MONASH University

Comprehensive care for people with severe mental illness in rural Vietnam: Addressing policy evidence gaps

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Global and Women's Health

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List of abbreviations

CALD	Culturally and linguistically diverse
CBT	Cognitive Behaviour Therapy
CHEC	Consensus on Health Economic Criteria
CMDs	Common mental disorders
DALYs	Disability adjusted life years
DAS-I	World Health Organization Disability Assessment Scale
DFID	UK Department of International Development
DOH	Department of Health
EMERALD	Emerging Mental Health System in low and middle income countries program
EPOC	Cochrane Effective Practice and Organization Care
FEIS	Family Experience Interview Schedule
GAAS	Global Activity Assessment Scale
GAF	Global Assessment of Functioning
GHQ12	General Health Questionnaire 12 items
HICs	High income countries
HITS	Short form Domestic Violence Screening Tool
ICCP	Informal community care providers
ICD-10	International Classification of Diseases, Tenth Version
ICD-9	International Classification of Diseases, Ninth Version
IDEAS	Indian Disability Evaluation Assessment Scale
IQR	Inter Quartile Range
LLMICs	Low and lower middle income countries
LMICs	Low and middle income countries
MARDS	Montgomery-Asberg Depression Rating Scale
MOH	Ministry of Health

MOLISA	Ministry of Labor, Invalids, and Social Affairs
NGOs	Non-government Organizations
NIMH	US National Institute of Mental Health
PANSS	Positive and Negative Symptoms for Schizophrenia Scale
PSMI	People with severe mental illness
RCTs	Randomized Controlled Trials
RTCCD	Research and Training Center for Community Development
SASCAT	Adapted Social Capital Assessment Tool
SBSAS	Social Behaviour Assessment Scale
SLaM	South London and Maudsley NHS Foundation Trust
SLOF	Specific Level of Functioning Scale
SMDs	Severe mental disorders
SMI	Severe mental illness
SRQ	WHO Self-Reporting Questionnaire
UK	The United Kingdom
UN	United Nations
UNICEF	United Nations Children's Fund
WHO AIMS	WHO Assessment Instrument for Mental Health System
WHO QOL-BREF	WHO Quality of life Brief version
WHO	World Health Organization
WHO-CIDI	WHO Composite International Diagnostic Interview
WONCA	World Organization of Family Doctors
YLD	Years lived with disability
YLL	Years of life lost
YMRS	Young Mania Rating Scale

Abstract

Background: Severe mental illness (SMI) has become a global health problem in low and middle income countries (LMICs) due to the large treatment gap experienced by people with SMI in these countries. Integrating mental health into primary care with task-shifting is recommended by the World Health Organization. There is limited evidence of the effectiveness of interventions using the task-shifting approach for SMI in LMICs.

Aims: The aims of this research were to: (1) review the available evidence about informal mental health interventions for people with SMI in low and lower middle income countries, (2) determine the prevalence of common and severe mental disorders among adults, (3) describe the delay to diagnosis of adults with SMI, and (4) describe the development and proof of concept of a community-based intervention for people with SMI, all in rural Vietnam.

Methods and results: There were four main components to this research. A systematic review included five interventions delivered by informal community care providers for people with SMI in LLMICs. The interventions were reported to improve participants' outcomes (psychosocial functioning, psychotic symptoms, and social inclusion) and mental health literacy of caregivers and the community.

Study 1 was a cross-sectional survey of 611 households with 1528 adults. The point-prevalence of clinically significant symptoms was 14.4% for common mental disorders (CMDs) and 8.2% for severe mental disorders (SMDs). CMDs were associated with living in a Northern province, a household with disadvantaged economic status, in which a family member(s) misused alcohol, the family lacked links to instrumental support, and the person experiencing a CMD not having completed primary school. SMDs were associated with living in the Northern province, a household with disadvantaged economic status, family violence and being older than 50 years.

Study 2 was another cross-sectional study of 404 people with SMI from 370 households. The delay to diagnosis was defined as the period of time between the first psychotic symptoms being observed by family members and the first diagnosis of a psychotic illness. The median delay to diagnosis was 11.5 months (Inter Quartile Range 0 – 168.0 months). Living in a Northern province; older age, and having a psychosis diagnosed before the implementation of the National Community Mental Health program (2003) were associated with a delay of more than twelve months to diagnosis.

Study 3 was a before-and-after evaluation of an evidence-informed community-based intervention facilitated by Women's Union staff for 68 people with SMI in one rural commune in Hanam province, Vietnam. The intervention was highly acceptable and feasible. It improved personal functioning and reduced stigma and discrimination experienced by the intervention participants significantly. The cost of the intervention was USD 733.7 per participant per year.
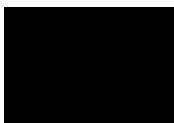
Conclusions: These population-based data provide Vietnam with high quality evidence about the huge burden of CMDs and SMDs on which to base policies and programs. National policies have a positive impact, including on reducing the delay to diagnosis of people with SMI. The results of the community-based intervention suggest that it is an appropriate way to address the challenges of integrating mental health into primary care in Vietnam and to assist the country to meet WHO Guidelines

Declaration

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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.

Signature

Thi Thu Trang Nguyen

Date: 25/01/2019

Publications during enrolment

1. **Nguyen T**, Tran T, Tran H, Tran TD, Fisher J. The burden of clinically significant symptoms of common and severe mental disorders among adults in Vietnam: a population-based cross-sectional survey. *BMC Public Health* 2018. (Under review)

2. **Nguyen T**, Tran T, Green S, Hsueh A, Tran TD, Tran H, Fisher J. Development, proof of concept, and cost analysis of participant informed psycho-educational community-based intervention for people with severe mental illness in rural Vietnam. *Applied Health Economics and Health Policy* 2018. (Under review)

3. **Nguyen T**, Green S, Hsueh A, Tran T, Tran TD, Tran H, Fisher J. Delays to diagnosis among people having severe mental illness in Vietnam, a population-based cross-sectional survey. *BMC Psychiatry* 2018. (Under review)

4. **Nguyen T**, Holton S, Tran TD, Fisher J. Informal mental health interventions for people with severe mental illness in low and lower middle income countries: a systematic review of effectiveness. *International Journal of Social Psychiatry* 2018. (Accepted)

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6. **Nguyen T**, Sweeny K, Tran TD, Luchters S, Hipgrave D, Hanieh S, Tran T, Tran H, Biggs B-A, Fisher J. Protocol for an economic evaluation alongside a cluster randomised controlled trial: cost-effectiveness of Learning Clubs to improve women's health and infant's health and development in Vietnam. *BMC Public Health* 2018. (Under review)

7. Fisher J, **Nguyen T**, Tran TD, Tran T, Tran H, Luchters S, Hipgrave D, Hanieh S, Biggs B-A. Protocol for a process evaluation of a cluster randomized controlled trial of the Learning Club intervention for women's health, and infant's health and development in rural Vietnam. *BMC Public Health* 2018. (Under review)

8. Fisher J, **Nguyen T**, Tran TD, Tran H, Tran T. Community-based Learning Club for Women's Health and Infant Development in rural Vietnam. *Innovation in Global Mental Health*. Springer 2018. (Under review)

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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 01 original papers published in peer reviewed journals and 04 submitted publications. The core theme of the thesis is the burden of severe mental illness and a community-based intervention delivered by informal community care providers for people with severe mental illness in the community. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the student, working within the Global and Women's Health under the supervision of Professor. Jane Fisher, Professor. Sally Green and Doctor. Arthur Hsueh.

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, 3, 5, 6 & 7, my contribution to the work involved the following:

Thesis Chapter	Publication Title	Status *(published, in press, accepted or returned for revision, submitted)*	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
2	Informal mental health interventions for people with severe mental illness in low and lower middle income countries: a systematic review of effectiveness.	Accepted	*60%, protocol preparation, database search, study selection and extraction, quality assessment, writing first draft, revised the draft, submission for publication, revising as requested*	1) *Sara Holton, input to quality assessment, input into manuscript 15%* 2) *Thach Tran, database search, data selection and extraction, input into manuscript 10%* 3) *Jane Fisher, input to protocol prepartion, study eligibility, input into manuscript 15%*	N
3	Challenges in Policy Advocacy for Primary Mental Health Care in Vietnam	Submitted	*65%, data analysis, writing up the book chapter for publication, and revision as requested*	1) *Tuan Tran, input into manuscript 10%* 2) *Ha Tran, input into manuscript 5%* 3) *Thach Tran, input into manuscript 5%* 4) *Jane Fisher, input into manuscript 15%*	N
5	The burden of clinically significant symptoms of common and severe mental disorders among adults in Vietnam: a	Submitted	*60%, data analyses, writing of the paper, submission for publication & drafting revision as requested*	1) *Tuan Tran, input into manuscript 5%* 2) *Ha Tran, input into manuscript 5%* 3) *Thach Tran, data analysis, input into manuscript 10%* 4) *Jane Fisher, input into manuscript 20%*	N

	population-based cross-sectional survey.				
6	Delays to diagnosis among people having severe mental illness in Vietnam, a population-based cross-sectional survey	Submitted	*60%, data analyses, writing of the paper, submission for publication & drafting revision as requested*	1) *Thach Tran, data analysis, input into manuscript 10%* 2) Sally Green, input to manuscript 5% 3) Arthur Hsueh, input to manuscript 5% 4) *Tuan Tran, input into manuscript 5%* 5) *Ha Tran, input into manuscript 5%* 6) *Jane Fisher, input into manuscript 10%*	N
7	Development, proof of concept, and cost analysis of participant informed psycho-educational community-based intervention for people with severe mental illness in rural Vietnam	Submitted	*60%, data analyses, writing of the paper, submission for publication & drafting revision as requested*	1) *Tuan Tran, input into manuscript 10%* 2) Sally Green, input to manuscript 5% 3) Arthur Hsueh, input to manuscript 5% 4) *Thach Tran, data analysis, input into manuscript 5%* 5) *Ha Tran, input into manuscript 5%* 6) *Jane Fisher, input into manuscript 10%*	N

*If no co-authors, leave fields blank

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Student signature: ███████ **Date: 25/01/2019**

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

Main Supervisor signature: ████████████ **Date:29/01/2019**

Acknowledgements

CHAPTER 1: BURDEN OF SEVERE MENTAL ILLNESS AND TREATMENT GAP IN LOW AND MIDDLLE INCOME COUNTRIES

Severe mental illness (SMI) among people living in low- and middle-income countries has become a global health concern because of the burden experienced by individuals, families, and society. However, these settings also experience resource scarcity, mental health workforce shortages, services focused in custodial hospitals, and serious human rights violations. Consequently, the treatment gap for people with SMI is very large.

