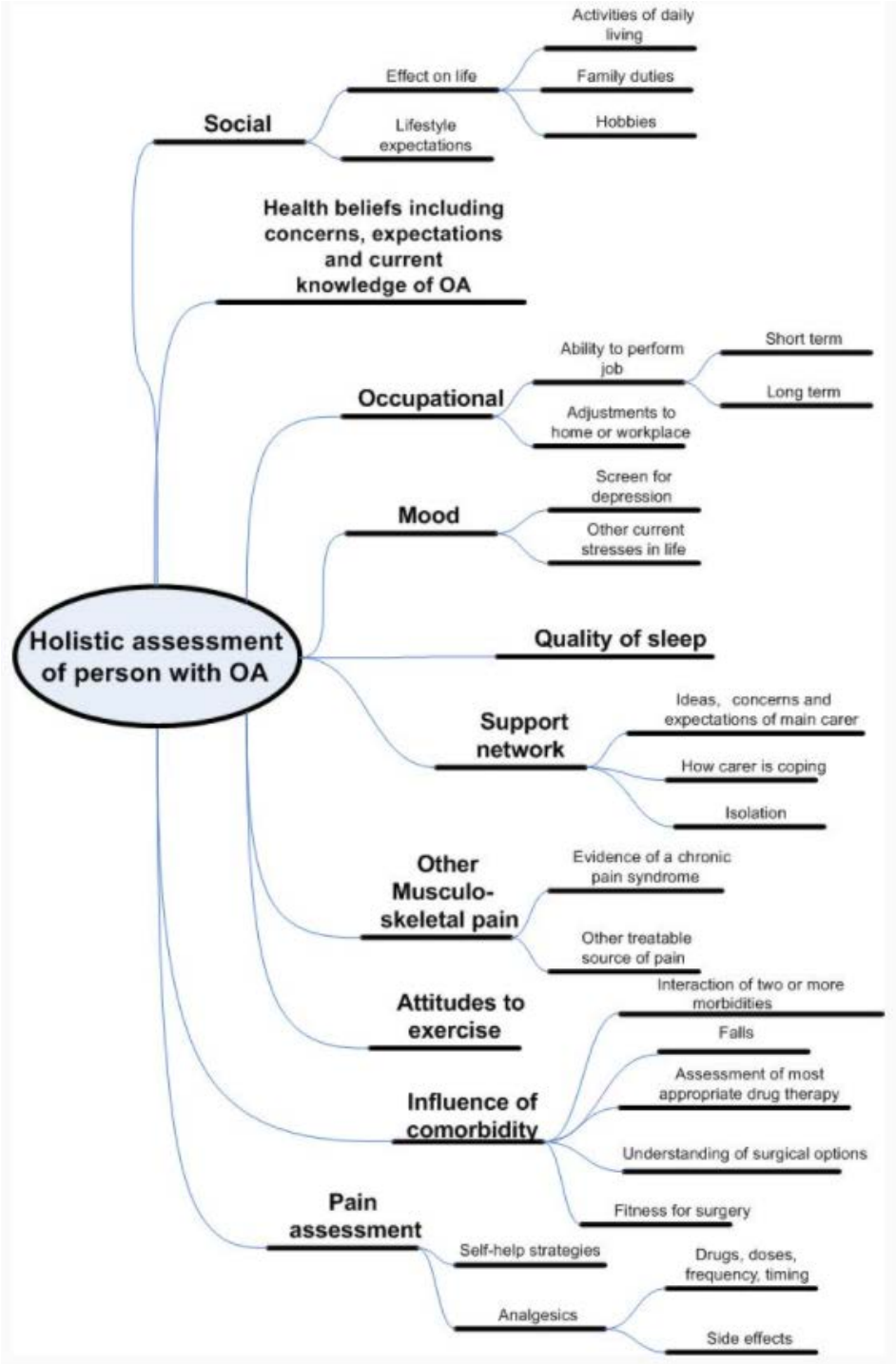

Figure 3: Diagram of the NICE Guidelines of Holistic Assessment of a Person with Osteoarthritis, reproduced from the National Institute for Health and Care Excellence (29)

There are five components to the NICE osteoarthritis guidelines:

1. Holistic Care: The overarching principal of the NICE guidelines is that osteoarthritis care should be holistic. It is important to assess the effect of osteoarthritis on a person's function, QoL, occupation, mood, relationships, and leisure activities, taking into account the subjective needs of each individual.
2. Education and Self-Management: The second principal of the guidelines relate to education and management, with the guidelines stating that health professionals should offer accurate information about osteoarthritis to all people living with the disease. It is important that health professionals not only provide information, but so too counter misconceptions and misinformation about the disease.
3. Non-Pharmacological Management: The guidelines state that exercise (both muscle strengthening and aerobic fitness) are vital to osteoarthritis management. Support to participate in exercise should be provided, including access to appropriate footwear, braces/joint supports/insoles where needed, and assistive devices from an occupational therapist (for example, walking sticks) to participate in ADLs where necessary.
4. Pharmacological Management: General practitioners and rheumatologists are advised by the guidelines to first offer people non-pharmacological management, however, other medications, including non-steroidal anti-inflammatory drugs, or intra-articular corticosteroid injections, may be considered in conjunction with exercise to promote pain relief.
5. Referral for Consideration of Joint Surgery: Only once people with osteoarthritis have participated in the four aforementioned components of the NICE guidelines should individuals be referred for surgery. Surgery should only be considered based on experiencing prolonged functional limitation and severe pain.

1.8 Guidelines for Treatment and Management of Rheumatoid Arthritis

As for osteoarthritis, there is a range of guidelines to support best practice and patient-focused management of inflammatory arthritis (192-194). As an example, this section will summarise the NICE recommendations for the management of rheumatoid arthritis (182). The NICE recommendations for the treatment of spondyloarthritis are similar to those for rheumatoid arthritis, although there is a stronger focus on specific joint sites affected, and side-effects of biologic DMARDs (184). These are summarised in Appendix B. There are six components to the NICE rheumatoid arthritis guidelines:

1. Treat-to-Target Strategy: The key goal of rheumatoid arthritis treatment is to achieve remission or low disease activity. Rheumatologists should therefore prescribe DMARDS, or biologic DMARDs, with regular monitoring of CRP levels until the target outcome is achieved.
2. Communication and Education: The second principle of the guidelines state that health professionals should explain the risks and benefits of treatment options in simple, verbal, and written form. This will not only enhance people's knowledge of rheumatoid arthritis, but so too counter misconceptions relating to the disease.
3. Pharmacological Management: Finding the appropriate medication regime for each individual living with rheumatoid arthritis is vital to achieving low disease activity. The guidelines therefore state that for people newly diagnosed with rheumatoid arthritis, rheumatologists should offer first-line DMARD therapy (for example, Methotrexate), within three months of onset of persistent symptoms. Where DMARDs fail to reduce inflammation levels and symptoms, rheumatologists may prescribe biologic DMARDs. Biologic DMARDs work to interfere with cytokine function/production to target a specific pathway of the immune system to halt disease progression. Each individual with rheumatoid arthritis responds to pharmacological treatment differently, and many different drug combinations could be trialled. The process of pharmacological management is depicted in Figure 4.

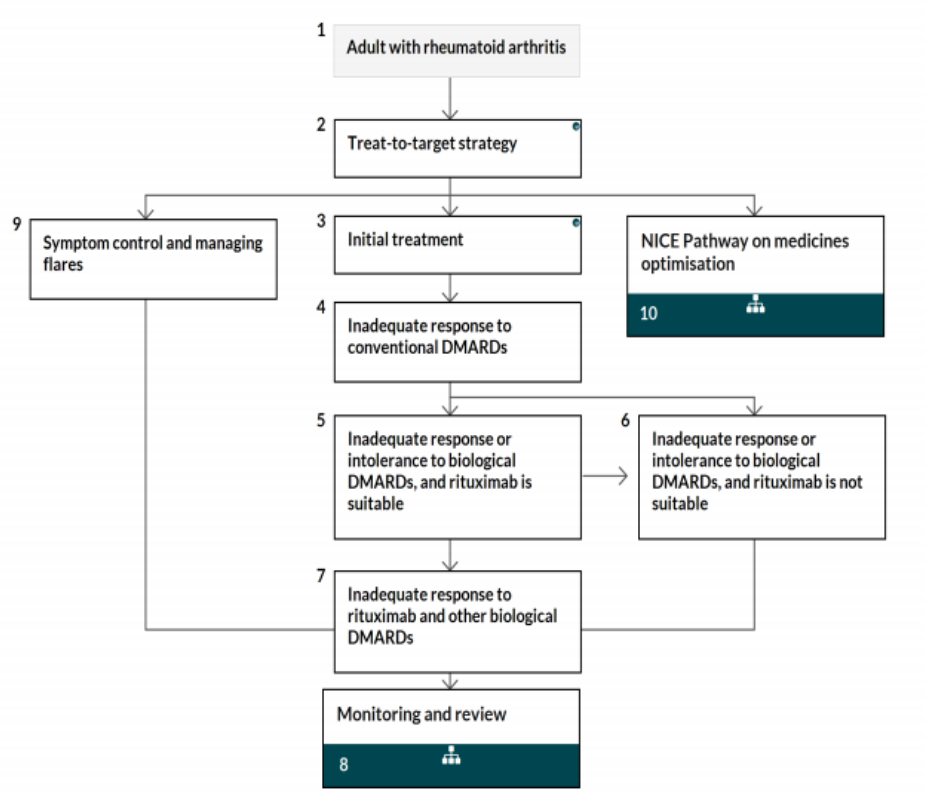

Figure 4: Flowchart of Drug Treatment for Rheumatoid Arthritis, reproduced from the National Institute for Health and Care Excellence (195)

4. Non-Pharmacological Management: In addition to pharmacological management, the NICE rheumatoid arthritis guidelines recommend that people attend periodic physiotherapy appointments to improve general fitness and encourage regular exercise, to learn exercises for joint flexibility, muscle strength, and managing other functional impairments. For people struggling to complete ADLs, engaging an occupational therapist, physiotherapist, or specialised hand therapist may also provide benefit. A counsellor, mental health social worker, or psychologist may offer mental health-related interventions to help individuals with rheumatoid arthritis adjust to living with the condition.
5. Monitoring: Regular monitoring by a rheumatologist is essential for all people with rheumatoid arthritis, to ensure maintenance of low disease activity or remission, and to remain informed about the most up-to-date treatment options and relevant information.
6. Timing and Referral for Surgery: Rheumatologists or general practitioners should only refer people with rheumatoid arthritis for surgical intervention if they do not respond to non-surgical management as outlined in the five components of the NICE rheumatoid arthritis guidelines above. Ongoing symptoms that may prompt surgery include persistent pain due to joint damage and progressive deformity.

1.9 Societal and Health System Impacts of Arthritis in Australia

1.9.1 Costs to the Health System

From 2008 to 2009, estimated government healthcare expenditure on arthritis and other musculoskeletal conditions (including back problems and osteoporosis) totalled 5.5 billion Australian Dollars (AUD) , which accounted for close to nine percent of all healthcare expenditure in Australia (AUD 65.2 billion) (196). More than half (54%) of this expenditure was dedicated to healthcare services provided during a hospital admission (AUD 3.0 billion), such as surgery. Nearly one third (30%) of this expenditure was dedicated to out-of-hospital medical expenses, including general practitioner (GP) and specialist consultations, medical imaging, pathology, and other diagnostic services (AUD 1.6 billion). Less than one fifth (16%) of total healthcare expenditure was attributed to prescription pharmaceuticals (AUD 922.0 million) (196).

Concerningly, over the past decade, healthcare expenditure has more than doubled. In 2015–2016, an estimated eleven percent (AUD 12.5 billion) of all disease expenditure in Australia was related to arthritis and other musculoskeletal conditions (1). Direct healthcare costs for osteoarthritis alone were estimated to be over AUD 2.1 billion in 2015; and this figure was projected to exceed AUD 2.9 billion by 2030 based on population growth and ageing (197). However, these conservative projections have already been surpassed. In 2015–2016, osteoarthritis cost the Australian healthcare system an estimated AUD 3.5 billion, representing 28% of disease expenditure on musculoskeletal conditions (21).

Government healthcare expenditure for rheumatoid arthritis (including hospitalisations and pharmaceuticals) were estimated to be 550 million AUD in 2015; this figure was projected to reach AUD 755 million by 2030 (197). These projections have also been surpassed. In 2015–2016, rheumatoid arthritis cost the Australian health system AUD 1.2 billion, representing 9.6% of disease expenditure on musculoskeletal conditions (198). A large component of rheumatoid arthritis healthcare costs relate to expenditure on biologic DMARDs, which has also increased sharply over the past decade as novel and expensive therapies emerge. In 2007, the Australian Pharmaceutical Benefits Scheme (PBS) reimbursed 27,970 biologic DMARD prescriptions at a cost of AUD 53.1 million (199). Less than a decade later, annual PBS expenditure on biologic DMARDs was estimated at AUD 2.29 billion (200).

Despite high levels of expenditure on direct hospital expenses and pharmaceutical benefits, there are many aspects of healthcare related costs that are not well measured or understood. These include, but are not limited to: the cost of non-medical services, aids and appliances, over the

counter medications (for which no rebate is available from the government), and formal arthritis self-management programs (47). Commonly, patients will need to contribute their own funds (known as out-of-pocket (OOP) costs) to pay for these types of services or assistive devices. Such OOP costs could potentially restrict access to care, despite Australia's publicly funded healthcare system (201). Financial barriers to accessing care have been found to correlate with preventable hospitalisations, which can in turn increase healthcare expenditure (202).

1.9.2 National Sources of Monetary Loss

In 2015, approximately 52,000 individuals (representing 0.33% of those unemployed in Australia) were out of the workforce due to arthritis (18). In the same year, people with arthritis who were unable to work received a median weekly welfare payment of AUD 329.50 and paid negligible tax, resulting in substantial national economic loss (18). In Australia, the median weekly welfare payment for an adult with arthritis out of the workforce comprised only one-quarter of the median weekly income of employed adults without arthritis in 2015, resulting in a substantial individual financial burden (203). In 2020, this welfare payment represented just one fifth of the average weekly salary for an adult employed full-time (203). By the year 2030, 60,000 individuals aged 45–64 years are projected to be out of the workforce due to arthritis (14).

On a national scale, the economic impacts of arthritis from lost labour force participation totalled AUD 1.75 billion in lost income in 2015. Additional welfare payments for people with arthritis due to lost labour force participation were AUD 635 million in the same year. There was also AUD 458 million lost in taxation revenue due to lack of workforce participation from people with arthritis in 2015. In the same year, withdrawal from the workforce by adults aged 15–64 years due to arthritis resulted in AUD 7.2 billion lost in gross domestic product (GDP) (18).

Lost productivity due to arthritis and back pain cost Australia AUD 14 billion in 2015, and this is expected to grow to more than AUD 22 billion by 2030 unless measures are implemented to improve work productivity for this population group (14). Chronic pain specifically, which includes pain associated with arthritis, is responsible for an estimated 9.9 million absent days from work each year, which costs Australian workplaces close to AUD 1.4 billion per annum (204).

Finally, in Australia, approximately 41,000 people were primary carers for someone with arthritis in 2015. Nearly half of carers (46%) for people with arthritis were out of the workforce in 2015 (18). In the same year, primary carers who were out of the workforce caring for someone with arthritis received weekly welfare payments of AUD 246.70 and paid negligible tax per week (18).

1.10 The Impacts of Living with Arthritis as a Working-Age Adult

As osteoarthritis is the most common type of arthritis, and until more recently was considered a disease predominantly affecting older adults, the majority of existing arthritis research focuses on older adult populations. The age ranges or mean age of study participants included in studies (where provided) is highlighted in Section 1.5, where the majority of studies examining arthritis-attributable symptoms and impacts include older adult populations with few studies focusing on the needs of younger, working-age populations.

Recently published articles and editorials have advocated for research targeting younger adults with osteoarthritis or inflammatory arthritis (51, 205). Australia's National Strategic Action Plan for Arthritis (NSAPA), published in 2019, also highlights the misconception that arthritis only affects older people, and recommends the inclusion of younger and working-age adults with osteoarthritis or inflammatory arthritis in research, to better understand and raise awareness of applicable issues (206). Whilst there is research that focuses on working-age populations (given that inflammatory arthritis is most frequently diagnosed in adults <50 years of age), these studies often include older adults too, and rarely focus on the unique needs of younger, working-age individuals.

Some of the specific concerns of younger people with arthritis have been discussed in this chapter. These primarily relate to physical and psychological symptoms, which contribute to potential difficulties completing certain work tasks and ADLs, participating fully in work and social roles, and the mental toll of family planning and fulfilling family roles (207).

Further, whilst the societal and health economic impacts of arthritis are informed by considerable data (described in Section 1.9), it can be considered that younger adults will likely bear a personal financial toll associated with managing arthritis symptoms across their lifespan. For example, researchers have found that younger people with arthritis spend more money on arthritis-related healthcare and self-management measures than older adults with arthritis, to improve functional capacity and to remain independent and productive at work, in social settings, and within their family (208, 209).

1.10.1 The Impact of Arthritis on Work

The impacts of arthritis on work are diverse, ranging from physical symptom burden that can restrict the ability to perform work-specific tasks, to medication side effects that require leave periods from work, to potential stigma that may impact employment. As stated earlier, despite some existing knowledge, few studies have solely included participants of working-age, or focused on their unique work-related needs.

Qualitative research involving 39 adults under 30 years of age with arthritis of any diagnostic category described the side effects experienced and other medication impacts, which translate into recurrent time off work and contributed to education and employment disruptions (210). A study involving working-age adults with rheumatoid arthritis in Sweden (n=25) also found that the side effects of DMARDs impeded their ability to fulfil their work roles to the best of their ability, and as a result many ceased treatment (211). A recent synthesis of qualitative studies found that working-age adults with rheumatoid arthritis or spondyloarthritis were influenced by observing other people's experiences on Methotrexate. Side effects of the drug led to colleagues taking time off work, which influenced others to refuse medication initiation (212).

In addition to medication side effects, previous research has shown that young adults in the workplace report that arthritis flares, fatigue, and reduced energy and strength pose challenges for productive working (10). Younger people in the workplace have also discussed concerns around inflammatory arthritis symptoms causing fluctuations in their ability to perform work tasks, which may affect their credibility (213). Canadian research has found that individuals with osteoarthritis or rheumatoid arthritis are hesitant to accept future work commitments because of difficulty anticipating symptoms and fear of not meeting work-related commitments (214). Another study reported that individuals with arthritis avoided work activities or tasks that involved potentially strenuous activities (including social events) due to pain and fatigue, leading to feelings of embarrassment, and representing a barrier to gaining steady employment (215).

Perceived stigma from the public and workplace managers towards people with arthritis has also been shown to negatively influence people's work outcomes (216). For men with rheumatoid arthritis, many continue to work despite physical pain, in fear of familial judgement and stigmatisation (217). Individuals with arthritis have also reported concerns related to experiencing stigma (for example, negative or damaging attitudes) that can manifest in the form of lost credibility with employers, lost opportunities for promotion, or even job loss (218).

Despite this evidence, only one (non-systematic) literature review has focused on arthritis-related work experiences among younger populations. The included studies were homogeneous, and comprised small samples of participants with juvenile idiopathic arthritis only (219). The extant literature currently provides limited insight into the work-related impacts of arthritis types that disproportionately affect people of working age.

1.10.2 The Individual Financial Burden of Arthritis

In Australia, even within the publicly funded healthcare system, healthcare costs borne by the patient comprise approximately 18% of health spending, which exceeds the Organisation for Economic Cooperation and Development (OECD) median of 15.8% (201). This level of OOP expenditure is particularly concerning, given that people with arthritis in Australia earn, on average, AUD 100 below the poverty line each week (220).

The most recent data (albeit from 2002) showed that individuals with rheumatoid arthritis spent on average AUD 1,513 yearly managing the disease (221); AUD 71 yearly on aids and home modifications in 2012, and AUD 26 extra for each appointment comprising travel-related and parking costs in 2004 (222). These incurred costs are prominent for people with arthritis, yet expenditure estimates are clearly outdated and contemporary arthritis-related healthcare costs remain unquantified in the literature.

1.11 Research Gaps and Rationale for this PhD

This chapter has highlighted the high community prevalence of osteoarthritis and inflammatory arthritis and the societal and personal impacts. An overview of disease risk factors, symptom burden, and the common healthcare requirements for managing arthritis across the lifespan has also been provided.

As described in this chapter, arthritis is a lifelong disease that can affect any individual at any age. The existing body of literature captures the experiences and health needs of older adult populations; however, less attention has been paid to younger, working-age adults living with arthritis.

The work-related impacts of arthritis and the personal financial burden of living with arthritis are highlighted as two primary issues pertinent to younger, working-age individuals living with the disease. Whilst working productively is an important life phase, little research has examined the influence of arthritis on people's early work experiences, career progression and career choices (207). There have also been calls for a bottom-up costing approach to capture the current personal financial burden of people living with arthritis, as even within Australia's publicly funded healthcare system, personal OOP costs are still concerningly high (47). Such expenditure forms an important component of the financial burden of arthritis, with potential downstream impacts on financial distress, mental health, and ongoing costs across the lifespan.

This PhD focuses on the work-related experiences, and personal financial burden, of younger, working-age adults with osteoarthritis or inflammatory arthritis in Australia. Specifically, this PhD will examine work impacts in line with the WHO ICF by considering:

1. Work participation restrictions;
2. Activity limitations related to work-specific tasks;
3. Environmental factors contributing to workplace difficulties; and
4. The role of body function impairments on perceived ability to work.

Further, this PhD seeks to quantify the financial burden borne by younger, working-age adults with osteoarthritis or inflammatory arthritis in Australia. Specifically, this PhD seeks to address current evidence gaps by:

1. Identifying the most common categories of personal arthritis-related expenditure;
2. Investigating healthcare costs in relation to disease duration;

3. Quantifying levels of financial distress and the relationship between healthcare costs and financial distress; and
4. Exploring the perceived financial impacts of arthritis, and financial concerns, among the population of interest.

1.12 PhD Aims and Objectives

The overarching aim of this PhD is to examine the experiences of younger, working-age adults (defined as those aged 18 – 50 years) living with and managing osteoarthritis or inflammatory arthritis. The specific objectives are to:

1. Examine the work impacts of arthritis for younger, working-age adults;
2. Determine the personal financial burden (comprising direct and indirect healthcare costs) of arthritis on younger, working-age adults;
3. Develop recommendations around personal, financial, and work-related impacts for clinicians treating younger, working-age adults with arthritis, to support person-centred care.

CHAPTER 2: SYSTEMATIC REVIEW

This chapter contains a published systematic review undertaken as part of this PhD. The systematic review aimed to identify, appraise, and synthesis evidence on work-related outcomes experienced by younger and middle-aged adults with arthritis. This aligns with the first PhD objective, which sought to examine the work impacts of arthritis on younger, working-age adults. It also contributes to the third objective: to develop recommendations around the work-related impacts of arthritis for clinicians, to support person-centred care. The systematic review findings and how they contribute to the PhD overall will be discussed in Chapter 9.

Supplementary material for the systematic review is provided in Appendices C (Medline Search Strategy Example), D (Critical Appraisal Scores), and E (Results of Low Quality Studies).

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Arthritis-related work outcomes experienced by younger to middle-aged adults: a systematic review

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ABSTRACT

Objective The aim of this review was to systematically identify, appraise and synthesise evidence on work-related outcomes experienced by younger to middle-aged adults (aged 16–50 years) with arthritis.

Methods Eligible studies were identified in Medline, PsycINFO, Embase and CINAHL in January 2020. Quantitative and qualitative studies containing self-reported data on work-related outcomes on younger/middle-aged adults with arthritis were included. Quality assessment was undertaken using validated quality appraisal tools from the Joanna Briggs Institute.

Results Thirty-four studies were identified for inclusion. Work outcomes were organised around five themes: (1) arthritis-related work productivity outcomes, (2) arthritis-related work participation outcomes, (3) other arthritis-related workplace outcomes, (4) barriers to work participation associated with arthritis and (5) enablers to work participation associated with arthritis. Arthritis was associated with work limitations on the Workplace Activity Limitations Scale (average scores ranging from 5.9 (indicating moderate workplace difficulty) to 9.8 (considerable workplace difficulty)), and higher work disability prevalence rates (range: 6%–80%) relative to healthy populations. Arthritis was not associated with decreased absenteeism on the Work Productivity and Activity Impairment Questionnaire (mean (SD) 7.9% (14.0%)), indicating low levels of absenteeism, similar to healthy populations. As work outcomes were commonly binary, person-centred (qualitative) perspectives on barriers and enablers augmented the quantitative findings.

Conclusion Arthritis is commonly associated with poorer work outcomes for younger/middle-aged adults relative to healthy populations. Additional research focusing solely on the workplace needs of younger/middle-aged population groups is required to inform tailored interventions and workplace support initiatives to maximise productive working years.

Key messages

What is already known about this subject?

- Research suggests that younger adults with arthritis are less likely to be employed, more likely to face productivity challenges at work and are at increased risk of early retirement compared with healthy peers. The work-related impacts of arthritis on adults in their peak income-earning years remain largely unexplored in a systematic manner and rarely considered within routine arthritis care.

What are the new findings?

- Moderate-to-high-quality evidence indicates that arthritis in younger and middle-aged people is associated with work limitations and higher work disability prevalence rates to healthy populations. The magnitude of impact may increase with age. There are a number of barriers to work participation among people with arthritis, including lack of workplace support and discord with colleagues; identified enablers include motivation to work, and managerial and collegiate support.

How might this impact on policy or clinical practice in the foreseeable future?

- Increased attention to work-related impacts of arthritis on young and middle-aged people may facilitate work participation and inform tailored interventions and workplace support programmes to maximise productive working years.

INTRODUCTION

Arthritis is typically characterised by joint pain, swelling and stiffness that limits normal function and reduces participation in productive work.[1] Globally, it is estimated that adults in their peak income-earning years (18–64 years) are disproportionately impacted by arthritis.[2] Younger adults with arthritis experience unique school-to-work transitions associated with lower levels of employment[3] and increased productivity challenges at work, compared with healthy peers.[4–6] Evidence suggests that many middle-aged adults living with inflammatory arthritis (IA) or osteoarthritis (OA) are forced into early retirement.[7]

The work-related impacts of arthritis on younger to middle-aged adults remain largely unexplored in a systematic manner and are rarely considered within routine arthritis care.[8] In current arthritis literature, work outcomes are generally measured through presenteeism and absenteeism measures, for example, via validated tools, economic costs or employment rates.[9] These measures provide objective data on work-related outcomes, but do not provide a broader perspective on work experiences.

To date, only one (non-systematic) literature review has focused on arthritis-related work experiences among younger adults. However, the included studies were homogeneous and comprised small samples of participants with juvenile idiopathic arthritis (JIA).[3] Another systematic review

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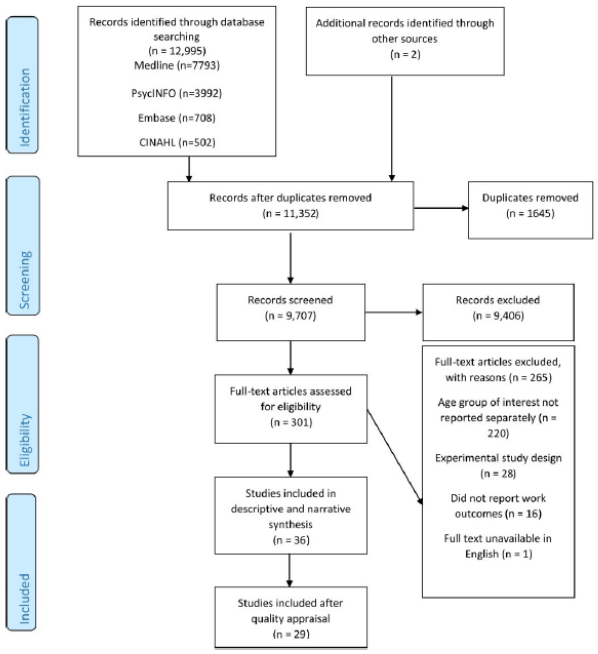

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram.

assessed workplace disclosure and accommodations for adults with disabilities. Four studies within this review focused on arthritis populations (ages 8–71 years); yet the studies included only participants with JIA, systemic lupus erythematous (SLE) or 'general disability'.[10] The extant literature therefore provides limited insights into the work-related impacts of arthritis, as more common arthritis conditions (eg, rheumatoid arthritis (RA)) disproportionately affect people of working age, that is, younger to middle-aged adults.[11 12]

This systematic review aimed to identify, appraise and synthesise the work-related outcomes associated with arthritis experienced by younger to middle-aged adults (defined for this review as those aged 16–50 years).

METHODS

Design

A systematic literature review was undertaken. The systematic review protocol was registered on the PROSPERO International Prospective Register of Systematic Reviews (registration number 106919). The review is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement (figure 1).[13]

Search strategy

An electronic literature search was undertaken in Medline, PsycINFO, CINAHL and Embase databases. With specialist research librarian assistance, a comprehensive search strategy was designed using customised search terms. Online supplementary file 1 contains the Medline search strategy as an example, which was adapted accordingly for the other databases (available from the authors on request). The reference lists of previously identified key literature and systematic reviews identified in the initial search yield were hand searched to identify any additional primary studies. The search strategy was limited to English language and to papers published during January 2000-January 2020 to focus on data related to contemporary work contexts. The search strategy did not include grey literature, intervention studies or systematic reviews.

Study selection

Eligible studies were primary qualitative, quantitative or mixed-methods design studies that reported on participants aged 16–50 years with IA and/or OA. The lower age limit of 16 reflects a common entry point to the part-time workforce. The upper age limit of 50 years is consistent with existing arthritis-related literature.[11 14] Where studies involved a broader range of age groups, these were included if data within the 16–50-year age band were reported separately. Studies where the outcomes were not directly reported by people who lived with IA or OA (eg, where outcomes were reported only by employers or spouses), studies focusing on non-arthritis musculoskeletal conditions and studies where the full text was not available in English or unavailable in its entirety were excluded.

Two reviewers (DB and CP) independently screened the titles and abstracts of all retrieved studies using Covidence software (Veritas Health Innovation Ltd, Melbourne, Australia) to determine eligibility. All potentially eligible studies were reviewed independently at the full-text stage and their reference lists were checked for potentially relevant studies (DB and CP). At each review stage, discordance regarding eligibility was discussed and resolved through consensus.

Data extraction

Two reviewers (DB and CP) independently extracted data using a custom template. Variables included the study design, country, proportion of participants aged 16–50 years, gender, arthritis type, years since diagnosis and relevant outcomes (qualitative and quantitative) concerning work.

Outcome measures

As there is no accepted gold standard outcome for work,[15] all work-related definitions and instruments reported in primary studies were included. Qualitative outcomes emerged through second-order author-derived themes and categorised through first-order examination of direct quotes.

Quality and risk of bias assessment

The methodological quality of all included studies was assessed independently by two reviewers (DB and CP) using validated critical appraisal tools from the Joanna Briggs Institute (JBI).[16] The JBI is an international research organisation based at the University of Adelaide in South Australia. Its aim is to improve health outcomes across the globe by working with universities and hospitals to synthesise and implement the best available evidence to inform healthcare decisions.[17]

The critical appraisal tools included 8 (for cross-sectional studies)–11 (for cohort studies) items depending on the study design. Scores were converted to percentages to allow for comparison of evidence quality scores across different study types (online supplementary file 2). The JBI reviewer's manual states that the higher the score of the study, the less bias present.[18] This manual also advises that studies should not be included in the analysis if they are of low quality (score ≤50%); as such, we excluded these studies. We included all moderate quality studies (51%–70%) and good quality studies (80%–100%).[18] Two reviewers (DB and CP) independently conducted the quality assessment; where there was disagreement, the study was assessed in tandem and a consensus score derived.[16]

Data synthesis

For the quantitative studies, study characteristics and participant demographics were reported descriptively and by age bracket where possible. Given the considerable heterogeneity in participant samples and outcome measures, data were unable to be pooled for meta-analysis. Given heterogeneity across qualitative studies, a narrative meta-synthesis approach was undertaken to categorise verbatim participant quotes into representative themes.[19] This was deemed more suitable than thematic analysis of second-order data, as themes within the qualitative studies varied by participant samples, arthritis diagnoses and work-related results. Narrative meta-synthesis of participant quotes facilitated an examination of work outcomes based on primary data.

RESULTS

Study selection and inclusion

The study selection and inclusion process is shown in figure 1.[13] The screening process yielded 36 articles for quality and risk of bias assessment. Seven articles were deemed to be of low methodological quality and were excluded from the review (online supplementary file 3).[20–26]

Study characteristics

Twenty-nine studies from 13 countries (Australia,[6 14] Canada,[27–33] Denmark,[34–36] Italy,[37] India,[38] Japan,[39] Lithuania,[40] the Netherlands,[41–44] Norway,[45 46] Sweden,[47] Turkey,[48] UK,[49–52] USA[53]) with a wide range of work-related outcomes were included in this systematic review. The included studies were published from 2000 to 2019. Of the 29 studies, 17 adopted a cross-sectional design with quantitative outcomes (table 1)[14 27 29–33 37 39–46 53] and 12 adopted a qualitative design (table 2).[6 28 34–36 38 47–52] Ten of the qualitative studies collected data through interviews,[6 28 34 36 38 47 48 50–52] one used focus groups[35] and one used both techniques.[49]

While all studies reported an overall sample size, 19 of the 29 included studies (65%) specifically reported the number of participants aged 16–50 years.[6 14 28–31 34–38 45–50 52 53] This number ranged from 1 (in a qualitative study where most participants were >50 years) to a sample size of 2120 participants.[34 53] Where the mean age of participants was reported, the range spanned 21.1–52.1 years.[39 49] Three studies did not report the number or mean age of participants but still reported stratified results.[33 44 51] Both male and female participants were included in 25 studies; three studies included men only[36 47 52] and one study included only one female participant between 16 and 50 years.[34]

A range of arthritis conditions were included: 11 (38%) studies included participants with RA[28 35 38–40 43–45 47 50 51]; 5 (17%) included participants with SLE[27–30 52]; 4 (14%) included participants with OA[14 28 34 41]; 4 (14%) included participants with ankylosing spondylitis (AS)[36 42 47 48]; 3 (10%) included participants with JIA[29 30 49]; 2 (7%) included participants with psoriatic arthritis (PsA)[46 47] and 1 (3%) included participants with spondyloarthritis.[37] Three (10%) studies additionally defined their diagnostic criteria as doctor-diagnosed arthritis,[31] arthritis-associated disability[33] or arthritis-attributable work limitation (AAWL).[53] Two further studies described participants as having arthritis (7%).[28 32] One study (3%) included participants with OA and a range of IA types.[6]

Work outcomes

Due to varying arthritis types and outcome measures used (table 3), work outcomes were diverse. For data reporting purposes, quantitative outcomes were classified into three key categories: (1) arthritis-related work productivity outcomes,[29 30 32 37 39] (2) arthritis-related work participation outcomes[29 31 33 37 40–44] and (3) other arthritis-related workplace outcomes.[14 27 30 40 42 44–46 53] Within these three categories, outcomes were subcategorised by age band to examine outcomes for individuals beginning their career versus individuals with a longer work history. For the qualitative studies, the derived themes were classified into barriers[6 28 35 36 38 48–52] or enablers[6 34 35 38 47–51] to work participation associated with arthritis, each supported by relevant subthemes (online supplementary file 4). Emergent themes were independent of age, and for this reason they were not disaggregated by age band.