1.1 Definition of severe mental illness

There is a lack of consensus about definitions of the term 'severe mental illness' among health workers, health researchers, and the major diagnostic systems. There are several terms which refer to similar mental health conditions such as chronic mental illness, severe and persistent mental illness, serious mental illness, and psychotic disorders. Several efforts have been presented to provide a consistent definition that will be useful for mental health researchers. The most significant of these efforts is a literature review conducted by Schinnar et al. (Schinnar, Rothbard, Kanter, & Jung, 1990). The review included 17 definitions used in the context of mental health care in the United States to test their precision and applicability in estimating the prevalence of SMI. Among these definitions, two were provided by the US government (National Institute of Mental Health, 1977, 1987), six were used to estimate the population-based prevalence of SMI (JW Ashbaugh, Leaf, & Manderscheid, 1983; JW Ashbaugh & Manderscheid, 1985; Goldman, Gatozzi, & Taube, 1981; Hargreaves, LeGoullon, & Gaynor, 1984; Krute & Burdette, 1978; Szymanski, Schulberg, & Salter, 1982), five were presented for service policy purposes (Minkoff, 1978; Peele & Palmer, 1980; Strauss, 1980; Test & Stein, 1978; J.

Turner & Tenhoor, 1978), and four were referred to the definition of the US National Institute of Mental Health (NIMH) in 1977 with minor revision (Baker & Intagliata, 1984; Goldstrom & Manderscheid, 1982; Hoff, Ashbaugh, & Schneider, 1983; Lynch & Kruzich, 1986; Shern, 1983; Tessler, Bernstein, & Rosen, 1982).

In general, there are three common criteria among the 17 definitions: diagnosis, disability, and duration. A sample of 222 community mental health centre patients who were adults in the city of Philadelphia was recruited. The 17 definitions were applied to this sample to estimate the prevalence of SMI using each definition. The prevalence of SMI ranged from 4% to 88% of the recruited population. The NIMH 1987 definition was selected as a reference due to its middle-range estimation of 45% to 55% (Schinnar et al., 1990). This definition includes three criteria: (1) diagnosis of a non-organic psychosis or personality disorder using the International Classification of Diseases, Ninth Version (ICD-9, pp. 299 and 301); (2) disability described as having conditions in at least three out of five domains of dysfunction (social behaviour demanding intervention by mental health system or courts, moderate impairment in performance at work, mild impairment in activities of daily living and basic needs, moderate impairment in performance at work, and moderate impairment in non-work activities); and (3) duration of long-term treatment of the diagnosis and disability in the two criteria above (National Institute of Mental Health, 1987). The review set up a common framework and a definition for reference after decades of inconsistent definitions. The NIMH 1987 definition criteria are not specific, especially the disability and duration criteria, and so this definition is difficult to apply. Nevertheless, all definitions were used for people with SMI in the USA during the period 1972–1987. Therefore, there is still a need for a definition or definitions that are suitable for the health system, research, health insurance, and mental health diagnostic systems.

In 2000, in order to extend the review of Schinnar et al. (1990) (Schinnar et al., 1990), Ruggeri et al. tested two definitions which were derived from the NIMH 1987 definition to be used in European countries. The NIMH 1987 definition with three criteria was described as the three-dimension definition. It was compared to a broad definition with two dimensions. Ruggeri et al. developed more specific and practical criteria for the three-dimension definition, including: (1) diagnosis of non-organic psychosis (excluding personality disorder); (2) disability as measured by the Global Assessment of Functioning (GAF) scale using two cut-off point scores of 70 or less for moderate dysfunction, and 50 or less for severe dysfunction; (3) duration defined as at least two years of treatment. The two-dimension definition included only the disability and duration criteria. The test was conducted among 723 adults (over 18 years old) who had been diagnosed with a psychotic illness using ICD-10 criteria in community mental health services in the United Kingdom (South London) and Italy (South Verona). The authors found that the three-dimension definition was more sensitive in identifying a small group of people with SMI among the large group of people with a mental disorder. In contrast, the two-dimension definition covered a larger group of people with both psychotic and non-psychotic disorders causing disability and requiring long-term treatment (Ruggeri, Leese, Thornicroft, Bisoffi, & Tansella, 2000). Ruggeri et al. provided a more practical and simple way of applying the two definitions in both community-based and clinical settings, which indicates evidence of the feasibility of the definition. Similar to Schinnar et al.'s review, this research also highlighted the impacts of different socioeconomic characteristics on the prevalence estimates of SMI.

In 2006, Parabiaghi et al. continued to investigate the two-dimension definition (GAF score less than 50 and more than two years of illness duration) in the community for its external and predictive validity against the diagnosis of psychosis by mental health professionals in the community-based service of South Verona. The study was

a longitudinal design which was conducted for two years among 343 patients in Italy with a follow-up rate of 70%. Parabiaghi et al. tested both external and predictive validity. External validity was tested by comparing participants with and without SMI at baseline; and non-psychotic and psychotic participants with regards to other associated factors (socio-demographic and clinical status). Predictive validity was tested by measuring the sensitivity, specificity, and positive and negative predictive value. The authors reported that the two-dimension definition of SMI was high in predictive and external validity (Parabiaghi, Bonetto, Ruggeri, Lasalvia, & Leese, 2006). This definition is suitable for service providers because it is useful for mental health care planning and service provision. However, it may not be highly applicable at the patient level due to its lack of information about the circumstances and needs of those suffering from SMI.

In 2009, a definition of SMI was presented by the Spanish Ministry of Health and Social Policy. The definition was derived from the NIMH definition in 1987. However, it was revised towards an intervention-oriented and social approach. The previous definitions reflected a purely medical and clinical approach:

> a group of heterogeneous people who suffer from severe psychiatric disorders, together with long-term mental disturbances, which entail a variable degree of disability and social dysfunction, and who must be cared for by means of different social and health resources of the psychiatric and social healthcare network (Spain Ministry of Health and Social Policy, 2009).

This definition has three criteria: (1) diagnosis of a psychotic disorder (such as schizophrenia, schizotypal disorders, persistent delirious disorders, induced delirious disorders, schizoaffective disorders, other non-organic psychotic disorders, bipolar disorder, serious depressive episode with psychotic symptoms, recurrent serious depressive disorders, and compulsive obsessive disorder) using the ICD-10;

(2) moderate to severe disability at individual, family, and social levels using the Global Activity Assessment Scale (GAAS) with scores less than 50 and the WHO disability assessment scale (DAS-I) with scores more than 3 for all items; and (3) duration of at least two years since the development of the psychotic disorder (Spain Ministry of Health and Social Policy, 2009).

This definition has a broader approach compared to the previous definitions because it is applicable in the community and includes consideration of the role of both social and health sectors in supporting people with SMI. The definition is aligned with the concepts of psychosocial rehabilitation and recovery (Spanish Ministry of Health and Social Policy, 2009). It provides a broader view of the crucial mental health conditions, their impacts on the individual and society, and the need to fully integrate them into the community.

1.1.1 Description of the conditions

SMI significantly affects a person's perceptions, thoughts, moods, and behaviour. Its symptoms may vary among individuals due to their physical health and other socioeconomic characteristics. In general, during an acute psychotic episode, people have some deterioration in personal function. For schizophrenia, "difficulties may include memory and attention problems, social withdrawal, unusual and uncharacteristic behaviour, disturbed communication, and unusual perceptual experiences, which are accompanied by bizarre ideas, poor personal hygiene, and reduced interest in day-to-day activities", which may be followed by typical symptoms such as "hallucinations (hearing, seeing or feeling things that others do not), delusions (markedly unusual or bizarre ideas), behavioural disturbances such as agitation and distress, and disorders of thinking so that speech becomes muddled and hard to understand" (National Collaborating Centre for Mental Health, 2014). According to the ICD-10 (World Health Organization, 1992), bipolar disorders' typical symptoms are at least two episodes which include mania or hypomania. They

significantly disturb the moods and activities of people with bipolar disorders. "The disturbance consists of either an elevation of mood and increased energy and activity (mania or hypomania). Episodes can be further specified as hypomanic, manic without psychotic symptoms, manic with psychotic symptoms, mild or moderate depression, severe depression without psychotic symptoms, severe depression with psychotic symptoms, mixed, or in remission." Manic episodes last from two weeks to five months. Depressive episodes often lasts longer than manic episodes, for around six months (National Institute for Health and Care Excellence, 2005).

As a result of having such symptoms, the person's ability to study, to work, and to maintain relationships are seriously adversely affected. When people with SMI are treated properly, these acute episodes may be relieved and other potentially lasting symptoms such as poor motivation, poor concentration, poor memory, and being isolated may be reduced (National Institute for Health and Care Excellence, 2005). However, many people are still not able to make a full recovery.

1.2 Prevalence of severe mental illness

The understood prevalence of SMI is mainly based on the prevalence of schizophrenia and bipolar disorders in publications in peer-reviewed journals. It is estimated that there are around 29 million people with schizophrenia globally. Among these, approximately 20 million are from low- and middle-income countries (LMICs) (Barbato, 1998). One of the most foundational systematic reviews of the prevalence of schizophrenia was conducted by Saha et al. in 2005 with a total of 1721 prevalences estimated from 188 studies. A search was conducted in MEDLINE, PsychINFO, EMBASE, and LILACS to include studies which reported primary data on the prevalence of schizophrenia published between January 1965 and December 2002. Studies which reported the prevalence in sub-populations such as people in prison or forensic populations, or in participants in genetic epidemiological studies, were excluded. Meta-analyses were used to combine the prevalences of the included

studies. Point prevalence was defined as "the number of cases at a specific point in time", period prevalence measured "the number of cases over a defined period of time", and lifetime prevalence indicated "the proportion of individuals who have been affected by a disorder at any time during their lives" (Barbato, 1998; Saha, Chant, Welham, & McGrath, 2005).