Arthritis-related work productivity outcomes

There is no evidence to show any association between arthritis-related work productivity outcomes and age.

Ages 16–34

Two studies assessed absenteeism and presenteeism as a measure of work productivity.[29 32] Absenteeism and presenteeism among employed participants (ages 25–34) with arthritis were no different than for the age and gender-matched Canadian population (absenteeism and presenteeism OR=1 (95% CI not provided).[32] A separate Canadian study reported that the mean (SD) number of work days missed due to disease in the last 6 months was 6.4 (7.8) among 143 employed Canadian participants (ages 18–30) with SLE or JIA.[29]

Two studies assessed career satisfaction as a measure of work productivity.[29 30] On average, career satisfaction for employed participants (ages 18–30) with SLE or JIA was moderate (mean=3.4 (SD 1.0)).[29] A similar level of career satisfaction was evident when unemployed participants with SLE or JIA were

Table 1 Summary of included quantitative studies

Author and country	Study design	Age range included (years)	Participants aged 16–50 (n)	% Female	Arthritis diagnosis	Years since diagnosis	Tools used to measure work	Results			Were the study results compared with the general population?	Interpretation of study results
								Arthritis-related productivity outcomes	Arthritis-related participation outcomes	Other arthritis-related workplace outcomes		
Ackerman *et al*,[34] Australia	Cross-sectional	20 to 29 30 to 39 40 to 49 50 to 55	101	–	Knee OA Hip OA	–	WALS			**WALS mean (SD)** *Age 20–39*: 8.13 (6.90) *Age 40–49*: 9.84 (6.72)	Yes	Participants reported high levels of work limitations based on WALS.
Baker *et al*,[27] Canada	Cross-sectional	36 to 50 51 to 65 >65	NR	–	SLE	–	Researcher-developed questionnaire: 1. Work disabled (not being able to work due to illness). 2. A homemaker—FT. 3. Retired. 4. A student. 5. Working for pay for 10 or more hours per week.			**Self-reported WD (1 selected from researcher-developed questionnaire)** *Age 36–50:* OR=1.69 (1.03–2.78)*	No	Participants with SLE were more likely to report levels of WD compared with no WD.
Bieleman *et al*,[41] the Netherlands	Cross-sectional	45 to 49 50 to 54 55 to 59 60 to 64	NR	–	Knee OA Hip OA	–	EARA Researcher-developed questionnaire: employed participants asked about their present condition and whether they would like to adapt their work (tasks/hours/workplace). Non-employed participants asked the reason for not having a job		**LF participation RR (graduated secondary school)** *Age 45–49 Men* 1.15 (0.5–1.6)† *Age 45–49 Women* 1.1 (0.9–1.4)† **LF participation RR (graduated high school)** *Age 45–49 Men* 1.1 (0.3–1.19)† *Age 45–49 Women* 1.0 (0.6–1.4)†		Yes	The rate ratio for all subgroups equalled, or was >1, but did not reach levels of significance (95% CI includes 1).
Boonen *et al*,[42] the Netherlands	Cross-sectional	15 to 25 22 to 34 35 to 44 45 to 54 55 to 60	NR	–	AS	–	HLQ WD as defined by the Dutch social security benefit programme		**% Employed (FT employed)** *Age <20*: 0 (0) *Age 20–24*: 50.0 (42.9) *Age 25–29*: 70.4 (55.8) *Age 30–34*: 74.2 (57.8) *Age 35–39*: 73.1 (53.9) *Age 40–44*: 70.2 (51.5) *Age 45–49*: 64.5 (43.9)	**% WD (FT WD)** *Age 15–25*: 0 (0) *Age 22–34*: 15.3 (6.3) *Age 35–44*: 27.0 (18.1)	Yes	Participants with AS were more likely to experience reduced LFP and increased WD.
Chorus *et al*,[43] the Netherlands	Cross-sectional	20 to 29 30 to 39 40 to 49 50 to 59	NR	–	RA	–	Researcher-developed questionnaire: participants indicated whether or not they had a paid job at the time of diagnosis, and indicated what their current work status was. LF participation defined as having a paid job at the time of the study		**LF participation (graduated primary school)** Rates men *Age 20–29*: 0 *Age: 30–39*: 77.8 (50.9–100.0)† *Age 40–49*: 55.2 (45.2–65.0) †† Rates women *Age 20–29*: 22.2 (0.0–49.1)† *Age 30–39*: 20.0 (6.5–33.5)† *Age 40–49*: 23.9 (16.6–31.2)† **LF participation (graduated secondary school)** Rates men *Age 20–29*: 75.0 (32.7–100)† *Age 30–39*: 84.2 (8.3–100)† *Age 40–49*: 85.5 (77.3–93.7)† Rates women *Age 20–29*: 78.8 (65.3–92.3)† *Age 30–39*: 45.2 (36.2–54.2)† *Age 40–49*: 46.3 (37.9–54.7)† **LF participation (graduated higher education)** Rates men *Age 20–29*: 50.0 (0.0–100.0)† *Age 30–39*: 80.0 (45.1–100.0)† *Age 40–49*: 89.5 (76.7–100.0)† Rates women *Age 20–29*: 66.7 (29.9–100)† *Age 30–39*: 75.0 (59.5–90.5)† *Age 40–49*: 54.8 (40.9–68.7)†		Yes	Male participants with RA with primary level education had reduced LFP in 20–29 and 40–49 age brackets. Female participants with RA with higher level education had reduced LFP in the 40–49 age bracket. An association between arthritis and LFP was not found across other age brackets.
Chorus *et al*,[44] the Netherlands	Cross-sectional	20 to 29 30 to 39 40 to 49 50 to 59	NR	–	RA	–	VHQ Researcher-developed questionnaire: reasons for LF withdrawal: 1. Work-related reasons. 2. Disease-related reasons. 3. Other personal reasons		**% Paid employment** *Age 20–29*: 6.2 *Age 30–39*: 10.2 *Age 40–49*: 27.5	**LF withdrawal % post diagnosis** *Age 20–29*: 1.8 *Age 30–39*: 10.2 *Age 40–49*: 27.5	No	The percentage of employed participants with RA compared with those withdrawn from the workforce is detailed, but the significance between the two figures is unclear.

continued

Table 1 continued

Author and country	Study design	Age range included (years)	Participants aged 16–50 (n)	% Female	Arthritis diagnosis	Years since diagnosis	Tools used to measure work	Results: Arthritis-related productivity outcomes	Results: Arthritis-related participation outcomes	Results: Other arthritis-related workplace outcomes	Were the study results compared with the general population?	Interpretation of study results
Dadoniene *et al*,[40] Lithuania	Cross-sectional	20 to 24 25 to 29 30 to 34 35 to 39 40 to 44 45 to 49 50 to 54 55 to 59 60 to 64	NR	–	RA	–	Researcher-developed questionnaire: current and past LFP, days absent from work during the last year in those with a paid job		**% Employed** *Age 20–24*: – *Age 25–29*: 75.0 *Age 30–34*: 40.0 *Age 35–39*: 57.1 *Age 40–44*: 75.0 *Age 45–49*: 52.2†	**% WD** *Age 20–24*: 0 *Age 25–29*: 12.5 *Age 30–34*: 80 *Age 35–39*: 80 *Age 40–44*: 41.7 *Age 45–49*: 56.6	Yes	Women aged 35–39 and women and men 45–49 years had reduced employment. Other age brackets were comparable with the general population.
de Hooge *et al*,[37] Italy	Cross-sectional	<45	51	59	Spondyloarthritis	–	WPAI	**WPAI, mean (SD)** *Age 16–45*: 36.6 (30.0) **WPAI absenteeism, mean (SD)** 7.9 (14.0) **WPAI presenteeism, mean (SD)** 32.6 (31.2)§	**Paid hours worked per week, mean (SD)** 35.7 (12.9) **Hours missed per week, mean (SD)** 3.4 (6.8)		Yes	All outcomes were comparable with the Italian population.
Jetha *et al*,[29] Canada	Cross-sectional	18 to 30	143	79	JA SLE	Mean (SD) 10.2 (7.1)	Researcher-developed questionnaire: employment status; job characteristics; career satisfaction scale (1=not at all satisfied, 5=extremely satisfied); perceived likelihood of remaining employed and perceived job control (1=very unlikely, 5=very likely); workplace support and disclosure (1=not at all, 5=a great deal); absenteeism and job disruptions (the number of workdays missed in the last 6 months and 10 items about job disruptions); perceived productivity loss (1=not at all, 5=a great deal)	**Absenteeism, mean (SD)** 6.4 (7.8) **Job disruptions, mean (SD)** 3.0 (2.2) **Perceived productivity loss, mean (SD)** 2.7 (0.87) **Career satisfaction, mean (SD)** 3.4 (1.0) **Job control, mean (SD)** 3.2 (1.4) **Perceived likelihood of remaining employed, mean (SD)** 4.4 (0.90) **Managerial support, mean (SD)** 4.0 (1.1) **Workplace disease disclosure, mean (SD)** 2.4 (1.3)	**Hours worked per weak, mean (SD)** 31.2 (13.2) **Years employed, mean (SD)** 2.1 (2.4)		No	Employment rates and hours worked per week are comparable with the national average, but nearly half of employed participants reported absenteeism, job disruptions and perceived productivity loss. Participants reported moderate levels of career satisfaction and job control, but high levels of perceived likelihood of remaining employed.
Jetha *et al*,[30] Canada	Cross-sectional	18 to 30	143	79	JA SLE	Mean (SD) 10.8 (6.2)	WALS 5-item Career Satisfaction Scale (1=not at all satisfied, 5=extremely satisfied). Researcher-developed scale of perceived helpfulness of job accommodations (12 benefits)	**Career satisfaction, median (SD)** *Employed*: 3.4 (1.0) *Not working*: 3.3 (0.90) **Perceived helpfulness of job accommodations benefits, median (SD)** *Employed*: 5.0 (3.5) *Not working*: 8.1 (4.8)		**WALS median¶** *Employed*: 5.9 *Unemployed*: 7.5	No	Participants reported moderate levels of work limitations based on WALS. The majority of participants were satisfied with their career progression, but reported 50% of job accommodations missing from the researcher-provided list to help with future career progression.
Jetha *et al*,[31] Canada	Cross-sectional	18 to 29	1393	64	Doctor-diagnosed arthritis	–	NHIS		**% Employment participation** *Age 18–23*: 60.3 (53.7–66.6)† *Age 24–29*: 63.6 (59.6–67.4)†		Yes	The prevalence of employment participation is lower for participants aged 24–29 years compared with the population. Employment participation is similar for participants aged 18–23 compared with the population without arthritis.
Kaptein *et al*,[33] Canada	Cross-sectional	25 to 34 35 to 44 45 to 54 55 to 64	NR	–	Arthritis-attributable disability	–	Researcher-developed questionnaire: 1. Employed. 2. Not in the labour force. 3. Unemployed.		**Non-participation OR men** *Age 25–34*: 1.00 *Age 35–44*: 1.71 (0.43–5.12)† **Non-participation OR women** *Age 25–34*: 1.00 *Age 35–44*: 1.71 (0.74–3.98)†		No	For men and women aged 35–44, odds of non-participation in the workplace are high, yet the figure does not reach significance. For men and women aged 25–34, there is no difference in workplace participation rates.

continued

Table 1 continued

Author and country	Study design	Age range included (years)	Participants aged 16–50 (n)	% Female	Arthritis diagnosis	Years since diagnosis	Tools used to measure work	Results: Arthritis-related productivity outcomes	Results: Arthritis-related participation outcomes	Results: Other arthritis-related workplace outcomes	Were the study results compared with the general population?	Interpretation of study results
Sruamsiri *et al*,[39] Japan	Cross-sectional	18–≤45 45 to 55 >55	NR	–	RA	–	WPAI % of absenteeism and presenteeism multiplied by participants' annual salaries to calculate productivity loss in monetary values	**US$ value, mean (SD)** *Age ≤45*: 6881 (9284) **% Productivity loss, mean (SD)** *Age <45*: 20.28 (20.94)			No	Productivity loss for participants is expressed in US$, but the significance of the value relative to population levels is not discussed.
Theis *et al*,[53] USA	Cross-sectional	18 to 25 25 to 44 45 to 64	2120	–	Arthritis-attributable work limitation	–	NHIS. Researcher-developed questionnaire: In the past week, 1. Worked for pay at a job or business. 2. Been employed with a job or business. 3. Worked but not for pay at a job or business. 4. Looked for work. 5. Did not work and did not look for work.			**OR AAWL** *Age 18–24*: 1.0 *Age 25–44*: 1.5 (0.7–3.2)†	No	Participants aged 25–44 have increased odds of experiencing AAWL, but this does not reach levels of significance (95% CI includes 1). There is no difference in AAWL for participants aged 18–24.
Wallenius *et al*,[46] Norway	Cross-sectional	18 to 45	271	38	PsA	Mean (SD) Women: 6.9 (7.1) Men: 5.6 (6.4)	WD Pension in Norway			**% WD women** 32.7 **% WD men** 17.4	No	Percentage WD is detailed, but significance or comparison with the population is not discussed.
Wallenius *et al*,[45] Norway	Cross-sectional	18 to 45	474	78	RA	Mean (SD) Women: 5.9 (6.0) Men: 4.8 (6.2)	WD Pension in Norway			**% WD women** 24.7 **% WD men** 8.1	No	Percentage WD is detailed, but significance or comparison with the population is not discussed.
Wei *et al*,[32] Canada	Cross-sectional	25 to 34 35 to 44 45 to 54 55 to 64	NR	–	Arthritis	–	Canadian Community Health Survey	**OR absenteeism** *Age 25–34*: 1.00 *Age 35–44*: 0.75 (0.66–0.84)* **OR presenteeism** *Age 25–34*: 1.00 *Age 35–44*: 1.18 (1.07–1.31)*			Yes	Arthritis was positively associated with increased presenteeism for participants aged 35–44. Absenteeism rates for the same age bracket were negatively associated with arthritis. No difference was found in presenteeism or absenteeism rates for participants aged 25–34 compared with the population.

*Statistically significant 95% CI.
†Reported measure of effect 95% CI.
‡Statistically significant compared with general population rates.
§P<0.05.
¶OR not reported.
AS, ankylosing spondylitis; EARA, economic aspects in rheumatoid arthritis; FT, full time; HUQ, Health and Labour Questionnaire; JIA, juvenile idiopathic arthritis; LF, labour force; NHIS, National Health Interview Survey; NR, not reported; OA, osteoarthritis; PsA, psoriatic arthritis; RA, rheumatoid arthritis; RR, rate ratio; SLE, systemic lupus erythematosus; ULR, univariate logistic regression; WD, Vocational Handicap Questionnaire; WAIS, Work Activity Limitation Scale; WD, work disability; WPAI, work productivity and activity impairment.

Table 2 Summary of included qualitative studies

Author	Country	Age range included (years)	Participants aged 16–50 (n)	% Female	Arthritis diagnosis	Years since diagnosis	Data collection technique	Data analysis technique
Bagcivan *et al*[48]	Turkey	Reported as 18+	23	30	AS	Mean 5.39±3.52	Interviews	Descriptive phenomenological approach
Bukhave *et al*[34]	Denmark	Reported as 35+	1	100	Hand OA	Not stated	Interviews	Interpretive phenomenological analysis
Berkovic *et al*[6]	Australia	18–50	21	90	RA, OA, PsA, AS, SLA, JIA	Not stated	Interviews	Thematic analysis
Crooks [28]	Canada	Reported as 18+	6	84	SLE, OA, RA, arthritis	Not stated	Interviews	Thematic analysis
Hanson *et al*[49]	UK	16–25 26–31	29	66	JIA	Range 5–21	Interviews Focus groups	Thematic analysis
Holland *et al*[50]	UK	32–58	9	89	RA	Range 1–15	Interviews	Thematic analysis
Jain *et al*[38]	India	28–63	16	31	RA	Range 6 months–23	Interviews	Thematic analysis
Kristiansen *et al*[35]	Denmark	31–81	10	80	RA	Range 2 months–15	Focus groups	Content analysis
Lempp *et al*[51]	UK	25–45 Reported as other	Not reported*	–	RA	–	Interviews	Content analysis
Osterholm *et al*[47]	Sweden	25–65	5	0	RA, PsA, AS	–	Interviews	Empirical phenomenological psychological method
Pendeke *et al*[52]	UK	20–69	6	0	SLE	Range 1–3	Interviews	Interpretive phenomenological analysis
Primholdt *et al*[36]	Denmark	21–37	5	0	AS	Mean 5.4	Interviews	Meaning condensation

*Data were derived from in-text quotations from participants aged between 16 and 50 years.
AS, ankylosing spondylitis; JIA, juvenile idiopathic arthritis; PsA, psoriatic arthritis; RA, rheumatoid arthritis; SIA, seronegative inflammatory arthritis; SLE, systemic lupus erythematosus.

included in the analysis (mean=3.5 (SD 0.95)), although how unemployment was classified was unclear. Employed and unemployed participants viewed job accommodations and benefits as major enablers to work productivity, yet experienced moderate workplace accommodations themselves (mean=6.1 (SD 4.2)).[30] Employed participants with SLE or JIA had high perceptions of remaining employed (mean=4.4 (SD 1.0)) and were content with managerial support (mean=4.0 (SD 1.0)), both of which aided career satisfaction, but had moderate levels of perceived job control (mean=3.2 (SD 1.4)). Opportunities for disease disclosure in the workplace were very low (mean=2.4 (SD 1.3)).[29]

One study assessed job disruptions and perceived productivity loss as a measure of work productivity.[29] Nearly half (44%) of employed Canadian participants (ages 18–30) with SLE or JIA reported high levels of job disruptions (mean=3 (SD 2.2)) in the last 6 months, and productivity loss was perceived to be low (mean=2.7 (SD 0.9)).[29]

Ages ≤45

Three studies assessed absenteeism and presenteeism as a measure of work productivity.[32 37 39] In two studies,[37 39] results were not stratified by smaller age brackets for participants aged 16–45. For 35 employed participants with spondyloarthritis, mean (SD) proportion of absenteeism was 7.9% (14.0%) per week. When participants who undertook non-paid work were included in the analyses, mean (SD) absenteeism was 8.3% (13.9%). Mean (SD) presenteeism was 32.6% (31.2%) per week. When participants who undertook non-paid work were included in the analysis, mean (SD) presenteeism was 18.6% (28.8%). All proportions were reported as similar to the general Italian population.[37] Similar to employed Italian participants with spondyloarthritis, employed Japanese participants with RA (ages 18 to ≤45) reported low levels of overall productivity loss, which was calculated by multiplying self-reported presenteeism and absenteeism rates by participants' annual salaries (mean=20.3 (SD 20.9)).[39] For participants with arthritis in Canada, odds of absenteeism were lower than the general population (OR=0.75, 95% CI 0.66 to 0.84), but arthritis was positively associated with increased presenteeism (OR=1.18, 95% CI 1.07 to 1.31).[32]

Arthritis-related work participation outcomes

There is moderate evidence to show an association between lower labour force participation (LFP) rates, employment and age, for adults at both ends of the 16–50 years age spectrum. Younger adults in the age band 24–29 years experienced lower LFP rates than healthy populations the same age, based on the National Health Interview Survey.[31] Based on current LFP prevalence, middle-aged adults in the age band 45–49 years also experienced lower employment rates.[40]

Ages 16–34

Two studies assessed LFP as a measure of work participation.[31 33] Among Canadian participants aged 18–23 years with doctor-diagnosed arthritis, LFP rates were comparable with the general population (60.3% vs 57.3%). LFP rates were lower for older participants (ages 24–29 years) from the same sample compared with the general population (63.6% vs 76.0%).[31] Similar LFP outcomes were reported in Canadian participants relative to the general population (ages 25–34 years OR=1).[33]

Table 3 Work outcome measures used in quantitative studies

Work constructs identified from included quantitative studies	Definition and/or measurement of work outcomes mapped to quantitative studies		
	Arthritis-related work productivity outcomes	Arthritis-related work participation outcomes	Other arthritis-related workplace outcomes
Work limitations			WALS: 0 (no workplace activity limitations)—36 (greatest workplace activity limitations)
Presenteeism	WPAI Questionnaire: 0–10 scale, reduced productivity due to disease[35] Researcher-developed definition: 'sometimes or often reducing activities at work due to long-term physical or health problems'[30]		
Absenteeism	WPAI: 0–10 scale, percentage of hours missed due to disease[35] Number of workdays missed in the last 6 months[27] Researcher-developed definition: 'those who indicated that they had a job or business from which they were absent in the last week'[30]		
Job disruptions	Number of workdays missed in the last 6 months[27]		
Perceived productivity loss	Researcher-developed questionnaire: 1–5 scale[27]		
% of overall productivity loss	WPAI[37]		
LFP		Researcher-developed categories: employed, not in the labour force and unemployed[31] Work entry—the duration of time until first reported work entry among those unemployed at baseline[22] Working status in the last week[29] Having a paid job at the time of the study[41] Having a paid job for ≥8 hours/week[17 39]	
Employment		Paid hours worked per week[27 35] Having a paid job at the time of the study[42] Working 32 hours a week or more[23 38 40] Years employed[27] Missed hours worked per week[35]	
Unemployment		Days on unemployment benefits in the past year[21]	
WD			Do arthritis or joint symptoms now affect whether you work, the type of work you do or the amount of work you do?[51] Patients who received a permanent or part time (50% minimum) national WD pension[43 44] Recognised WD under the Lithuanian social security system[38] Self-reported final date the patient was working, followed by continuous WD attributed to RA[18] 'Officially recognised inability to perform paid production because of AS' under the Dutch social security system[23 40] Researcher-developed definition: 'the inability to do paid work due to illness'[25]

continued

Table 3 continued

Work constructs identified from included quantitative studies	Definition and/or measurement of work outcomes mapped to quantitative studies		
	Arthritis-related work productivity outcomes	Arthritis-related work participation outcomes	Other arthritis-related workplace outcomes
Withdrawal from labour force			Risk of work loss—the duration of time until first reported work loss among those employed at baseline[22] Vocational Handicap Questionnaire: those who reported withdrawing from the labour force were asked to indicate whether this was for work, disease or personal reasons[42] Those who had a paid job before diagnosis and had to leave their job completely because of AS related WD[23 40]
Sick leave	Temporary inability to work as a consequence of RA treatment complications, resulting in absence from work[19] Days with sickness benefit registered by the SSIA[20] Annual days sick leave[21]		
Career satisfaction	5-item Career Satisfaction Scale[27 28]		
Job control	Researcher-developed 1–5 scale question: 'in the past 6 months, to what extent have you had control over your work activities?'[27]		
Perceived likelihood of remaining employed	Researcher-developed 1–5 scale delivered to participants about their perceived likelihood of remaining employed over the next year[27]		
Managerial support	Researcher-developed 1–5 scale about the extent to which participants perceive that their manager/supervisor was supportive[27]		
Workplace disease disclosure	Researcher-developed 1–5 scale about the extent to which participants discussed the details of their health condition with their employer[27]		
Job accommodations and benefits	Researcher-developed list of 12 health benefits and job practices where respondents were asked to indicate whether they believed the accommodation/benefit would help them maintain or enable employment[28]		

LFP, labour force participation; SSIA, Swedish Social Insurance Agency; WALS, Work Activity Limitations Scale; WD, work disability; WPAI, Work Productivity and Activity Impairment.

One study assessed hours worked per week as a measure of work participation. Average hours worked per week for Canadian participants aged 18–30 with SLE and/or JIA were 31.2 (SD 13.2). These rates were not compared with the general population.[29]

Ages 20–49

Two studies assessed employment rates as a measure of work participation for participants aged 20–49 years.[42 44] Employment rates for Dutch participants with RA were low 43.9%,[44] although these rates were not compared with the general population. For male and female Dutch participants with AS across all age groups (ages 20–24, 25–29, 30–34, 35–39, 40–44, 45–49), employment rates tended to be lower compared with the general population, yet significance testing was not reported.[42] One study assessed hours worked per week among participants aged ≤45 years. Hours worked per week were stated to be similar among participants with spondyloarthritis compared with the general Italian population, although general population rates were not reported.[37]

Ages 35–50

One study assessed LFP for Canadian participants with arthritis aged 35–44 relative to the general population and found no difference (ages 35–44 years men OR=1.48, 95% CI 0.43 to 5.12; ages 35–44 years women OR=1.71, 95% CI 0.74 to 3.98).[33] Two studies assessed LFP for participants aged 45–49.[41 44] Comparable LFP rates were reported in Dutch participants (ages 45–49 years) with hip or knee OA compared with the general population, regardless of gender and level of education.[41] Lower LFP rates were reported in Dutch participants with RA compared with the general population, however a difference was found only in men aged 45–49 years whose highest educational attainment was primary school (55.2% vs 70.4%).[44]

Two studies assessed employment rates for participants aged 20–49 with RA relative to the healthy Lithuanian and Dutch population. In Lithuania, significant findings were found for three subpopulations (women aged 35–49=57.1%; men aged 45–49=52.2%; women aged 45–49=61.1%).[40] General population rates were not presented to interpret these data; rather study authors note that a significant difference was found between participants with RA and normative date for the general population within the same age bands. In the Netherlands, employment rates for Dutch participants with RA were low (43.9%) although these rates were not compared with the general population.[43]

Other arthritis-related workplace outcomes

There is moderate evidence to show an association between high WD rates for those aged 30–34 years (80%), in contrast to younger populations aged 25–29 years (12.5%) based on days absent from paid work during the last year.[40] Based on the Vocational Health Questionnaire, younger adults were more likely to report withdrawal from the workforce due to physical symptoms than middle-aged adults (ages 20–29=1.8%; ages 30–39=10.2%).[44]

Ages 18–39

Two studies assessed WD. Dutch participants with AS reported higher percentages of WD compared with the general population (ages 22–34, AS total=6.3%, Dutch total=2.7%), although the reported WD was from all causes and not exclusively AS-attributable.[42] Lithuanian participants with RA reported high WD, ranging from 12.5% (ages 25–29 years) to 80% (ages 30–34 years).[40]

Two studies assessed work limitations both using the Workplace Activity Limitations Scale (WALS). Moderate scores of work limitations were found among employed Canadian participants (ages 18–30 years) with SLE or JIA (median=5.9 (SD 4.9)).[30] Among participants with OA aged 20–39 in Australia, the mean (SD) WALS score was high: 8.1 (6.9).[14] One study assessed labour force withdrawal following arthritis diagnosis. Based on the Vocational Health Questionnaire, Dutch participants with RA reported need to withdraw from the labour force due to physical symptoms (ages 20–29=1.8%; ages 30–39=10.2%).[44]

Ages 35–50

Two studies assessed WD. Living with SLE was associated with greater self-reported WD (OR=1.68, 95% CI 1.03 to 2.78) among Canadian participants aged 36–50 years.[27] Dutch participants with AS also reported higher percentages of WD compared with the general population (ages 35–44, AS total=18.1%, Dutch total=4.2%).[42]

One study assessed work limitations for participants aged 40–49, and the mean (SD) WALS score was 9.8 (6.7).[14] Based on the Vocational Health Questionnaire, 27.5% of Dutch participants with RA aged 40–49 reported need to withdraw from the labour force due to physical symptoms.[44]

Age ≤45

Two studies assessed WD. In both studies, results were not stratified by smaller age brackets. Norwegian women with RA aged 18–45 years reported higher WD rates compared with non-WD rates among the same population with RA (of 372 included women, 277 (75.3%) participants reported no WD, and 91 (24.7%) reported WD). Younger age was associated with WD (mean WD=38.5%, mean non-WD=35.4%, p≤0.001), with no difference between male groups (p=0.91).[45] Participants with PsA in Norway reported similar levels of WD and non-WD (women p=0.24; men p=0.56).[46]

One study assessed AAWL for US participants aged 25–44 years with doctor-diagnosed arthritis. The odds of experiencing AAWL were not different to the general population (OR=1.3, 95% CI 0.8 to 2.3).[53] Finally, 27.5% of Dutch participants aged 40–49 with RA reported labour force withdrawal following arthritis diagnosis.[44]

Barriers to work participation associated with arthritis

Ten qualitative studies[6 28 35 36 38 48–52] explored barriers to work participation associated with arthritis. Selected quotes are presented for each subtheme and other supporting quotes are provided in online supplemental file 4.

Four studies explored incapacity to work.[6 38 48 52] Participants with AS explained: 'this condition increased my pain. I quit my job'.[48] For men with AS, negative perceptions of self were reported in relation to work: 'I am frustrated that I have no stamina … that I can't just suck it up and stay work, that I have to go home'.[36]

Four qualitative studies explored lack of workplace support.[6 35 38 49] Participants with RA repeatedly stated 'I have a joint disease' when their workplace contribution was questioned.[35] Other participants with RA described the stigma when requesting workplace accommodations: 'When you stand up and your desk is going (makes sound of desk moving) and you are the only one you might as well wear a big hat "look at me—disabled"'.[50]

Four qualitative studies explored discord with colleagues.[28 48 50 51] Participants with RA attempting to return to work explained that 'if I go back and fail they'll (colleagues) regard it as worse than if I stay off that bit longer'.[50] Participants with AS acknowledged the effects of their disease on colleagues: 'when I am absent, the burden of the work is put on the shoulders of my colleagues, this makes them feel uneasy'.[48]

Enablers to work participation associated with arthritis

Nine qualitative studies[6 34 35 38 47–51] explored enablers to work participation associated with arthritis. Further supporting quotes are provided in online supplemental file 4.

Five qualitative studies explored motivation to work.[38 48–51] Participants with RA from two UK studies explained that 'whenever I can I push myself to go to work'.[50] Participants with RA in India provided insight that they 'come to work to keep (their) mind balanced'.[38] Participants with AS explained that internal motivation to work was beneficial for psychosocial health: 'I became quite depressed inside … Even if I've only made it to work for two hours I feel better in myself'.[48]

Six qualitative studies explored managerial and collegiate support as enablers to work participation.[6 38 47 49–51] Participants with RA explained that their 'bosses are quite supportive',[51] that 'they have allowed me to work as I can'[50] and that 'they care about me all day at work'.[38] Participants with JIA explained that they were 'lucky because I get on with my managers so they're understanding'.[49]

Five qualitative studies explored flexible working arrangements and their perceived benefits.[6 34 38 47 51] Participants with OA explained that 'initially I worked in the goods department which was very tough on my fingers; luckily it has been arranged that I can also work in the typing department'.[34] Similar sentiments were echoed in other studies, with participants explaining 'I have negotiated flexible working arrangements'.[51]

Four qualitative studies explored participants' understanding of legislation and workplace antidiscrimination policies.[6 35 38 49] Participants with IA conditions viewed this as a protective mechanism to continue to work, as 'you don't want to be discriminated against if there's another job opening up',[6] and that 'you're more likely to be made redundant'.[49] In contrast, participants with RA viewed workplace regulations through a positive paradigm: 'it is a gift that the system helps you maintain work so you can earn money'.[35]

DISCUSSION

There is a paucity of high-quality research examining the work-related outcomes of arthritis for younger people commencing

their career through to the peak income-earning years in middle age. To the best of our knowledge, this review is the first to systematically identify, appraise and report the available evidence (both quantitative and qualitative) on work outcomes in this area. Our findings indicate that work outcomes are highly variable and depend on participant samples, arthritis diagnoses and the outcome measures used to quantify work-related constructs. Although there were some signals in the data that age was positively associated with work impact, the evidence for this association was weak and inconsistent. This creates challenges in making recommendations regarding workplace practice and policy yet provides a starting point to consider work-related concerns within routine clinical care for arthritis.

The impact of arthritis on work productivity was a prominent outcome, represented in five quantitative studies. This impact likely relates to the multitude of physical impairments commonly associated with arthritis, including but not limited to joint pain, stiffness and fatigue. Existing patient-reported outcome measures (PROMs) appear to focus on measuring permanent WD and/or work loss, and this may partly explain why we found no associations between age and work productivity outcomes. PROMs that instead focus on work limitations and quality of life domains rather than time away from work (in addition to qualitative research findings) highlight the impact of arthritis on workplace productivity, providing insight into younger age groups at risk of at-work productivity loss and providing opportunities for early intervention.[54]

The association between arthritis and lower work participation was a common outcome, represented in nine quantitative studies. Although heterogeneous in definition and measurement, similarities existed in that work participation was seldom measured beyond paid employment. This is important to note, as people of younger age groups are more likely provide informal and unpaid care to dependent children or parents. Our results highlight that participation in these unpaid work roles need to be quantified to provide a more complete picture of 'work' participation, including in low-and-middle income countries where unpaid work is more common, to more fully capture the types of work undertaken by younger adults living with arthritis.[55]

Findings related to other arthritis-related workplace challenges provide further insight into younger populations at risk of experiencing work impairment. In two studies in this review, the WALS scores highlighted high levels of work limitations for employees with arthritis.[14 30] Assessing arthritis-related work impairment within routine arthritis care (eg, by rheumatologists or allied health professionals) is a necessary starting point and would be best undertaken prior to progression towards long-term productivity loss.[56] Regular re-review of work impairment would enable deterioration to be detected and suitable management plans and appropriate vocational specialist referral to be implemented. Effective communication with employers is also needed to avoid individuals with arthritis being viewed as a workplace burden that can perpetuate the cycle of limitations and reduced productivity.[6 48]

The quotes provided from the qualitative studies provide a starting point to filling the 'gaps' in our understanding, which to date have been largely based on quantitative data. For example, where quantitative research has identified that younger people with arthritis have minimal opportunity for workplace disease disclosure,[29] qualitative data highlight that self-disclosed arthritis in the workplace results in reduced workplace stress.[57] This review highlights the importance of participants' narratives to inform the development of person-centred interventions and policies to support younger/middle-aged people with arthritis to maintain employment and thrive in their careers.[58]

Strengths and limitations

This systematic review has incorporated both quantitative and qualitative evidence focusing on work outcomes for younger and middle-aged adults with a broad range of arthritis conditions. Further strengths include a comprehensive and systematic search of the literature spanning 20 years, and examination of study design, quality of evidence and outcome measures to compile the best evidence base of work-related outcomes for this group. The quality of the included evidence was also strong; on average, quantitative and qualitative studies scored 79.4% and 79.1%, respectively, on the JBI critical appraisal tools.

We also acknowledge the review limitations. First, only observational and qualitative studies published in English were included. Second, the relationship between arthritis and work outcomes may be influenced by factors that were not measured or reported, including the temporal relationship between disease progression and impact and comorbid conditions. Third, generalisability of results is potentially limited due to small sample sizes, a lack of comparators and the majority of studies being conducted in high-income countries (93%). Results may not be transferrable to specific workplaces, or low and middle-income countries, where the impact of persistent musculoskeletal pain on work is known to be substantial.[59]

CONCLUSION

Although current evidence varies greatly in how work and work outcomes are defined and measured, there are consistent signals in the data to suggest that arthritis is associated with work limitations and the magnitude of impact may increase with age. Qualitative data provide individual patient perspectives and augment our understanding of barriers and enablers to working productively with arthritis. Additional research focusing solely on the workplace needs of younger/middle-aged population groups is required, to inform tailored interventions and workplace support initiatives that maximise productive working years.

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CHAPTER 3: METHODS

3.1 Introduction

This chapter summarises the mixed-methods approach of this PhD, and provides a brief description of the four studies that comprise the research program. Detailed recruitment, data collection, and data analysis techniques for each of the individual studies can be found in the published manuscripts (Chapter 2 and Chapters 4-8).

3.2 Mixed-Methods Research

Mixed-methods research is an approach whereby researchers collect and analyse both quantitative and qualitative data within the same research project. Mixed-methods research draws on the potential complementary strengths of qualitative and quantitative methods, allowing researchers to explore diverse perspectives and uncover relationships that exist between various research questions (223), as well as providing the opportunity to triangulate findings. Mixed-methods research designs are appropriate for answering research questions that neither quantitative nor qualitative methods could answer alone (224, 225). In rheumatology specifically, there have been calls to include more qualitative research. A recent overview of qualitative research found that it comprises just one percent of studies published in top-tier rheumatology journals (226). Further, a recent analysis of survey data found that musculoskeletal conditions are frequently neglected. For example, out of national health surveys from 170 countries, only 5.9% (n=10) assessed rheumatoid arthritis prevalence (227). While this PhD did not seek to evaluate arthritis prevalence, the collection of data through quantitative means (for example, surveys) is crucial for the development and evaluation of musculoskeletal health services, programs and policies. In the context of this PhD, a mixed-methods research design was used to qualitatively examine the work and financial-related experiences of people with arthritis, and to quantify the financial burden related to the disease.

There are four mixed-methods subtypes: (1) triangulation, (2) embedded, (3) explanatory, and (4) exploratory (228). This PhD employed an exploratory mixed-methods design, where qualitative data were collected and analysed first, followed by quantitative data collection and evaluation to test the findings empirically (229, 230). Data were collected in a sequential manner, where the qualitative interviews informed the development of the quantitative cost diary. For example, the financial burden initially described by interview participants was subsequently quantified in the cost diary, providing more in-depth data to further understand the qualitative findings.

3.3 Study Design

This PhD used an exploratory sequential mixed-methods study design, comprising two primary studies:

1. **Qualitative:** Semi-structured interviews exploring individuals' work and financial-related experiences of living with arthritis; and
2. **Quantitative:** Online cost diary to capture direct and indirect healthcare costs attributable to arthritis.

Two additional studies were also included as part of the PhD:

3. **Systematic Review:** A systematic review to identify, appraise, and synthesise evidence on work-related outcomes experienced by working-age adults with arthritis. The gaps identified in the systematic review contributed to the development of the qualitative interview guide.
4. **Twitter Study:** A content and sentiment analysis of tweets by people with arthritis during the early phase of the COVID-19 pandemic, to identify proxy topics of importance for this population, and to understand the emotional context of arthritis-related tweets.

Finally, data arising from the four studies encompassing this PhD have been brought together to develop person-centred recommendations for clinicians treating working-age patients with arthritis. Importantly, although the studies and corresponding manuscripts completed throughout this PhD are published separately, these works are inter-related and build on each other to create a robust narrative about the population of interest. This process is depicted in Figure 5.

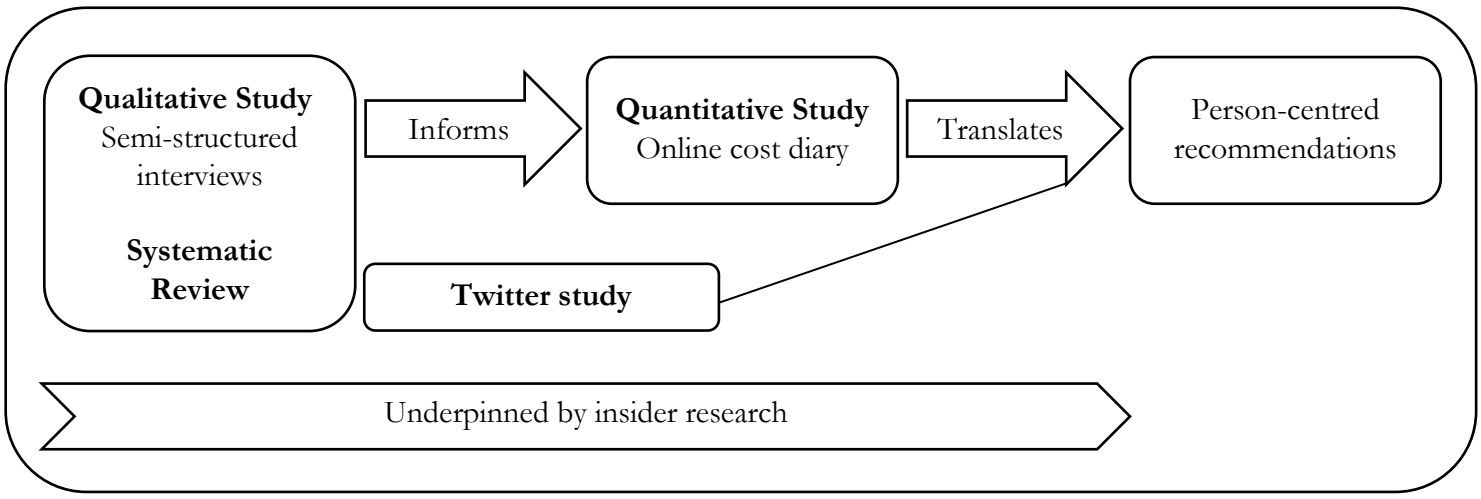

Figure 5: Mixed-Methods Research Design of the PhD

3.3.1 Participants for the Qualitative and Quantitative Studies

Working-age individuals with osteoarthritis or inflammatory arthritis were recruited from the Australian community through advertisements disseminated by arthritis support groups, stakeholder organisations, and social media posts. Potential participants met inclusion criteria if they were:

1. Aged between 18 – 50 years (inclusive);
2. Diagnosed with osteoarthritis or inflammatory arthritis by a rheumatologist or GP;
3. Living in Australia.

Individuals were unable to participate in the research if they were:

1. Aged <18 or >50 years;
2. Currently pregnant;
3. Living outside of Australia;
4. Unable to communicate in English and/or unable or unwilling to provide consent for participation.

Participants were recruited for the qualitative and quantitative components of the PhD through the same channels, that is, arthritis support groups, stakeholder organisations, and social media posts. However, none of the qualitative participants participated in the quantitative study. They were two separate samples.

3.4 Insider Research

Importantly, this entire PhD program is underpinned by a concept known as "insider research". Insider research can be described as a phenomenon where the researcher relates to their participants' identity and language through personal experience (231). For context, the PhD candidate is a young adult living with psoriatic arthritis, and the research program that was conceptualised and undertaken was borne out of their lived experience with the disease. This lived experience generated an interest in the welfare of other working-age adults living with arthritis. Lived experience leading to insider research, occurs through a process of positionality, which involves intentionally aligning one's self-interests with one's research (232). Whilst insider research has both strengths and weaknesses, a process referred to as 'bracketing' can be used to ensure that the research methods used are not biased and that they do not unduly influence the participant narrative.

Bracketing is a method used in qualitative research to identify, examine, and mitigate researcher preconceptions that may influence the research process (233). Bracketing works by explicitly noting one's own beliefs and interaction with a research topic, in an attempt to remain impartial throughout the research process (Appendix F). Bracketing promotes methodological rigour and trustworthiness in the conclusions drawn from qualitative research, which is pivotal in the context of insider research. Bracketing is also a component of the Consolidated Criteria for Reporting Qualitative Research (COREQ-32), a validated checklist for explicit, comprehensive reporting of qualitative studies, which aims to improve the rigour and credibility of qualitative studies (234). The Joanna Briggs Institute (JBI), an international research organisation that specialises in promoting and supporting evidence-based healthcare (235), also recommends that the researcher critically examines their potential influence during qualitative data collection (236). Insider research, positionality, and bracketing are discussed in further detail in the published editorial presented in Chapter 4.

3.5 An Overview of Qualitative Methods in Musculoskeletal Research

Within musculoskeletal research, qualitative research can be used to explore the meaning attached to health-related experiences, views, opinions, and practices by individuals within their personal, social, and cultural context (237). Where quantitative methods predominantly examine relationships between various outcomes and variables – represented largely by numeric values – qualitative methods examine prominent themes that arise through interviews, focus groups, and observations – represented by words (238). The interactive nature of qualitative research can enable researchers to gain in-depth insight into a respective population of interest, and to understand their experiences with the potential to promote person-centred care, rather than to seek definitive answers (239). Qualitative data analysis is conducted through a technique called coding, which involves the identification of similar participant narratives in interview or focus group transcripts, and grouping these similarities together into themes to present the findings in a coherent and meaningful manner (240). In the published literature, such themes are commonly presented with supporting participant quotes.

Qualitative research influences clinical practice by shedding light on the patient experience (241). For example, through focus groups undertaken with rheumatologists and people with rheumatoid arthritis, van Tuyl et al. (242) discovered that some rheumatologists are hesitant to prescribe aggressive treatment based on their assumption that patients are averse to taking multiple medications. In contrast, patients were actually positive about trialling aggressive approaches. These findings gleaned from qualitative research have the potential to influence how clinicians approach rheumatoid arthritis treatment with their patients. The qualitative research presented in this thesis also aims to inform clinical practice, with potential to improve patient outcomes and satisfaction of care.

3.5.1 Qualitative Component of the PhD: Interviews

The aims of the qualitative study were to examine the work-related and financial impacts of living with arthritis for adults aged 18 – 50 years. As the interviews were exploratory, they were guided by the overarching research aim rather than a specific research question or hypothesis. A qualitative exploratory study design was used with an interview guide based on the WHO ICF. Using a thematic analysis approach, deductive and inductive coding techniques were used to identify emerging work-related and financial-related these from the data. The analysis was supported using NVivo software (QSR International Pty Ltd, Melbourne, Australia). More

detailed qualitative study methods, together with the results, are published as two manuscripts as they were guided by separate analysis questions relating to work and finances (Chapters 5 and 6).

3.6 An Overview of Cost Diary Methods in Musculoskeletal Research

For over two decades, cost diaries have been promoted as a valid method of capturing direct and indirect out-of-pocket (OOP) costs borne by individuals living with chronic illness (243). Cost diaries were used to determine OOP costs related to living with rheumatoid arthritis in 2002 (221) and osteoarthritis in 2001 (244). Both studies found that despite having access to heavily subsidised healthcare and pharmaceuticals in Australia, OOP costs for arthritis patients were high. More recently (in 2021), researchers used a two-week cost diary to quantify OOP costs for adults aged 20-55 years with persistent shoulder pain in Australia (245). This type of data collection enables a broader assessment of the impacts of can be used to collect detailed of musculoskeletal conditions such as arthritis, beyond the physical sequelae.

3.6.1 Quantitative Component of the PhD: Cost Diary

An overarching theme that arose from the qualitative study was the financial burden experienced by younger, working-age adults with arthritis. To explore this phenomenon further, the aim of the cost diary study was to quantify arthritis-related costs borne by working-age adults aged 18 – 50 years living in Australia. An exploratory, observational study was undertaken involving administration of a self-reported, online cost diary over six weeks. The cost diary contained seven sections relevant to arthritis-related OOP expenditure (as identified in the qualitative study), including:

1. Medical appointment costs;
2. Allied health appointment costs;
3. Other health practitioner appointment costs;
4. Medication and nutraceuticals costs;
5. Paid self-management item costs;
6. Diagnostic and medical imaging costs; and
7. Costs related to accessing healthcare for arthritis, for example, parking or travel costs for a medical appointment.

A modified version of the InCharge Financial Distress/Financial Well-Being (IFDFW) scale (246) was also administered to participants at the start of each week during the study period, prior to the cost diary. Medians and interquartile ranges were used to describe the demographics of the study population, OOP costs, and financial distress scores. Mann-Whitney U tests, linear regression, and Spearman's rho, were used to examine relationships between variables. All analyses were

performed using Microsoft Excel and SPSS Statistics (IBM, New York City, US). Further detail is provided in Chapter 7, which presents the cost diary manuscript (which has been submitted for journal publication and is currently under review).

3.7 An Overview of Systematic Reviews in Musculoskeletal Research

The purpose of a systematic review is to deliver a thorough summary of available evidence in response to a particular research question, thereby making this information accessible to those responsible for guiding clinical practice and policy-making (247). Many systematic reviews conducted by musculoskeletal researchers have focused on clinical topics related to physiology (168, 248, 249), medication efficacy (250-252), and workplace and physical activity interventions (11, 253-257). Yet qualitative systematic reviews can complement quantitative data, to identify evidence related to experiences, which guide clinicians on how to treat patients through a person-centred lens (258). Mixed-methods systematic reviews are therefore becoming increasingly common, where quantitative and qualitative data are both analysed to address the research question (259).

3.7.1 Systematic Review Component of the PhD

The aim of the systematic review was to identify, appraise, and synthesise evidence on work-related outcomes experienced by working-age adults with arthritis. Eligible quantitative and qualitative studies containing self-reported data on work-related outcomes on younger and middle-aged adults with arthritis were identified in Medline, PsycINFO, Embase and CINAHL. Quality assessment was undertaken using validated quality appraisal tools from the JBI. The systematic review protocol was registered on the PROSPERO International Prospective Register of Systematic Reviews (registration number 106919). The review is also reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement. More detail regarding the systematic review methods was provided in Chapter 2.

3.8 COVID-19 Related Research Impacts

Originally, this PhD consisted of studies 1-3, that is, the qualitative interviews, quantitative cost diary, and systematic review. However, as the COVID-19 pandemic escalated in Australia, there were delays and challenges to recruiting participants into the cost diary study (which was completed in full by some participants prior to the pandemic). The main concern was that arthritis-attributable costs incurred during the pandemic might be either substantially lower, or higher for some, when compared with pre-COVID-19 costs. For example, the sudden shift to telehealth appointments saw an increase in fully-reimbursed medical appointments (due to healthcare funding changes implemented swiftly by the Australian government), and a decrease in OOP costs, bearing little resemblance to the traditional financial burden of face-to-face appointments (260, 261). Anecdotal evidence also suggested that some people with arthritis chose to purchase their medications in bulk at the start of the pandemic, in anticipation of medication shortages (262). As such, cost data from these purchases would also not be reflective of regular OOP costs for medications. Given the focus on protecting the healthcare system for COVID-related care and that individuals chose to reschedule or delay their medical appointments, many patients also experienced reduced access to non-COVID related care in 2020 (263).

In addition, there were potential ethical issues around recruiting individuals to non-COVID-19 related research during the pandemic, which was a time of peak anxiety for many people. For example, inflammatory arthritis medications commonly act as immunosuppressants, which are advantageous in controlling arthritis-mediated inflammatory responses (264), but may increase the risk of infection (265, 266). Individuals with arthritis subsequently reported increased psychological distress during the COVID-19 pandemic (267), and as such, the research team (and our University human ethics guidelines) deemed it unethical to recruit vulnerable populations into research that would not provide direct benefit to those participants. Although some participants had completed the cost diary in full, it was considered inappropriate to continue recruitment during the pandemic. We therefore sought to introduce a supplementary study into the PhD, exploring a contemporary issue of relevance to people with arthritis with respect to COVID-19.

3.8.1 An Overview of Social Media in Musculoskeletal Research

As it was unfeasible to directly collect data from research participants for most of 2020, the PhD candidate endeavoured to instead conduct research using available social media data. Social media contains a plethora of health information from individuals living with arthritis, and provides a unique opportunity to observe thoughts, feelings, and interactions between individuals living with lifelong illnesses (268). For example, in 2014, researchers found that on Twitter there were 497,595 tweets relating to arthritis, suggesting that the social media application has the potential to be a valuable tool in collecting patient-oriented data (269). Social media research is still in its infancy, but this novel method of data collection enables an exploration of topics of importance for people with arthritis through a person-centred lens, without the aforementioned ethical issues. Researchers have begun recognising the potential benefits of social media research (270). In rheumatology research specifically, social media research has been used to learn about lived experiences (271), and to advance doctor-patient communication (272).

3.8.2 Twitter Study

After ceasing recruitment into the cost diary study, a Twitter study was conducted to identify proxy topics of importance for individuals with arthritis during COVID-19, and to explore the emotional context of arthritis-relevant tweets during the early phase of the pandemic. Publicly available tweets that were posted in English and with hashtag combinations related to arthritis and COVID-19 were extracted retrospectively from Twitter in March - April 2020. Content analysis was used to identify common themes within tweets, and sentiment analysis was used to examine positive and negative emotions in themes to understand the COVID-19 experiences of people with arthritis. Further detail about these methods can be found in Chapter 8.

3.9 Summary

This chapter has summarised the mixed-methods research design used for this PhD, including the concept of insider research, and how the research program was required to pivot (but still with an integral focus on issues relevant to people with arthritis) due to the COVID-19 pandemic. Greater detail regarding the specific research methods, together with the findings of each study, are presented in the subsequent chapters.

CHAPTER 4: EDITORIAL

This chapter comprises the published editorial describing the PhD candidate's experience of living with inflammatory arthritis, and how that informed the mixed-methods conceptualisation, data collection, and data analysis. Such patient-led research is becoming increasingly popular, enabling the 'patient voice' to inform and drive the research agenda.

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The View From the Inside: Positionality and Insider Research

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Qualitative research has traditionally prioritized consumer and community engagement (Attree et al., 2011; Sarrami-Foroushani et al., 2014). Similarly, clinical research is placing increasing value on consumer and community engagement, commonly labeled as "patient and public involvement" (PPI; Boivin et al., 2018; Lalani et al., 2019). PPI aims to enhance the quality, acceptability, and relevance of research (and priority setting in research) to ensure that issues of importance to patients, their families, and the broader public are addressed (Brett et al., 2014). It has been acknowledged that PPI can improve the quality of health-care delivery and patient outcomes (Boaz et al., 2016). However, despite the demonstrated positive impacts of PPI, many research projects are still conceptualized and undertaken with relatively minimal input from those with lived experience of the condition (Vayena et al., 2016). Most commonly, PPI is sought at the conceptualization phase of research where topics of prioritization are identified; yet, there may be minimal input after this stage (Manafo et al., 2018). These limitations have motivated patient-led research, where an individual with lived experience of a health condition is taught research-related skills to examine the topic of interest from conceptualization through to dissemination of outcomes (Grant et al., 2019; Streuli & Vayena, 2015).

The research program that I conceptualized, developed, and am currently undertaking with the support of my supervisory team was borne out of my lived experience as a young adult with inflammatory arthritis. The concept where I am the researcher is known as "insider research." Within the insider research paradigm, I, the researcher, relate to my participants' identity and language through personal arthritis-attributable experience (Greene, 2014). Insider research, which occurs through a process of positionality, involves intentionally aligning one's self-interests with one's research (Jacobson & Mustafa, 2019). There are advantages and disadvantages of conducting insider research in the qualitative research sphere. Some advantages of an insider position include (1) facilitating a nuanced perspective that builds credibility with participants, (2) promoting an equalized relationship between the researcher and participants, and (3) building rapport between the researcher and participants. In contrast, potential disadvantages can include compromised researcher objectivity and professionalism and participant misunderstanding of a researcher's capacity to provide health advice (Chavez, 2008).

As a young adult with inflammatory arthritis, I am particularly interested in the impacts of musculoskeletal conditions on working-age populations. There is a large body of research conducted with pediatric populations with arthritis (Cartwright et al., 2015; Cohen et al., 2017; Soriano LeBovidge et al., 2003) as well as with older adults with arthritis (Focht et al., 2017; Havens et al., 2017; Song et al., 2006). However, there is a paucity of research dedicated to working-age populations. This is particularly concerning, given that in Canada, over 50% of the population with arthritis are aged under 65 years (Statistics Canada, 2019), and similarly in Australia, 50% of the population with arthritis are of working age (Australian Bureau of Statistics, 2018). A large number of Australians are forced into early retirement each year, and females retiring early have been found to accumulate, on average, 83% less in retirement savings than their healthy peers (Schofield et al., 2013). Based on my lived experience and personal interests, and in recognition of the limited research undertaken to date, our research program seeks to explore the broader impacts of arthritis (beyond joint pain and stiffness) with respect to work implications and

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financial stresses. This research is also supported by a consumer organization with similarly aligned interests.

This research program is a qualitative-dominant mixed-methods project. The first research aim was to explore the physical, psychosocial, and financial impacts of living with arthritis. This aim was examined through 21 semistructured interviews with female and male participants who had a range of arthritis conditions. Prior to designing the interview guide, I recognized that I needed to reflect on my own experiences with arthritis, to ensure that the questions used were open and not biased by my own experiences, or expectations of potential participant narratives. To achieve this, and with guidance from my supervisory team, I undertook a bracketing exercise. Bracketing is a method used in qualitative research to identify, examine, and mitigate researcher preconceptions that may influence the research process (Tufford & Newman, 2010). Bracketing works by explicitly noting one's own beliefs and interaction with the research topic, in an attempt to remain impartial throughout the research process. Bracketing promotes methodological rigor and trustworthiness in the conclusions drawn from qualitative research, which is pivotal in the context of insider research.

I began my bracketing exercise by preparing brief points about my own arthritis journey. I was diagnosed with psoriatic arthritis (a type of inflammatory arthritis) nearly 8 years ago. I take disease-modifying antirheumatic medications that control my disease activity, and I have an excellent health-care team. I have supportive family and work environments, where I am surrounded by individuals with high health literacy and empathy. Reflecting on my personal arthritis-related experiences—at the very beginning of my bracketing exercise—unexpectedly drew my attention to how fortunate I am in my experiences. It was, therefore, important for me to be aware that my research participants might have vastly different circumstances. To assist the data collection process, I developed some guidelines to adhere to during my interviews:

1. It is essential that I do not assume to understand the lived experience of my participants. It is important to remember that individuals have unique biological determinants and clinical profiles, are raised in different environments, and have varied psychosocial experiences.
2. It is imperative to remain impartial during the interview process. It is not my role as the researcher to view my participants' experiences through my own lens.
3. In maintaining impartiality, it is important to collect rigorous data via semistructured and probing questions rather than to engage in general conversation that is based on shared or divergent experiences. Some emotional investment is perhaps natural, but to maintain awareness around it is vital.
4. It is important for me to recognize my privilege with regard to the level of support that I receive, including but not limited to access to the private health-care system in urban Australia. My participants may not have access to the same resources.
5. It is also crucial to maintain my role as the researcher. I am not a medical professional, and I am not qualified to provide my participants with health-care advice based on my own experiences.

I continued this bracketing exercise through each stage of the research project to acknowledge, and mitigate, my own biases. I had to ensure that my research aim was exploratory, as opposed to confirmatory, with clear and robust direction. Further, I wrote a reminder on my interview guide, next to my probing questions, to ask participants to explain or expand on concepts that may not be clear to individuals without arthritis. In the data analysis stage, I highlighted the importance of giving adequate voice to my participants through a process of open, axial, and thematic coding, with independent verification from my supervisory team to ensure that derived themes were representative of the data. Further, my supervisory team who are experienced in arthritis-related research reviewed my processes to ensure that our research was clinically relevant and methodologically sound. Overall, the bracketing exercise redirected my research program away from being influenced by my experiences to focusing on data generated by other young adults living with arthritis.

However, when reflecting on interviews I conducted with some younger participants, I did notice that my perspective shifted. I found myself speaking with a compassionate tone, which helped build rapport but also led to a more conversational approach than structured data collection:

Participant:	Actually, I tore my meniscus in January, so I've been hobbling around a bit anyway.
Interviewer:	And was that unrelated to the arthritis? Was it a gym thing, or
Participant:	That was a sport-related injury, not related to my arthritis at all.
Interviewer:	Ouch, I came close to tearing my meniscus, it wasn't quite a tear and I was in so much pain so I could only imagine.
Participant:	Yeah, it was not fun.
Interviewer:	It's so frustrating, there's just no blood flow there and it doesn't heal.
Participant:	No, no, the worst. Yep, I know!

Being an "insider researcher" has taught me several valuable lessons. Most interestingly, I observed that some of my participants became tense and closed off to answering questions when I revealed that I too had arthritis. On reflection, our shared experience may have diminished their perceived neutrality of the interview, potentially creating distrust. Other participants were happy to find out that I could relate to their experiences. In return, they answered the interview questions in detail and trusted me with their story. Contemplating these experiences, I consider there is no right or wrong way to position oneself when undertaking insider research, as long as one always maintains respect and ensures that ethical principles and

objectivity underpin the research. In addition to the lessons learned, there are aspects of insider research which warrant future consideration and perhaps recommendations to guide the field. Is positionality a type of competing interest that should be declared uniformly to participants and/or to ethics committees? Are extra efforts needed to promote objectivity and rigor? In my situation, this was achieved by pilot testing my interview schedule and consulting regularly with colleagues who brought an "outsider" perspective to interpreting the emerging themes.

Overall, we have much to gain from insider research. As health research increasingly supports person-centered care and qualitative approaches, it is timely for patients to initiate and drive research that they prioritize based on their unique lived experiences. The perceived value of insider research is also apparent; through this process, I have spoken to many young adults with arthritis who have expressed excitement that their narratives are being highlighted for the first time. This type of inclusive research can only promote positive outcomes for people with health conditions.

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CHAPTER 5: QUALITATIVE RESUTS - WORK IMPACTS

This chapter comprises the work-related findings from the qualitative study. This chapter examines work impacts in relation to the WHO ICF. In combination with the systematic review (reported in Chapter 2), this chapter seeks to address the first aim of the PhD: to examine the work impacts of arthritis. These results also contribute to the recommendations around the work-related impacts of arthritis, which will be discussed in Chapter 9.

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"I Would be More of a Liability than an Asset": Navigating the Workplace as a Younger Person with Arthritis

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Abstract

Purpose Over half the population in Australia with arthritis and other musculoskeletal conditions is aged 25–64 years. This reflects the peak income-earning years for most, yet little research has examined the influence of arthritis on work issues specific to younger people. The aim of this research was to examine the work-related experiences of younger people (defined as those aged 18–50 years). *Methods* A qualitative exploratory design was used. Participants with inflammatory arthritis or osteoarthritis were recruited from the community, including urban and rural settings. An interview guide was based on the World Health Organization's International Classification of Functioning, Disability and Health. Deductive and inductive coding techniques were used to identify emerging work-related themes from the data. *Results* Semi-structured interviews were conducted with 21 younger people (90% female) with a mix of arthritis conditions, vocational backgrounds and career stages. Three themes were identified: (1) the perceived impacts of arthritis on career trajectories, (2) the impacts of arthritis on participants' workplace environment, employers, and colleagues, and (3) the personal toll of working with arthritis. The personal toll of working with arthritis relates to the arthritis-attributable impacts of physical and psychological symptoms on productivity and presenteeism in the workplace. *Conclusion* Younger people with arthritis experience numerous challenges at key stages of their careers, from career planning through to productive working. This can be used to inform workplace accommodations for people with arthritis and increase awareness of likely barriers to work productivity among colleagues, employers and clinicians.

Keywords Arthritis · Musculoskeletal diseases · Employment · Adult · Qualitative

Introduction

Traditionally associated with old age, arthritis is increasingly recognised as a disease that also affects people of working age [1]. In Australia, based on the most recent National Health Survey data, it is estimated that 50% of the population with arthritis are aged 25–64 years—the peak income-earning years [2]. Osteoarthritis (OA) is the most common type of arthritis, followed by other inflammatory arthritis conditions. Based on population growth, the number of people with OA aged < 55 years is projected to increase by 20% over the next 15 years [1, 3], with potential for substantial workforce impacts, such as a loss of productive life years [4]. Inflammatory arthritis (IA) conditions also disproportionately affect people of working age. Rheumatoid arthritis (RA) is the most common condition affecting women of childbearing age and/or in the workforce, (age range of RA onset: 30–60), and ankylosing spondylitis (AS) primarily affects younger men (age range of AS onset: 15–40 years) [1, 5, 6].

The personal and societal economic impacts of arthritis relating to younger populations cannot be understated. In Australia in 2015, a loss of $7.2 billion Australian dollars (AUD) in gross domestic product (GDP) was recorded due to the impact of arthritis-related early retirement, welfare costs, and loss tax revenue [7–10].This figure is projected to increase to $9.4 billion (AUD) in the year 2030 [7, 11]. Although some individuals with arthritis aged over 50 years remain in the workforce, many people are forced into early retirement due to the condition [12–14]. In Australia in 2012, as a result of 80,032 Australian workers aged 45–64

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forced to retire early due to arthritis, there was a total lost income of $3787 million (AUD), and $394 million (AUD) in lost taxation revenue [8].

People of working age can face unique challenges living with and managing arthritis, particularly in the workplace [15, 16]. Of particular relevance for younger populations is the impact of arthritis on ability to work and maintain employment [16]. Previous research has found that unpredictable arthritis flares, fatigue, and impaired physical function pose challenges for people in the workplace [17–20]. People of working age also perceive their impaired health to be a key challenge to finding work, which leaves younger people with arthritis at higher risk of unemployment, lost productivity, absenteeism, and reduced income [21, 22]. Overall, evidence suggests that younger populations with arthritis are less likely to be employed or will face productivity challenges at work when compared to healthy similar-aged peers [23]. Whilst working productively is an important life phase, little research has examined the influence of arthritis on issues specific to younger people, especially early work experiences and career progression [1, 24, 25]. To provide person-centred care and support for younger people with OA or IA in the workplace, it is essential to understand their specific experiences.

The aim of this research was to examine the work-related experiences of younger people (defined as those aged 18–50 years) living with arthritis. Arthritis studies with participants in similar age ranges employ the term younger; the same definition is applied to this research [1, 26]. Based on the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF), which provides a structured framework for categorising arthritis-related impairments [27], specific objectives were to:

1. Evaluate work participation restrictions;
2. Examine activity limitations related to work-specific tasks;
3. Explore environmental factors contributing to workplace difficulties; and
4. Determine the role of body function impairments on perceived ability to work.

Methods

Study Design

We adopted a qualitative, exploratory study design. Individual semi-structured interviews were conducted via telephone. A thematic analysis approach was adopted. Ethics approval was obtained from the Monash University Human Research Ethics Committee (Project ID 12657). Reporting of the study was undertaken according to the COREQ-32 Checklist.

Setting: The Australian Workplace

The Australian work context is broad. Individuals can be employed on a full time, part time, or casual basis. According to the Australian Bureau of Statistics, there are eight main job categories: Managers, Professionals, Technicians and Trade Workers, Community and Personal Service Workers, Clerical and Administrative Workers, Sales Workers, Machinery Operators and Drivers, and Labourers. There are no regulations as to how long people have to work per week, yet there are policies within individual workplaces to ensure that employees are not overworked. The Australian Government established Safe Work Australia to improve work health and safety and workers' compensation arrangements in case of injuries or accidents in the workplace [28]. However, this does not extend to funding arrangements for workplace accommodations. There is currently no federal scheme to support younger people with arthritis in the workplace to pay for required accommodations.

Participants

Males and females aged 18–50 years who reported they had been diagnosed with OA or IA by a registered health professional and who were living in Australia were eligible to participate. We did not verify diagnosis through medical records review or contact with health practitioners. A purposive sampling frame was employed to recruit a broad study sample with regard to disease type, gender, geographic location (metropolitan, regional, rural), employment status (full time, part time, casual, looking for work, retired, etc.) public versus privately insured patients, and socioeconomic status [29]. The study was advertised via arthritis consumer organisations, university staff newsletters, community-based rheumatology and physiotherapy clinics, and through social media in 2018. Those who expressed an interest in participating were provided with further information by the lead researcher (DB) and asked to complete a brief screening questionnaire to confirm their eligibility.

Those who were unable to identify the type of arthritis they had been diagnosed with, had not had their diagnosis diagnosed by a rheumatologist or general practitioner, were unable to communicate in English, or were unable or unwilling to provide consent were ineligible to participate. Females who were pregnant were also ineligible to participate, as it was anticipated that pregnant women might have additional arthritis concerns beyond the scope of this study, and which have been explored in prior research [30, 31].

Data Collection

We developed an interview guide based on the WHO ICF. The ICF has a flexible structure, and has been used to highlight the significant personal burden of OA on younger people [1]. Whilst the ICF has been previously applied to investigate workplace issues for people with arthritis, our study differs by using the ICF as a lens for classifying complex issues faced by younger people with arthritis [1, 32, 33].

The ICF has four domains applicable to young people in the workplace (participation restrictions, activity limitations, environmental factors, and impairments in body function) [32]. The interview guide incorporated open-ended questions and probing questions in relation to these domains (Table 1):

The research team developed the interview guide. DB piloted the interview guide with three people of varying educational and vocational backgrounds. Open questions and probing questions were modified based on feedback received. Data collection was also iterative, and probing questions were based on the participants' responses. Themes identified in early interviews were incorporated into later interviews. All individual, semi-structured interviews were conducted via telephone by the same researcher (DB) who has experience in qualitative data collection. Telephone interviews have been shown to be advantageous: for the participant it enhances their anonymity and privacy, decreases social pressure, and can increase rapport between the interviewer and interviewee [34]. All interviews were audio-recorded to enable verbatim transcription.

Data Analysis

A thematic analysis approach was adopted. Thematic analysis is used to identify, organise, and develop themes from interview transcripts. It is useful for examining the perspectives of different participants, highlighting similarities and differences between participants, and contextualising unanticipated insights [35]. As this research was exploratory and included participants with varying arthritis diagnoses and experiences, a thematic approach to data analysis was suitable [35]. Data analysis commenced alongside data collection. Participant recruitment and data collection ceased when data saturation was reached [36].

NVivo Version 12 (2018, Melbourne, Australia) was used to support data management and analysis. Inductive and deductive coding methods were adopted using a process of open, axial, and thematic coding [29]. Open codes were generated by looking for initial concepts from participants about their work experiences. Axial coding was conducted to connect common themes identified by participants. For example, each participants' individual work experience was analysed collectively, to identify similar patterns across different vocations and workplaces. Using deductive coding, themes that correspond to the four ICF domains were identified. Coding and data analysis were conducted by DB. Regular discussions around theme development were held with the research team throughout the data analysis process, to increase rigour [37].