The review reported that the median values per 1000 population were 4.6 (point prevalence), 3.3 (period prevalence), 4.0 (lifetime prevalence), and 7.2 (lifetime morbid risk). In the systematic review, period prevalence reported prevalence estimates between 1 month and 12 months. The prevalence was similar across gender and rural/urban/mixed sites (Saha et al., 2005). However, the prevalence was higher among migrants. Lifetime morbid risk was different from lifetime prevalence. It reflected "the probability of a person developing the disorder during a specified period of their life or up to a specified age" (Saha et al., 2005). The evidence was drawn from 18 low-income countries, 13 middle-income countries, and 54 high-income countries. The results reported a lower combined prevalence per 1000 persons in LMICs (3.05 in low-income countries and 5.69 in middle-income countries) when compared with high-income countries (5.82). This was explained as being due to fewer included studies from LMICs than high-income countries (31/85) in this systematic review. In addition, more females participated in the included studies than males. Hence, it concluded that there was a remaining need for more studies from LMICs (Saha et al., 2005).

The prevalence of bipolar spectrum disorder was estimated in a 2011 population-based World Mental Health Survey among eleven countries, of which three were World Bank classified as low- and lower-middle-income, five as upper-middle-income, and three as high-income nations. It used a multi-stage clustered area probability sampling method. The total sample size was 61,392 people and there was an average recruitment rate of 75.0%. The study participants were aged at least 16

years old. All data were collected in face-to-face interviews conducted by trained data collectors using the standardized WHO Composite International Diagnostic Interview (WHO-CIDI) version 3.0. The aggregate lifetime prevalence of Bipolar I disorder was 0.6%, of Bipolar II disorder 0.4%, of sub-threshold Bipolar disorder 1.4%, and of Bipolar spectrum 2.4%. The prior 12-month prevalences were 0.4% (Bipolar I disorder), 0.3% (Bipolar II disorder), 0.8% (sub-threshold Bipolar disorder), and 1.5% (Bipolar spectrum). The prevalence varied slightly among countries. Among high-income countries, the USA had the highest prevalence (4.4% for lifetime prevalence and 2.8% for 12-month prevalence), but Japan reported a low prevalence (0.7% and 0.2%, respectively). Regarding low- and lower-middle-income countries, the prevalence rates among the Indian sample were the lowest (0.1% and 0.1%, respectively), while those in Colombia were high (2.6% lifetime prevalence). There was no obvious link between national income level and bipolar disorder prevalence. The WHO survey is the first international evidence investigating the prevalence of bipolar disorder using common diagnostic definitions and measurement methods (Merikangas et al., 2011). However, the number of countries included in the study is small (11 out of 195 countries) and it may not predict global prevalence.

1.3 Burden of severe mental illness

The burden of SMI is experienced by individuals, families, societies, and health care systems. In addition, it also creates negative impacts on the economy at all levels.

1.3.1 Burden on individuals

1.3.1.1 Risk to morbidity

At the individual level, SMI creates long-term impairment and disability which have direct effects on personal, social, and occupational lives (National Collaborating Centre for Mental Health, 2014). Years of life lost (YLL) to premature mortality are defined as "the number of deaths multiplied by the standard life expectancy at the age at which death occurs". Years lived with disability (YLD) are "the number of

incident cases in a period multiplied by the average duration of the disease and a weight factor that reflects the severity of the disease on a scale from 0 (perfect health) to 1 (dead)". Disability adjusted life years (DALYs) are calculated as "the sum of the YLL due to premature mortality in the population and the YLD for people living with the health condition or its consequences" (Murray & Lopez, 1996). According to the Global Burden of Disease Study 2010, mental illness and substance abuse accounted for 183.9 million DALYs, 8.6 million YLLs, and 175.3 million YLDs worldwide annually. They are also the leading cause of YLD worldwide. The burden of mental health and substance abuse was found to have increased by nearly 40% in the 20 years since the first Global Burden of Disease study conducted in 1990. Schizophrenia and bipolar disorder were reported to account for 14.4% of total DALYs caused by mental illness and substance abuse (Whiteford et al., 2013).

According to Raj's 2013 review, people with schizophrenia reported needing assistance from caregivers and antipsychotics to motivate them to perform daily activities such as personal hygiene and bathing. They were described by their caregivers as being lazy due to their lack of interest in everyday activities (Raj, 2013). However, the study methods were not provided. Wiersma et al. reported in their (2000) cohort study on 349 patients with SMI from six European countries (Bulgaria, Germany, Ireland, the Netherlands, the Czech Republic, and the United Kingdom) with a drop-out rate of 25%. Their social functioning was assessed using the WHO Disability Assessment Schedule in a standardized method. It was found that after 1, 2, and 15 years of treatment, nearly 25% of patients still had poor functioning in the long-term (Wiersma et al., 2000). The World Mental Health Survey (2011) found a striking result that one in every four to five persons in the community with Bipolar I and II had a history of suicide attempts. Suicidal behaviours have a positive association with the severity of bipolar spectrum disorder (Merikangas et al., 2011).

As a consequence of the serious effects of SMI on personal functioning, people experiencing this have difficulty in maintaining relationships with others, especially their family members and partners. Sometimes, people with schizophrenia suspect their families or do not know how to initiate or make meaningful conversation with others (Raj, 2013). In 2008, Solanski et al. conducted a cross-sectional survey of 50 people with schizophrenia using outpatient services of the Department of Psychiatry in Jaipur, India. Their quality of life was assessed using the WHO Quality of Life instrument (WHO QOL-BREF). It was found that people with schizophrenia had the lowest score in the social relationship domain. There was a significant association between poor social relationships and unemployment, suggesting that lacking interpersonal skills makes it more difficult to find income-generating work (Solanki, Singh, Midha, & Chugh, 2008). The unemployment rate for people with schizophrenia is much higher than the general population. However, employment has a strong link with reduced symptom severity (Luciano & Meara, 2014; National Collaborating Centre for Mental Health, 2014). These data were all generated in high-income countries, including the USA and the UK. Little is known about employment for people with schizophrenia or its links to symptoms in LMICs (Shekhar Saxena et al., 2011).

1.3.1.2 Risk to mortality

The excess mortality rate among people with SMI is an emerging priority for policy and research interventions (Liu et al., 2017). The life expectancy of people with SMI is shorter by 10–20 years compared with the general population (Chesney, Goodwin, & Fazel, 2014; Hayes JF, Miles J, Walters K, King M, & Osborn DP, 2015; Saha, Chant, & McGrath, 2007; Walker ER, McGee RE, & Druss BG, 2015). In 2007, Saha et al. conducted a systematic review including 37 studies from 25 countries completed between January 1980 and January 2006 to explore the distribution of standardized mortality ratios for people with schizophrenia. They reported that people with

schizophrenia had a risk of dying which was 2.5 times higher than for the general population (Saha et al., 2007). In addition, a meta-review of 20 reviews conducted by Chesney et al. in 2014 reported mortality risk in 20 mental disorders using data from over 1.7 million patients about more than a quarter of a million deaths. It was found that the mortality risk among people with schizophrenia and bipolar disorders was five times higher than among the general population. However, the quality of evidence of the included reviews varied (7 reviews were given low-quality rating scores, 12 had medium scores, and only one had a high score) (Chesney et al., 2014). People with SMI also have a higher rate of physical health problems than the general population, which makes them at risk of developing chronic physical health problems (Davies, 2013). Most data are from high-income countries and there is limited evidence from LMICs (World Health Organization & Fountain House Inspiring Communities for Mental Health, 2015). Cardiovascular diseases, respiratory diseases, and infections are the most common causes of death among people with SMI (Fekadu A et al., 2015; TM, 2011).

1.3.2 Burden on families

Due to the de-institutionalization trend and downsizing of large psychiatric institutions to provide mental health services in the community, which began in the mid-1950s in the UK and USA, then in European countries during the 1970s (Shen & Snowden, 2014), the family has become the main source of care and support for people with SMI. In the UK, more than 50% of people with schizophrenia have close relationships with their parents or partners (Roick et al., 2007). This proportion is higher in Africa (60%) and especially in Asian countries such as China (90%) (Berg-Weger, Rubio, Tebb, & Tebb, 2000; El-Tantawy, Raya, & Zaki, 2010; Mari, Razzouk, Thara, Eaton, & Thornicroft, 2009). Since then, the treatment approach has shifted from being individually based to being family based after people are discharged from inpatient mental health facilities (Ohaeri, 2003). The burden on caregivers is the

consequence of having to provide long-term care to family members with SMI (Caqueo-Urizar & Gutierrez-Maldonado, 2006). The definition of the caregivers' burden consists of two components: objective and subjective burdens (Hoenig & Hamilton, 1966). The objective burden is the impact on household activities and living standards such as the physical and emotional health of family members, financial difficulties, and changes in the family's daily activities (Caqueo-Urizar & Gutierrez-Maldonado, 2006). The subjective burden is caregivers' experiences of feeling overloaded, having a feeling of self-blame, and suffering stigma and discrimination (Awad & Voruganti, 2008; Caqueo-Urizar & Gutierrez-Maldonado, 2006; National Collaborating Centre for Mental Health, 2014).

Perlick et al. (2007) investigated 500 caregivers of patients with a bipolar disorder from eight mental health clinics in the USA using the Social Behavior Assessment Scale (SBSAS) to assess their burden. It was found that nearly 90% experienced moderate or high burdens from patients' problem behaviours. The authors also reported higher rates of physical and emotional problems, health risk behaviours, and health service utilization among those experiencing higher burdens of care (Perlick et al., 2007). Another study was implemented by Zhou et al. (2016) to examine the burden in relation to 443 patients with either schizophrenia or a bipolar disorder in a psychiatric hospital in China using a cross-sectional survey. The caregiver burden was measured by the Family Experience Interview Schedule (FEIS), which had been validated in China. It was mentioned that caregivers suffered from violent behaviour and suicidal risk. Caregivers were reported to perceive distress and disrupted routines from both disorders (Zhou et al., 2016). The two studies were conducted among caregivers of people with SMI recruited in clinical settings who were experiencing acute episodes; as a consequence, caregivers might perceive a greater burden than those in the general community.