Results

As part of recruitment, thirty-nine expressions of interest were received. Five people could not be contacted, and within our purposive sampling, six others were not recruited to prevent over-sampling of specific arthritis conditions. Of the remaining 28 people who were screened for eligibility, 25 participants were eligible. Of the 25 eligible participants, 21 were included in the final sample (the remaining four participants declined to participate due to other commitments or illness). The 21 interviews ranged in length from 30 to 95 min. Data saturation was identified in the final four interviews when it became apparent that no new themes were being generated.

Table 1 Interview guide as mapped to the WHO ICF

ICF domain	Open question/s	Probing questions
Participation restrictions (problems experienced in work situations)	What is your field of work? How long have you been in that role?	Are you still able to work? Do you enjoy your work? How frequently do you work?
Activity limitations (difficulties executing workplace activities)	Are you able to perform tasks that you are expected to at work?	What tasks are you able or unable to perform? How has this affected your position in the workplace?
Environmental factors (physical, social, attitudinal work environment)	Do you feel supported in the workplace?	Have you disclosed your arthritis to your colleagues? Do you receive adequate support at work?
Impairments in body function (physiological functions of body systems)	Have there been changes to your body that have affected your work?	Have you had to change your role/job? Has this impacted other areas of life, i.e. mental health/family role?

Table 2 Participant demographics

Demographics	N = 21	%
Female	19	90.0
Age bracket		
18–30	8	38.0
31–40	6	28.5
41–50	7	33.5
Education status		
High school	2	9.5
Certificate/diploma	5	24.0
Undergraduate university degree	9	42.5
Postgraduate University degree	5	24.0
Living status		
Lives with partner/spouse and children	6	28.5
Lives with partner/spouse	4	19.0
Lives alone	3	14.0
Lives with parents	3	14.0
Lives with other adults (non-family members)	3	14.0
Lives with own children	2	9.5
Employment status		
Full time, paid work	7	33.5
Part time/casual, paid work	7	33.5
Student	3	14.0
Unable to work because of arthritis	3	14.0
Unemployed or looking for work	1	5.0
Arthritis diagnosis		
Rheumatoid arthritis	8	38.0
Psoriatic arthritis	4	19.0
Osteoarthritis	2	9.5
Ankylosing spondylitis	2	9.5
Seronegative inflammatory arthritis	2	9.5
Combination of arthritis types	2	9.5
Juvenile idiopathic arthritis	1	5.0

Participant characteristics are shown in Table 2. The majority of participants were female (90%), and aged over 30 years (62%). Over one-third had been diagnosed with RA (38%), with psoriatic arthritis being the next most common diagnosis (19%). Almost one-third of participants lived with their partner and children (29%). Nearly half the participants had an undergraduate university degree (43%), and two-thirds were in full-time, part-time, or casual paid employment (67%). Fifteen percent of participants reported they were unable to work because of their arthritis.

Three major themes were evident from the interviews. The first theme was the perceived impacts of arthritis on career trajectories, including limited career choices and need for career changes. The second theme centred on concerns about the impacts of arthritis on their workplace environment, employers, and colleagues; including the perceived risks associated with employing an individual with a chronic disease, and the need for workplace accommodations. The third theme encompassed the personal toll of working with arthritis, relating to the personal impact of fluctuating productivity at work, the need for arthritis-specific support at work, and the burden of absenteeism, inconsistent work hours, and use of sick leave. The three major themes and subthemes are reported in detail below.

Theme 1: Impact of Arthritis on Individual Career Trajectory

The impact of arthritis on influencing individual career paths was a prominent theme throughout the interviews. It was clear that arthritis exerted an influence across the career spectrum, from early career choices (for example, the perspective of an adolescent participant attempting to choose their university degree) through to workforce exit decisions for those with more established careers (for example, participants aged 40 years who needed to retire early due to their arthritis). This was particularly evident for participants who preferred a "really physically demanding job", who felt as though they were unable to take on their career of choice.

Limited Career Choices and Career Changes

Participants described the impact that arthritis had on both their career choice prior to entering the workforce, and subsequent career changes they needed to make as their symptoms progressed or changed.

> "I was looking at library work. I read a position description and it was all this manual handling stuff. I was like no way… it's not worth it" Participant 6, F, 31–40

> "When finishing Year 12 I got offered an interview to do physiotherapy. I decided that it would not be a great career because it is a really physically demanding job" Participant 8, F, 26–30

Several participants felt that they were limited in their career choice, and did not attempt to pursue the career path they would have liked because of their arthritis:

> "I mostly went for office work so I could sit down… It is not what I want to do. It's not my career. It's not what I've chosen for myself" Participant 4, F, 31–40

In addition to describing limited career choices, many participants spoke of changing careers earlier than anticipated. Participants largely attributed this to their joint pain, and their ensuing inability to participate in tasks that required high dexterity or strength:

"I'm a qualified artist, but the big thing was the pain in painting, that was the pun that I used for a while" Participant 10, F, 18–25

"I worked on a few film sets… I really enjoyed it. After a few years I realised that I couldn't be standing all day. So I started to step back from that" Participant 4, F, 31–40

"Within my field I can specialise in ultrasound or MRI. I don't think I'm going to go down the ultrasound route because there is a lot more pressure on your joints. I don't think that it would be the smartest idea" Participant 8, F, 26–30

Participants who had lived with arthritis for an extensive time expressed that their knowledge of the condition, and understanding its impact on the body, had influenced their career path. Participants used their lived experience to direct them either towards or away from specific careers. For example, some felt that personal experience of being a patient hindered their ability to work in clinical roles, whereas others were drawn to these types of roles:

"I almost have too much empathy when I'm in a clinical setting, because I know what it's like to be there. You'll find yourself siding with patients more than practitioners. I found it hard to be in the middle. I'm a patient but I'm also supposed to be a practitioner and just in this weird middle space" Participant 1, F, 18–25

"Anything I do I get breakout pain quickly. I actually work [in mental health] so I can see the cognitive issues I have. I panic easily through varying levels of pain. I want to look at that CBT [cognitive behavioural therapy] side of things and see what they can do to relieve that emotional side of it. I think that's most of the problem." Participant 10, F, 18–25

Theme 2: Impact of Arthritis on the Workplace and Employers

The perceived impact of an individual's arthritis on their workplace environment, employer and colleagues was another common theme that emerged throughout the interviews. Some participants were hesitant to transition out of unemployment to a new workplace due to the perceived risk (for example, being injured at work) of hiring an individual with a chronic disease. Within the workplace, participants also perceived that their need for ergonomic modifications (for example, asking for a standing desk) and potential inability to perform certain tasks (for example, repetitive typing) would be burdensome for their employers.

Perceived Risks Associated with Employing an Individual with a Chronic Disease

Participants perceived themselves to be a liability to employers, and considered that the burden arthritis could impose on the workplace was not something an employer would want to accept. Even if they were employed, participants highlighted foreseeable implications for the employer, such as increased risk of being injured in the workplace, and greater need of requiring assistance:

"Nobody would hire me. I would be more of a liability than an asset. Even though what I do might be great, the risk of injuring myself, falling or whatever, even just the flexibility of if I can't come in one day, to say I can't come in today. I am a liability. People just don't want to run that risk" Participant 7, F, 41–50

"You don't know what's around the corner and with me it's been so unpredictable, all the surgery. I don't know what's next. I don't know that I'd put an employer through that" Participant 12, F, 31–40

"I'm looking for a job. It has been a point of contention that I've had to fight with myself about, because there is always that fear that you're not going to be able to live up to it and then people are going to be disappointed and angry. The last thing I want to do is disappoint someone or put them in a position that's going to negative affect their business" Participant 3, F, 18–25

Participants highlighted the burden on the workplace of completing additional administrative tasks and risk management procedures due to injury. Potential discrimination for a promotion was also a concern due to discrimination:

"I had a three-month role up to December last year. I was doing a lot of data entry and that affected my hands, my wrist, and my forearms. I ended up having to put in a Risk Man [risk management incident reporting] thing about it. You have to be careful with the tasks you do and that they're not too repetitious" Participant 6, F, 31–40

"Stress is greatly linked to how I feel with my arthritis. There's less of an acknowledgement that just overburdening me with work actually impacts my arthritis. You don't want to be discriminated against if there's another job opening up at work and you want that and somebody else is going for it" Participant 15, F, 31–40

Disclosure and Support at Work

Alongside the perceived risk that participants placed on their employer, a common theme throughout the interviews was

that participants "didn't want to tell anybody" about their arthritis. Yet, the majority of participants were surprised to find that when they did reveal their condition to their manager, this disclosure was met with understanding and support:

> "I didn't want to tell anybody, because I didn't want people feeling sorry for me. I started reaching out and going hey, I need support, and there have been times where I've needed to take a day off work. My team leader understands" Participant 4, F, 31–40

> "Most of my team know and my supervisors know… Everyone's very supportive, I have a very nice team, so any time off for doctors, no questions are asked" Participant 1, F, 18–25

> "I had to take a lot of time off and they were understanding… When I was able to go back to work, they made some adjustments for me, and it meant it was manageable" Participant 11, F, 41–50

Workplace Accommodations

Participants considered that workplace accommodations necessary for them to function adequately would be burdensome for others:

> "I bought one [a standing desk] myself, a second-hand one but it just broke down on me… My boss's boss regularly says "we should buy you one" and then nothing happens. I don't want to ask. If someone wants to give me something that's fine but asking is embarrassing and awkward so I avoid it. That's where I'm at with the standing desk" Participant 15, F, 31–40

> "I'm having these flares and I don't know what's triggering them and my fingers… One was like a sausage for weeks on end. It was painful. I'm a little reluctant to do a lot of manual handling… I'd have to get someone to help me or someone else to do it" Participant 6, F, 31–40

> "I can't lift things, I can't carry things, I struggle to write. They would feel like they're needing to help me all the time, do things for me all the time" Participant 7, F, 41–50

Theme 3: The Personal Toll of Working with Arthritis

The majority of participants made a clear distinction between what they considered career-related impacts, and broader impacts on their work environment. However, there were some elements of work that participants considered affected them personally, whilst also having an effect on the workplace. These included reduced productivity at work, the need for support at work, and fluctuating work hours. In contrast, some participants considered that workplace support had a positive effect on their functioning within the workplace.

Lost Productivity due to Arthritis Symptoms

Some participants reported that physical symptoms (for example, physical pain and fatigue) reduced their productivity within their role:

> "My job at the moment is sitting at a desk. It's bad for my right side, my right shoulder and elbow because I use the mouse constantly. I like getting up walking around… It's frustrating and time consuming" Participant 15, F, 31–40

> "I'm exhausted… I don't want to get up as much so I probably won't, I'll just sit and not readily roam around the room" Participant 14, F, 26–30

Absenteeism, Hours Worked, and Use of Sick Leave

Participants also emphasised how they had needed to reduce their work hours in order to maintain a healthy work-life balance, and to continue functioning in the workplace:

> "I have one day off on a Thursday. It's hard to imagine not having a day to catch up" Participant 11, F, 41–50

> "I've worked 0.8 for most of my career. That helped me manage when fatigue was an issue" Participant 6, F, 31–40

> "I had to take quite a bit of time off. I'm able to work four days now. I'm normal levels of tired but it's manageable" Participant 11, F, 41–50

One of the biggest challenges that participants faced was navigating the need for sick leave (for conditions not limited to their arthritis) and missing work. Participants also discussed the cycle of absenteeism, receiving less pay, and experiencing more stress, on a background of dealing with arthritis symptoms. This led to personal financial impacts, financial burden on their families, and increased fatigue.

> "I take too much time off. When I had to take a day off last week, and then was sick with a migraine another day, it ended up with a fortnight pay with me being three days of no pay. I'm in the negative with my leave" Participant 4, F, 31–40

> "I stress a lot about sick leave. I try to go to work even if I'm not doing well. To call in sick you need to get a medical certificate. Then you need to slap on the admin

costs of going to the doctor. That's a big source of stress" Participant 10, F, 18–25

Discussion

There is a paucity of research exploring the work-related experiences of younger people living with arthritis. As the majority of people in Australia living with arthritis are of working age [7], our research was undertaken to address this knowledge gap. This study aimed to examine the work-related experiences of younger people living with arthritis. Our three main findings augment our understanding of young people's capacities and concerns in the workplace whilst living with arthritis.

Some participants believed that having arthritis precluded them from entering certain professions. Many also described needing to reorient their career paths, or to retire at a younger age than their peers without a chronic condition. This led to feelings of dissatisfaction and frustration in the workplace. Similar concerns have been documented in other countries. In the United States (US), people in the workforce with arthritis have reported concerns that fluctuations in their ability to perform work tasks affected their credibility in the workplace [19, 38]. Canadian research reported that individuals affected by arthritis are hesitant to accept future work commitments or take opportunities to advance their career due to difficulty anticipating arthritis-related symptoms [18, 39]. This leads to feelings of embarrassment, prompting barriers to gaining steady employment, such as being unable to cope with workplace demands [40]. Our research augments these findings by adding new narratives around how arthritis and arthritis-attributable symptoms have affected young people's career trajectories. Considering the magnitude of arthritis prevalence in the working population, these findings suggest that many young workers may be unfulfilled in their careers, which has potential for workplace and workforce dissatisfaction at scale.

An intriguing finding was that participants were hesitant to disclose their condition to their employer or colleagues based on fear of unequal treatment in the workplace. However, many described their experience of revealing their arthritis as positive, with most being understanding and supportive. This complements research across other musculoskeletal conditions (fibromyalgia, low back pain), where studies have shown that healthy workplace relationships, high levels of collegiate camaraderie, and positive workplace culture increase an individual's self-efficacy to reveal their condition and to discuss required support systems and workplace accommodations [9, 41, 42].

Fostering positive workplace culture is a recognised area for improvement—interventions in the US and Canada have been implemented in an attempt to improve work-related experiences and outcomes for people with different types of arthritis conditions, with minimal or no effect on job loss, work instability, productivity, or supervisor support. [43, 44]. By providing unique personal perspectives, our research has identified the types of workplace support(s) that younger people with arthritis would value, including accessible workplace accommodations, practical considerations from employers in terms of understanding the need for flexible working hours, and equal opportunity regardless of disability in the workplace. There is clear opportunity to develop educational materials for colleagues and employers on what arthritis is, what the symptoms are, and what support would be helpful for employees with arthritis [45].

Our inductive analysis revealed that participants were concerned about becoming a burden on their workplace, employers and colleagues. Participants perceived their arthritis-related symptoms and functional limitations to not only impact on their individual careers and trajectories, but additionally perceived impacts on the efficiency and reputation of their workplace. We are not aware of other studies that have documented these broad viewpoints. Some studies suggest that feeling liable to the workplace may also be enhanced for younger people with arthritis, as people with chronic disease are more likely to be subjected to workplace bullying [46, 47], withdraw early from the workforce [14, 48, 49], and experience poorer psychological health outcomes and overall quality of life [50, 51]. These issues may be more prominent for younger people compared to older workers, as they have less experience in the workplace and less resilience to navigate these perceptions. Through exploring and reporting these challenges, our findings provide a starting point for working towards improving the experiences and productivity of young people with arthritis in the workplace. In particular, education and support, e.g. from arthritis consumer organisations, may be provided to, or accessed by, workplaces to improve their understanding of the impacts of arthritis on work experiences and motivate co-design of workplace accommodations to support younger people with arthritis who strive to remain productive at work.

Strengths and Limitations

There are several strengths to this research. As our study was exploratory in nature, it was important to examine a spectrum of arthritis-attributable experiences within the workforce, through recruitment of a heterogeneous participant sample. Within our sample, a range of younger age groups was included. This enabled us to capture individual perspectives at different career stages; for example, the perceptions of participants aged 18–30 years who were making career

decisions or looking for work, as well as the experiences of participants aged 31–40 who were considering early retirement due to their arthritis. In-depth semi-structured interviews elicited detailed data from participants, and the broad recruitment strategy spanning arthritis consumer organisations, university networks, and clinical settings generated a sample that was diverse across age and disease characteristics.

It is also important to recognise the research limitations. Females and males were eligible to participate in the study; however, only two of the 21 participants were males. Whilst it was not our intention to look for differences across gender, arthritis type, or work type, it is still important to acknowledge that recruitment of additional male participants would have allowed their narrative to be more fully captured, which may have been different to perspectives of female participants. A potentially important area of future research, therefore, will be to explore these issues among males with chronic health conditions. Similarly, while our sample included participants in varying work capacities (for example, full time, part time), we did not seek to contrast the findings across employment types. It is plausible that different arthritis types and work hours may have informed participants' experiences. We recognise that only one researcher coded and analysed the interviews which has potential to reduce rigor.

We also recognise the strengths and limitations of using the WHO ICF to guide interviews. The WHO ICF has been used in several arthritis-based studies. This ensured that the domains of questions for the interviews covered topics that are well-established as being important to human function. However, we recognise that participants may have had work-related experiences that were not captured by this framework. The analysis was still undertaken inductively, ensuring that themes were generated from data provided by participants.

Whilst qualitative research is representative of participants' experiences, our research cannot be generalised to the broader working population with arthritis. We acknowledge the potential for participant bias, where those with negative experiences in the workplace may have been more likely to volunteer to be a part of this research. Whilst people from across Australia participated, those living in rural areas often face additional challenges to accessing work that require more detailed exploration.

Conclusion

This study highlights the complex nature of navigating the workplace as a younger person with arthritis. The in-depth interviews elicited new perspectives on how young people with arthritis perceive themselves to be a burden on their workplace, employers and colleagues. These findings can be used to raise awareness of key issues relevant to younger people with arthritis in the workforce, and to educate employers, colleagues and clinicians about the wide-ranging impacts of arthritis.

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Compliance with Ethical Standards

Conflict of interest Danielle Berkovic, Darshini Ayton, Andrew Briggs, and Ilana Ackerman declare that they have no conflict of interest.

Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all study participants.

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CHAPTER 6: QUALITATIVE RESUTS - FINANCIAL IMPACTS

This chapter reports the financial impact findings of the qualitative study. It explores the perceived financial impacts of arthritis and financial concerns amongst working-age adults with arthritis, and identifies common categories of arthritis-related expenditure. This chapter addresses the second aim of the PhD: to determine the personal financial burden of arthritis. These results also contribute to recommendations around the financial-related impacts of arthritis, which will be discussed in Chapter 9.

Please note that this chapter has been accepted for publication in Arthritis Care & Research (209), however, it is yet to go through copyediting, typesetting, pagination, or proofreading. As a result, apart from the abstract, the article is presented in this chapter in its accepted Microsoft Word format.

The author permissions policy for this journal (Arthritis Care & Research) states that the author of a published article has the right to reuse the full text as part of a thesis. The full citation for the published manuscript is provided below:

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Arthritis Care & Research

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ORIGINAL ARTICLE

"The financial impact is depressing and anxiety inducing": A qualitative exploration of the personal financial toll of arthritis

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Abstract

Objectives

The financial experience faced by working-age people with arthritis include living below the poverty line for many. Financial distress amongst people with arthritis is known to contribute to poorer health outcomes, including high psychological distress and more severe pain. Despite the demonstrated societal cost of arthritis care and management, the personal costs borne by the individual are not well understood. The aim of this study was to explore the perceived financial impacts of living with arthritis amongst younger adults (defined as those aged 18 – 50 years).

Methods

A qualitative descriptive study design was used. Participants with inflammatory arthritis or osteoarthritis were recruited from the community, including urban and rural settings. An interview schedule was developed, informed by existing literature, which was piloted prior to data collection. Deductive and inductive coding techniques were used to identify financial-related themes arising from the data.

Results

Semi-structured interviews were conducted with 21 adults (90% female) with a mix of arthritis conditions including rheumatoid arthritis, psoriatic arthritis and osteoarthritis. Four themes were identified: direct arthritis-attributable medical costs, indirect arthritis-attributable costs, insurance and pension costs, and broader financial impacts on the family. Non-subsidised costs were frequently referenced by participants as burdensome, and existed even within the publically-funded Australian healthcare system.

Conclusion

Adults with arthritis experience significant arthritis-attributable financial burden and related distress. Financial concerns should be actively identified and considered within shared clinical decision making, in order to provide more patient-centred care for these individuals.

Significance and Innovations

- Adults with arthritis experience financial hardship associated with their disease, and many live below the poverty line despite access to a publically-funded healthcare system.
- Financial impacts identified by participants included for the costs of clinical care and medication, reduced employment wages, and burden on the family financial situation.
- These financial implications were associated with considerable distress and anxiety, highlighting the wide-ranging impacts of arthritis on adults.
- Discussion of arthritis-related financial concerns should form part of shared clinical decision-making, to facilitate patient centred-care.

Introduction

Arthritis is increasingly recognised as a disease that affects people of working age (1). In Australia, based on the most recent National Health Survey data, it is estimated that 24% of people with arthritis are aged 25 – 54 years – the peak income-earning years for most (2). Given the breadth of biopsychosocial impacts associated with arthritis, including pain and reduced physical function, and higher levels of anxiety and depression, individuals with arthritis are likely to experience career disruption, reduced work productivity and financial burden sequelae (3-6).

The economic impacts of arthritis in working-age populations are profound, as many transition into early retirement due to the condition (7-9). At a population level, the sequence of arthritis-attributable early retirement and welfare-related costs in working-age persons cost Australia $AUD7.2 billion in 2015. By 2030, this is projected to increase to $AUD9.4 billion (10). At a personal level, the median weekly income for an individual with arthritis is $AUD333.13 (11). In contrast, the poverty line for a single adult living alone is $AUD433.00 (12). Financial distress is known to contribute to poorer health among people with lifelong illness and pain, including high psychological distress and severe physical pain (13-15).

A limited body of research provides preliminary insights into the personal financial burden borne by working-age people with arthritis. Evidence suggests that individuals with rheumatoid arthritis (RA) who are aged less than 65 years spend significantly more on self-management measures and prescription medication than people with RA aged over 65 years, to improve their functional capacity and assist with activities of daily living (ADLs) (16). In Australia, females retiring early due to arthritis have an average of 83% less savings to fund their retirement compared to females who work to retirement age (17). It has been estimated that the financial burden on individuals with arthritis and musculoskeletal conditions is higher than the burden experienced by individuals with other lifelong conditions (18). Individuals living with arthritis report a high number of general practitioner (GP) appointments for prescription medications, higher psychology-related healthcare costs (the prevalence of major depression is 1.6 times higher in people with arthritis than their healthy peers), and additional pain management costs (19, 20).

Direct healthcare costs can include general practitioner (GP) and specialist visits (for example, rheumatologists) as well as consultations with allied health professionals (for example, physiotherapists) (21). Pharmaceuticals, diagnostic tests, dietary supplements and/or natural therapies, and supervised exercise programs further add to the cost burden (21). In addition to direct costs, indirect costs include reduced number of hours worked, forced early retirement, home

modifications, travel to and from healthcare appointments, and contributions from family members (for example, unpaid carer responsibilities) (22).

The personal financial burden borne by working age people with arthritis is yet to be explored in depth. The current study sought to examine the perceived financial impacts of living with arthritis amongst younger adults (defined as those aged 18 – 50 years).

Methods

Design

A qualitative descriptive study was undertaken in 2019 to explore the perceived work and financial impacts of arthritis on adults. A separate paper has previously reported findings around work participation restrictions and workplace impacts (6). This paper focuses on the financial impacts. Human Research Ethics approval was granted from the Monash University Human Research Ethics Committee (Project ID 12657) in May 2018. Reporting of the study was undertaken according to the COnsolidated criteria for REporting Qualitative research (COREQ-32) (23).

The Australian Healthcare System: An Overview

Australia adopted a taxpayer-funded universal healthcare scheme (known as Medicare) in 1984 (24). It is comprised of the Medicare Benefits Schedule, and the Pharmaceutical Benefits Scheme. The Medicare Benefits Schedule is a list of health services subsidised by the Australian government. There are over 57,000 items which provide benefits for a range of services, including specialist consultations, diagnostic tests, and procedures (25).

The Pharmaceutical Benefits Scheme subsidises the costs of over 5,000 medications. Via the scheme, the Australian government contributes the majority of the medication cost, and the consumer pays the remaining fee which is termed the out-of-pocket cost (24).

Australia also has a parallel private health system, supported by private health insurance policies, that individuals can choose to purchase alongside access to Medicare (24). Private hospital insurance covers the cost for some (or all, depending on the healthcare practitioner) treatment in a private hospital. Private ancillary insurance covers other health services not always included as part of Medicare, including dental treatment and other allied health services and programs (24). The most recent data indicate that 45.1% of the Australian population were covered by private health insurance in 2018 (26).

Participants

Males and females aged 18 – 50 years who reported a diagnosis of inflammatory arthritis (IA) or osteoarthritis (OA) by a registered medical practitioner (GP or rheumatologist) and were living in Australia were eligible to participate. The study was advertised through arthritis consumer organisations, university staff newsletters, and social media. Individuals with a range of arthritis disease types, genders, employment status, geographic locations (urban, rural) and socioeconomic status were recruited via a purposive sampling frame. Those who expressed an interest in participating were provided with further information by the lead researcher (DB) and asked to complete a brief screening questionnaire to confirm their eligibility.

Females who were pregnant were excluded from the study, as it was anticipated that they might have additional concerns related to pregnancy (27, 28). Those who had an unconfirmed arthritis diagnosis, were unable to communicate in English, or were unable or unwilling to provide consent were also ineligible to participate.

Data Collection

An interview schedule informed by existing literature and validated framework was developed by DB and DA (1, 29). DB has lived experience with an inflammatory arthritis condition, and in this context was able to assess the relevance of the interview schedule (30). As this is one of the first instances of arthritis-attributable costs for the individual being explored using a qualitative approach, interview questions were intentionally broad. The interview guide incorporated open-ended questions and probing questions in relation to financial factors (Table 1). Data collection was also iterative, and probing questions were used based on the participants' responses. Responses related to new financial themes captured in early interviews were incorporated as additional questions in later interviews. All individual, semi-structured interviews were conducted via telephone by the same researcher (DB) who has experience in qualitative data collection. All interviews were audio-recorded to enable verbatim transcription. Researcher reflections were captured in writing during the data collection process and used to optimise the conduct of subsequent interviews but are not reported here.

Table 1: Interview Guide as mapped to arthritis-attributable financial factors

Topic	Open Question/s	Probing Question/s
Current financial factors (direct costs)	What do you currently spend your money on to help manage your arthritis?	What experiences have you had paying for medical and specialist appointments? What experiences have you had paying for medications and other types of tablets? Do you pay for different types of insurance (health, life, travel) because of your arthritis? What level of financial distress do these out-of-pocket costs cause?
Current financial factors (indirect costs)	Do you have costs that are not directly attributable to arthritis, but that you find affect you financially?	Are you still able to work, and if so, have you had to take time off work for medical appointments or sick days? Do you have the level of productivity that you would like to at work? Has this changed since your arthritis diagnosis? Has missing work, or having reduced productivity at work, led to any financial concerns?
Future financial factors (direct and indirect costs)	Do you have financial concerns looking into the future?	What concerns do you have moving forward about continuing to produce an income? What concerns do you have about the progression of your arthritis, and the out-of-pocket costs associated with that? Are you worried about the financial burden that your arthritis may place on the people around you?

Data Analysis

A thematic analysis approach was adopted. Thematic analysis is a method used in qualitative research to determine, analyse, and compile themes from participant-oriented data (31). Thematic analysis is useful for contextualising similarities and differences across a range of participant perspectives, and to highlight unanticipated insights and novel data (31). As this research was exploratory and included a sample with varying arthritis-related experiences, a thematic approach to data analysis was suitable (32). Data analysis commenced alongside data collection, to enable themes identified in earlier interviews (interviews 1 – 5) to be explored in subsequent interviews. Participant recruitment and data collection ceased when data saturation was evident (33).

NVivo Version 12 was used to support data management and analysis via a process of inductive and deductive coding methods using open, axial, and thematic coding (34). Open codes were generated by looking for initial concepts from participants about their arthritis-attributable financial experiences. Axial coding was conducted to connect common themes identified by participants. For example, each participants' individual financial concerns were analysed collectively, to identify similar patterns. Using deductive coding, themes that correspond to the three interview guide topics were identified. Coding and data analysis were conducted by DB. To ensure construct validity, the emergent framework of codes was continuously presented back to a multidisciplinary research team, comprised of qualitative researchers and physiotherapists specialising in arthritis care (35). Where participant quotes are cited, these are provided verbatim. All monetary amounts are expressed in Australian dollars (1 AUD= 0.67 USD)

Results

Thirty-nine expressions of interest to participate were received. Five people could not be contacted, and within our purposive sampling approach, six others were not recruited to prevent over-sampling of specific arthritis conditions. Of the remaining 28 (71.8%) people who were screened for eligibility, 25 (64.1%) participants were eligible. Of the 25 eligible participants, 21 (53.8%) were included in the final sample (the remaining four participants declined to participate due to other commitments or illness). The 21 interviews ranged in length from 30 minutes – 95 minutes. Data saturation was reached in the final four interviews when it became apparent that no new themes were emerging.

Participant characteristics are shown in Table 2. The majority of participants were female (90.0%), and aged over 30 years (62.0%). Over one third had been diagnosed with RA (38.0%), with psoriatic arthritis being the next most common diagnosis (19.0%). Almost one third of participants lived with their partner and children (29.0%). Nearly half the participants had an undergraduate university degree (43.0%). Nearly three quarters participants had private health insurance (71.5%). Only one third of participants were in full-time paid employment (33.5%). One third of participants were in part-time or casual paid employment (33.5%). Fifteen percent of participants reported they were unable to work because of their arthritis.

Table 2: Participant Demographics

Demographics	**n (%)**
Gender, female	19 (90.0)
Age bracket	
18 – 30 years	8 (38.0)
31 – 40 years	6 (28.5)
41 – 50 years	7 (33.5)
Highest education status	
High School	2 (9.5)
Certificate / Diploma	5 (24.0)
Undergraduate University degree	9 (42.5)
Postgraduate University degree	5 (24.0)
Current living status	
Lives with partner/spouse and children	6 (28.5)
Lives with partner/spouse	4 (19.0)
Lives alone	3 (14.0)
Lives with parents	3 (14.0)
Lives with other adults (non-family members)	3 (14.0)
Lives with own children	2 (9.5)
Current employment status	
Full time, paid work	7 (33.5)
Part time/casual, paid work	7 (33.5)
Student	3 (14.0)
Unable to work because of arthritis	3 (14.0)
Unemployed or looking for work	1 (5.0)
Arthritis diagnosis	
Rheumatoid Arthritis	8 (38.0)
Psoriatic Arthritis	4 (19.0)
Osteoarthritis	2 (9.5)
Ankylosing Spondylitis	2 (9.5)
Seronegative Inflammatory Arthritis	2 (9.5)
Combination of Arthritis types	2 (9.5)
Juvenile Idiopathic Arthritis	1 (5.0)

Private health insurance status	
Yes (own policy)	12 (57.5)
Yes (parents' policy)	3 (14.0)
No	6 (28.5)

Four major themes were evident from the interviews (Table 3): 1) the financial burden of direct arthritis-attributable healthcare costs; 2) the unexpected financial burden of indirect costs of living with arthritis; 3) benefits versus the financial burden of paying for insurance; and 4) and the broader financial impacts on the family.

Table 3: Arthritis-attributable themes, subthemes, and illustrative quotes

Theme	Sub-theme	Illustrative quote(s)
The financial burden of direct arthritis-attributable healthcare costs	Medical specialist costs	I see it [the rheumatologist] as a money-grabbing thing, so I go every six months. They feel your joints and they go yeah, see you in three months' time. Like, I've just sat in your waiting room for two hours, you've just charged me $200 for that two hours of sitting for like a three minute appointment. Seeing your rheumatologist all the time is expensive. (Participant 7, F, 41 – 50, RA) The rheumatologist that I'm seeing is very expensive and the rebate isn't huge. (Participant 11, F, 41 – 50, RA) The dermatologist who I went to for my psoriasis did not recognise the fact that I had arthritis as well… I've probably paid for his speedboat since then… That's probably where he could have said hey, I can't help you. (Participant 2, M, 41 – 50, PsA)
	Allied health costs	I've been referred to strengthen my core through Pilates because I've got quite a lot of wear and tear in my spine. So just this week I'm going to start Pilates with a physio. The cost is quite shocking and I suppose that's the thing that's really frustrating. (Participant 15, F, 31 – 40, CA: RA, OA) I've seen a Bowen therapist before, she's quite good, she is quite expensive though, so it hasn't been really on my top priority list. (Participant 9, F, 18 – 30, OA) I used to see a physio and we'd do hydrotherapy. I don't know why but I just sort of stopped. You know, it was quite expensive. (Participant 3, F, 18 – 30, RA) I see a professor of physiotherapy who specialises in arthritis but he's very expensive. One of the public [hospital] practicing physios, but expensive, not a run of the mill physio (Participant 10, F, 18 – 30, JIA).

	Medication costs	I recently did a budget and I added up all my medications. And then there's calcium and fish oil and those sorts of things as well. Like I added all this up and it was like, $1,500. I was in the red and it made me realise that there's actually quite a lot of money attached to having this condition. I actually have to budget for this. (Participant 12, F, 31 – 40, PsA). I was fortunate growing up that my parents sort of paid for the medication. But now I realise wow, this stuff, not exactly the cheapest thing, and I'm a student, it's a little bit more expensive. (Participant 1, F, 18 – 30, CA: RA, SLE)
The unexpected financial burden of indirect costs of living with arthritis	Financial impacts of home modifications and household assistance	I remember struggling to mow the lawns and things like that, and not being in a financial position to be able to pay someone to do it. (Participant 5, F, 18 – 30, AS). I think if I didn't have chronic illness we would probably have a lot more money. We probably would have paid off the house. (Participant 14, F, RA, 41 – 50). We put a big extension on the back of the house for my arthritis, which we borrowed ... We owe a lot, it's not good, it's not manageable. (Participant 12, F, 31 – 40, PsA). I couldn't really get up in the morning so I went out and bought a new bed thinking that that might fix all the problems. I spent a few thousand dollars on buying a bed. I don't think it helped at all. (Participant 21, M, 31 – 40, AS).
	Transport and parking costs	I pay extra money for fuel because it's easier for me to drive places than to walk. (Participant 10, F, 18 – 30, JIA).

		When you're on drugs that lower your immune system and you catch public transport – one year I got sick six times, so now I drive. And of course, I have to pay for parking which is really expensive too, so that's another added cost. (Participant 15, F, 31 – 40, CA: RA, OA) Parking, like when I was in hospital for seven months, parking cost us a fortune. We spent heaps on the parking, we didn't save money at all with me being in hospital. Those parking costs just come right out of the budget. (Participant 7, F, 41 – 50, RA).
Benefits versus the financial burden of paying for insurance	Private health insurance	It is expensive – my mum says 'are you planning any holidays?' and I say 'no, we've got private health insurance, we can't afford all that'. (Participant 12, F, 31 – 40, PsA) We can't afford not to have private health because if I need an operation, I can get it done tomorrow. It just has a limit and once you reach that limit it's pretty hard. My expenses wouldn't be as high as the sun now, but anything is better than nothing. (Participant 13, F, 18 – 30, RA).
	Travel and life insurance	Things like travel insurance; that tends to be a lot more expensive when I need that. So that's definitely something I need to think about more when planning to travel. (Participant 9, F, 18 – 30, OA). I got life insurance before I got the rheumatoid. It came with our credit card or whatever it was. They don't know I've got rheumatoid. It's so expensive. I got it before I had it, and nobody else will insure me. (Participant 7, F, 41 – 50, RA)
	Disability pension and healthcare card	I am on a disability pension, like I think the full disability pension, they get about $800 a fortnight, but I get $200 a fortnight. (Participant 12, F, 31 – 40, PsA).

		I couldn't get a healthcare card because I earn $20 more than I should. Ridiculous. I'm very fortunate that my partner promised to pay for my medical expenses. Otherwise I wouldn't be able to afford it. (Participant 10, F, 18 – 30, JIA).
Broader financial impacts on the family	Single income household	Obviously I can't work. We are a single income family. Um, so that single income family, that does impact everything. Going away, it impacts where you can go, stuff like that. (Participant 7, F, 41 – 50, RA). Being on a single income we couldn't really afford to put the kids in childcare every day, that sort of thing. (Participant 12, F, 31 – 40, PsA).
	Financial strain on parents and children	Even though it is my parents' role I do still worry about it. Because it is still very expensive and I'd hate to put a financial burden on my parents and my family. So yeah it is still definitely a concern, even though I'm not actually paying for it. (Participant 3, F, 18 – 30, RA) My son, he's in year five of university now, and I think if I was ordinary I think he probably would have gone and got a job properly by now. He might have been able to have holiday or something, it would have been nice for him to have some extra money. (Participant 12, F, 31 – 40, PsA).

F: Female; RA: rheumatoid arthritis; CA: combination of arthritis types; OA: osteoarthritis; PsA: psoriatic arthritis; SLE: systemic lupus erythematosus; JIA: juvenile idiopathic arthritis; AS: ankylosing spondylitis

Theme 1: The financial burden of direct arthritis-attributable medical costs

Participants reported that the out-of-pocket or non-subsidised costs associated with arthritis-attributable medical expenses were *"bloody depressing" and "anxiety inducing"*. In contrast to an acute or short-term illness, participants emphasised the sustained financial burden due to the lifelong nature of arthritis: *"it's the rest of your life you're paying for this stuff"*. The greatest expenditure incurred was for specialist rheumatologist consultations, although the reported figures varied between participants. For some participants, rheumatologist appointments incurred no out-of-pocket costs, as they accessed specialist consultants through the public hospital system. One participant stated that they had an initial consultation with a rheumatologist whose fees were $AUD500, whereas the majority of participants reported paying approximately $AUD200 per appointment. Regardless of the charge, many perceived specialist consultation to be costly: *"seeing your rheumatologist all the time is expensive"*. For those with psoriatic arthritis, seeing a dermatologist to manage the psoriasis component of the condition was considered an additional financial burden.

In addition to rheumatologists' fees, participants highlighted the significant expense associated with medications and allied health services. Many expressed gratitude for publicly-funded Medicare healthcare, as illustrated by a quote from one participant: *if Medicare didn't cover my etanercept it would be a thousand dollars a fortnight, stupid money"*. Although participants acknowledged that medications were made more affordable under the Pharmaceutical Benefits Scheme, they noted the substantial expense associated with multiple concurrent medications: *"when you're on two or three that's a monthly cost that adds up"*. Participants described using allied health to help manage arthritis-attributable symptoms, but *"when the physio costs $65.00 and I'm looking at probably the next ten years of things like physio and acupuncture"*, the non-subsidised costs become burdensome. One participant described paying for preventative health services, as *"I need to proactively improve my health and arthritis from a non-drug related perspective… particularly being anxious in the workplace about my limitations about being able to pick up things"*.

Theme 2: The unexpected financial burden of indirect arthritis-attributable costs

Participants stated that arthritis-related physical symptoms caused career disruptions and hindered their ability to work full-time. Many specified that they *"weren't able to work for many years after diagnosis"*, and that even years after diagnosis *"it still works better for me to work part-time"*. As a result, a common sentiment was that *"it would be nice to have some extra money"*. For some participants, having less money was compounded by unanticipated costs associated with the invisible nature of arthritis. For example, participants explained that it was easier for them to drive to work and social events

than to take public transport, as *"standing on the train my legs actually get quite sore"*. Fellow commuters tend to *"look for visual symptoms like crutches or walking sticks"* and as a result, *"no one's going to give up their seat because obviously they assume nothing's wrong"*. Participants therefore *"often just end up driving to events"*, which creates additional costs where you *"have to pay for parking"*, and need *"extra money for fuel because it's easier to drive places than to walk or take the train"*.

In addition to transport costs, participants described financial constraints to the extent that they were unable to afford non-medical assistance with arthritis-related physical limitations. For example, some participants' symptoms inhibited them from completing ADLs, yet they were unable to afford professional assistance. Several participants described *"scrounging pennies"* to pay for home-based ergonomic devices, from less expensive aids such as a *"basket on wheels so if the washing needs to be done I can carry it"*, to a more expensive *"gadget that lifts the bottom shelf of the dishwasher so you don't have to bend over"*.

Theme 3: Benefits versus the financial burden of paying for insurance

Participants reported that private health insurance was one of their largest health-related expenses. Individuals or families often choose to purchase private health insurance in case of injury, or flare up of symptoms. However, those living with arthritis perceived private health insurance as essential expenditure, stating *"I can't afford to not have private health"*. Many confirmed that they *"took out private health insurance because of arthritis"*, and that this was *"because if I need an operation I can get it done tomorrow and not wait for 12 months when you're in desperate agony"*.

Over a quarter of participants did not have private health insurance, as *"contemplating the premiums would be a lot higher for someone like me with arthritis and I already have no money"*. Participants who stated they were unable to afford private health insurance were frustrated that others are allowed to access both the public and private healthcare systems simultaneously. Many expressed sentiments such as *"we don't really have the money for health insurance but I probably would like to have it because then I can have my neck fixed straight away"* and that as a result *"it's frustrating that people can double dip and go public or private, financially it's abuse"*.

In addition to private health insurance, other insurance costs were perceived to weigh heavily on people with arthritis. Participants were frustrated that travel and life insurance was more expensive due to the presence of a pre-existing medical condition. Many were left uninsured and expressed concern at the potential financial burden placed on their families. Participants fretted over their limited funds and their frustration at minimal government compensation in the form of disability

pensions and healthcare cards to provide those living with lifelong conditions supplementary income, and reduced medical costs. However, participants stated that *"I was on a disability pension for the arthritis"* but that it was rendered futile when *"not a lot of doctors do a special concession rate for people on a pension"*.

Theme 4: Broader financial impacts on family

Alongside concern for their own finances, participants voiced distress about the broader financial impacts of arthritis on their families. Younger participants (those aged 18 – 21 years) explained that they lived at home with *"a supportive family that would help me out in any situation"*, but that *"it's still a bit concerning that I'm not paying for my own appointments and my parents shouldn't have to"*. Those who were slightly older (aged 25 – 30 years) acknowledged that their parents noticed when they were having a flare-up, and that they would *"try and pitch in with costs where they can but I don't like it because they should enjoy their retirement without worrying about my financial state"*.

In contrast to children placing financial pressure on their parents, participants who were parents expressed similar worry about imposing a financial burden on their own children. For example, one participant explained, *"I don't want my children to think that they can't have careers because they have to look after me if I'm much worse when I'm older"*.

The financial consequences of living with arthritis extended into broader implications for the whole family. For example, living on a reduced income for an extended time meant that families were unable to take holidays, mortgage repayments had to be defaulted or extended, and children were forced to enter the workforce earlier than they otherwise would have. As one participant explained, *"we live like grey nomads [but] in Australia, no overseas travel, with a chronic condition attached to it"*.

Discussion

Arthritis is clearly associated with profound financial impacts and associated financial distress among adults. This study is one of the first to examine these financial concerns from an in-depth qualitative approach, involving a community-based sample of people with different arthritis conditions. Our findings indicate that a range of financial impacts and concerns, including direct arthritis-attributable medical costs, and other impacts that lie outside of direct healthcare, characterise people's experiences of living with arthritis.

Study participants highlighted the high fees for access to rheumatologists. The financial burden of paying for specialist appointments is topical in Australia: a recent review found that the average non-subsidised cost for an initial rheumatology consultation – net of the subsidised Medicare rebate – is $AUD120.00 (36). It has been found that the cost of medical intervention is not related to improved health outcomes or superior quality of care (37). Those with lower health literacy levels may be vulnerable to excess healthcare expenditure and financial burden without receiving best-practice care (38, 39). A taskforce has been developed and aims to ensure that all Medicare Benefits Schedule items provide real clinical value, or high-value care, and do not expose patients to unnecessary expense (36).

In addition, participants expressed their surprise at the expense of non-subsidised allied healthcare costs incurred through the outpatient public hospital system, despite access to universal healthcare in this country. Due to changing health needs, increasing healthcare costs, health inequities, and complex health conditions, patients are shouldering growing out-of-pocket costs (40). However, within the 'fee-for-service' payment model, health professionals are permitted to set their own fees (which are typically above the schedule fee that is reimbursed), this can lead to high non-subsidised costs for some patients (41).

Evidence suggests that the current out-of-pocket costs for people living with lifelong illness in Australia are strongly associated with experiencing poverty (42). Similar trends are documented in Nordic countries, which also have combination public and private healthcare systems (43, 44). In Australia, growing out-of-pocket costs are partially attributed to increased uptake of private health insurance due to lengthy waiting periods for a rheumatology, pain medicine or surgery consultation through the public system (45, 46). Participants also highlighted their fiscal concerns extending beyond direct healthcare costs, including reduced capacity to pay for their mortgage, childcare and the impacts on travel and life insurance.

There is emerging data on the effects of lifelong illness on financial domains beyond medical expenses. People living with coronary artery disease have outlined challenges relating to driving costs where public transportation or walking is unfeasible (47). People affected by Types 1 and 2 diabetes have explained that only by limiting expenditures on non-medical related items were they able to afford medication (48). However, to the best of our knowledge, this study is one of the first dedicated to examining the perceived financial burden of living with arthritis.

It is perhaps unsurprising that adults with arthritis face much broader personal economic challenges beyond their direct medical costs. It is well documented that this population have shorter work careers, are less confident to pursue career progression opportunities, and earn significantly less throughout their income-earning years than their healthy peers (6, 49). Lower work participation rates and financial sequelae present as concurrent challenges to navigate for people with arthritis. Through reporting these fiscal challenges, our findings provide a starting point for understanding the concerns of younger populations with arthritis, beyond the health impacts. In particular, education and support from arthritis consumer organisations or other advocacy groups may be provided to, or accessed by, clinicians treating people of working age with arthritis. Clinicians need to be cognisant that their patients may be experiencing financial distress, and that identifying these concerns as part of routine clinical care can help inform shared decision making, particularly as it relates to accessing interventions or services that are high-value, and identify available services that may be feasible (for example, referring a patient to a community physiotherapy program, versus a private practice).

Strengths and Limitations

As our study was exploratory in nature, it was important to examine broad arthritis-attributable financial experiences and we were able to recruit a heterogeneous participant sample to achieve this. Our recruitment strategy spanning arthritis consumer organisations, university networks, and clinical settings generated a sample that was diverse across age and disease characteristics. In-depth semi-structured interviews were used to elicit detailed data from participants. However, we did not directly ask about non-medical related costs (for example, home modifications, childcare), although these were reported by some participants during the interviews. In this context, we may have under-represented this theme in the analysis.

Qualitative research is representative of participants' experiences, however, our research cannot be generalised to all people's arthritis-attributable finances. Two thirds of participants were

university-educated, which may indicate higher income levels amongst our sample compared to the broader population with arthritis. We also recognise that a relatively high proportion of our sample had private health insurance, compared with the general population, but that this does not necessarily reflect the socioeconomic status of our sample given ongoing government initiatives designed to lower the cost of private health insurance and improve uptake. We also acknowledge the potential for participant bias, where those with higher financial burden may have been more likely to volunteer to be a part of this research. There was an oversampling of females (reflecting the demographics of arthritis); a potentially important area of future research, therefore, will be to explore these issues amongst males with IA and OA.

Conclusion

This study highlights the spectrum of ongoing direct and indirect costs borne by adults living with arthritis conditions. The in-depth interviews provided novel insight into the range of financial concerns experienced by younger patient groups and the personal distress associated with these. These findings can be used to raise awareness of key fiscal issues relevant to adults with arthritis, and to educate clinicians about the wide-ranging impacts of arthritis beyond physical symptoms.

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CHAPTER 7: QUANTITATIVE RESULTS – COST DIARY

This chapter reports the results of the quantitative cost diary study. This chapter describes the key healthcare cost categories for younger, working-aged adults with arthritis, quantifies levels of financial distress, and examines the relationship between healthcare costs and financial distress. Together with Chapter 6, this chapter addresses the second aim of the PhD: to determine the personal financial burden of arthritis (comprising direct and indirect healthcare costs). These results also contribute to recommendations around the financial-related impacts of arthritis, which are discussed in Chapter 9.

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Personal healthcare costs borne by younger people living with arthritis: an exploratory study

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Abstract *(281 words)*

Arthritis is a long-term musculoskeletal disease, requiring ongoing management. However, the financial burden of managing arthritis is under-explored and is yet to be quantified from the perspective of individuals with the condition. Using an exploratory observational design, this study aimed to quantify arthritis-related costs borne by working-age adults aged 18 – 50 years living in Australia. Participants completed a weekly cost diary for six weeks, detailing their personal non-reimbursed (out-of-pocket) arthritis-related costs. Financial distress was measured using the InCharge Financial Distress/Financial Well-Being Scale. Costs data were analysed descriptively. Mann Whitney U tests were used to examine relationships between residential location or employment status and out-of-pocket costs. Linear regression and Spearman's rho were used to estimate relationships between age or years since diagnosis and out-of-pocket costs, and between out-of-pocket costs and financial distress, respectively. Sixteen adults (median age 40 years, 100% female) with a range of arthritis conditions (median (IQR): 8 (7.5) years since diagnosis) including rheumatoid arthritis, osteoarthritis, psoriatic arthritis, and ankylosing spondylitis completed the six-week cost diary. All participants reported out-of-pocket expenditure related to arthritis. The median per-person expenditure across the six weeks was AUD 1635. The highest reported costs per participant across the six weeks were for medical expenses (median AUD 197) and allied health appointments (median AUD 190). In total, the cohort spent AUD 15,272 across the study period. Perceived financial distress was high: median (IQR) financial distress 7 (2.25) on a 1 (lowest) to 10 (highest) scale. Positive relationships between age and costs, and between costs and financial distress were identified. These findings help us understand fiscal expenditure and related distress relevant to younger individuals with arthritis, and can be used to raise awareness of their financial concerns.

1. Background

The most recent data from the Australian National Health Survey data indicate that 50% of the population with arthritis are aged 25 – 64 years, aligning with the peak income-earning years (Australian Bureau of Statistics, 2018a). Inflammatory arthritis (IA) – an umbrella term for lifelong, autoimmune, inflammatory diseases such as rheumatoid arthritis (RA) and ankylosing spondylitis (AS) – most commonly presents in people of working age (Australian Institute of Health and Welfare, 2020a). Osteoarthritis – a predominantly non-inflammatory disease also presents in people of working age (Ackerman, Kemp, Crossley, Culvenor, & Hinman, 2017), as well as in older individuals. There are a breadth of biopsychosocial impacts associated with arthritis, including persistent pain and reduced physical function and quality of life (Hunter, McDougall, & Keefe, 2008; Oakman, Kinsman, & Briggs, 2017), higher levels of anxiety, depression and other co-morbidities (Sharma, Kudesia, Shi, & Gandhi, 2016), detrimental career and work sequelae, and financial distress (Berkovic, Ayton, Briggs, & Ackerman, 2020b; Jetha et al., 2015).

The personal and societal economic impacts of arthritis for working-age populations are substantial. The most recent estimates for Australia showed that the impact of early retirement, welfare costs, and lost tax revenue due to arthritis was estimated to total 7.2 billion Australian dollars (AUD) in lost gross domestic product (GDP) in 2015 (Schofield, Shrestha, & Cunich, 2016). Many individuals with arthritis are forced into early retirement (Crawford et al., 2020), which has led to total lost annual income estimates of AUD 387 million (Schofield et al., 2013). The arthritis-attributable costs to health systems and workplaces are also well-documented. Arthritis-related care cost the Australian healthcare system AUD 5.5 billion in 2015 and this is predicted to approach AUD 7.6 billion annually by 2030 (Arthritis Australia, 2019). Chronic pain (which includes pain associated with arthritis) is responsible for an estimated 9.9 million absent days from work each year, which costs Australian workplaces approximately AUD 1.4 billion per annum (Pain Australia, 2020). International data portray a similar picture: lost productivity due to arthritis is estimated to cost workplaces 3.5 billion US dollars (USD) per year in the United States (US) (Vuong, Wei, & Beverly, 2015), and €3.3 billion euros (EUR) across Europe (Oxford Economics, 2010).

While our understanding of the societal and health system costs of arthritis have been informed by considerable data, the personal financial cost of living with arthritis remains relatively under-explored. The latest data - from 2016 - from the US show that among 154 health conditions, the US government allocated

the highest number of healthcare dollars to musculoskeletal diseases between 1996 – 2016 (estimated $134.5 billion), of which 9.2% was paid by individuals as non-reimbursed payments (estimated to total USD 12.4 billion) (Dieleman et al., 2020). Data from the US Medicare Expenditure Panel Survey (1996 - 2005) highlighted that women with osteoarthritis spent an additional USD 1,379 per annum in non-reimbursed healthcare expenditure, compared to women without osteoarthritis. (Hunter, Schofield, & Callander, 2014).

In Australia, healthcare costs borne by the patient (non-reimbursed, or out-of-pocket (OOP) costs) comprise approximately 18% of health spending, which exceeds the Organisation for Economic Cooperation and Development (OECD) median of 15.8% (Laba et al., 2015). Evidence suggests that in 2002, individuals with RA spent on average $1,513 AUD yearly managing the disease (Lapsley et al., 2002); $71.30 yearly on aids and home modifications in 2012, and $26.00 extra for each appointment comprising travel-related and parking costs in 2004 (Arthritis and Osteoperosis Victoria, 2012). These incurred costs are prominent for people with arthritis, yet expenditure estimates are outdated and remain unquantified in the contemporary literature with little evidence as to whether costs are associated with demographic characteristics (e.g. age) or financial distress. There have also been calls for a bottom-up costing approach to best capture the current personal financial burden (Ackerman, Bohenski, Pratt, Gorelik, & Liew, 2016). A recent qualitative study found that direct medical expenses were perceived to comprise only a small component of arthritis-related costs. In addition to other direct non-medical and pharmaceutical costs, participants also reported that paying for pain management and assistive devices were additional sources of financial strain (Berkovic, Ayton, Briggs, & Ackerman, 2020a). Since cost data were not prospectively collected in that qualitative study, an exploratory quantitative study is now warranted which may later inform a larger population-based study.

To more fully understand the personal financial burden of arthritis, this exploratory study aimed to quantify arthritis-related costs borne by working-age adults with arthritis. Specific research objectives were to: (1) identify the most common categories of arthritis-related expenditure, (2) investigate whether costs related to age and disease duration, and (3) quantify levels of financial distress and the relationship between costs and financial distress.

2. Methods

2.1 Study Design

An exploratory, observational study was undertaken from September 8, 2019 to March 18, 2020, involving weekly administration of a self-reported, online cost diary over six weeks. Ethics approval was obtained from the Monash University Human Research Ethics Committee (Project ID 18892). Reporting of the study was undertaken according to the Strengthening of the reporting of observational studies in epidemiology (STROBE) Statement (Supplementary File 1) (von Elm et al., 2008).

2.2 Context: The Australian Healthcare System

Australia has a taxpayer-funded universal healthcare scheme (known as Medicare) that incorporates a Medicare Benefits Schedule (MBS) and a Pharmaceutical Benefits Scheme (PBS) (Australian Government Department of Health, 2019). The MBS comprises more than 57,000 healthcare items including general practitioner, medical specialist and limited allied health consultations, diagnostic tests, and medical and surgical procedures. The PBS is a list of approved medications that are subsidised. For both the MBS and PBS, the Australian government provides full or partial reimbursement of healthcare costs, and any non-reimbursed costs are considered 'OOP' that are borne by the patient.

While all Australians and permanent residents have access to Medicare, they can also access the parallel private health system if they purchase private health insurance. Private hospital insurance covers the cost for some (or all, depending on the healthcare practitioner and level of cover) treatment in a private hospital. Private ancillary insurance covers other health services that are not always included as part of Medicare, including allied health services and prostheses. The most recent data indicate that just under 50% of the Australian population are covered by private health insurance (Australian Institute of Health and Welfare, 2018). Work injury and traffic accident compensation schemes also fund care for compensable injuries (Sherry, Briggs, & Pizzari, 2020).

2.3 Participants and Protocol

Working-age individuals with an arthritis condition were recruited from the community through advertisements disseminated by arthritis support groups, stakeholder organisations, and social media posts.

Participants met inclusion criteria if they were: (1) aged between 18 – 50 years, (2) diagnosed with IA or OA by a rheumatologist or general practitioner (GP), and (3) living in Australia. Exclusion criteria for this study were: (1) aged <18 or >50 years, (2) pregnant, (3) living outside of Australia, or (4) unable to communicate in English and/or unable or unwilling to provide consent.

Potential participants were able to respond to advertisements by contacting the first author (via email or phone) to express their interest in participating. After providing consent online, participants were able to access week one of the cost diary. The remaining five cost diaries were scheduled to be sent out once per week, on the same day and at the same time each week, until the conclusion of the study period. To facilitate full data completion, participants were sent reminder emails twice each week (on days four and six).

2.4 Outcome Measures

We developed the cost diary based on our previous research with working-age individuals with arthritis residing in Australia, where they highlighted specific costs associated with living with arthritis (Berkovic et al., 2020a), alongside existing literature of patient-reported financial burden.

Participant demographics (age, gender, location of residence, arthritis diagnosis and duration of disease, qualifications, living status, and employment status) were collected prior to the week one cost diary. The cost diary contained seven sections relevant to arthritis-related OOP expenditure, including: (1) medical appointment costs, (2) allied health appointment costs, (3) other health practitioners, (4) medication or nutraceuticals costs, (5) symptom or pain self-management item costs, (6) diagnostic and medical imaging costs, and (7) costs related to accessing healthcare for arthritis, for example, parking or travel costs for a medical appointment. For all questions, participants were asked to only report OOP costs, and to exclude any reimbursement received from Medicare, private health insurance or other sources. The cost diary was delivered online via Qualtrics (Qualtrics, Provo, UT, USA).

An overview of sections 1-7 is provided below:

- ***Section 1:*** During the past 7 days, have you attended any medical appointments related to your arthritis, and what were the out of pocket fees that you paid? Response options included, for example, rheumatologist, GP, orthopaedic surgeon, and dermatologist. Blank sections were

provided for participants to write in other medical appointments not listed, for example, pain physician.

- ***Section 2:*** During the past 7 days, have you attended any allied health appointments related to your arthritis, and what were the out of pocket fees that you paid? Response options included, for example, physiotherapist, osteopath, occupational therapist, psychologist, and podiatrist. Blank sections were provided for participants to write in other allied health appointments not listed, for example, exercise physiologist or chiropractor.
- ***Section 3:*** During the past 7 days, have you attended any other health practitioner appointments related to your arthritis, and what were the out of pocket fees that you paid? Response options included, for example, Chinese medicine and Bowen therapy. Blank sections were provided for participants to write in other health practitioner appointments not listed, for example, shiatsu massage.
- ***Section 4:*** During the past 7 days, have you purchased any medications or supplements (prescribed or non-prescribed) related to your arthritis, and what were the out of pocket fees that you paid? Blank sections were provided for participants to write in their respective medications (for example, prescription Methotrexate, over-the-counter Paracetamol) and supplements (for example, Magnesium, Vitamin D).
- ***Section 5:*** During the past 7 days, have you used any symptom or pain self-management items related to your arthritis, and what were the out of pocket fees that you paid? Blank sections were provided for participants to write in items such as Pilates, gym membership and foam roller.
- ***Section 6:*** During the past 7 days, have you had any diagnostic and medical imaging costs tests related to your arthritis, and what were the out of pocket fees that you paid? Blank sections were provided for participants to write in tests such as x-ray, ultrasound, and blood test.
- ***Section 7:*** During the past 7 days, have you had any non-health related costs related to your arthritis, and what were the out of pocket fees that you paid? Blank sections were provided for participants to write in costs such as home modifications, and fuel/parking costs at medical appointments.

2.5 Financial Distress

A modified version of the InCharge Financial Distress/Financial Well-Being (IFDFW) scale was administered to participants at the start of each week during the study period, prior to the cost diary (Safe Work Australia, 2018). This tool asks participants a single item: "What do you feel is the level of your financial stress today, on a scale of 1 to 10 where 1 is not at all stressed and 10 is as stressed as can be?" The IFDFW scale has been found to be valid and reliable for measuring financial distress (Prawitz et al., 2006), and the modified version was recently added to Safe Work Australia's National Return to Work Survey (Safe Work Australia, 2018).

2.6 Analysis

All analyses were performed using Microsoft Excel (Microsoft Corporation 16.0.12026.20174) and SPSS Statistics (IBM). Cost data were not normally distributed due to the high costs reported by some participants with. We therefore used medians and interquartile ranges (IQR)) to describe the demographics of the study population (with means and standard deviations used where appropriate), OOP costs, and financial distress scores. Mann-Whitney U tests were used to examine relationships between residential location (metropolitan, regional, rural) and OOP costs, and between employment status (full time, part time) and OOP costs. Linear regression was used to estimate the relationship between age, disease duration, and OOP costs. Spearman's rho (r_s) was used to examine the relationship between OOP costs and financial distress. A significance level of $p<0.05$ was used for all analyses.

3. Results

3.1 Participant Characteristics

Sixteen participants completed the full six weeks of the cost diary, with demographic characteristics summarised in Table 1. Although the study was open to any gender, all participants were female. A further 11 participants did not provide full six-week data; our analysis was restricted to those who completed the entire cost diary. Average age was 38 years (standard deviation (SD) 7.9). Average disease duration was eight years (SD 5.6). The sample included people living in metropolitan areas (69%), as well as those in regional or rural locations (31%) according to the Socio-Economic Indexes for Areas (Australian Bureau of Statistics, 2018b). Over half of participants had an undergraduate or postgraduate university degree (69%), and the majority were in paid employment (88%). The most common arthritis diagnosis was RA (38%), followed by AS (24%) and psoriatic arthritis (PsA) (24%). More than one third of participants reported two or three concurrent arthritis diagnoses.

Table 1: Participant characteristics

Characteristics		n (%)
Gender	Female	16 (100.0)
Location	Metropolitan	11 (68.75)
	Regional	4 (25.0)
	Rural	1 (6.25)
Arthritis Diagnosis	Rheumatoid Arthritis	8 (38.1)
	Ankylosing Spondylitis	5 (23.8)
	Psoriatic Arthritis	5 (23.8)
	Osteoarthritis	2 (9.5)
	Juvenile Idiopathic Arthritis	1 (4.8)
Highest Qualification	Postgraduate University Degree (Masters, PhD)	4 (25.0)
	Undergraduate University Degree (Bachelors)	7 (43.75)
	Certificate or Diploma	4 (25.0)
	High School	1 (6.25)
Current Living Status	With partner or spouse	11 (44.0)
	With children	9 (36.0)
	With other adults (non-family members)	2 (8.0)
	With other adults (family members)	1 (4.0)
	With parents	1(4.0)
	Alone	1 (4.0)
Current Employment Status	Part time or casual, paid work	8 (50.0)
	Full time, paid work	6 (37.5)
	Full time carer for children	1 (6.25)
	Arthritis-attributable inability to work	1 (6.25)
	Unemployed	0 (0)

3.2 Overall Costs

All participants reported OOP expenditure related to arthritis, with the cohort spending AUD 15,272 in total across the six-week period. The median per-person expenditure was AUD 1,635 across the six-week period, with per-person expenditure ranging from AUD 129 to AUD 2,690. There was no significant difference in OOP costs across the study period between participants living in regional or rural locations (median AUD 663) and those living in metropolitan zones (median AUD 586) (p=0.32). There was also no difference in OOP costs between participants in part time or casual paid work (median AUD 589) and those in full time paid work (median AUD 449) (p=0.59).

3.3 Costs by Category

Table 2 provides a summary of expenditure by category. All participants reported OOP expenditure for prescription medication during the study period. Three quarters of participants (n=12, 75%) reported expenditure on medical appointments (for example, GP, rheumatologist) and allied health appointments (for example, physiotherapy, occupational therapy). Over two thirds (n=11, 69%) reported expenditure on symptom or pain self-management items (for example, heat packs, back brace). Over one third of participants reported expenditure on other health practitioner appointments such as Chinese massage (n=6, 38%). Figure 1 provides a scattergram of OOP expenditure per participant for each cost diary category and highlights the considerable between-person variation in healthcare spending, in particular for expenditure on allied health and medical tests.

Table 2: Cost categories and expenditure across the six-week study period

Cost diary category	Participants reporting cost categories, n (% cohort)	Example	Total cohort expenditure AUD	Median per-person expenditure AUD (IQR)
Allied Health Appointments	12 (75)	*Physiotherapist, occupational therapist*	4,402	190 (234)
Medical Appointments	12 (75)	*GP, rheumatologist*	2,892	197 (168)
Medications and Supplements	16 (100)	*Prescription medication (e.g. Methotrexate), non-prescription medication (e.g. Paracetamol), supplements (e.g. vitamin tablets)*	2,333	125 (99)
Medical Tests	5 (31)	*Blood tests, bone density scan*	1,635	134 (65)
Costs related to healthcare appointments for arthritis	8 (50)	*Petrol and parking costs*	1,514	126 (221)
Symptom / Pain Self-Management Items	11 (69)	*Heat packs, wrist brace*	1,486	120 (86)
Other Health Practitioner Appointments	6 (38)	*Chinese medicine, Bowen therapy*	1,010	132 (92)
Total Expenditure			15,272	1,635 (1,112)

IQR: Interquartile range

3.4 Costs by Age and Financial Distress

Linear regression identified that only 10% of the variance in OOP costs could be explained by age (R^2=0.10), with disease duration accounting for less than one percent of the variance in OOP costs (R^2=0.0001). Across the six-week study period, the median level of financial distress was seven (out of a possible 10), ranging from 3.5 – 9.3. There was a modest positive relationship between higher OOP costs and financial distress (r_s=0.3), as shown in Supplementary File 2.

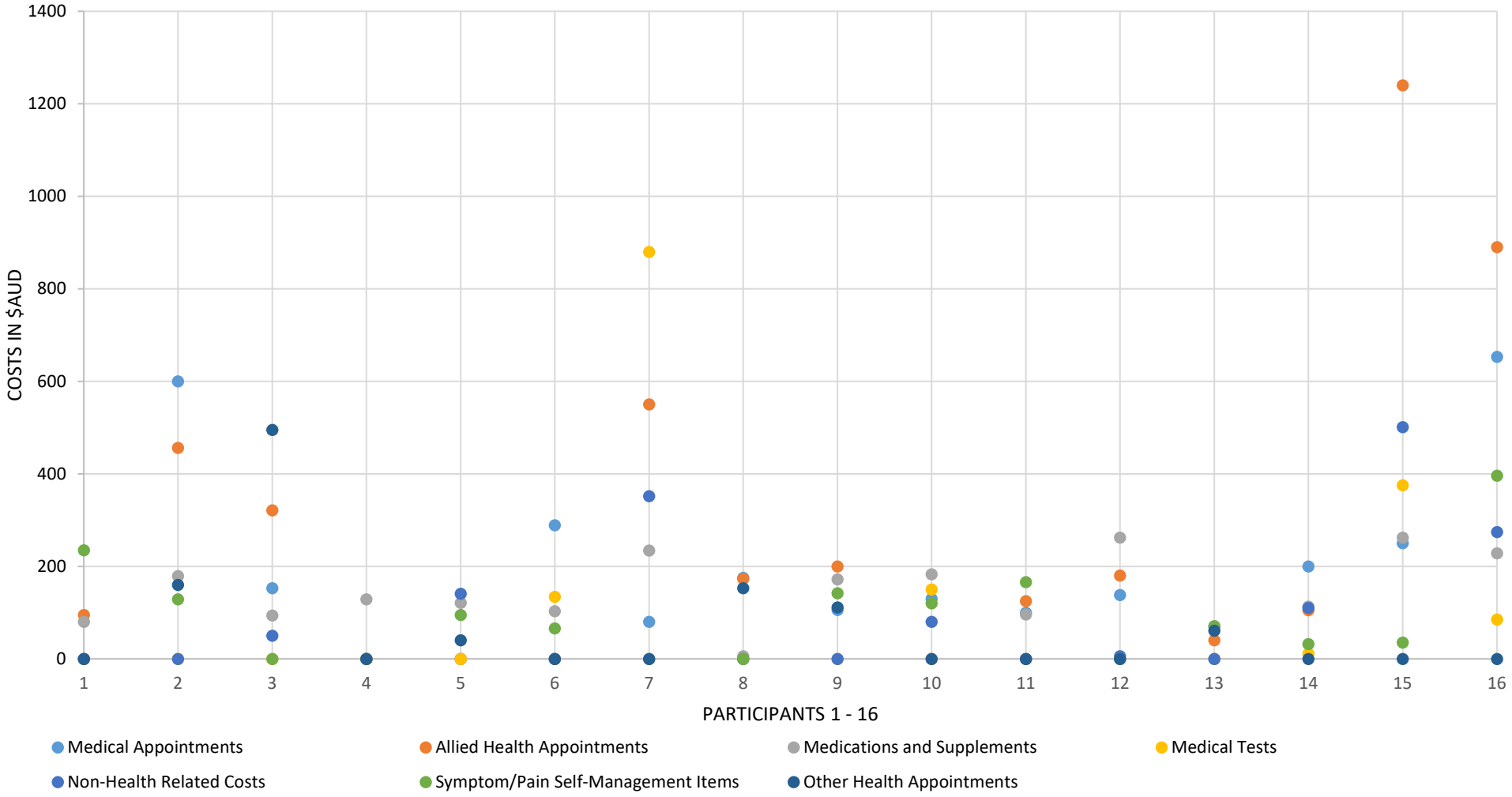

Figure 1: Scattergram of each participant's arthritis-related expenditure over the study period, by cost category

4. Discussion

Arthritis is associated with high personal financial costs and financial distress amongst working-age adults, despite these individuals having access to universal and largely-subsidised healthcare in Australia. Adopting a bottom-up costing approach, this exploratory study has uniquely examined individual expenditure through the use of comprehensive cost diaries administered to a community-based sample of people with arthritis conditions. Our formative findings indicate that participants incurred the highest expenditure on medical consultations, allied health appointments, medications and supplements, but with substantial between-participant variation. We also found that OOP costs increased to a small degree with age, and that perceived financial distress increased with higher OOP costs.