1.3.3 Burden on society

1.3.3.1 Burden on the health care system

Most people with SMI have at least one relapse during their life, hence long-term treatment and health service use are required. In addition, they also have a higher risk of having comorbid medical illnesses than the general population (Liu et al., 2017). Salsberry et al.'s and Hackman et al.'s studies found that people with SMI used emergency medical services more than the general population (Hackman et al., 2006; Salsberry, Chipps, & Kennedy, 2005). Salsberry et al. examined the use of general medical services among 669 people with SMI using three years of Medicaid claims (1996–1998) data. The authors reported that approximately 80% of people with a schizophrenic disorder used an outpatient service or had at least one emergency department visit in the three-year period. However, there were some limitations of this study, including that service use which was paid for by other sources (such as out-of-pocket money) was not included. In addition, other problems were not considered in this study such as the clinical appropriateness of care, patient preferences, and service provider preferences (Salsberry et al., 2005).

In Hackman et al.'s study, 200 people with SMI who were receiving community-based psychiatric care were recruited randomly from patient lists. Around 40% had used emergency department services. This service use among people with SMI was associated with several factors such as age, comorbid diseases, smoking, and recent injury. However, the study did not take some relevant factors into account such as recall bias due to the use of self-report data and the purposes of the emergency department visit (Hackman et al., 2006). In order to improve the quality of care for people with SMI, a wide range of medical services – not just pharmacological treatment and monitoring of side effects, but also psychological interventions to support individuals with SMI and their families (Viron & Stern, 2010) – are required. As a result, these health care needs impose a huge burden on the health care system.

1.3.3.2 Burden on society

The reported negative impacts of SMI on society focus mainly on unemployment and criminality. People with SMI can experience long-term psychotic symptoms which affect directly their capacity to engage in an income-generating occupation. It is difficult for them to secure jobs and devote their capacity to society. The employment rate of people with schizophrenia is much lower than for the general population (National Collaborating Centre for Mental Health, 2014). In addition, people with SMI are more likely to be homeless or have casual accommodation (Taylor, 1987). Hence, it requires great social and financial support from the government to maintain their basic living standards.

In terms of criminality, a study in Sweden used the national registers dataset of 98,082 people diagnosed with schizophrenia or other psychoses. The authors reported that, over a 13-year period, 45 violent crimes were committed per 1000 inhabitants. So the attributable risk fraction of violent crime of people with SMI per 1000 population every five years was 5.2% (Fazel & Grann, 2006). The dataset was reported to have high quality; however, the study had several drawbacks. The dataset only included people who had ever been admitted to a hospital, so those with SMI in the community were not included (it was estimated that there were 10% of such patients in the community). In addition, the study defined violent crime by officially recorded conviction data, and other violent behaviours which were not recorded officially were excluded. Hence, the results from this study may underestimate the attributable risk fraction of people with SMI to violent crime (Fazel & Grann, 2006). A review was conducted by Soyka (1994) to examine the relationship between schizophrenic disorders and violent behaviours. This review was supported by other relevant publications in finding that people with schizophrenic disorders are at risk of violent behaviour due to abuse of substances or alcohol (Soyka, 1994). Studies which investigated this association suggested that the violent behaviours of people with SMI shared risk factors with those in the general population including

being young, male, single, of low socio-economic status, and substance dependent (Hiday, 1995; Marzuk, 1996; Monahan, Steadman, & Silver, 2001; Mullen, 1997; Stuart, 2003). However, these studies were conducted among high risk samples such as people who are hospitalized or with official conviction records which were not representative of the population of people with SMI. Therefore, the prevalence of perpetration of violence was higher among people with SMI than in the general population. In order to compare the crime rate between people with SMI and the general population, in 1998, Steadman et al. conducted a survey among 1136 adult patients with mental disorders in inpatient mental health facilities with a group of 519 people who were neighbours of these patients. After controlling for substance abuse, the prevalence of violence among the group with mental disorders was similar to that in the group living in their neighborhoods (Steadman et al., 1998). More evidence was reported to confirm that people with SMI did not have a higher violence perpetration rate than the general population (Stuart, 2003). Due to their symptoms and their limited social life, violent behaviours are more likely to be directed towards their family members (Monahan et al., 2001; Zhou et al., 2016) rather than the community. However, the misunderstanding of the association between mental disorders and violence leads to stigma in the general population against people with SMI.

On the other hand, the people with SMI are more likely to be victimized by violent acts in mental health facilities and in the community, especially in low and middle income countries (Mfoafo-M'Carthy & Huls, 2014; Poreddi, Ramachandra, Reddemma, & Math, 2013).

1.3.4 Economic impact

SMI has been found to create huge economic costs for families, and for the health care and social support systems. Due to the conditions of SMI, it is common that caregivers have to give up their jobs and time for income generation to take care of

people with SMI (Franks, 1990). Magliano et al. found in a sample of 236 caregivers of people with schizophrenia in mental health care centres in five European countries that carers spent an average of 6 to 9 hours per day providing informal care (Magliano et al., 1998). This cost is considered indirect, due to productivity loss. However, there is limited available evidence about this "invisible health care system" (Awad & Voruganti, 2008; Ohaeri, 2003).

In 1983, Weisbrod conducted the first cost–benefit analysis of a randomized controlled trial (RCT) to compare a hospital-based approach and a community-based approach, with a sample of 65 people for each approach. Productivity loss was mentioned as a small component under the family burden of the total cost. It was reported that the lost earnings due to the patient were $120 in the community-based program and $72 in the hospital-based program per year (Weisbrod, 1983). Mangalore and Knapp analyzed data from several sources such as the UK Schizophrenia Care and Assessment Program survey, Psychiatric Morbidity Surveys, Department of Health and other government publications. All costs related to schizophrenia were included, such as health and social care, informal care, private expenditure, lost productivity, premature mortality, and other public expenditure. In the total societal costs of GBP6.7 billion in 2004–2005, the burden of informal care accounted for GBP604.1 million. Although the study provided a comprehensive picture of the costs related to schizophrenia from a societal perspective, one of the most important limitations of this study was the data sources, which included different years and cost-calculation methods for different sources (Mangalore & Knapp, 2007).

Similarly, in an effort to estimate the costs of schizophrenia to society, the UK National Health Service, local authorities, and the Home Office, Guest and Cookson conducted a discrete event model based on a literature review of data sources over five years (1992–1997) with 7500 new cases of schizophrenia. The total discounted

cost to society of newly diagnosed patients with schizophrenia over their first five years with the illness was GBP862 million, of which the cost born by families due to productivity loss accounted for 49% of the total. The authors reported that the results were an underestimate due to inability to include several types of costs such as community psychological treatments, employment schemes, direct costs to carers, and care provided by social services (Guest & Cookson, 1999). In addition to the economic burden on the family of people with SMI, the study also found the that the National Health Service, local authorities, and the Home Office spent GBP441.2 million over five years, equivalent to GBP11,766 per patient per year (Guest & Cookson, 1999). Andrew et al. reported in their discussion paper that the cost of schizophrenia to English society is GBP11.8 billion per year (Andrew, Knapp, McCrone , Parsonage, & Trachtenberg, 2012). However, there is very little published evidence from LMICs about the economic burden of people with SMI.

1.4 Treatment of severe mental illness

In order to manage symptoms of SMI, two main strategies have been used: pharmaceutical therapy and psychosocial interventions.

1.4.1 Pharmacological treatment

Pharmacological treatments using antipsychotic medications is the most common treatment approach for SMI in both clinical and community settings. The effectiveness evidence of antipsychotic drugs in symptom reduction is well established. It is reported that this type of treatment is effective in both acute psychotic episodes and relapse prevention (Horst, Klein, Williams, & Werder, 2005). Byrne reported that typical antipsychotics (or first-generation antipsychotics) such as haloperidol and chlorpromazine were effective in addressing acute psychosis (Byrne, 2007). However, the first-generation antipsychotics were found to have adverse side effects such as weight gain, lethargy, sedation, and sexual dysfunction (National Collaborating Centre for Mental Health, 2014).

In an effort to address this limitation, atypical antipsychotics (second-generation antipsychotics) were developed. The impact of these medications was evaluated in a meta-review by McDonagh et al. (2017) which included 13 systematic reviews and 56 trials. The quality of evidence of the trials was low to moderate. It found that the first-generation antipsychotics had similar effects on the treatment outcome of schizophrenia (both core illness symptoms and negative symptoms) to the second-generation antipsychotics, but greater side effects. It was recommended that treatment choice should always be balanced against side effects. Some side effects such as weight gain and other metabolic problems may increase the risk of type 2 diabetes (McDonagh et al., 2017). The flow-on economic costs to individuals and families of different treatments are not yet well evaluated, including in LMICs.

1.4.2 Psychosocial interventions

The search identified 3659 abstracts, but only 12 RCTs with a total of 929 participants could be included in the review. Because of clinical heterogeneity, few meta-analyses were possible. The main outcome was the reduction of severity (response) of depression, not of psychosis. We found no evidence for the efficacy of monotherapy with an antidepressant or an antipsychotic. However, evidence suggests that the combination of an antidepressant plus an antipsychotic is more effective than antidepressant monotherapy (three RCTs; RR 1.49, 95% CI 1.12 to 1.98, P = 0.006), more effective than antipsychotic monotherapy (four RCTs; RR 1.83, 95% CI 1.40 to 2.38, P = 0.00001) and more effective than placebo (two identical RCTs; RR 1.86, 95% CI 1.23 to 2.82, P = 0.003). Risk of bias is considerable: there were differences between studies with regard to diagnosis, uncertainties around randomization and allocation concealment, differences in treatment interventions (pharmacological differences between the various antidepressants and antipsychotics) and different outcome criteria.

Given the emerging evidence of the side effects and health risks of pharmacological treatment, there has been growing interest in the effectiveness of psychosocial interventions (National Collaborating Centre for Mental Health, 2014). McDonagh et al.'s systematic review also reported that, compared to the usual standard of care, psychosocial interventions improved personal functioning, quality of life, core illness symptoms, and relapse among people with SMI (McDonagh et al., 2017).

Psychosocial interventions aim to support people with SMI in the community by improving their personal functioning and occupational and social skills, in order to be rehabilitated and reintegrated into the community (National Collaborating Centre for Mental Health, 2014; Spain Ministry of Health and Social Policy, 2009). The psychosocial interventions are targeted at different levels such as individuals with SMI, the family, the community, and health care services. According to the Clinical Practice Guidelines for Psychosocial Interventions for people with SMI, psychosocial interventions have four main components: psychological interventions, social intervention, service-level interventions, and interventions with specific subpopulations (Spain Ministry of Health and Social Policy, 2009). Among these components, the largest body of evidence is for psychological interventions to treat people with SMI (Byrne, 2007; Penn, Waldheter, Perkins, Mueser, & Lieberman, 2005).

Among the seven sub-components of psychological interventions (Spain Ministry of Health and Social Policy, 2009), cognitive behaviour therapy (CBT) has the most well-established research evidence in reducing psychotic symptoms and preventing relapse, especially in high-income countries (Almerie et al., 2015; Chiang et al., 2017; Gregory, 2010; Jauhar et al., 2014; Laws, Darlington, Kondel, McKenna, & Jauhar, 2018; Michail, Birchwood, & Tait, 2017; Oud et al., 2016; Tan, Lee, & Lee, 2018; D. T. Turner et al., 2018; Xia & Li, 2012). Other therapies, such as psychodynamic and psychoanalytical therapies, interpersonal therapy, supportive therapy, and cognitive

rehabilitation, are not strongly supported by research evidence (Buckley, Maayan, Soares-Weiser, & Adams, 2015; Josias, 2009; Leichsenring & Rabung, 2008; Malmberg, Fenton, & Rathbone, 2001; Swartz, Levenson, & Frank, 2012).

However, common drawbacks of psychosocial interventions are their lack of adaptation to culturally and linguistically diverse (CALD) groups and the shortage of trained human resources (Byrne, 2007). These disadvantages are more apparent and there is less feasibility for application of these approaches in LMICs. Therefore, family and psychoeducational interventions are the most common, feasible, and applicable psychological therapies in resource-constrained settings due to their family and community-based care, low cost, simplicity, and lower requirement for staff training (Byrne, 2007).

1.4.2.1 Family intervention

Research evidence reports a strong relationship between the family environment and the relapse rate of people with SMI (Schlosser, Pearson, Perez, & Loewy, 2012). People with schizophrenia suffering from a "negative family environment" such as over-protection, criticism, and domestic violence are more likely to relapse (National Collaborating Centre for Mental Health, 2003). In addition, most people with SMI are cared for by family members due to weak mental health services and the shortage of mental health professionals in LMICs (Bruckner et al., 2011; Shekhar Saxena et al., 2011). Therefore, there is a necessity to address the family care environment to improve the quality of life of people with SMI.

Family interventions are considered a core component by international mental health researchers. They support the combination of pharmacological therapy, family intervention, and Assertive Community Treatment (Falloon, 1999; Lehman AF, 1995) or social skills training (Hogarty GE et al., 1996). However, this therapy is generally not included in national mental health plans as a standard of care (Spain Ministry of Health and Social Policy, 2009). Family interventions aim to support caregivers of

people with SMI in terms of stress management, psychosis symptom management or problem-solving, and relapse prevention by delivering structured education to family members and caregivers with the participation of people with SMI (National Collaborating Centre for Mental Health, 2014).

Two Cochrane reviews have been conducted, one by Pharoah et al. (2010 and updated without change to the conclusions in 2012) and the other by Justo et al. (2007 and updated without change to the conclusions in 2010) for schizophrenia and bipolar disorders, respectively (Justo, Soares, & Calil, 2007; Pharoah, Mari, Rathbone, & Wong, 2010). The review by Pharoah et al. included 53 RCTs for schizophrenia and seven RCTs for bipolar disorders using family-based interventions. The quality of evidence of the included studies was low or moderate due to the lack of reporting on randomization, allocation concealment, blinding assessment of outcomes, and attrition rates. The results showed that family interventions were beneficial to people with schizophrenia in terms of reducing hospitalization and relapse rates, and increased pharmacological treatment adherence. However, due to the risk of bias of the included studies, the effectiveness of these interventions may be overestimated (Pharoah et al., 2010).

In Justo et al.'s review (2007), seven RCTs with a total of 393 people with bipolar disorders were included. The quality of the evidence was low to moderate. However, due to the diversity of interventions and outcomes, the findings are inconsistent. Only limited evidence of the efficacy of family interventions for bipolar disorders was available and therefore no conclusion could be drawn (Justo et al., 2007).

No economic evidence was reported in either of these two Cochrane reviews (Justo et al., 2007; Pharoah et al., 2010). There is limited evidence from low- and lower-middle-income countries.

1.4.2.2 Psychoeducational intervention

Psychoeducation refers to the provision of information to service users who have SMI in terms of the nature of their diagnoses, treatment, and access to recommended resources. It is often delivered in a group format with the involvement of family members and caregivers; therefore, it can overlap with family intervention (National Collaborating Centre for Mental Health, 2014).

Two updated reviews (one Cochrane and one systematic review) are available about the effectiveness of psychoeducational interventions for schizophrenia (Xia, Merinder, & Belgamwar, 2011) and bipolar disorders (Bond & Anderson, 2015). The review conducted by Xia et al. was published in 2010 and updated in 2012. This review included 44 trials implemented between 1988 and 2009 with a total of 5142 participants. The interventions were found to increase compliance with medical treatment in the short term, to decrease the relapse and readmission rates, and to improve social and global functioning of people with schizophrenia. However, the risk of bias was moderate; therefore, the positive effect of the psychoeducational interventions may be overestimated (Xia et al., 2011).

In 2015, Bond and Anderson implemented a systematic review to investigate the effectiveness of psychoeducation on relapse prevention for people with bipolar disorders. The review included 16 RCTs. The authors reported that group psychoeducation was effective in preventing both poles of relapse. In addition, the interventions were found to increase adherence to medication and knowledge about medications. Regarding the quality of evidence, there were uncertain risks of selection and attribution bias in several studies. A minority of included studies had a low quality of evidence. Further, the included studies had small sample sizes and used a variety of methodologies; hence, its conclusions on the effectiveness of these interventions for people with bipolar disorders could only be made with caution.

There is no clear evidence of the economic impact of psychoeducational intervention. Most evidence was generated in high-income countries.

1.5 Mental health in low- and middle-income countries

The WHO Mental Health Atlas (Department of Mental Health and Substance Abuse, 2017) and the WHO Assessment Instrument for Mental Health System (WHO AIMS) (World Health Organization, 2005) are the most comprehensive projects to collect data about the mental health systems in WHO member states. The Mental Health Atlas includes the most recent data from LMICs (2017), while the WHO AIMS data were updated in 2010. According to the Atlas, the mental health system is divided into four main components: governance; financial and human resources for mental health; mental health service availability and uptake; and mental health promotion and prevention (World Health Organization, 2018). The Atlas includes data contributed by 177 out of 194 WHO member states (a participation fraction of 91%). Ministries of health or related ministries in each country were requested to complete a 14-item questionnaire covering eight service development indicators: financial resources, human resources, capacity building, stakeholder involvement, service availability, inpatient care, service continuity, and social support (World Health Organization, 2014). The ministry that completed the questionnaires was recontacted to clarify any unclear responses. The final questionnaires were aggregated by WHO region. The data were analyzed to estimate the frequency distributions and central tendency measurements. All rates per 100,000 population were calculated using the UN population data for 2015. Indicators of global targets and service development were compared to those from 2014.

However, there are several limitations of this source such as missing data, unavailable data at a national level, different times of data completion, lack of specific information for particular populations (gender, children, adolescents, the elderly), and the quality of self-reported data, making impossible comparison with

other published information (World Health Organization, 2018). In addition, another limitation of the 2017 Atlas is that data are reported by WHO region (Africa, Southeast Asia, Western Pacific, Europe) and not by World Bank income group (low, lower-middle, upper-middle, and high-income countries). Hence, it is sometimes difficult to summarize the data for LMICs. The three main components relevant to this research are outlined below.

1.5.1 Mental health system governance

1.5.1.1 Mental health policies and plans

Mental health system governance is described by mental health policies or plans, mental health legislation, and stakeholder collaborations (World Health Organization, 2018). It was reported that the mental health governance in LMICs is generally poor, which is identified as the key barrier to addressing the huge burden and treatment gaps in these settings (Petersen et al., 2017). In addition to budget constraints, these countries are at higher risk of unstable political systems, military conflicts, and natural disasters, which seriously affects the prioritization of a comprehensive and complete mental health policy and plan (Votruba, Ziemann, Grant, & Thornicroft, 2018).

A mental health policy is defined as "an official statement of a government that conveys an organized set of values, principles, objectives, and areas for action to improve the mental health of a population" whereas a mental health plan is more specific and describes "an official statement of a government that conveys an organized set of values, principles, objectives, and areas for action to improve the mental health of a population" (World Health Organization, 2018). It is clear that mental health policies and plans both play crucial roles in strengthening the mental health system, especially in LMICs. They contribute to reducing the treatment gap and promote effective mental health service provision (Votruba et al., 2018).

More than 30% of people who live in LMICs are protected and included by mental health policies and legislation. This proportion is much lower than in high-income countries (approximately 90%) (World Health Organization, 2013). There are 40 African and Southeast Asian countries reported as having standalone mental health policies or plans out of 139 countries globally. Among these African and Southeast Asian countries, 31 countries updated their policy/plan in the last five years. It is estimated that 80% of African countries and 50% of Southeast Asian countries meet the five checklist items of human rights in their policies/plans. There were 50% of LMICs that reported including human and/or financial resources in their mental health policies/plans. This proportion is lower than those in low-income countries (66%) and upper-middle-income countries (57%) (World Health Organization, 2018).

1.5.1.2 Mental health legislation

Mental health legislation refers to a nation's laws about "civil and human rights protection of people with mental disorders, involuntary admission and treatment, guardianship and professional training and service structure". In total, 111 countries have standalone mental health laws globally. Fewer countries from African and Southeast Asian regions have these laws (44–50%) compared to other regions. Thirteen African and Southeast Asian countries updated their legislation in the last five years. In addition, less than 35% of LMICs had fully functioning authorities or bodies, while this percentage is more than 70% in high-income countries. Low-income countries reported the highest prevalence of not having an authority or independent body (60%), which was just over the prevalence in LMICs (56%). The lowest percentages of inspection and reporting to stakeholders of mental health services were found in Southeast Asian and African countries (World Health Organization, 2018).