Three quarters of participants reported OOP costs for medical and allied health appointments, which when combined, comprised nearly half of all expenditure during the study period ($7,294, 48%). Participants spent close to the same OOP amount on medical appointments as they did on allied health consultations. By way of context, the Australian Medicare system subsidises a larger portion of medical appointment fees, as opposed to allied health, which is only partially reimbursed by Medicare and private health insurance (or in many cases, not reimbursed at all). These large costs complement a recent analysis of OOP costs to patients across medical specialties in Australia, which found rheumatology to be one of the top three most expensive medical specialties with respect to patient-borne costs, with a median OOP cost of AUD 111.70 (Freed & Allen, 2017). The ensuing financial burden has potential health consequences for younger people. Fifty per cent of men and women in Australia aged 25-44 years reported delaying or avoiding medical specialist appointments due to high costs, and 59% of men and women in the same age bracket report delaying or avoiding general practitioner appointments due to high costs (Australian Bureau of Statistics, 2014). Building on our earlier qualitative findings around perceived financial burden, this study has now quantitatively confirmed the high levels of financial distress experienced by people living with arthritis.

All sixteen participants reported expenditure on medication in the study period. Medication spending was relatively high despite existing PBS subsidies, with weekly expenditure for all participants ranging from AUD 71 per person to AUD 262 per person. Individuals bear a spectrum of costs for various arthritis-related medications. For example, disease-modifying anti-rheumatic drugs (DMARDs) commonly used to

treat IA, such as Methotrexate, are heavily subsidised; the cost borne by the individual is AUD 41.00 per 50-item packet, lasting 26 to 52 weeks (Australian Government Department of Health, 2020b). Where medication costs increase substantially is for biologic DMARDs. Biologic DMARDs are a costly but frequently used disease-modifying treatment for IA, first listed on the PBS in 2003 (Hopkins et al., 2016). PBS expenditure on biologic DMARDs was estimated at AUD 2.29 billion in 2015-16 (Gleeson, Townsend, Lopert, Lexchin, & Moir, 2019), dramatically decreasing the cost for the individual, but it still costs patients AUD 41.00 per fortnight (Australian Government Department of Health, 2020a). Understanding the financial burden related to medication use is important given a growing body of literature linking OOP medication costs with medication non-adherence in adults with arthritis (Heidari, Cross, & Crawford, 2018; Pasma et al., 2017; Verhoef, Selten, van den Hoogen, den Broeder, & Hulscher, 2016). Further, nearly seven percent (6.8% (CI 6.-7.3)) of Australians reported delaying or avoiding filling a prescription due to cost from 2018-2019 (Australian Institute of Health and Welfare, 2020b). This has clear implications for clinical practice, with a recent call for rheumatologists to consider their patients' level of financial distress before prescribing expensive treatments (Heidari et al., 2019), and to discuss health-related financial concerns as part of routine care and shared decision making.

Reasons for using non evidence-based care are not well understood. Nearly half of participants reported expenditure on treatments for arthritis for which there is only low-quality evidence or no supporting evidence, including Chinese massage and Bowen therapy. This is concerning given that such treatments are not recommended in current clinical care guidelines (National Health and Medical Research Council, 2009; Royal Australian College of General Practitioners, 2018). Whilst participants in this study were highly educated, people with lower health literacy levels may be particularly vulnerable to unnecessary healthcare expenditure and financial burden without receiving best-practice care that provides real clinical value (Barton et al., 2014; Hill et al., 2015). Qualitative studies exploring patient experiences have detailed individual financial concerns around affording arthritis-related treatment across the lifespan (Berkovic et al., 2020a; Binder-Finnema, Dzurilla, Hsiao, & Fraenkel, 2019; Dures et al., 2019). Rheumatologists have also acknowledged patients' financial concerns as a major barrier to affordable and sustainable care (Heidari et al., 2019; Kalkan, Roback, Hallert, & Carlsson, 2014). It is critical therefore, that patients' limited financial resources are directed to high-value, evidence-based interventions for arthritis.

Financial distress levels were high in this study. It is well documented that working-age populations with arthritis earn significantly less throughout their income-earning years than their healthy peers (Schofield et al., 2016). At the same time, individuals with arthritis incur substantial healthcare costs. For example, the average Australian household spent AUD 1,099 per annum on healthcare consultations (including medical and allied health appointments) in 2014 (Callander, Fox, & Lindsay, 2019). Across the six-week cost diary, expenditure on healthcare professionals by study participants averaged over half this annual figure at AUD 608. Albeit within a small sample, our results demonstrate that high healthcare costs and financial distress represent concurrent challenges to navigate for individuals with arthritis.

There was a small positive correlation between increasing age and arthritis-related OOP costs in this study. These findings complement existing Australian data, which broadly report higher OOP costs with older age (Carpenter, Islam, Yen, & McRae, 2015; Islam, Yen, Valderas, & McRae, 2014). Figures from the 2009-2010 Household Expenditure Survey demonstrate variation in the type of healthcare spending. Whilst older households (defined as age $\geq$65 years) spent more on medications than households aged <65 years (mean AUD 1,563 versus mean AUD 764 per annum), younger households spent more on health practitioner fees, for example, GP and specialist fees (mean AUD 1,054 versus mean AUD 753 per annum) (Yusuf & Leeder, 2013). Despite our small sample, we observed a modest relationship between age and higher OOP costs, but with considerable variation in the type of healthcare spending between participants.

4.1 Strengths and Limitations

This study has used a purpose-designed methodological approach to quantify OOP costs for individuals with arthritis. Based on qualitative research insights, we carefully developed the cost diary to focus on categories of expenditure most relevant to people with arthritis. Our sample included people with a range of arthritis conditions and incorporated those living in metropolitan, regional and rural areas given potential differences in access to care by residential location.

We also acknowledge the research limitations. Our sample was small, and we acknowledge that the reported costs are unlikely to be representative of all individuals with arthritis. In this context, our research should be considered exploratory and could be used to inform a larger, population-based evaluation. Two thirds of our sample were university-educated, so they may have higher levels of disposable income to spend on

healthcare and may also have greater health literacy regarding arthritis interventions. A third of participants presented with comorbid arthritis diagnoses, which is likely to increase disability and healthcare costs. However, we maintain that our study provides an important snapshot of contemporary arthritis-related costs, highlighting the substantial financial burden and associated financial distress. All study participants were female and had IA. Although IA is more common amongst women, costs may differ for males living with arthritis and among people living with osteoarthritis where medicines (largely used to manage pain) are less expensive and hematologic monitoring is not usually required. It was not intended to analyse the costs data according to type of arthritis. Pregnant women were not included in the study, given likely costs associated with pregnancy and childbirth. We did not have access to data on private health insurance membership or disability benefits, although all participants had access to the universal Medicare system. Finally, we chose to cease data collection at the onset of the COVID-19 pandemic given the sudden shift to telehealth appointments, potential medication shortages, and reduced access to non-COVID-related care.

5. Conclusion

This study has quantified the personal financial costs borne by a sample of working-age adults living with arthritis. Our findings provide evidence that demonstrates the significant financial burden imposed by arthritis-related medical and allied health consultations and medications and supplements. At the same time, our results highlight the great variability in OOP costs, with some patients incurring high costs for alternative and complementary therapies that do not have a strong evidence base. Concerningly, perceived financial distress was high among our sample and this was consistent with the costs data. These results enable us to better understand arthritis-related financial expenditure and can be used to raise awareness of the broader financial impacts of arthritis across the lifespan.

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CHAPTER 8: SOCIAL MEDIA STUDY – TWITTER RESULTS

This chapter comprises the published results of the Twitter study. The Twitter study was incorporated into the PhD at the onset of the COVID-19 pandemic as a supplementary study, due to the necessary cessation of recruitment into the cost diary study. Given the research pivot, this study does not explicitly address the overarching aim and objectives of this PhD; however, it provides novel information about topics of importance to people with arthritis during the pandemic and provide insights into how social media might be used to support arthritis-related research and healthcare delivery. This is discussed in more detail in Chapter 9.

The full citation for the published manuscript is provided below:

Berkovic D, Ackerman IN, Briggs AM, Ayton D. Tweets by People With Arthritis During the COVID-19 Pandemic: Content and Sentiment Analysis. J Med Internet Res. 2020;22(12):e24550. doi: 10.2196/24550

Original Paper

Tweets by People With Arthritis During the COVID-19 Pandemic: Content and Sentiment Analysis

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Abstract

Background: Emerging evidence suggests that people with arthritis are reporting increased physical pain and psychological distress during the COVID-19 pandemic. At the same time, Twitter's daily usage has surged by 23% throughout the pandemic period, presenting a unique opportunity to assess the content and sentiment of tweets. Individuals with arthritis use Twitter to communicate with peers, and to receive up-to-date information from health professionals and services about novel therapies and management techniques.

Objective: The aim of this research was to identify proxy topics of importance for individuals with arthritis during the COVID-19 pandemic, and to explore the emotional context of tweets by people with arthritis during the early phase of the pandemic.

Methods: From March 20 to April 20, 2020, publicly available tweets posted in English and with hashtag combinations related to arthritis and COVID-19 were extracted retrospectively from Twitter. Content analysis was used to identify common themes within tweets, and sentiment analysis was used to examine positive and negative emotions in themes to understand the COVID-19 experiences of people with arthritis.

Results: In total, 149 tweets were analyzed. The majority of tweeters were female and were from the United States. Tweeters reported a range of arthritis conditions, including rheumatoid arthritis, systemic lupus erythematosus, and psoriatic arthritis. Seven themes were identified: health care experiences, personal stories, links to relevant blogs, discussion of arthritis-related symptoms, advice sharing, messages of positivity, and stay-at-home messaging. Sentiment analysis demonstrated marked anxiety around medication shortages, increased physical symptom burden, and strong desire for trustworthy information and emotional connection.

Conclusions: Tweets by people with arthritis highlight the multitude of concurrent concerns during the COVID-19 pandemic. Understanding these concerns, which include heightened physical and psychological symptoms in the context of treatment misinformation, may assist clinicians to provide person-centered care during this time of great health uncertainty.

(J Med Internet Res 2020;22(12):e24550) doi: 10.2196/24550

KEYWORDS

COVID-19; SARS-CoV-2; novel coronavirus; social media; Twitter; content analysis; sentiment analysis; microblogging; arthritis

Introduction

Social media contains a plethora of health information pertaining to individuals living with chronic illness [1,2]. Social media provides a unique opportunity to observe thoughts, feelings, and interactions between individuals living with chronic illness, and to leverage this information to promote positive health outcomes [3,4]. The COVID-19 pandemic has seen widespread uptake of social media use. Twitter, a well-known social media platform primarily used for microblogging, plays a significant role in crisis communications and can be a powerful tool to communicate to entire populations during a time of rapid change [5]. Twitter is already frequently used by individuals with arthritis to communicate with peers [6] and to receive up-to-date

information from health professionals and services about novel therapies and management techniques [7].

Many inflammatory arthritis medications act as immunosuppressants, which are advantageous in controlling arthritis-mediated inflammatory responses, but can increase the risk of infection [8]. Long-term use of immune-modulating therapies or glucocorticoids may place individuals with arthritis in a higher-risk category for contracting the novel coronavirus SARS-CoV-2, although the level of risk is poorly understood [9-12]. Current guidelines suggest that individuals living with arthritis should physically distance from other individuals and their communities [13], and will likely need to do so for a longer duration than the general public. Heightened stress due to potential medication shortages, reduced opportunities to personally consult health care professionals, and enforced limitations on physical activity (which, for many, is a core component of arthritis self-management [14]) contribute to worsening arthritis symptoms, including disease flares. At present, individuals with arthritis have already reported increased physical pain and psychological distress during the COVID-19 pandemic [15,16].

In the current COVID-19 outbreak, Twitter's overall daily usage has surged by 23% in 2020 [17], presenting a unique opportunity to assess the content and sentiment of tweets. Examining publicly available tweets allows exploration of important proxy topics through microblogging data, without directly burdening this population. This research aims to identify proxy topics of importance for people with arthritis (of any diagnostic category) during the COVID-19 pandemic by characterizing the textual content and sentiment of tweets, and to explore the emotional context of tweets by people with arthritis during the early phase of the pandemic.

Methods

Design

An exploratory content and sentiment analysis was undertaken. All data were collected and reported according to the terms and conditions of Twitter, which state that content posted by individuals is publicly available to syndicate, broadcast, distribute, retweet, promote, or publish, excluding private information (eg, home addresses or identity documents) [18]. Use of tweets by individuals outside of Twitter can be carried out with no compensation paid to the individual tweeter, as use of Twitter is agreed upon as sufficient compensation [18]. The Monash University Human Research Ethics Committee (Project ID 24354) approved this project.

Inclusion and Exclusion Criteria

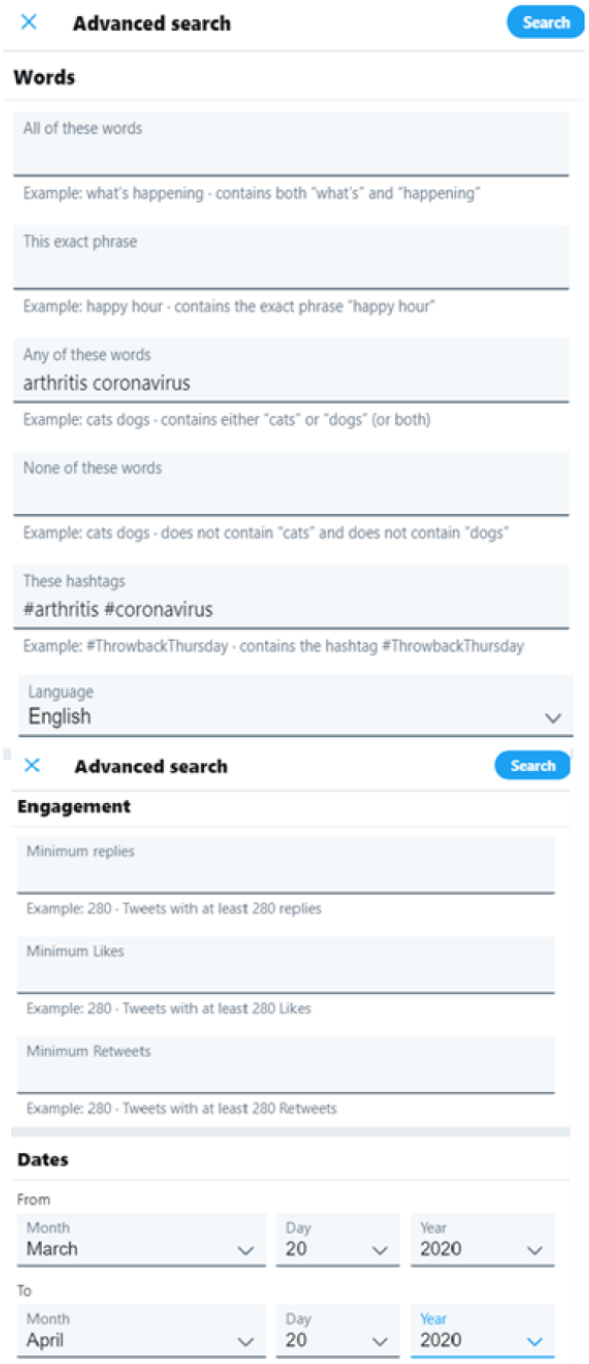
Publicly available tweets posted in English or with English translation (automated through Twitter), with the hashtags shown in Table 1 were included.

Table 1. Hashtags categorized by topic.

Topic	Hashtag
COVID-19	• #coronavirus • #covid19 • #isolation • #socialdistancing
Arthritis	• #arthritis • #spoonie • #rheumatologist • #rheumatology

Hashtags were selected based on trialing various combinations through Twitter's search function. The highest number of tweets retrieved were for the hashtags #coronavirus, #covid19, #arthritis, and #spoonie (the latter term coined by people living with chronic illness to describe various methods of pain management [7]). Hashtags were also searched as words; for example, where #arthritis was searched, arthritis without a hashtag was searched as well. This ensured that specific arthritis types mentioned in tweets without hashtags (eg, rheumatoid arthritis or psoriatic arthritis) were included. Hashtags and words were combined through the advanced search function on Twitter using the domains Hashtags, Words, Language, and Dates (Figure 1 [19]). Tweets were excluded if they originated from organizations, news outlets, or health professionals rather than individuals in order to focus on the personal perspective.

Figure 1. The advanced search function on Twitter [19].



Data Collection

Tweets were retrospectively extracted from March 20 to April 20, 2020. The search strategy and search results are included in Multimedia Appendix 1. The search timeframe was chosen to align with the early phase of the COVID-19 pandemic and the period when many developed countries (eg, the United States, the United Kingdom, Italy, Australia) announced enforceable physical distancing or isolation measures [20-23].

The desktop version of the Twitter website (versus the mobile app) was used for data collection for ethical purposes with only publicly available tweets extracted, rather than through a private login. In addition to the tweets themselves, accompanying data fields were extracted from each tweet using a customized template. Extracted data fields included (where possible): Twitter profile blurb, gender of tweeter, country of tweeter, number of likes, number of retweets, number of replies, hashtags used, number of hashtags, and use of accompanying photos.

Data were stored in a Microsoft Excel spreadsheet (v16.0, Microsoft Corp).

Data Analysis

To address the research aims, two data analysis techniques were utilized: summative content analysis and sentiment analysis. Content analysis was used to characterize the textual contents of tweets related to arthritis and COVID-19. Content analysis is exploratory; it aims to quantify and describe unknown phenomena [24]. During the content analysis process, the primary researcher (DB) read each tweet and categorized the tweets into a representative theme and subtheme related to a topic of importance for people with arthritis during the study period.

Summative content analysis occurred through a process of coding, which involved counting and comparisons of Twitter content, followed by interpretation of the underlying context [25]. To begin with, the first 10 tweets were analyzed and allocated a summary code. The code represents the theme of a tweet (eg, "health care experiences"). As additional tweets were examined, they were given one of the original codes or allocated a new code based on new content. This process was repeated until each tweet was coded and themed. Once these original themes were finalized, they were recoded for additional context, and a second researcher (DA) checked the coding. For example, "health care experiences" was coded for similarities in people's health care experiences, such as difficulties accessing medications. Given Twitter's character limits, each tweet only contained one theme. The frequency of original themes and subthemes was counted to indicate importance [26].

Sentiment analysis enables an examination of written and spoken words for positive and/or negative emotion. When applied to health care or social media research, sentiment analysis facilitates interpretation of textual information about patient experience from a person-centered perspective [27]. Once tweets were coded and categorized into themes, sentiment analysis was employed to assess the emotion associated with the theme using Glaser and Strauss's [28] 6 codes for sentiment analysis, a common framework used for Twitter-based research [29,30]:

1. No sentiment: the tweet has no emotion or words or special punctuation; is matter-of-fact sounding;
2. Wretched: the tweet is purely negative;
3. Bad: the tweet contains mainly negative phrases and words that outweigh any positive sentiment;
4. So-so: the tweet has a mediocre and balanced sentiment where positive and negative statements are balanced;
5. Swell: the tweet contains mainly positive phrases and words which outweigh negative sentiment;
6. Great: the tweet is purely positive.

The presence of emojis, which are shorthand facial expression symbols that are frequently used to facilitate communication of mood and emotion, in tweets were also analyzed. To provide information regarding the emotional content of the tweets, Emoji Sentiment Ranking, as outlined by Kralj Novak et al [31], was applied. Tweets containing an emoji were categorized into one of three sentiment scores: (1) negative, (2) neutral, and (3) positive. Together, the content and sentiment analyses provide a proxy indicator of the topics of interest for, and perceived emotions of, people with arthritis during the COVID-19 pandemic.

Even in social media studies, it is imperative to protect participant anonymity [32]. To avoid reverse identification of participants based on their tweets (which can be found through internet searches), tweets analyzed in this study are not quoted verbatim. Instead, all data are expressed in aggregate form through descriptive statistics and qualitative syntheses.

Results

The analysis included 149 tweets posted during the study period. The majority of tweeters were female and based in the United States. The most common arthritis type was rheumatoid arthritis. Table 2 outlines gender, country of residence, and arthritis type.

Table 2. Demographics of Twitter users sampled.

Characteristic	Users (N=149), n (%)
Gender	
Female	105 (70.0)
Male	31 (21.0)
Unknown	13 (9.0)
Country	
United States	68 (45.5)
United Kingdom and Northern Ireland	39 (26)
Canada	18 (12.0)
Australia	1 (0.7)
France	1 (0.7)
Germany	1 (0.7)
India	1 (0.7)
New Zealand	1 (0.7)
Unknown	19 (13.0)
Diagnostic category	
Arthritis (specific arthritis type unclear)	86 (58.0)
Rheumatoid arthritis	32 (21.0)
Systemic lupus erythematosus	12 (8.0)
Psoriatic arthritis	10 (7.0)
Ankylosing spondylitis	3 (2.0)
Osteoarthritis	3 (2.0)
Juvenile idiopathic arthritis	3 (2.0)

Content analysis revealed seven themes from the tweets: (1) health care experiences, (2) personal stories, (3) links to or advertisements of relevant blogs, (4) discussion of arthritis-related symptoms, (5) advice sharing, (6) messages of positivity, and (7) stay-at-home messaging. Table 3 details the original themes and subthemes.

Table 3. Content analysis of themes and subthemes.

Theme and subthemes	Tweets, n (%)	Examples of phrases or #hashtags describing content
Health care experiences	55 (37.0)	• "I'm a long-term user of #hydroxychloroquine"
Difficulties accessing hydroxychloroquine	20 (36.5)	• "#Hydroxychloroquine destroyed my red blood cells"
Past experiences using hydroxychloroquine	20 (36.5)	
Support for President Trump's advice to use hydroxychloroquine to cure COVID-19	9 (16.0)	
Experiences within the National Health Service (UK NHS)	4 (7.0)	
Managing medication changes during COVID-19	2 (4.0)	
Personal stories	29 (20.0)	• "My rheumatologist has asked that I go into isolation. Now all I can do is enjoy the world from my window"
Explanation of history of managing arthritis, and subsequent fears of contracting or dying from COVID-19	9 (31.0)	• "My immune system is compromised but I'm being told to go to a germy hospital???"
Description of ways to self-manage physical symptoms (eg, exercising, staying connected with friends)	7 (24.0)	
Physical and psychological challenges of socially distancing	7 (24.0)	
Perceived barriers to attending rheumatologist appointments (eg, discomfort of wearing masks, fear of entering a high-risk location)	6 (21.0)	
Links to or advertisements of relevant blogs and forums	22 (14.0)	• "To our members, subscribers, followers, and fans: we are here for you. #BeSafe"
Recommendations and links from individuals to official patient- and consumer-led blogs (eg, CreakyJoints)	10 (45.0)	
Personal blogs on individual COVID-19 experiences (eg, how to manage worsening symptoms)	7 (32.0)	
Unofficial patient blogs (eg, online communities and forums) to create support networks for individuals	5 (23.0)	
Discussion of arthritis-related symptoms	15 (10.0)	• "Anyone else's arthritis flaring due to extra phone use?"
Increased physical pain	11 (73.5)	
Difficulty sleeping	2 (13.5)	
Reduced dexterity	2 (13.5)	
Advice seeking and sharing	14 (9.0)	• "Any suggestions for chronic pain sufferers? Coronavirus has been very rough #arthritis #spoonie"
Questions directed at government bodies (eg, the NHS and national working-from-home regulations)	5 (36.0)	• "Do we know if those of us with autoimmune conditions (arthritis) have a higher risk from #coronavirus"
Seeking advice from physiotherapists on at-home exercises to manage physical symptom burden	3 (22.0)	
Advice on whether to temporarily cease taking immunosuppressant medications	2 (14.0)	
Advice on how to protect airways if dexterity limitations prevent mask-wearing	2 (14.0)	
Questions directed to delivery services regarding delays	2 (14.0)	
Messages of positivity	8 (6.0)	• "It's amazing how motivating isolation can be! On my bike but knee sore #arthritis"
Gratitude for friends, family, and to still be able to appreciate life	4 (50.0)	
Spare time as a result of physical distancing facilitating more time to exercise and reduce physical symptom burden	4 (50.0)	
Stay-at-home messaging	6 (4.0)	• #stayathome
Emotional appeals for people to stay at home	4 (67.0)	• #arthritissucks
Angry appeals for people to stay at home	2 (33.0)	• #arthritiswarrior

The most common theme identified was experiences of navigating the health care system during the COVID-19 pandemic. Hydroxychloroquine (brand name Plaquenil) featured prominently in tweets, in terms of difficulties accessing the

medication, past experiences using the medication, and recommendations from the President of the United States to use this medication to cure or prevent COVID-19, despite the lack of evidence or medical advice. Some individuals tweeted about their experiences within the National Health Service (NHS) in the United Kingdom, where patients were subject to longer-than-usual delays for rheumatology appointments, medication infusions, and general health check-ups.

Many individuals used Twitter as a platform to connect with and seek support from peers with arthritis. Tweets contained personal stories, links to personal and consumer-led blogs, discussion of arthritis-related symptoms, and advice seeking and sharing. Some individuals shared their challenges managing arthritis symptoms whilst being confined to their homes and questioned their physical and psychological capacity to function if they were to contract COVID-19. Others described the physical and emotional challenges associated with isolation, including increased physical pain, reduced dexterity, and missing family. Strategies to manage these symptoms included exercising and staying socially connected online with friends to ease mental strain. Tweeters were willing to guide others to potentially helpful resources, particularly blogs run by professional organizations (eg, CreakyJoints, the Arthritis Society [Canada]). Several tweets contained questions were directed toward government bodies (eg, regarding national working-from-home policies), whereas others reached out to physiotherapists or peers with arthritis for advice on appropriate exercises or lifestyle modifications to manage symptom burden during the isolation period. Some tweeters noted dexterity limitations that were highly relevant to COVID-19, such as being incapable of placing a mask behind their ears.

Some tweets were positive with tweeters noting they used their newfound spare time to concentrate on exercise, which was beneficial for mental health and pain reduction. Finally, some individuals expressed their desire for people to stay at home to flatten the curve of infections to return to normal life. Disapproval was voiced toward those refusing to practice physical distancing, whereas others expressed anger toward people not adhering to stay-at-home orders.

Sentiment analysis provided complementary information about the emotions associated with the content analysis themes. Table 4 details the original themes and corresponding sentiment, with phrases or hashtags describing tweeters' personal experiences.

Table 4. Sentiment analysis of tweets.

Original theme and sentiment[a]	Tweets, n (%)	Examples of phrases or #hashtags
Health care experiences	55 (37.0)	
Great	5 (9.0)	"doddle," "virus gone in 3 days," "NO SIDE EFFECTS," "credible and good"
Swell	3 (5.0)	"thankful," "it must be working," "don't be afraid"
So-so	8 (15.0)	"hope it helps," "minimal risk," "might work," #BeWarnedBeWell, "it might fight COVID-19," "take care world!" "interesting to see"
Bad	6 (11.0)	#plaquenilshortage," "no tests will be done for 2 months," "facing shortages," "no proof #Hydroxychloroquine makes us safe"
Wretched	28 (51.0)	"seriously ill," "madness," "pissed off," #coronavirushoax, #painsomnia, "f*ck all chance," "made me sick," "I could die," "harmful results," "side effects unbearable," "I call bullsh*t," "[medication] shortages & living with symptoms," #EVIL!!, "shorten my life," "life threatening for us," "true danger," "scared," "fear a shortage," #drugshortage, "will end up in hospital," "write us all off," "it made me so sick," "NO real testing," "it's not safe"
No sentiment	5 (9.0)	"research says," "UK government wants," "prove hypothesis," "IL-6 is raised," "from the CDC"
Personal stories	29 (20.0)	
Great	5 (17.0)	"all good during this #covid19," "it makes me feel better on a personal level," "bring it on world," "I am a champion!" #livingmybestlife
Swell	5 (17.0)	#AloneTogether, #nevergiveup, #hope, #makethebestofit, "trying to keep active"
So-so	3 (10.0)	"it is what it is," "I hope they have a lot of masks and sanitizer!"
Bad	2 (7.5)	"I didn't want to risk heading out," "limiting my usual walk"
Wretched	12 (41.0)	"give us a break, FFS!" #HighRiskCovid19, "I hate #Coronavirus," "literally a pain," "holy sh*t," "screaming into the void," "I am not #expendable," "being told to go to a germy hospital," "my chances of surviving #covid19 are horrible," "vulnerable patients like me"
No sentiment	2 (7.5)	"info is changing daily," "I'm immunocompromised because"
Links to or advertisements of relevant blogs and forums	22 (14.0)	
Great	1 (5.0)	"so grateful"
Swell	2 (9.0)	"talking about work/life balance," "we are here for you"
So-so	4 (18.0)	"coping in isolation," "trying to deal," "hoping to support others"
Bad	2 (9.0)	"how to handle flares," "learn what's happening to people with arthritis"
Wretched	4 (18.0)	"covid19 scariness," "fear of dying," "unpredictability and fear," "we worry about everyone"
No sentiment	9 (41.0)	"video games during covid19," "questions I have," "share with your networks," "breaking news," "please consider sharing," "please retweet," "I found this information"
Discussion of arthritis-related symptoms	15 (10.0)	
Great	0 (0.0)	—[b]
Swell	0 (0.0)	—
So-so	1 (7.0)	"not the end of the world"
Bad	1 (7.0)	"I have to take a break"
Wretched	13 (86.0)	"struggling to sleep/be active," "spoonie fail," "the arthritis flared out of control," "my shoulder is a casualty," "pain in the knees," "I'm screwed," "ouchy grouchy," "feet are burning," "f*ck you coronavirus," "worsening arthritis pain," "I'm already achy," "flaring due to extra phone use"
No sentiment	0 (0.0)	—
Advice seeking	14 (9.0)	
Great	0 (0.0)	—

Original theme and sentiment[a]	Tweets, n (%)	Examples of phrases or #hashtags
Swell	1 (7.0)	"thanks to the doctors for their expertise"
So-so	0 (0.0)	—
Bad	1 (7.0)	"some chance of developing complications"
Wretched	8 (57)	"lowered immunity more than it already is," "significantly increase risk of infection," "things have been rough," "zero immune system," "so stressed about #coronavirus," "no money for food let alone masks," "I'm disabled"
No sentiment	4 (29.0)	"grateful for info," "where can I volunteer to get tested," #lockdownUK, "would appreciate a video of exercises for in #lockdown"
Messages of positivity	8 (6.0)	
Great	2 (25.0)	"coronavirus caused some good things to happen," "amazing how motivating boredom is"
Swell	3 (37.5)	#selfmanagement, "right exercises to keep arthritis at bay," "enjoy the little things"
So-so	1 (12.5)	"life is too short to be scared"
Bad	1 (12.5)	"keeping positive a challenge"
Wretched	0 (0.0)	—
No sentiment	1 (12.5)	"this information might help"
Stay-at home-messaging	6 (4.0)	
Great	0 (0.0)	—
Swell	0 (0.0)	—
So-so	0 (0.0)	—
Bad	0 (0.0)	—
Wretched	5 (83.0)	"#selfisolation only because of my immune system," #arthritissucks so stay the f*ck home," "coronavirus could kill me #StayHomeSaveLives," "#PLEASESTAYHOME I'm devastated," "arthritis shot to sh*t stay home"
No sentiment	1 (17.0)	#GoHomeStayHome

[a]Great: the tweet is purely positive; swell: the tweet contains mainly positive phrases and words that outweigh negative sentiment; so-so: the tweet has a mediocre and balanced sentiment where positive and negative statements are balanced; bad: the tweet contains mainly negative phrases and words that outweigh any positive sentiment; wretched: the tweet is purely negative; no sentiment: the tweet has no emotion or words or special punctuation and is matter-of-fact sounding.

[b]Not available.

A few tweets contained messages of positivity. While overall "keeping positive [was] a challenge," some people encouraged others to "enjoy the little things" and that "life is too short to be scared." Still, the extent to which people with arthritis were concerned for their health was evident in people's stay-at-home messaging. Tweeters were notably anxious and angry, writing that "#arthritissucks so stay the f*ck home," that "coronavirus could kill me #StayHomeSaveLives," and "#PLEASESTAYHOME I'm devastated."

Using Glaser and Strauss's [28] classifications, more than half of the tweets contained wretched (purely negative) or bad (mainly negative) sentiment (n=83, 56%), whereas only one-fifth of tweets contained great (purely positive) or swell (mainly positive) sentiment (n=27, 18%). In total, 16 (11%) tweets contained sentiment that was so-so (balanced negativity and positivity), and 22 (15%) tweets contained no sentiment (matter-of-fact sounding).

Individuals in the United States appeared particularly despondent regarding their health care experiences during the COVID-19 pandemic. When referencing interactions with the health care system, tweets contained phrases such as "true danger," "seriously pissed off," and "scared." Tweeters noted "it's not safe" for people with arthritis facing hydroxychloroquine shortages, and that the #drugshortage was "life threatening." Some individuals mused that there is "minimal risk" trying hydroxychloroquine to cure COVID-19, and that it might be "interesting to see" the results of this medication. Outside of the United States, Canadians tweeted that engaging with the health care system during the pandemic was a "doddle" and that they were "thankful" to continue to have access to their health professionals.

Many individuals described their personal stories negatively. People with arthritis discussed barriers to accessing care, such as being surprised at "being told to go to a germy hospital" and that they "didn't want to risk going out." Tweets with links to blogs were accompanied by captions "fear of dying," "unpredictability and fear," and "we worry about everyone." Some were more positive, encouraging followers that they are "hoping to support others." Although their representation was small, people with arthritis in Ireland and New Zealand viewed

the isolation measures as an opportunity for #hope, encouraging others to #makethebestofit and to #nevergiveup.

A consistent sentiment was that people with arthritis were negative in their discussion of physical and psychological symptoms, with many individuals seeking advice from peers and health professionals to remedy symptoms. Tweets highlighted the spectrum of symptoms that individuals experienced during the pandemic, with people "struggling to sleep/be active," experiencing "worsening arthritis pain," and having "pain in the knees." Some noted that attempting to manage physical symptoms while in isolation was "literally a pain" and that the psychological toll was like "screaming into the void." One tweeter mentioned that their arthritis was "flaring due to extra phone use," which was frustrating since this was a primary method of maintaining social connection and communication with family or colleagues during the pandemic. Similarly, individuals tweeting and asking for advice did so by prefacing that "things have been rough," that they have "zero immune system," and that they are "so stressed about #coronavirus."