Good mental health governance also depends on successful stakeholder collaborations. Relevant stakeholders include people from "social affairs/social

welfare, justice, education, housing and employment sectors (government or non-governmental agencies), media, academia/institutions, local and international non-governmental organizations who deliver or advocate for mental health services, private sector, professional associations, faith-based organizations/institutions, traditional/indigenous healers, service users and family or caregiver advocacy groups". Stakeholder formal collaboration is assessed by meeting at least two out of three requirements: (1) formal agreements or joint plans with partners; (2) available funding from or to these partners for service provision; and (3) regular meetings with partners (at least once per year). Among 126 countries which stated that they have formal collaborations globally, 87 were LMICs. Various types of formal collaboration were reported such as in the employment sector or the housing sector, and with traditional/indigenous healers. The proportions of collaboration with service users/family/caregivers/advocacy groups were highest in African countries (67%) and lowest in Southeast Asian countries (50%) (World Health Organization, 2018).

1.5.2 Human resources for mental health

LMICs have a shortage of mental health professionals. It is reported that almost half the world's population lives in settings where there is less than one psychiatrist per 200,000 population (World Health Organization, 2013). Among the 149 countries that reported their mental health workforce in the Atlas 2017, the number of mental health workers per 100,000 population differs by WHO region. In African countries the number is 0.9, while it is higher in Southeast Asian countries (2.5). According to World Bank income groups, there is a huge gap between low- (1.6) and lower-middle-income countries (6.2), upper-middle-income countries (20.6), and high-income countries (71.7). The average numbers of psychiatrists per 100,000 population in 2017 in low- and lower-middle-income countries were 0.1 and 0.5, respectively. This number is higher in upper-middle-income countries (2.1). There is a similar shortage in LMICs of other members of mental health workforces such as specialist

child and adolescent psychiatrists, mental health nurses, psychologists, social workers, occupational therapist, speech therapists, and other paid mental health workers. In general, there is a large gap in the size and constitution of the mental health workforce between LMICs and high-income countries, especially the number of psychiatrists per 100,000 members of the population (World Health Organization, 2018).

In 2011, in an effort to measure the deficit in the mental health workforce in LMICs by comparing the available mental health workforce with the need-based mental health workforce targets, Bruckner et al. analyzed data from 58 WHO member states and territories which were collected using the WHO AIMS assessment from 2005 to 2009. The authors reported a total shortage of 11,000 psychiatrists, 128,000 nurses, and 100,000 psychosocial caregivers in these settings. In total, 239,000 full-time mental health staff were needed to fill the workforce gap in LMICs. However, the data were considered at the regional scale and are not considered to be nationally representative (Bruckner et al., 2011). As the data reported in the Mental Health Atlas 2017 demonstrate, progress to address this shortage of mental health workers is slow and may require a clear and specific approach to guide LMICs from WHO and other related international mental health agencies.

1.5.3 Mental health service provision

According to the Mental Health Atlas 2017, mental health service provision consists of inpatient and residential care, and outpatient care (World Health Organization, 2018). These main mental health services are provided by the government and/or the private health sector. Overall, there is a huge gap between low- and lower-middle-income countries and high-income countries in terms of mental health service provision.

1.5.3.1 Community and family care

According to the Mental Health Atlas 2017, no evidence of services provided by the family, the community, or self-care was reported. Meanwhile, Rathod et al. mentioned the significant role of communities and families in sharing the burden of mental disorders (Shanaya et al., 2017). It is reported that most people with mental disorders are cared for by their family members. This statement is supported by a ten-year longitudinal study of 90 people with a first episode of schizophrenia who were recruited via the Department of Psychiatry in an Indian government general hospital. The follow-up rate was 84%. The authors reported that approximately 90% of people with schizophrenia were cared for by their family members. The family plays an important role in making the decision to seek diagnosis, treatment, and other daily life support such as employment and marriage (Thara, Henrietta, Joseph, Rajkumar, & Eaton, 1994).

The role of community and family care is also mentioned in an evaluation of the community mental health care program conducted by a local non-government organization in Vietnam. The study used secondary data from the health routine information system and data collected in a community-based survey in two provinces in Vietnam. The survey included 190 people with schizophrenia and 90 people with epilepsy who were managed by the community mental health program in the community. The authors found that all people with schizophrenia were cared for by family members or their relatives with support from community members. Family members were the key factor in providing care to people with schizophrenia in the community (Tuan, La, & Nguyen, 2007).

1.5.3.2 Inpatient and residential care

Inpatient mental health care includes mental health hospitals, psychiatric wards in general hospitals, and other specific inpatient mental health services (such as for children or elderly people). In general, the numbers of mental health hospital beds are under 0.05 per 100,000 population, especially in low- and lower-middle-income

countries (0.01 and 0.03, respectively). Upper-middle-income countries had a higher number of 0.07, which was still much lower when compared with high-income countries (0.17). Similarly, there was a moderate gap between low- (0.03) and lower-middle-income countries (0.07) and upper-middle-income countries (0.15) in terms of the numbers of psychiatric wards in general hospitals per 100,000 population. However, this gap increased when comparing LMICs with high-income countries (0.40). Around 90% of people with mental disorders spent less than one year in mental hospitals in low- and lower-middle-income countries. This proportion was lower in upper-middle-income countries (70%) and high-income countries (81%) (World Health Organization, 2018).

These data indicate that the purpose of mental hospitals may be different between the group of low- and lower-middle-income countries, and the group of upper-middle- and high-income countries. The duration of stay in mental hospitals is shorter than in upper-middle- and high-income countries. This means that mental hospitals are functioning as acute treatment wards in low- and lower-middle-income countries, while they are more likely to be used as long-term residential rehabilitation care in the upper-middle- and high-income group (Shekhar Saxena et al., 2011).

Community-based residential care facilities provide care to people with severe and chronic psychiatric symptoms in the community. This type of service is rare in LMICs (fewer than 2.0 beds per 100,000 population), whereas it is more common in high-income countries (23.3 beds per 100,000 population). The data suggest there is a need to develop community-based residential care service in LMICs as used successfully in high-income countries.

1.5.3.3 Outpatient care

Outpatient care consists of hospital outpatient departments, outpatient clinics, community mental health centres, and community-based mental health care centres

including day care centres. Similar to other mental health services, the numbers of outpatient care facilities per 100,000 population are under 0.1 in low-income countries and 0.5 in LMICs. This number is higher in upper-middle-income countries with 1.68. Among visits to outpatient care services, people in LMICs use hospital-based outpatient services more than community-based services. In contrast, high-income countries have higher visits to community-based facilities than hospital-based ones (World Health Organization, 2018).

1.6 Treatment gap in low- and middle-income countries

It is reported that around 80% of people with SMI in LMICs do not receive any type of treatment (Demyttenaere et al., 2004; World Health Organization, 2013). In Demyttenaere et al.'s (2004) survey of 60,463 adults in the community in 14 countries from 2001–2003, the authors found that the proportion of people with SMI who did not receive treatment in the previous 12 months was from 76.3% to 85.4% in LMICs, while this proportion was from 35.5% to 50.3% in high-income countries. However, the study encountered several limitations such as a low response rate, high level of missing data, and the exclusion of schizophrenia and other non-affective psychoses in the survey (Demyttenaere et al., 2004). According to the Atlas 2017 data, among the 52 LMICs that responded, the highest numbers of people per 100,000 population who received any type of mental health service over the previous 12 months were for psychosis. Bipolar disorder accounted for the lowest number of treated people in LMICs. Due to the poor mental health system in low-income countries, the numbers of people treated for psychosis and bipolar disorder were the lowest (67.7 and 18.5, respectively) when compared with lower- and upper-middle-income countries. There was not a large difference between the number of people with bipolar disorder receiving treatment in lower- and upper-middle-income countries (35.5 and 33.1, respectively). There was nearly a twofold difference among the numbers of people per 100,000 members of the population with psychosis treated in low- (67.7), lower-

middle- (134.3), and upper-middle-income countries (223.5) (World Health Organization, 2018).

However, in addition to several limitations of the survey as mentioned previously, the data which were contributed by 54 out of 110 LMICs may not be generalizable to all nations. In addition, the quality of the data from LMICs is also a concern. It was reported by WHO that nearly 20% of the data about psychosis and bipolar disorder treatment was not generated at the national level (with data of localities or specific sites). The data mainly came from the routine health information system. However, the mental health information systems in LMICs lack reliability and accountability. Some LMICs do not even have an information system to report basic mental health data (Bruckner et al., 2011).

SMI creates a huge burden on individuals, families, health care systems and society. In addition, SMI also has negative economic impacts on all levels. There are two main strategies to treat SMI, pharmaceutical therapy and psychosocial therapy. Pharmacological treatment using antipsychotics has been found to be effective to treat SMI; however, they have side effects. Psychosocial interventions are suggested to be more effective and have no side effects. Among psychosocial interventions, family and psychoeducational interventions are the most feasible to implement in LMICs. In terms of mental health in LMICs, there is poor mental health governance and a lack of mental health policies and plans. LMICs also face shortages of mental health professionals. There is a huge gap between LMICs and high-income countries in terms of mental health service provision, with no evidence of community and family care mentioned in the WHO Mental Health Atlas 2017. As a consequence, there is a large treatment gap for SMI in these resource-constrained settings.

CHAPTER 2 – INFORMAL INTERVENTIONS IN MENTAL HEALTH CARE IN LOW- AND LOWER MIDDLE-INCOME COUNTRIES

The burden of severe mental illness (SMI) on individuals, families, the health care system, society, and the economy is enormous in low- and middle-income countries (LMICs). There is limited mental health governance, a general shortage of mental health workers, and few mental health services in these resource-constrained settings. Therefore, there is a huge gap between needs for and access to mental health care for SMI, known as the treatment gap. In order to address this problem, providing mental health care at the primary level and using non-specialist and non-professional workforces in supporting people with SMI are argued to be cost-effective and culturally appropriate (Lancet Global Mental Health Group et al., 2007; Mari et al., 2009; S Saxena, Thornicroft, Knapp, & Whiteford, Sep 2007). This approach fits Objective Two of the World Health Organization (WHO) Mental Health Action Plan 2013–2020, which aims to provide comprehensive mental health care services in community-based settings (World Health Organization, 2013).