Our sentiment analysis included an overview of emoji use in tweets, as summarized in Table 5.

Table 5. Sentiment analysis of emoji use in tweets.

Emoji[a]	Count, n	Emoji name	Phrases or #hashtags accompanying the emoji	Emotion	Link to original themes
	3	Face with no good gesture	"my feet are burning," things are very painful," "my chances of surviving are horrible"	Negative	Discussion of arthritis-related symptoms, personal stories
	2	Clapping hands sign	"my team have worked so hard," "massive thanks"	Positive	Links to or advertisements of relevant blogs and forums, advice seeking
	2	Smiling face with smiley eyes	"hope it helps all"	Positive	Health care experiences
	2	Confused face	"I might be screwed," "I think my consultant is wrong"	Negative	Health care experiences, discussion of arthritis-related symptoms
	2	Person with folded hands	#lupuswarrior	Positive	Personal stories, health care experiences
	2	Red heart suit	"hoping to support others," #BeSafe	Positive	Links to or advertisements of relevant blogs and forums
	2	Purple heart	"choose to spread awareness"	Positive	Personal stories
	1	Crying face	"#coronavirus has opened my eyes"	Neutral	Health care experiences
	1	Smirking face	"#makingthebestofit	Positive	Personal stories
	1	Fisted hand sign	"I've got a morphine patch on to help"	Positive	Personal stories
	1	Face with tears of joy	"happy sitting in the sun"	Positive	Messages of positivity
	1	Leaves fluttering in the wind	"I'm laying outside"	Positive	Personal stories
	1	Face with mouth open	"could potentially lead to the cure for #Coronavirus"	Positive	Health care experiences
	1	Winking face	"I made healthy Easter treats in self is-lation"	Positive	Personal stories
	1	Pill	"I really miss anti-inflammatories"	Negative	Stay-at-home messaging
	1	Front-facing baby chick	#livingmybestlife	Positive	Personal stories

Emoji[a]	Count, n	Emoji name	Phrases or #hashtags accompanying the emoji	Emotion	Link to original themes
	1 each	See-no-evil monkey, speak-no-evil monkey, hear-no-evil monkey, monkey, monkey face	"my rheumatologist said I wasn't at high risk"	Positive	Health care experiences

[a]Emoji Sentiment Ranking did not include the upside-down face, the spectacle face, or the high-five emoji. There was one of each included in our data collection.

The emoji within tweets established tone and emphasized emotions. Most tweets used an emoji to express positive sentiment, such as clapping hands to thank colleagues for their support and a person with folded hands in acknowledgment of the personal commitment to the ongoing management of arthritis symptoms in isolation. The main emoji used to express negative sentiment were the face with "no good" gesture, and the confused face. Tweeters used the face with "no good" gesture to highlight their physical pain, and the confused face was used to express confusion around what arthritis patients perceived to be ill-informed health advice during the pandemic.

Discussion

Principal Findings

This study aimed to identify proxy topics of importance for people with arthritis during COVID-19 by characterizing the textual content and sentiment of tweets, and exploring the emotional context of tweets by people with arthritis during the early phase of the pandemic. We anticipated that this novel approach would ascertain contemporary topics of importance for immunocompromised and isolated individuals. Content analysis revealed seven themes relating to health care experiences, and sentiment analysis revealed that the majority of tweets contained negative emotion, particularly around medication shortages, increased arthritis symptoms, and the physical and mental toll of physical distancing or living in isolation. Our findings provide a starting point for understanding the impacts of COVID-19 on vulnerable arthritis populations and provide some insights for physicians and researchers regarding current concerns that may inform tailored care.

More than one-third of tweets discussed health care experiences, primarily focusing on the reduced availability of hydroxychloroquine. Individuals were highly anxious about hydroxychloroquine shortages after preliminary research found that the drug might act as a potential preventive measure, or possible cure, for COVID-19 and these early findings were highly publicized around the world. The original published article has since been retracted after researchers were unable to verify the reliability of their results [33]. Regardless, President Trump tweeted his support for hydroxychloroquine as "one of the biggest game changers in the history of medicine" [34], causing panic about medication shortages, particularly from those with systemic lupus erythematosus for which it is the first-line therapy [35]. Due to off-label prescriptions and hoarding practices, difficulties accessing hydroxychloroquine have been reported globally [36]. Hydroxychloroquine shortages pose a threat to the health and safety of people with inflammatory arthritis, with reports that many will experience flare-ups and may develop irreversible organ damage without their regular dose [35]. Our findings highlight the need for accurate information about treatments and their effectiveness and the critical role that clinicians play in dispelling myths and inaccuracies during times of rapidly changing information. A growing body of literature describes the potential benefits of using Twitter in clinical settings, and reports ways that clinicians are using platforms such as Twitter to communicate health information to the broader population [37-39]. In the context of infectious diseases in particular, evidence suggests that Twitter is beneficial to translate real-time clinical information [40,41]. Use of Twitter, being a component of mobile health (mHealth), also empowers patients to more positively perceive their abilities to manage chronic illness [42]. This presents an opportunity for clinicians and professional societies to use social media platforms such as Twitter to overcome evidence dissemination methods (eg, peer-reviewed articles and care guidelines) that are traditionally slow. Together, clinicians and patients can contribute to care in adults with arthritis, encouraging positive health outcomes throughout, and beyond, the pandemic.

Several tweets contained very personal narratives that highlighted individual fears of contracting COVID-19, and the challenges associated with being vulnerable to infection. Individuals described perceived barriers to accessing care, citing discomfort caused by wearing medical-grade personal protective equipment. Tweets contained accounts of neck pain attributed to wearing a mask; a documented side effect in other vulnerable populations [43]. Fitting a mask is also a dexterous task that some people with arthritis struggled to perform, and as a result, encountered abuse from others when buying groceries or going for a walk. The long-term psychosocial impact of this stigma should receive consideration in future research. Clinicians should consider COVID-19–related functional concerns for physically impaired patients, and incorporate new aspects of information-seeking into clinical consultations. For example, asking patients about their degree of difficulty with COVID-19–related functional tasks would help to elicit relevant functional challenges faced by people with arthritis and inform the provision of tailored patient education. Asking these questions also contributes to factors beyond patient education and care, such as facilitating access to nonacute symptom or pain management services such as allied health. These health services still need to be maintained during and after the pandemic, and for musculoskeletal health in particular, there is emerging commentary around the physical and psychosocial impacts of inhibited access [44,45].

Tweets detailed marked increases in general physical symptom burden; a concerning prospect as COVID-19 has impacted face to face consultations, with indications that disruptions to traditional service models will likely persist for some time. Evidence about the utility of telemedicine to manage pain is emerging, with consideration of barriers to implementation, and potential inequity in access [46], although health systems have been generally slow to implement this approach at scale. While the included tweets provide preliminary information about the growing symptom burden during the pandemic, the collection of systematic patient-reported outcomes data is needed to ensure that health care services are meeting the needs of people with arthritis during and after the COVID-19 pandemic.

A proportion of tweets related to social connection, that is, people reaching out to likeminded peers with arthritis through potentially informative blogs. Most links provided were to official (eg, CreakyJoints) or unofficial (eg, online communities and forums) blogs and provided information on how to manage physical and mental health in isolation, a range of arthritis-appropriate exercises, and existing evidence on the association between arthritis and risk of COVID-19 infection. Access to resources that are relevant, credible, and trustworthy appears to have been challenging for people with arthritis throughout the pandemic [47], and combined with high levels of misinformation online [48,49], this may account for the recent growth of platforms such as Twitter for sourcing information and advice.

Before the COVID-19 pandemic, people with arthritis primarily used social media for self-expression and positive messaging [50,51]. Our sentiment analysis (enhanced by classifying emojis to further characterize common emotions) demonstrates that the role of Twitter has evolved throughout the current pandemic to act as a space for people to share symptoms; to reach out to peers, organizations, and health professionals for information; and to create a sympathetic community of care. This is advantageous as it fosters connection between individuals with shared experiences but conversely may enable proliferation of misinformation [52]. Already, Twitter has been shown to inform clinical practice by capturing the experiences of patients with multiple sclerosis during the pandemic [53]. Understanding the COVID-19–related concerns of people with arthritis is also key to providing person-centered care and reducing distress during these rapidly changing times.

Strengths and Limitations

The observational exploratory nature of this study enabled us to examine topics of importance for individuals with arthritis through a person-centered lens, without ethical issues or compromising the well-being of immunocompromised patients during the pandemic. Social media research is still in its infancy, and this novel method of data collection demonstrates the concerns of people with arthritis during a time of peak anxiety. There is some indication that tweeters were representative of the general inflammatory arthritis population; the majority were female and the most common arthritis type identified was rheumatoid arthritis. Nearly half (44.0%) of tweeters were based in the United States, which currently leads the world in COVID-19 cases and deaths [54].

We also acknowledge the research limitations. It is important to note that only 15% of adults regularly use Twitter, and that younger adults and minority communities tend to be more highly represented on Twitter than the general population [55], although minority communities have been significantly impacted by COVID-19 [56,57]. Our results should therefore be interpreted as representing a small subset of people with arthritis, and not all people with the disease. Data were extracted rather than collected directly from people with arthritis and critics of social media research purport that posts or tweets are often curated and may not be reflective of reality. We have attempted to minimize this potential bias by conducting sentiment analysis, which helped us determine the emotional tone associated with Twitter content. Regardless, sentiment analysis has its limitations: populations and individuals are constantly stimulated by their political and socioeconomic surroundings and individual demographics, which can influence the content and sentiment of people's tweets [58,59]. We also recognize the potential limitations of our search strategy (eg, we did not search for hashtags related to specific symptoms, such as pain or function, that are not unique to arthritis) that may have impacted the number of retrieved tweets. While we had a modest sample size of tweets due to our focused study aims, sentiment analysis has previously been conducted in studies with comparable sample sizes of tweets (n=260 and n=200) [60,61]. We were unable to determine the specific diagnostic category for over half the people tweeting; while a small number of tweets were from people with osteoarthritis, it is possible that more may be represented within the "diagnosis not specified" category. We were only able to analyze tweets in English, and these largely came from high-income, developed countries. Tweets in other languages and those from people in low-and-middle income countries may provide further insights, especially where the prevalence of COVID-19 infection is high [62].

Conclusion

This study highlights the spectrum of concerns facing people with arthritis during the COVID-19 pandemic. By exploring the content and sentiment of recent tweets, we found that individuals with arthritis conditions experience marked anxiety about medication shortages and increased physical symptom burden, and are seeking connection with and information from peers. These findings can be used to raise awareness of key issues relevant to people with arthritis during the pandemic, and to guide clinicians to tailor care that addresses the specific concerns and needs of their patients during the pandemic.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Twitter search strategy and results.
[DOCX File , 15 KB-Multimedia Appendix 1]

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Abbreviations

mHealth: mobile health
NHS: National Health Service

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CHAPTER 9: DISCUSSION, RECOMMENDATIONS, AND FUTURE DIRECTIONS

9.1 Overview

Arthritis is one of the leading causes of disability worldwide (2). In Australia alone, it affects over 3.5 million individuals (19). Concerningly, the prevalence of arthritis is growing amongst younger, working-age adults: osteoarthritis diagnoses are increasing amongst people aged under 50 years (50), and inflammatory arthritis remains the most prevalent form of arthritis in working-age individuals (6). At the personal level, the impacts of arthritis are profound and include physical and psychological symptom burden (21), reduced work productivity and/or work loss (10), and lowered income and retirement wealth (15). The societal and health system impacts of arthritis in working-age populations in Australia are also substantial, relating to healthcare costs and a loss of national income and taxation revenue (1, 18).

The majority of existing arthritis-related research focuses on older adult populations due to the relatively higher prevalence of osteoarthritis in older adults. Whilst there is research involving working-age populations (given that inflammatory arthritis is most frequently diagnosed in adults under 50 years of age), these study samples often include older adults too, and so it has been challenging to elicit the specific issues relating working-age individuals. To address this knowledge gap, Australia's NSAPA recommends the inclusion of working-age cohorts in research, to better understand and raise awareness of applicable issues (206).

Current evidence suggests that the work-related impacts of arthritis, and the personal financial burden of living with arthritis, are the two primary issues pertinent to younger individuals living with the disease. Yet at this stage, little research has examined the influence of arthritis on people's career choices, early work experiences, or career progression. The personal financial burden of living with arthritis also remains unquantified, despite evidence of high OOP costs for people living with chronic health conditions, even within Australia's publicly funded healthcare system (273). By comprehensively investigating these specific issues of concern, this PhD has provided new information pertaining to working-age adults with arthritis that will be of value to clinicians, health policymakers, third-party worker support schemes and workplaces, and can inform person-centred care.

This chapter draws together the key findings from this thesis, together with an overview of the strengths and limitations of the research. The clinical and policy implications are also presented,

with particular emphasis on avenues for translation into routine clinical care and workplace policy for people with arthritis. The work and financial-related recommendations developed from this research are described, and recommendations for future research to build on these findings are presented.

9.2 Key Findings Mapped to Thesis Objectives

A summary of the PhD objectives, corresponding studies and the key findings are outlined in Table 3. This summary includes the supplementary social media study (Chapter 8) which was introduced into the PhD at of the start of the COVID-19 pandemic in March 2020. The third objective of the PhD – to develop evidence-informed recommendations – is addressed later in this chapter (Section 9.3).

Table 3: Summary of thesis objectives, studies, and key findings

Objective	Study	Key Findings
To examine the work impacts of arthritis for younger, working-age adults	A systematic review to identify, appraise, and synthesise evidence on work-related outcomes experienced by adults with arthritis aged 16-50 years. Chapter 2	• Moderate-to-high quality evidence indicates that arthritis in younger and middle-aged adults is associated with work limitations and a higher prevalence of work disability, compared with populations without arthritis. • The magnitude of arthritis-related work impacts appears to increase with age. • Three barriers to work participation associated with arthritis were identified: 1) incapacity to work, 2) lack of workplace support, and 3) discord with colleagues. • Four enablers to work participation associated with arthritis were identified: 1) motivation to work, 2) managerial and collegiate support, 3) flexible working arrangements, and 4) understanding of legislation and workplace antidiscrimination policies.
	Qualitative study based on interviews with 21 adults aged 18-50 years with a range of arthritis conditions. Chapter 5	• Participants perceived that living with arthritis precluded them from certain career choices, such as those that involved manual tasks. • In some cases, participants were forced to leave their chosen profession at an early age, switching from roles involving activity and movement to more sedentary jobs. • Participants voiced concern about the impacts of arthritis on their workplace environment, employers and colleagues, specifically citing anxiety around asking for ergonomic modifications. • The possible litigation risks relating to employing an individual at higher risk of workplace injury were of concern to participants.

		• Upon gaining employment, participants were concerned about disclosing their condition for fear of judgement from managers and colleagues. • Participants reported that physical symptoms of pain and fatigue reduced their productivity within their role. • Participants described the benefits of working part-time to rest their body, but that the frequent use of sick leave was challenging.
To determine the personal financial burden of arthritis on younger, working-age adults.	Qualitative study based on interviews with 21 adults aged 18-50 years (same study and participants as the qualitative study mentioned above) with a range of arthritis conditions. Chapter 6	• Participants reported that their OOP costs associated with arthritis-related medical expenses were distressing and that the greatest expenditure incurred was for consultations with rheumatologists. • Some participants expressed surprise at their inability to work from a young age, resulting in earning less money across the lifespan, which was compounded by high fees when needing to make accommodations for living with arthritis, for example, paying for petrol due to an inability to be physically comfortable on public transport. • Participants explained that private health insurance was one of their largest expenses, and expressed frustration at the higher costs of other types of insurance (for example, travel and life insurance) due to having a pre-existing condition. • Participants voiced distress about the broader financial impacts of arthritis on their families: younger participants described living with their parents for longer than anticipated to save money, whereas parents with arthritis were frustrated that fees relating to arthritis took precedence over taking a family holiday or paying for private school fees for their children.

	Exploratory cost diary study involving 16 adults aged 18-50 years with a range of inflammatory arthritis conditions. Chapter 7	• All participants reported OOP expenditure related to arthritis, with the cohort spending AUD 15,272 in total across the six-week study period. The median per-person expenditure was AUD 1,635 across the six-week study period. • Median per-person expenditure was highest for medical appointments (AUD 197) and allied health appointments (AUD 190), and lowest for symptom/pain self-management items (median AUD 120) across the six week period. • Financial distress was high (median 70% across the study period), and there was a modest positive relationship between higher OOP costs and financial distress (r_s=0.3).
To identify topics of importance for individuals with arthritis during the COVID-19 pandemic and to explore the emotional context of arthritis-relevant tweets.	A social media study, where publicly available tweets posted in English and with hashtag combinations related to arthritis and COVID-19 were extracted retrospectively from Twitter. Chapter 8	• People tweeted about difficulties accessing hydroxychloroquine after it had been publically touted as a cure for COVID-19, despite not being supported by research evidence. • Personal stories were a prominent feature in people's tweets, containing anecdotes of managing arthritis symptoms whilst being confined to their homes, as well as exacerbations of pain and reduced dexterity whilst being isolated. • The majority of tweets contained negative sentiment, demonstrating the impact that the pandemic (and subsequently rescheduled medical appointments, barriers to accessing non-COVID related care, and arthritis flares) had on their physical and psychological health.

9.2.1 Work-Related Impacts

The qualitative findings from this research program indicate that working-age adults with arthritis start to experience work-related challenges even before their careers begin (274). For example, many described avoiding certain roles due to arthritis symptoms, and instead, they entered a profession that was suited to their physical capabilities rather than being aligned with their interests. This phenomenon was recently described amongst adolescents aged 15-17 years with juvenile idiopathic arthritis, who stated that they abandoned their goal to become a physical education teacher, or to join the military, based on physical juvenile idiopathic arthritis symptoms (275). Similarly, young adults in the UK with arthritis have voiced feelings of pressure and anxiety associated with the realisation that they had to choose a career not just based on personal preference, but so too based on their physical limitations (210).

Some of the participants from this research did not consider their arthritis when choosing their profession, however, those participants employed in jobs involving repetitive dextrous hand movements, or lengthy periods of standing, expressed surprise and concern at how early they were forced to change careers based on their symptom progression (274). Young adults aged 16-30 years with juvenile idiopathic arthritis in the UK have expressed a similar sentiment, explaining that they had to cease their university degree as partway through it became evident that their arthritis symptoms were not conducive to their chosen profession (276). Research amongst people with osteoarthritis or rheumatoid arthritis in Canada also found that younger adults were more likely to report necessary changes to their work (214). Changing jobs due to rheumatoid arthritis is strongly associated with anxiety and depression in older adults (mean age 57 years), highlighting the impact of mental health on workplace outcomes (277). It is therefore pertinent to ensure that younger adults with arthritis who need to change career direction are provided with adequate support to minimise the psychological impacts. This also holds relevance for people with arthritis and return-to-work (RTW) support after an exacerbation of arthritis symptoms, where occupational rehabilitation providers and insurance schemes need to consider the mental health status of individuals in planning RTW options (278), particularly if new employment circumstances are being considered. In particular, they should be aware of The Workplace Injury Rehabilitation and Compensation Amendment (Provisional Payments Act), due to come into effect in the Workplace Injury Rehabilitation and Compensation Act 2013 and the Accident Compensation Act 1985 on 1 July 2021, which provides 13 weeks of payments to Victorian workers for mental injury (279).

Within a workplace, managers and fellow employees represent two potential sources of support. However, a common theme throughout our interviews was that participants did not want to disclose their arthritis to their workplace manager for fear of being judged, treated differently, or demoted (274). Similar sentiments were also identified in a separate study of adults working with chronic musculoskeletal pain, demonstrating the consistency of these findings across qualitative studies (280). Yet, to the surprise of most participants in the qualitative study presented in this thesis, when they did reveal their disease, it was met with understanding and support. Preliminary research into self-disclosure of arthritis at work suggests that it is positively associated with perceived managerial and co-worker support (218), as well as facilitating access to the required ergonomic modifications for productive working (281). While experiences will likely vary depending on industry, raising employer awareness about chronic conditions such as arthritis may be relevant for safe, inclusive workplaces and to mitigate discrimination (282). Importantly, research has found that not only does disease disclosure aid productivity, but that the opposite – a lack of disclosure and communication – may incorrectly interpret physical symptom burden from the perspective of managers to be perceived as poor job performance, culminating in job termination (283).

Much of the existing research relating to work impacts of arthritis focus on quantitative measures of productivity (for example, absenteeism, presenteeism and hours worked). The participants in this research provided contextual detail for these earlier findings by describing issues around reduced productivity due to physical pain and fatigue, and the need to reduce work hours to maintain a healthy work-life balance (274). This qualitative study is the first to characterise a broad continuum of arthritis-related work issues, from pre-career decision-making through to early retirement or exit from the workforce due to arthritis. Considering the prevalence of arthritis in working populations, these findings indicate that many younger and middle-aged workers may be unfulfilled in their careers, with potential for workplace and workforce dissatisfaction at scale. These findings can be used to raise awareness of key issues relevant to younger and middle-aged people with arthritis in the workforce, and specifically to educate employers, colleagues (and also clinicians) about the wide-ranging impacts of arthritis beyond pain and stiffness, in particular, the need for consideration of the mental health sequelae.

In addition to workplace impacts, people with arthritis commonly participate in informal and unpaid work, for example, providing care to dependent children or parents (284). Our systematic review revealed that work participation (although heterogeneous in the literature in both definition and assessment) is seldom measured beyond paid employment (10). This is important for low and

middle-income countries in particular, where informal care and work is more common, and the burden of arthritis is less well quantified (17, 285). Yet, where work limitations were measured, the impact of arthritis-related work productivity loss became clear, highlighting opportunities for early intervention to optimise productivity and keep people with arthritis in productive employment (286). Of note, there is currently no standardised method of reporting how people work within existing measures (287), which creates challenges in defining the concept and parameters of work. For example, the systematic review found that work was measured through various scales (the Workplace Activity Limitations Scale, the Work Productivity Activity Impairment questionnaire, the 5-item Career Satisfaction Scale, and various other bespoke indicators, such as the number of workdays missed in the past six months) (10). Further, existing multi-dimensional osteoarthritis instruments (for example, the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) (288), Hip Disability and Osteoarthritis Outcome Score (HOOS) (289), and Knee Injury and Osteoarthritis Outcome Score (KOOS) (290)) that are frequently used in practice do not contain any work-related items or sub-scales.

Considering the varied types of possible work within the development of new patient-reported outcome measures – from providing unpaid and/or informal care through to full-time, paid work – will enable the breadth of work undertaken by people living with arthritis and the corresponding arthritis-related work impacts to be more fully quantified.

9.2.2 Financial-Related Impacts

The qualitative findings from this thesis also indicate that working-age adults experience a spectrum of arthritis-related financial impacts. These include medical and allied health expenses, the cost of paying for assistance with ADLs or household maintenance (for example, employing a gardener or cleaner), and the financial burden of paying for private health insurance to improve access to healthcare (209). Given lower work participation rates are associated with lower financial resources (291), it is perhaps unsurprising that individuals with arthritis face broad personal economic challenges. By using a mixed-methods approach to better understand the scope and nature of these fiscal challenges, our findings provide a starting point for identifying the specific concerns of younger, working-age adults with arthritis, beyond the physical impacts, and rationalises the need for larger, population-based evaluation to enhance generalisability and confirm validity.

In Australia, two studies (conducted in 2015 and 2016, respectively) have previously examined if arthritis is related to poverty. The first study used an existing dataset of adults with arthritis aged 45-64 years and found that people employed full time, part time, or not in the labour force for reasons other than ill health were significantly less likely to fall into poverty than people with arthritis who were not working due to the condition (291). The second study used an existing dataset involving adults aged over 21 years with arthritis and found that the likelihood of falling into income poverty was significantly higher for men and women with arthritis compared to the population without arthritis (16). Research from low and middle-income countries showed similar results: one quarter of Bangladeshi adults (mean age 41 years) with musculoskeletal conditions had a history of work loss (292).

While intuitive, this PhD research has generated contemporary evidence that arthritis-related financial strain does not solely affect the individual living with the disease, but that the financial impacts also extend to their family. For example, participants in our qualitative sample described far-reaching monetary implications of being unable to repay their mortgage on time and the need to sacrifice family holidays in order to prioritise healthcare expenditure (209). Within our small quantitative sample and across the six week study period, participants reported median OOP costs of AUD 608 for medical specialist and allied health appointments combined, which is over half the annual average Australian household expenditure on the same healthcare consultations (293). Our research is the first to use qualitative methods to give voice to people with arthritis experiencing financial distress, with relevance for mental health and ongoing costs across the lifespan.

Indeed, it is important to remember that arthritis is a lifelong illness and that those living with the disease will bear ongoing healthcare costs as they age. Although living with arthritis is a known risk factor for poverty, few studies have quantified the OOP costs borne by individuals living with arthritis, which is what the exploratory quantitative study sought to address (294). Through the cost diaries, we found that the median per-person expenditure across the six-week study period was in excess of AUD 1,500, with the highest per-person expenditure attributed to medical expenses and allied health appointments. Each participant reported expenditure on medications and supplements. Levels of financial distress were also high and were related to higher OOP costs, aligning with our qualitative findings around perceived financial burden. Yet as described in Chapter 7, only 10% of variance in financial distress was explained by age. This suggests that other factors are important in explaining financial distress, which holds relevance for future research.

The Australian Medicare system subsidises a larger portion of medical specialist fees than other health services (for example, allied health, natural therapies), and so it is concerning that people with arthritis still incur high OOP costs for such appointments. Recently, rheumatology was found to be one of the top three most expensive medical specialties for patient-borne costs in Australia, with a median OOP consultation cost of AUD 111.70 per appointment (295). This has potential ramifications on health outcomes too, particularly for inflammatory arthritis when disease activity is not well controlled: in Australia, 50% of men and women aged 25-44 years report delaying or avoiding medical specialist appointments due to high costs (296). Similarly, despite extensive Medicare subsidies for DMARDs and biologic DMARDs (297), nearly seven percent of Australians report delaying or avoiding filling a prescription due to the cost (298).

9.2.2.1 Using Qualitative Methods to Understand Financial Impact

To the best of our knowledge, this PhD is the first to specifically explore the financial impacts of living with arthritis through qualitative methods, providing a unique personal narrative and 'patient voice'. One other study analysed open-text responses concerning the economic challenges of living with inflammatory conditions, although data were collected through quantitative survey means (299). The following quote from one of the current study participants highlights the profound financial strain experienced by younger people with arthritis:

> ***"I cannot afford to eat a good diet, and pay for my medications, treatments, supplements, and pay my bills on what I get from disability and the small amount I am allowed to earn. I have to choose to eat well or take the medications. I can't afford both. Without both, I cannot manage my disease well"*** (Female, age 35-44 years with Systemic Lupus Erythematosus).

Within arthritis research, qualitative methods are increasingly being used to understand and convey lived experiences, and to identify issues that can be addressed within routine clinical care. A recent overview of research in rheumatology highlighted the novel contributions of qualitative research and called for further qualitative research in the field to understand the psychosocial effects of the disease (226). There is also growing evidence supporting the benefits of qualitative research to support policy-making (300). The importance of understanding the financial burden of living with arthritis is highlighted in Australia's NSAPA, which sought to include pertinent quotes from community members living with arthritis describing their financial experiences (206):

"I am 32. Due to my condition, I can only work part time. I am limited by my pain and my medical appointments and tests. My physical pain I can cope with, but the shame and isolation from my financial hardship is debilitating".

"Last year I spent over $6,500 **[AUD]** *on medication alone!!! This doesn't take into account the many doctor visits, physiotherapy, podiatry, and specialised exercise programs that I require".*

9.2.3 COVID-19 Impacts

The ongoing COVID-19 pandemic poses global challenges for many individuals, but especially for people living with chronic health conditions. The PhD program pivoted during the pandemic to examine contemporary topics of concern for people with arthritis on social media, especially with regard to reduced opportunity for face-to-face healthcare consultations and potential medication shortages. The Twitter analysis found that people with arthritis faced numerous challenges during COVID-19, including difficulties accessing medication (particularly for those prescribed Hydroxychloroquine), managing physical and emotional challenges associated with isolation (including reduced dexterity and lack of in-person family support), and challenges accessing face-to-face healthcare, or receiving sufficient care via telehealth. Individuals used Twitter as a medium to connect with and seek support from peers with arthritis, with several tweets containing discussion of arthritis-related symptoms and sharing of potentially relevant information, including links to clinicians' tweets, potentially helpful resources, or their own advice (301). Whilst other researchers have also used Twitter data during COVID-19 to gauge the needs of people with arthritis (302), their focus was on one hashtag and only described the prevalence of Twitter content. The Twitter study presented in this thesis is a worthwhile addition to this emerging literature as it focused on multiple arthritis-related and COVID-19-related hashtags, and utilised multiple data analysis techniques to promote rigour.

The Twitter study presented in this thesis contributes detailed information by describing people's COVID-19 related experiences via sentiment analysis. Sentiment analysis enables an examination of written words for positive and/or negative emotion (303). When applied to social media research, it facilitates interpretation of contextual information about patient experience from a person-centred perspective, and lends credibility to social media data that critics suggest may be curated and not reflective of reality (304).

As the COVID-19 pandemic hit in early 2020, researchers sought novel means of collecting patient-reported experience and outcomes data (305). Twitter quickly became the starting point for rapid mobilisation of the international rheumatology community to address key knowledge gaps relevant to people with rheumatic diseases. This initiative was named the COVID-19 Global Rheumatology Alliance (306), and shortly after its advertisement on Twitter, the alliance evolved into an international collaboration of rheumatology providers, researchers, and patients, to collect data about patient experience during the COVID-19 pandemic, to address knowledge gaps relevant to people with rheumatic disease, and to disseminate resources to patients (307). Demonstrating its reach, the Global Rheumatology Alliance has registered 13,581 individuals into their patient experience survey and published over 20 peer-reviewed journal articles (308). From the results of this thesis and in view of the role that social media has played during the pandemic, it is evident that the Twitter platform is an important source of person-centred data relating to arthritis. Social media can be used to collect meaningful data from hard-to-access and/or vulnerable populations, and to disseminate reputable information in a streamlined and timely manner.

9.3 Clinical Implications

A major finding of this research program was that working-age adults experience profound work and financial impacts relating to their arthritis. However, given the traditional focus on pain and other physical symptoms in arthritis care, these two concepts are rarely considered within routine clinical care. The research presented in this thesis demonstrates that both concepts have clear clinical impact when people are in roles that exacerbate symptoms and cannot afford access to care, especially disease-modifying therapies.

It is important to note that the NICE osteoarthritis guidelines (29) and the Victorian Model of Care for Osteoarthritis (309) do recommend consideration of work by health practitioners. Yet Australia's most recent National Strategic Framework for Chronic Conditions (which advocates for person-centred approaches and seeks to provide tailored care to people with chronic conditions) does not explicitly consider work or personal economic factors within the model (310).

To provide holistic care, it is recommended that clinicians (for example, rheumatologists, GPs, and allied health professionals) incorporate the consideration of work and financial impacts into routine clinical care for people of working-age with arthritis. It is also imperative to ensure that clinicians are aware of, and can initiate, appropriate referral pathways and/or processes to ensure that those presenting with work and financial-related distress receive appropriate support and assistance to best address these concerns. A suggested pathway for enhanced support is depicted in Figure 6:

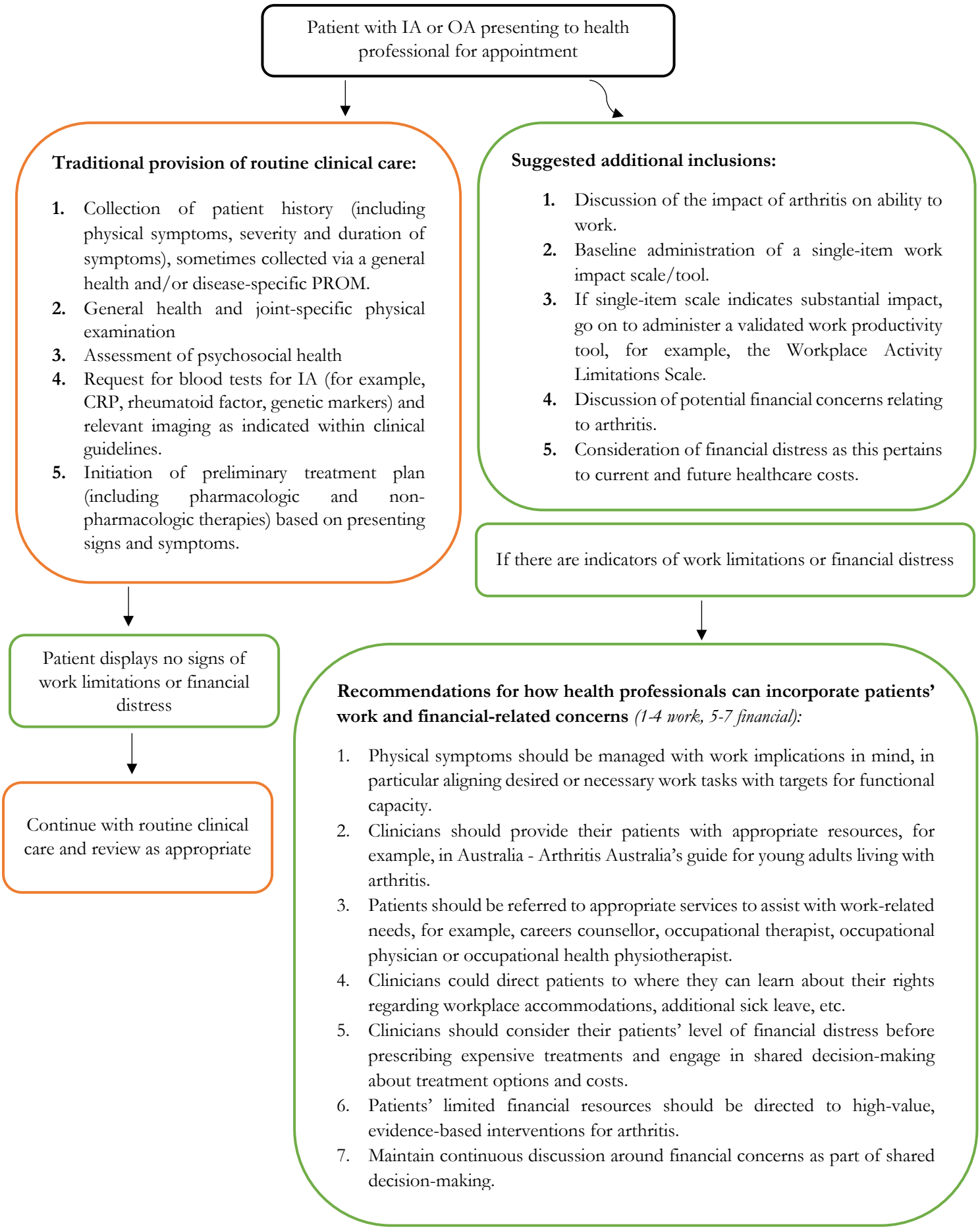

Figure 6: Suggested Pathway for Considering Arthritis-related Work and Financial issues within Routine Care

With employment, it is recommended that researchers work towards developing a universal definition of work. There is currently no gold standard for defining 'work', which creates challenges in providing advice to patients and in making recommendations regarding workplace practice and policy. A comprehensive definition of work should account for all types of work, from informal/unpaid caregiving (for example, raising children, caring for dependents) to full-time, paid employment. Given the high prevalence of arthritis in the working-age population, educating workplaces (in particular, workplace managers) on what arthritis is, and how to support employees with arthritis is recommended. Two randomised controlled trials have studied the effects of educating workplace employers as an intervention, and found that it improves work ability in populations with lower back pain (311, 312). This type of intervention may also aid disease disclosure in the workplace, which supports individuals with arthritis to access ergonomic modifications where needed, and in turn promotes productive working which is of benefit to both the individual and workplace.