2.1 Integrating mental health into primary care

2.1.1 WHO rationale for integration

Primary mental health care is defined as mental health services provided at the primary general health care level. These services include first-line interventions and mental health care delivered by skilled primary social or health workers (World Health Organization & World Organization of Family Doctors, 2008).

WHO argues that there are seven main reasons to support the approach of integrating mental health into primary care. The first is that the "burden of mental disorders is great" all over the world. The prevalence of mental disorders (including common and severe mental disorders) varies from 4.0% to 26% The wide variation

in these prevalence estimates is attributed to differences in access to diagnostic tools, study design and epidemiological methods, culture, and reporting bias (World Health Organization & World Organization of Family Doctors, 2008). If the mental disorders are untreated, there is a substantial burden on individuals with a mental disorder (National Collaborating Centre for Mental Health, 2014), their families (Hoenig & Hamilton, 1966), and society (Taylor, 1987; Viron & Stern, 2010).

The second reason is the close relationship between mental and physical health. People with mental disorders are more likely to have physical health problems, perhaps as a result of diminished self-care, and vice versa. The third reason is the huge treatment gap for mental disorders. The treatment gap for SMI was nearly 50% in the prior 12 months in high-income countries and around 80% in LMICs (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974). This gap is mainly due to the lack of primary mental health care services provided in the community, especially in LMICs, leading to under-detection and under-treatment of mental disorders (Berti et al., 1992). The fourth reason is that primary mental health care increases access to mental health services because of the short distance to local clinics; provision of mental health promotion and education; early detection and treatment of mental disorders; and multi-sectorial collaboration in rehabilitation.

The fifth reason is respect for human rights. Primary care reduces the risk of human rights violations in psychiatric hospitals. In addition, mental health services provided at the primary level may reduce stigma and discrimination because mental health problems can be treated like physical health problems by seeing the same health workers and receiving mental health services in the same facility (World Health Organization & World Organization of Family Doctors, 2008). The sixth reason is the affordability and cost-effectiveness of this approach (Babor, Higgins-Biddle, Saunders, & Monteiro, 2001). Primary mental health care is less costly for service users (due to improved access) and for governments (less investment

required in human resources and treatment). The seventh reason is the good health outcomes that primary mental health care can create (World Health Organization & World Organization of Family Doctors, 2008).

2.1.2 WHO best practice examples

To illustrate how a range of mental health services can be integrated into primary care, 12 best practice examples were collected by WHO from 11 countries, which included 4 high-income countries (Argentina, Australia, Saudi Arabia, and the United Kingdom), 4 upper-middle-income countries (Belize, Brazil, Chile, and South Africa), one lower-middle-income country (Iran), and two low-income countries (Uganda and India). These examples illustrate various transformations in transferring the roles of diagnosis, treatment, follow-up, and rehabilitation to trained primary health care workers such as physicians, psychiatric nurses, general practitioners, and primary care nurses or midwives. Essential mental health services are delivered at the primary care level like physical health problems, with support and supervision from mental health professionals such as psychiatrists, psychiatric nurses, and psychologists. The scale of these practices ranges from district to national levels. There are also collaborations of the health sector with other government sectors (in the UK), village and community health workers (in Argentina, India, and Iran), and non-government organizations (in South Africa, Argentina, Australia, and Uganda) (World Health Organization & World Organization of Family Doctors, 2008).

However, although the local context, integrating process, and results of each example are well described, the methodology used to measure the effectiveness of these examples is not reported. Therefore, it is not possible to assess the quality of the evidence on which the conclusions are based. In addition, the roles of community care providers (such as non-government organizations, village health workers,

volunteers, and family members) are not elaborated on in the process of integrating mental health services into primary care in these examples.

After consultation with stakeholders and synthesizing the best practices in 12 countries, WHO presented ten essential principles for integrating mental health care into primary care (World Health Organization & World Organization of Family Doctors, 2008). The first two principles are the government's commitment to policies and planning, and advocacy activities to create changes in the attitudes and behaviours of stakeholders. Training of primary care workers with appropriate tasks and providing ongoing in-service support from mental health professionals are also needed. Access to psychotropic medication is an essential criterion for successful integration into primary care. In addition, integration is not an event, but a process with a strong focus on a mental health service coordinator. WHO (World Health Organization, 2013) asserts that this process must be considered in collaboration with other non-health sectors and also financial and human resources perspectives.

2.1.3 Programme for Improving Mental Health Care

In 2011, the Programme for Improving Mental Health Care (PRIME) was implemented in five countries (Ethiopia, India, Nepal, South Africa, and Uganda) with the aim of generating evidence on the integration of mental health care at the primary level. The program was funded by the UK Department of International Development (DFID) (Lund et al., 2012). Compared to the 12 examples reported in the WHO guidelines (World Health Organization & World Organization of Family Doctors, 2008), a comprehensive method was designed to evaluate the implementation and impact of the program in these five LMICs. Multidisciplinary methods were employed at population, district, facility, and patient levels. The evaluation framework consisted of four corresponding components: a repeat cross-sectional population-based survey to assess the coverage of services for depression or alcohol use for adults; a repeat cross-sectional facility-based survey to assess the

implementation of detection and treatment of depression and alcohol-use disorders; treatment cohorts to measure the change in individual outcomes for people with depression, alcohol-use disorders, psychosis, or epilepsy; and case studies to assess the implementation process in each district (Silva et al., 2016).

Although, there are different contexts and resources for mental health services among the low-income countries (Ethiopia, Nepal, and Uganda) and the middle-income countries (India and South Africa), these countries have similar characteristics such as high levels of engagement of stakeholders in the PRIME program, overloaded primary care levels, and health system structures (Lund, Tomlinson, & Patel, 2016). The program has started to develop specific district mental health care plans for each country. Overall, there are four main challenges that the program has encountered: limited resources for mental health, such as a shortage of mental health professionals; unavailability of standardized service-quality monitoring tools for LMICs; weak health system environments, such as poor health information systems; and diverse cultural environments and pathways to care (Lund, 2018).

PRIME is considered as a flagship program in global mental health which provides one framework of how to integrate mental health into primary care in LMICs. Since 2018, after seven years of implementation, the project team has released promising results. The findings showed that this approach is feasible in resource-constrained settings, however, it requires substantial investments in terms of training, supervision, and health system strengthening. In general, the program increased the contact coverage and functioning outcomes of people with SMI in Ethiopia, Nepal and Uganda. There was a significant improvement in clinical outcomes of people with depression in all participating countries (BrookeSumner, Selohilwe, Mazibuko, & Petersen, 2018; Programme for Improving Mental Healthcare (PRIME), 2018).

2.1.4 Task-shifting in mental health

Task-shifting is a key component of the approach of integrating mental health into primary health care. It is defined as "a process whereby specific tasks are moved, where appropriate, to health workers with shorter training and fewer qualifications" (World Health Organization, 2008). This process is reported to use existing human resources more efficiently and to overcome shortages of human resources in mental health care services.

2.1.4.1 Cochrane review of task-shifting

A Cochrane review to investigate the effectiveness of interventions delivered by non-specialist health workers for mental, neurological, and substance-abuse disorders in LMICs was published by Ginneken et al. in 2011 and updated in 2013. The review included 38 studies from 22 LMICs. The definition of "non-specialist health workers" was "non-mental health professionals", which included physicians, general practitioners, nurses, teachers, midwives, and community-level workers. The authors used the Cochrane Effective Practice and Organisation Care (EPOC) group format to assess the risk of bias of each study. The adapted Consensus on Health Economic Criteria (CHEC) were employed to assess the economic studies. The authors found that the quality of evidence was low or very low. The review reported, however, that there were promising results from using non-specialist health workers in addressing general and perinatal depression, post-traumatic stress disorder, alcohol-use disorder, and dementia. Hence, it is difficult to draw a strong conclusion about the effectiveness of task-shifting in addressing the burden of mental disorders in these countries (Ginneken et al., 2013).

2.1.4.2 Padmanathan review of task-shifting

Regarding the acceptability and feasibility of task-shifting, Padmanathan and Silva reported in 2013 in their systematic review of 21 studies that there were several factors involved when applying this process in LMICs. First, the non-specialist

workforce experienced significant distress due to their lack of competence in delivering mental health interventions. This factor suggests the necessity for adequate training and supportive supervision of non-specialists during interventions from mental health specialists. Second, the review found that there were insufficient incentives for the task-sharing workforce. Some studies included in the review reported that this was generally a voluntary workforce. This contributed significantly to the unsustainability of the process. The last factor was the unrecognized role of the non-specialist workforce by the health care professionals. Hence, there is a need for a clear role for this workforce in the health system. However, only 9 out of 21 studies had an adequate quality of evidence, while the remaining had an unknown quality (Padmanathan & Silva, 2013). The Effective Public Health Practice Project's quality-assessment tool and a specific checklist for observational study designs were used to assess the quality of evidence of the quantitative studies (National Collaborating Centre for Methods and Tools, 2008).

Theoretically, task-shifting is a promising approach to overcoming the human resource shortages in mental and primary health care. However, in practice there is not yet clear evidence of the acceptability, feasibility, and effectiveness of this approach in these resource-constrained settings. Further investigations are needed. There are large differences in terms of mental health attitudes, knowledge, and practices among community care providers (village health workers, teachers, laypeople) and other health workers (physicians, general practitioners, nurses, midwives) in LMICs. Therefore, evidence about community care providers and their capacity to provide support to people with mental disorders is also needed.

In summary, the two approaches of integrating mental health care into primary care services and task-shifting are expected to be able to address the large treatment gap in resource-constrained settings. However, evidence of the benefits of these approaches is not yet clear. In addition, the role of informal community care

providers who are not part of the health or social sectors (such as laypeople and caregivers) has not been described or examined separately from that of non-specialist health workers, although community care providers are the most common human resource in LMICs (Shanaya et al., 2017). Therefore, there is a need for further evidence about the effectiveness and the cost of the approach of shifting these tasks to community care providers.

2.2 Manuscript 1: Informal mental health interventions for people with severe mental illness in low and lower middle income countries: a systematic review of effectiveness

The systematic review of existing evidence about interventions delivered by informal community care providers for people with SMI in low and lower middle income countries. The chapter identifies the evidence gap of a feasible, acceptable and cost-effective intervention for people with SMI in resource-constrained settings. The systematic review - manuscript one was accepted for publication in the *International Journal of Social Psychiatry*.