Finally, the Twitter study presented in this thesis demonstrated strong user engagement with the social media application and highlights how people with arthritis are using Twitter as a communication medium during COVID-19. Given that information dissemination in medicine is traditionally slow (for example, taking several years to develop new treatment guidelines), clinicians could use Twitter in a professional context to engage with people with arthritis, establish a professional online presence, and to enhance collaborative work between patients and clinicians. Younger rheumatologists (age 30-39 years) already use social media for sourcing information (313); we recommend that widespread Twitter use in the clinical setting provides a dynamic channel for medical education and interactive learning.

In summary, the following clinical recommendations are derived from the outcomes of this research program:

1. **Incorporation of work-related and financial-related concerns into routine clinical care,** including discussion of how physical and psychological symptoms impact on patients' functional capacity at work. Pre-emptively raise potential issues as part of routine dialogue and shared decision-making as this may alert clinicians and patients alike to applicable issues for early intervention. Administration of validated work productivity and disease-related financial distress scales based on dialogue and/or a single-item scale (mindful of competing clinical priorities and time restrictions) to provide baseline assessment and monitor changes over time.

2. **Only recommending or using high-value care interventions,** so that patients' limited financial resources are directed towards evidence-based treatments, with the highest likelihood of achieving health or quality of life gains in a cost effective way.
3. **Development of appropriate care and referral pathways relating to work and financial concerns:** healthcare practitioners should respond to their patients' concerns by being aware of various referral and services options for patients. For example, a careers counsellor for a patient needing to transition into a different job based on physical symptom burden, or available services (including psychology services and online/telephone-based support options) to assist with managing perceived financial distress. Specifically, it may be valuable to develop referral pathways between rheumatologists and occupational physicians, or occupational physiotherapists, who are highly trained in this regard. Consumer advocacy organisations could add this information into their clinician and consumer-facing educational materials, or an occupational rehabilitation provider or insurer could provide new employment seeking or retaining services for RTW in compensation schemes.
4. **Maximise participation in productive work** by tailoring treatment to improve patients' work capacity, as well as providing arthritis education to workplaces, employers and/or employees.

It is hoped that these recommendations – anticipated to be distributed through local advocacy agencies such as Musculoskeletal Australia – may improve the QoL of life of working-age Australians with arthritis, with implications for facilitating productive working careers and enhancing access to affordable healthcare. Given the large and growing proportion of people in the workplace with arthritis, it is expected that maximising work and financial health will provide downstream benefits not only to the individual, but also to workplaces and the broader economy.

9.4 Strengths and Limitations of this Research

The research presented in this thesis has methodological strengths and limitations. Although these have been described in detail in earlier chapters, an overview of the major strengths and limitations of this PhD program is provided here.

The research program presented in this thesis was borne out of lived experience with inflammatory arthritis and aligns with the highest level of community involvement in research, as it is both consumer initiated and led (described in Chapter 4). This type of research has proven beneficial in advancing patient advocacy efforts in musculoskeletal research (314) and complements a 'priority setting' approach, which is designed to involve patients and community members in setting research priorities (315). It is advantageous to conduct studies through the lens of an 'insider', as it allows for a potentially shared understanding of participants' lived experiences. In turn, this builds a credible relationship between the researcher and participants, facilitating in-depth data collection and detailed responses to interview questions. Overall, this contributed to achieving the qualitative research aims by promoting open and transparent storytelling from participants. Involving consumers and community members in research is also an important step towards producing meaningful research outcomes for those living with arthritis (316), as evidenced by the clinical recommendations informed by this research.

For the qualitative study, the use of broad inclusion criteria and recruitment strategies generated a sample that was varied across age and disease characteristics, to better reflect the demographics of the wider Australian population with arthritis. A purposive sampling frame was employed to recruit a wide-ranging study sample across disease type (38% rheumatoid arthritis, 10% ankylosing spondylitis, 10% osteoarthritis, amongst other diagnostic categories), sex (90% female), and employment status (68% in full-time and part-time/casual paid work, 14% unable to work due to arthritis, amongst other employment categories). Although qualitative research does not seek to achieve generalisable outcomes, the rigorous sampling and recruitment techniques used have generated a diverse study sample. Finally, using the WHO ICF to guide the qualitative component of this thesis is beneficial as it extends beyond the biomedical model of health to document work participation impacts across a range of constructs; however, it is acknowledged that the WHO ICF may not capture all arthritis-related work impacts in contemporary society, including issues relating to the gig economy, and vulnerable workers.

One of the major strengths of this research is its novelty. This thesis contains the first qualitative study to assess the personal financial burden of living with arthritis, as well as the first study in

nearly two decades to attempt to quantify arthritis-related OOP expenditure in Australia. The qualitative data provide important insight into the contemporary financial concerns and distress expressed by working-age patient groups, whereas the cost diary demonstrates that high OOP fees for medical and allied health appointments and medications and supplements, contribute to financial distress. Combined, this mixed-methods research enables us to better understand the pertinent issue of personal economic circumstances of working-age adults with arthritis.

Still, this research is not without its limitations. Whilst insider research can prove advantageous in many respects, potential disadvantages can include compromised researcher objectivity and professionalism, and participant misunderstanding of a researcher's capacity to provide health advice. To mitigate this risk, a bracketing exercise was undertaken (Appendix F), which involved actively identifying and examining preconceptions about other people's experiences of living with arthritis, and ensuring that these did not influence the research process. As a result, the research aims were exploratory and hypothesis generating.

There were some limitations associated with participant recruitment. Whilst both sexes were eligible to participate in our research, only two of the 21 interview participants were male, and all cost diary participants were female. Whilst it was not intended to examine work and financial impacts by sex, the recruitment of additional male participants would have allowed their experiences to be more fully captured. This may be relevant for financial distress levels, as some research suggests that men with arthritis experience higher levels of reduced income due to productivity loss than women (317). Separate to sex, there was no specific sampling of non-binary or other genders.

There are other limitations relating to the cost diary sample: it was relatively small (n=16), and it should be acknowledged that the reported costs are unlikely to be representative of all individuals with arthritis. Given the sample size, substantial variance around the median was expected. Within this sample, there is potential for participant bias, where those with a higher financial burden or OOP costs may have been more likely to take part of this research. Additionally, two-thirds of the sample were university-educated, so they may have had higher levels of disposable income and greater health literacy regarding available arthritis interventions. As outlined earlier, data collection was ceased for the cost diary study at the onset of the COVID-19 pandemic, precluding a larger cohort.

Finally, results from the Twitter study should be interpreted as representing a small subset of people with arthritis, and not all people with the disease. It is also acknowledged that social media

data are often curated, and may not be reflective of the full range of personal experiences. Whilst this is a limitation of social media-based research, sentiment analysis was used to determine the emotional tone associated with tweets, lending credibility to the content. There was only a modest sample size of tweets (n=149) potentially due to the search terms used. These terms can be validated in another study to determine their specificity, or broadened to increase sensitivity. Lastly, the diagnostic category of half the people tweeting was unable to be determined.

9.5 Future Research Directions

In exploring the work and financial-related impacts of arthritis on working-age adults, this research has identified several areas that warrant further investigation.

This research has identified that adults aged 18-50 years can experience a myriad of arthritis-attributable workplace and financial challenges. However, it was beyond the scope of this research to examine differences across demographic factors, for example, gender, arthritis type, or work type. In particular, few males participated in this research, and this is an important area for future research, as less is known about the experiences of men with arthritis (318). For example, case reports identify that men with musculoskeletal conditions may experience higher levels of chronic pelvic pain than women with musculoskeletal conditions, yet no primary research or systematic reviews have investigated this issue (319, 320). Further qualitative investigations targeting males with arthritis will offer insight into males' perspectives of working with the disease and ensuing financial challenges, particularly in situations where men are their family's primary income earner and may experience different social and emotional impacts to women (321).

In addition to sex, a more nuanced examination of age is required. Within our sample, the interview data found that adults aged closer to 50 years were already considering early retirement (274). The cost diary data also revealed that a 10% of the variances in OOP costs could be explained by age (294). Further, our systematic review showed that the prevalence of arthritis-related work disability appeared to increase with age (10). Middle-aged adults, in particular, experience arthritis-related work and financial distress, and women (aged over 40 years) participating in the recent Seattle Midlife Women's Health Study identified physical disability due to arthritic pain as one of the most challenging mid-life issues (322). The methods used for this PhD could also be applied to capture the patient perspective for other lifelong conditions (for example, multiple sclerosis) which are prevalent in working-age populations (323). Whilst the prevalence of arthritis increased with age in Australia, there is a particularly sharp increase in arthritis diagnoses in adults aged over 40 years (324). As a result, further qualitative research focusing on middle-age adults is required.

The cost diary study was exploratory, and could be used as the basis for a larger, population-based evaluation of arthritis-attributable OOP costs and related financial distress. With new knowledge that young adults with arthritis experience high OOP costs, a longitudinal study measuring people's costs and financial distress over time (for example, a 12 month period) is warranted. This may enable researchers to discover if certain variables (for example, arthritis type, disease severity,

medications and/or health services required, geography, socioeconomic status, level of education, etc.) are related to higher OOP cost and levels of financial distress, as age and disease duration did not account for a large proportion of the variance in financial distress. This may support researchers and clinicians to identify patients at risk of financial distress, with an opportunity for early intervention to best manage this possibility.

In the modern world, people of all ages are increasingly turning to social media for health information and advice. The most recent statistics show that 91% of adults aged 25-55 years in Australia use social media (325). Complementing this statistic, we found that individuals with arthritis sourced a substantial amount of information on Twitter during the COVID-19 pandemic, leading to two recommendations for future research: (1) exploring social media as a means of delivering rheumatologic information to patients, and (2) using social media as a data collection tool for hard to access populations, such as those that don't engage with the health system. This has the potential to improve arthritis patients' health-related knowledge and to give voice to those who may be less likely to participate in research but whose experiences warrant attention.

Clinicians are expected to treat their patients in a thorough yet timely manner, leaving many feeling time-poor throughout their day. Therefore, it is perhaps unfeasible to expect clinicians to add a work outcomes measure to their existing patient-reported outcome measure (PROM) batteries or other clinical assessment procedures. In consideration of likely time pressures, it is recommended that a single item measure of work impact (for example, presenteeism) be developed, validated, and embedded into routine care, which is both time efficient yet captures the patient perspective. For research purposes, a core minimum set of outcome measures that focus on issues specific to younger and middle-aged adults, for example, the impact of arthritis on career trajectory and/or career disruption, is more likely to capture the needs of this population than existing generic PROMs. Work-focused regulatory bodies (for example, WorkSafe Australia) are also likely to have an interest in people's capacity to maintain work and/or RTW after injury on a background of arthritis, and this item can contribute to collecting this type of data moving forward.

Finally, the research presented in this thesis was intended to be person-centred: from the conceptualisation of the project through lived experience and insider research, through to data collection via qualitative and quantitative methods, and the use of participant quotes and self-reported costs to report the findings. Whilst the patient perspective is paramount, an area of research that warrants further investigation is clinicians' perspectives of their patients' concerns. The relationship between patients and clinicians in the healthcare setting has evolved through advocacy for patient-centred care, where the emphasis is now on the clinician providing advice

and treatment tailored to the patients' concerns (326). As an example, in rheumatology, there is evidence that patient and rheumatologist perspectives diverge (327). Investigating where these differences lie has the potential to improve patient satisfaction with their care, and for clinicians to provide care that best meets their patients' expectations. Overall, both these concepts have been shown to improve patient QoL (328, 329).

9.6 Research Dissemination

As acknowledged earlier, the research presented in this thesis was funded through a scholarship awarded by Musculoskeletal Australia, a peak consumer organisation working with and advocating on behalf of people with arthritis (and other musculoskeletal conditions) in Australia. Being an industry-funded PhD, the ability to translate findings may be increased through this channel. Already, the findings have been presented to Musculoskeletal Australia in the form of reports, with the potential to disseminate findings and recommendations to their members and aligned partners, and to liaise with work-focused organisations. There is also potential to develop consumer-facing educational resources to raise awareness of the work and financial impacts of arthritis and to raise awareness in this regard.

This research has been published (or is currently under review) in international peer-reviewed journals. Research findings from this thesis have also been presented at key conferences in Australia and Europe (albeit online due to COVID-19). These include, but are not limited to the Australian Rheumatology Association in 2019 and 2020; the Australian Physiotherapy Association in 2019; the Health Services Research Association of Australia & New Zealand in 2019, and the European League Against Rheumatism (now known as the European Alliance of Associations for Rheumatology) in 2020.

9.7 Conclusion

Arthritis is prevalent amongst working-age adults, and many living with the disease experience substantial work and financial burden sequelae. These outcomes are detrimental for the individual, their families, workplaces, the health system, and the overall economy. The research presented in this thesis provides a comprehensive examination of the work and financial-related experiences of working-age adults with osteoarthritis or inflammatory arthritis aged 18-50 years in Australia. Using a mixed-methods approach, the qualitative and quantitative findings provide new evidence that contributes to a growing body of patient-centred research in the musculoskeletal sphere. The results from this thesis have the potential to raise awareness of the broader personal impacts of arthritis and inform positive changes to clinical assessment procedures and healthcare delivery to ensure the holistic provision of person-centred care.

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This list excludes references within published articles (Chapters 2, 4-8). These chapters have an individual reference list at the end of each article.

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APPENDICES

Appendix A: Classification of Rheumatoid Arthritis

	Score
Target population (Who should be tested?): Patients who	
1) have at least 1 joint with definite clinical synovitis (swelling)*	
2) with the synovitis not better explained by another disease†	
Classification criteria for RA (score-based algorithm: add score of categories A–D; a score of ≥6/10 is needed for classification of a patient as having definite RA)‡	
A. Joint involvement§	
1 large joint¶	0
2–10 large joints	1
1–3 small joints (with or without involvement of large joints)#	2
4–10 small joints (with or without involvement of large joints)	3
>10 joints (at least 1 small joint)**	5
B. Serology (at least 1 test result is needed for classification)††	
Negative RF *and* negative ACPA	0
Low-positive RF *or* low-positive ACPA	2
High-positive RF *or* high-positive ACPA	3
C. Acute-phase reactants (at least 1 test result is needed for classification)‡‡	
Normal CRP *and* normal ESR	0
Abnormal CRP *or* abnormal ESR	1
D. Duration of symptoms§§	
<6 weeks	0
≥6 weeks	1

Figure 7: ACR and EULAR Collaborative Initiative Classification of RA, reproduced from Aletaha et al (35)

Appendix B: NICE Recommendations for the Treatment of SpA

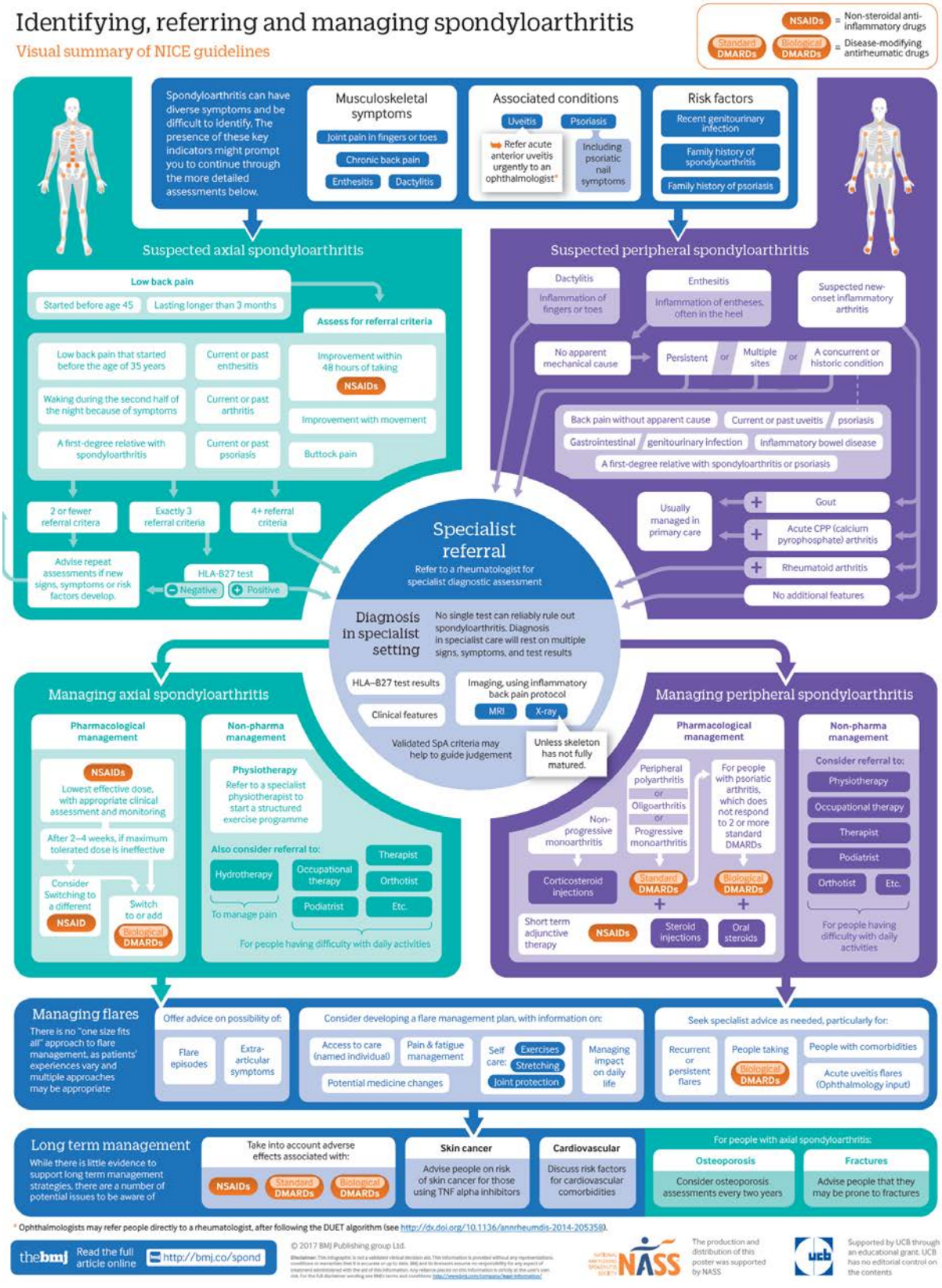

Figure 8: NICE recommendations for the treatment of SpA, reproduced from the National Institute for Health and Care Excellence (200)

Appendix C: Medline Search Strategy Example

1. OSTEOARTHRITIS, HIP/ or OSTEOARTHRITIS/ or OSTEOARTHRITIS, SPINE/ or OSTEOARTHRITIS, KNEE/
2. degenerative arthritis/ or gonarthrosis/ or coxarthrosis/
3. spondylarthritis/ or spondylarthropathies/ or arthritis, psoriatic/ or arthritis, reactive/ or spondylitis, ankylosing/
4. arthritis, juvenile/ or sacroiliitis/ or Polymyalgia Rheumatica/
5. arthritis, rheumatoid/ or caplan syndrome/ or felty syndrome/ or rheumatoid nodule/ or rheumatoid vasculitis/ or sjogren's syndrome/ or still's disease, adult-onset/
6. lupus erythematosus, systemic/ or mixed connective tissue disease/ or undifferentiated connective tissue diseases/
7. scleroderma, localized/ or scleroderma, systemic/ or scleroderma, diffuse/ or scleroderma, limited/ or crest syndrome/
8. giant cell arteritis/ or polyarteritis nodosa/ or takayasu arteritis/ or systemic vasculitis/ or granulomatosis with polyangiitis/
9. (inflammat* adj2 (arthrit* or arthrop*)).mp.
10. ((autoimmune or immune) adj1 (rhemat* or arthrit*)).mp.
11. (spinal arthritides or spinal arthritis or spondylarthrit* or bechterew* syndrome* or marie-strumpell spondylitis or spondylarthropath* or arthritic psoriasis or psoriasis arthropathica or psoriatic arthrit* or psoriatic arthropath* or post-infectious arthrit* or postinfectious arthrit* or reactive arthrit* or reiter* disease* or reiter* syndrome* or ankylosing spondylitis or bechterew* disease* or marie-struempell disease* or rheumatoid spondylitis or spondylitis ankylopo?etica or sacroiliitides or sacroiliitis or sacroilitis or sacroileitis).mp.
12. (ankylating spondylit* or ankylosing spine or ankylosing spondylarthros?s or ankylos?s spondylit* or ankylotic* spondylit* or spinal ankylos?s or spine ankylos?s or spondylarthros?s ankylopo?etica or spondylitis ankylopo?etica or vertebral ankylos?s or arthropathic psoriasis or psoriasis pustulosa arthropathic* or psoriatic polyarthrit* or psoriatic rheumatism or juvenile arthropath* or juvenile rheumatoid polyarthrit* or still* syndrome* or polymyalgi* arteritic* or polymyalgi* rheumatic* or pseudopolyarthrit* rhizomelic* or rheumatic myalgia or rheumatic vasculitis or rheumatoid ang?itis).mp.
13. (dacryosialoadenopathia atrophicans or mucoserous dyssecretosis or rheumatic sialosis or disseminated lupus or lupus erythematosus visceralis or schleroderma or sclerema or arteritis nodosa or kussmaul maier disease or kussmaul syndrome or nodular periarteritis or nodular polyarteritis or panarter?itis nodosa or periarterial fibrosis or polyarthritis nodosa).mp.
14. (juvenile arthrit* or juvenile chronic arthrit* or juvenile enthesitis-related arthrit* or juvenile idiopathic arthrit* or juvenile oligoarthrit* or juvenile onset still* disease or juvenile polyarthrit* or juvenile psoriatic arthrit* or juvenile rheumatoid arthrit* or juvenile systemic arthrit* or rheumatoid arthrit* or caplan* syndrome* or felty* syndrome* or rheumatoid nodul* or rheumatoid vasculit*).mp.
15. (sicca syndrome* or sjogren* syndrome* or sjogren* disease* or adult-onset still* disease* or forestier-certonciny syndrome* or peri-extra-articular rheumatism or polymyalgi* rheumatic* or rhizomelic pseudopolyarthrit* or libman-sacks disease* or lupus erythematosus disseminatus or systemic lupus erythemat* or mixed connective tissue disease* or sharp syndrome*).mp.
16. (scleroderma* or dermatoscleros?s or morph?ea* or systemic scleros?s or crest syndrome* or crst syndrome* or calcinosis raynaud phenomenon sclerodactyly telangiectasia or overlap syndrome* or undifferentiated connective tissue disease* or essential polyarterit* or necrotizing arterit* or periarter?itis nodosa or polyarter?itis nodosa).mp.
17. (anonymous artery occlusion or aort* arch syndrome* or arteritis brachiocephalic* or brachiocephalic arteritis or brachiocephalic artery occlusion or brachiocephalic isch?emia or brachiocephalic trunk occlusion or brachiocephalic vascular occlusion or martorell syndrome or takayasu* arteriopath* or takayasu ohnishi syndrome or necroti?ing respiratory granulomatous?s or pneumogenic granulomat* or Wegener* disease* or wegener* klinger churg syndrome or wegener* klinger granuloma* or wegener* syndrome or wegner* granuloma*).mp.
18. (cranial arteritis* or giant cell aortic arterit* or giant cell aortitides or giant cell aortitis or giant cell arteriti* or Horton* disease* or juvenile temporal arterit* or aortitis syndrome* or pulseless disease* or takayasu* arterit* or takayasu* disease* or takayasu* syndrome* or young female arteriti* or systemic vasculitides or systemic vasculitis or granulomatosis with polyangii* or Wegener* granuloma*).mp.
19. or/1-18
20. Work/ or Return to Work/ or Work Schedule Tolerance/ or exp "Activities of Daily Living"/
21. Work Capacity Evaluation/ or Workload/ or Job Satisfaction/ or Career Mobility/ or Vocational Guidance.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
22. Employment/ or Employment, Supported/ or Unemployment/ or Workplace/ or Occupations/
23. Occupational Health/ or exp Rehabilitation, Vocational/ or Work Simplification/
24. Retirement/ or Sick Leave/ or Absenteeism/ or Presenteeism/ or Disability Evaluation/
25. (job* or work* or nonwork* or vocation* or occupation* or employ* or unemploy* or reemploy* or RTW or presenteeism or labo?r-force or labo?rforce or labo?r market*).mp.

26. (retire* or rehire* or re-hire* or sick leave or sickness absence* or absenteeism).mp.

27. ((return* or resum* or reintegrat* or re-integrat* or reentry or re-entry or reenter* or re-enter* or recommence*) adj4 (activity or activities or duty or duties or capacity or capacities)).mp.

28. ((modified or modification or limited or limitation) adj3 (duty or duties or activity or activities or capacity or capacities)).mp.

29. ((career* or vocation* or occupation* or profession*) adj3 (choice* or change* or advice or counsel* or return* or resum*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

30. (efficien* or productiv*).mp.

31. or/20-30

32. 19 and 31

33. aged/ or "aged, 80 and over"/ or "aged, 65 and over"/ or frail elderly/

34. (elderly or senior citizen or old age citizen).mp.

35. (child* or infant or infancy or p*detiatric).mp.

36. 33 or 34 or 35

37. 32 not 36

38. randomi*ed control* trial*/ or RCT/ or clinical trial*/ or intervention*.ti.

39. randomi*ed control* trial*/ or RCT/ or clinical trial*/ or intervention*.ab.

40. 38 or 39

41. 37 not 40

42. limit 41 to (abstracts and english language and humans and yr="2000 -Current")

Figure 9: MEDLINE Search Strategy Example (Supplementary Systematic Review Material)

Appendix D: Critical Appraisal Scores

Table 4: Joanna Briggs Institute Critical Appraisal Scores (Supplementary Systematic Review Material)

Author	Year	Country	Study Design	JBI Score (%)
Ackerman et al (21)	2015	Australia	Cross-sectional	100.0
Bagcivan et al (55)	2015	Turkey	Qualitative	60.0
Baker et al (34)	2009	Canada	Cross-sectional	62.5
Berkovic et al (1)	2019	Australia	Qualitative	90.0
Bieleman et al (48)	2010	Netherlands	Cross-sectional	62.5
Bieleman et al (27)	2013	Netherlands	Cohort	45.5
Boonen et al (33)	2001	Netherlands	Cross-sectional	37.5
Boonen et al (49)	2001	Netherlands	Cross-sectional	75.0
Bukhave et al (41)	2014	Denmark	Qualitative	50.0
Chorus et al (50)	2000	Netherlands	Cross-sectional	62.5
Chorus et al (51)	2001	Netherlands	Cross-sectional	87.5
Chung et al (28)	2006	Finland, USA	Cohort	27.2
Crooks (35)	2007	Canada	Qualitative	50.0
Dadoniene et al (47)	2004	Lithuania	Cross-sectional	75.0
de Hooge et al (44)	2016	Italy	Cross-sectional	100.0
Gonzalez-Lopez et al (29)	2012	Mexico	Cohort	27.2
Hanson et al (56)	2018	UK	Qualitative	90.0
Holland et al (57)	2018	UK	Qualitative	80.0
Hubertsson et al (30)	2012	Sweden	Cohort	45.5
Jain et al (45)	2019	India	Qualitative	80.0
Jetha et al (36)	2015	Canada	Cross-sectional	87.5
Jetha et al (37)	2014	Canada	Cross-sectional	75.0
Jetha et al (38)	2017	Canada	Cross-sectional	75.0
Kaptein et al (40)	2009	Canada	Cross-sectional	75.0
Kristiansen et al (42)	2011	Denmark	Qualitative	80.0
Lempp et al (58)	2006	UK	Qualitative	80.0
Neovius et al (31)	2011	Sweden	Cohort	36.0
Osterholm et al (54)	2013	Sweden	Qualitative	80.0
Pendeke et al (59)	2016	UK	Qualitative	70.0
Primholdt et al (43)	2016	UK	Qualitative	80.0
Sruamsiri et al (46)	2018	Japan	Cross-sectional	75.0
Theis et al (60)	2007	USA	Cross-sectional	62.5
Wallenius et al (53)	2008	Norway	Cross-sectional	75.0
Wallenius et al (52)	2009	Norway	Cross-sectional	75.0
Yelin et al (32)	2009	USA	Cohort	27.2
Zhang et al (39)	2010	Canada	Cross-sectional	62.5

Appendix E: Results of Low Quality Studies

Table 5: Results of Low Quality Studies (Supplementary Systematic Review Material)

Author and Country	Study Design	Participants aged 16 – 50 (n)	% Female	Arthritis diagnosis	Years since Diagnosis	Tools used to measure work	Results			Were the study results compared to the general population?	Interpretation of Study Results
							Arthritis-Related Productivity Outcomes	Arthritis-Related Participation Outcomes	Other Arthritis-Related Workplace Outcomes		
Bielemen et al Netherlands	Cohort	NR	NR	Hip OA Knee OA	-	EARA, LF Researcher-developed questionnaire: Employed participants asked about their present condition and whether they'd like to adapt their work (tasks/hours/workplace); employed participants asked if they'd been on sick leave, and if so, was this because of hip/knee reasons, or other. Non-employed participants asked the reason for not having a job.		**LF Participation RR (Graduated Secondary School)** *Age 45-49 Men* 1.15 (0.23-2.07)* *Age 45-49 Women* 1.25 (0.77-1.72)* **LF Participation RR (Graduated High School)** *Age 45-49 Men* 1.08 (0.13-2.02)* *Age 45-49 Women* 0.94 (0.24-1.64)*		Yes.	The rate ratio for majority of subgroups equalled, or was >1, but did not reach levels of significance (95% CI includes 1). The RR for women age 45-49 graduating high school was <1, but did not reach levels of significance (95% CI includes 1).
Boonen et al Netherlands	Cross-sectional	83	NR	AS	-	Officially recognised inability to perform paid production because of AS based on the Netherlands Social Security Association's eligibility for disability payments.			**LF Withdrawal Risk Ratio** *Age <25:* 6.7 (1.8-17.1)* *Age 25-34:* 4.0 (2.9-5.5)* *Age 35 - 44:* 3.0 (2.1-4.1)*	Yes.	For men and women aged 18-44, labour force withdrawal risk is higher than for the general population
Chung et al US	Cohort	NR	NR	RA	Median (IQR) 5 months (3-12)	Self-reported final date on which the patient was working, followed by continuous RA-attributable			**Unadjusted HRs by Cohort (Men and Women)**	No.	The HRs by cohort, for men and women, did not reach levels of significant WD

Author and Country	Study Design	Participants aged 16 – 50 (n)	% Female	Arthritis diagnosis	Years since Diagnosis	Tools used to measure work	Results			Were the study results compared to the general population?	Interpretation of Study Results
						WD based on a self-reported questionnaire.			*Age 36-45 v ≤35 Nashville:* 0.3 (0.1-1.1)* *Age 26-45 ≤35 Jyvaskyla:* 1.7 (0.6-4.8)*		for cohorts in Nashville or Jyvaskyla.
Gonzalez-Lopez et al Mexico	Cohort	NR	NR	RA	Mean (SD) 7 (6)	Sick leave defined as the total number of days that a person was absent from work as a consequence of a sick leave.			**n (%) Development of Sick Leave** 4 (11) **Time to develop sick leave episode (mean days)** 334	No.	11% of workers in Mexico aged <40 developed an episode of sick leave, with mean 334 days to develop an episode of sick leave. Significance testing is not reported.
Hubertsson et al Sweden	Cohort	NR	NR	Knee OA	-	Sick leave defined as days with sickness benefit registered by the Swedish Social Insurance Agency			**Sick Leave Risk Ratio Men and Women** Age 16 - 34: 3.79 (3.14 - 4.59)** Age 35 - 44: 2.16 (1.95 - 2.40)**	Yes.	For men and women aged 16-44 with knee OA, the risk of sick leave is higher than for the general population. Validation of medical records was not performed.
Neovius et al Sweden	Cohort	8,115	NR	RA	-	Swedish Rheumatology Quality Register merged with the National Patient Register, the Social Insurance Office database, and the Longitudinal Integration Database for Health Insurance and Labour Marked Studies.		**Mean Gross Days on Unemployment Benefits (out of 365)** 19 - 29: 36 30 - 39: 32 40 - 49: 20	**Net Annual Days (out of 365)** 19 - 29: 25 30 - 39: 33 40 - 49: 34	Yes.	Findings only reached levels of significance for men and women aged 30-39 for mean gross days of unemployment. These results are only applicable to participants in the

Author and Country	Study Design	Participants aged 16 – 50 (n)	% Female	Arthritis diagnosis	Years since Diagnosis	Tools used to measure work	Results			Were the study results compared to the general population?	Interpretation of Study Results
											years preceding diagnosis.
Yelin et al US	Cohort	64	NR	SLE	-	Data collected from the San Francisco Lupus Outcomes Study and augmented with data from the US Bureau of the Census and the US Bureau of Labor Statistics. Employment defined as either working, with a job but not working, or doing any work for pay or profit in the last week.		**Employed Participants Work Loss HR (95% CI)** 18 - 34: 0.32 (0.16 - 0.65)** **Unemployed Participants Work Entry HR (95% CI)** 18 - 34: 3.78 (1.80 - 7.97)**		Yes.	Participants employed at baseline were not more likely to experience work loss. Unemployed participants at baseline were more likely to enter the workforce.

AS (Ankylosing Spondylitis); EARA (Economic Aspects in Rheumatoid Arthritis); HR (Hazard Ratio); LF (Labour Force); NR (Not Reported) OA (Osteoarthritis); RA (Rheumatoid Arthritis); RR (Rate Ratio); SLE (Systemic Lupus Erythematosus); WD (Work Disability).

* Reported measure of effect = 95% Confidence Interval (CI)
** Statistically significant 95% CI

Appendix F: Bracketing Exercise

Figure 10: Screenshot of Bracketing Exercise