Informal mental health interventions for people with severe mental illness in low and lower middle income countries: a systematic review of effectiveness

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Abstract
Background
The effectiveness of interventions for people with severe mental illness delivered by informal community care providers in low and lower middle income countries is not known. The aim was to conduct a systematic review of the impact of community-based interventions implemented by the informal sector for people with severe mental illness in these settings.

Methods
Five electronic databases (MEDLINE, EMBASE, PsycINFO, CINAHL, and Cochrane Central Register of Controlled Trials) were searched for English-language publications using both keywords and MeSH terms. All study designs were included.

Results
Five papers, reporting data from five studies conducted in four low and lower middle income countries in 2017, met inclusion criteria for the review. Of the five included studies, three had a before and after design, one was a randomized controlled trial, and one a qualitative investigation. Most interventions with a low-moderate quality of evidence used informal community care providers to deliver either self-help groups, traditional healing treatments, and/ or a rehabilitation program. The investigators reported data about improvements in the outcomes of intervention participants (psychosocial functioning, psychotic symptoms, and social inclusion) and positive impacts on their families (family's knowledge and skills of mental illness management, caregiving burden, social exclusion/stigma against people with severe mental illness, and financial burden). Cost-effectiveness of the intervention (in one study) found that it had a higher financial cost but greater effectiveness than the usual standard of care.

Conclusions
Although only a small number of studies were identified, the review provides promising evidence of the professionally-developed interventions for people with severe mental illness, delivered by the informal community workforce in low and lower middle income settings. Training and supportive

supervision for informal community care providers are crucial components of effective

interventions.

Introduction

Severe mental illness includes disorders characterized by psychotic symptoms such as schizophrenia and schizoaffective disorder, and severe forms of other disorders such as bipolar disorder that has a negative and serious impact on social and personal functioning. It requires caring from social and health resources (Spain Ministry of Health and Social Policy, 2009).

Medical treatment can reduce the severity of these conditions, however, people with severe mental illness (PSMI) may still experience poor self-care, and impaired memory, motivation, cognitive capacity and concentration (National Collaborating Centre for Mental Health, 2014). A person with a severe mental illnesses may also impose a large burden on family caregivers including financial difficulties due to the time required to care for mentally ill family members and limited opportunity to attend to their own health, which are reflected in increased depressive symptoms, and more physical health problems among them (Caqueo-Urizar & Gutierrez-Maldonado, 2006; DA et al., 2007; Papastavrou, Charalambous, Tsangari, & Karayiannis, 2010; Saunders, 2003; Tucker, Barker, & Gregoire, 1998).

Low and lower middle income countries are classified by The World Bank using gross national income (GNI) per capita, $US dollars. In 2018, there were 34 low-income countries with the GNI per capita of $995 or less, and lower-middle-income countries with the GNI per capita of more than $996 but less than $3,895 (The World Bank, 2018). Low-income countries had less than 1% of total world income, but represent nearly 20% of the global population (Taylor et al., 2015). These countries are associated with limited health care services, inadequate access to clean water and sanitation, a high prevalence of child malnutrition and poor living conditions, and risk of physical and mental disability (Banks, Kuper, & Polack, 2017).

Access to mental health care services differs between high-income, and low- and lower-middle income countries (LLMICs). In 2007, a World Health Organization (WHO) mental health survey conducted among 84850 adults in 17 high-, middle- and low- income countries reported that only 21.3% of PSMI in Nigeria and 11.1% in China had used mental health services in the prior 12 months. These rates are much lower than in high-income countries, including the USA (59.7%) and New Zealand (56.6%) (Wang et al., 2007). This difference

is attributed to a shortage of mental health professionals and limited publicly financed mental health care (Bruckner et al., 2011; Dixon, Mcdaid, Knapp, & Curran, 2006).

In high income countries, PSMI are commonly treated by a multi-disciplinary team which includes psychiatrists, psychologists, mental health nurses, and social workers. As PSMI in LLMICs often have limited access to mental health and cared for by their families and the community (Shanaya et al., 2017), WHO has promoted the approach of integrating mental health care into primary health care in these settings to reinforce the role of the community and family. WHO classifies community and family support as "informal services". These "informal community care providers" (ICCP) are not part of the formal health and welfare system and typically include teachers, traditional healers, police, village/community health workers, lay people, peers, self-help groups and caregivers (World Health Organization & World Organization of Family Doctors, 2008).

In 2013, a Cochrane review of interventions delivered by non-specialist health workers for people with mental, neurological and substance-abuse disorders in low and middle income countries by Ginneken et al. included thirty-eight studies from 22 countries. The definition of "non-specialist health workers" was non- mental health professionals including general doctors, nurses, paraprofessionals, teachers, and community-level workers. The review included randomized controlled trials, non-randomized controlled trials, controlled before-after studies and interrupted time series studies. Before-after studies with fewer than two control and two intervention sites; controlled and non-controlled interrupted time series studies with fewer than three time points both before and after the intervention were excluded. Ginneken et al. included first-level care/primary care or community care interventions for all mental health problems (common and severe mental disorders, neurological and substance abuse disorders). Overall, there was potential positive impacts on adults with depression and anxiety, perinatal depression, post-traumatic stress disorder, and dementia. The evidence of the use of non-specialist health workers on reducing post-traumatic disorder symptoms on children was uncertain. The review recommended that future systematic reviews should focus on the role of ICCP such as lay health workers who are a subset of non-specialist health workers and their role in supporting PSMI (Ginneken et al., 2013).

There are however diverse definitions of this cadre of workers in the published literature. Therefore, it is difficult to distinguish whether the "community health worker" is also considered to be an ICCP. According to Olaniran et al's (2017) systematic review, "community health workers" are the workforce with responsibility as frontline workers for health promotion activities. Based on their level of formal education and pre-service training, the review suggested that community health workers can be categorized into three groups: lay health workers (having little or no formal education with less than few weeks of informal training), paraprofessionals level 1 (having some form of secondary education and subsequent informal training) and paraprofessionals level 2 (having some form of secondary education and subsequent formal training lasting from few months to more than a year) (Olaniran, Smith, Unkels, Bar-Zeev, & Broek, 2017). Using this classification, lay health workers and paraprofessionals level 1 can be considered to be ICCP, but it might also include non-health workers who are engaged in providing care.

It is clear that, there is a need to understand whether interventions implemented by ICCP for PSMI in LLMICs are effective. Hence, this systematic review is conducted.

Methods

Protocol and registration

This review was registered with the PROSPERO (registration number: CRD42015019072). This database is managed by the National Institute for Health Research, Centre for Reviews and Dissemination at the University of York, UK.

Search strategies

The systematic review was guided by the PRISMA 2009 Checklist (Liberati et al., 2009). The search strategy was developed in consultation with a specialist librarian. The search terms including key words, and MeSH terms were chosen to address four domains: psychotic disorders AND informal community care providers AND low and lower middle income countries AND community-based interventions. Independent searches were conducted in five electronic databases: MEDLINE, EMBASE, PsycINFO, CINAHL, and CENTRAL. In

addition, the reference lists of papers meeting inclusion criteria were searched to identify papers that had not been identified in the search, (see Supplementary Table 1).

Eligibility criteria

Type of studies

All types of research design: randomized and non-randomized controlled trials, before and after studies, interrupted time series, pilot studies, economic evaluation and qualitative studies were included in the review. Only studies conducted in low and lower middle income countries as categorized by the World Bank in 2017 were selected (Bank, 2017). All identified studies published before 30th April 2018 in English were included.

Type of participants

Studies were included that investigated the effectiveness of mental health interventions delivered directly by ICCP which aimed to improve mental health outcomes among PSMI. ICCP included teachers, traditional healers, police, lay health workers, paraprofessionals level 1, lay people, peers, self-help groups and caregivers (World Health Organization & World Organization of Family Doctors, 2008). Severe mental illness included psychotic disorders such as schizophrenia, schizoaffective disorder, major depression, bipolar disorder (Kaltenthaler, Pandor, & Wong, 2014).

Type of interventions

Only interventions implemented in the community were included. Clinical and service interventions delivered by formal/professional health and welfare providers and systems were excluded.

Study selection and data extraction

The first author (TN) conducted the search. All identified studies were exported to Endnote X6.0.1 (Thomson Reuters, 2012) and duplicates identified and removed. Titles and abstracts screening was undertook by TN and SH. All full texts that were retrieved were read by all authors to ascertain whether or not they met inclusion criteria. Any disagreements were resolved by consensus. The following details were extracted for each included study: citation

details, study characteristics, sample characteristics, recruitment strategies, intervention and setting; outcome data/results.

Data items

All studies in the review were categorized by primary and secondary outcomes.

Primary outcomes

Primary outcomes are the improvements in psychotic symptoms and psychosocial functioning of PSMI.

Secondary outcomes

Secondary outcomes include: (1) Changes in caregivers'/family members' knowledge or/and caregiving practice; (2) changes in ICCP's knowledge and skills of mental illness; (3) changes in the knowledge, attitudes or behaviors of the community towards PSMI; (4) changes in quality of life for PSMI; and (5) cost analysis and cost-effectiveness of the intervention.

Risk of bias in individual studies

The quality of each study was assessed using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety Field guidelines (Kmet, Lee, & Cook, 2004) with two separate scoring systems (14 criteria for quantitative studies and 10 criteria for qualitative articles). Each item is scored from 0 to 2 (0 = "no", 1 = "partial", 2 = "yes"). Items which are "not applicable" are marked as "n/a" and excluded from the score calculation. The total score is the sum of the scores of all applicable items (maximum total score is 28 for quantitative studies and 20 for qualitative studies). The summary score was calculated by the total actual score divided by the total highest possible score (number of applicable items x 2). The summary score of each study ranges from 0 to 1.0 in which 1.0 indicates the highest quality (Kmet et al., 2004).

Synthesis of results

Due to the diversity of the included studies in terms of the interventions, study design, and data collection tools, a narrative synthesis was used to analyze the studies. A stepped approach

was followed, which included developing a theory, developing a preliminary synthesis, exploring relationship within and between studies, and assessing the robustness of the synthesis (Rodgers et al., 2009).

Results

Study selection

A total of 7785 articles were retrieved in the search and 16 additional papers were identified from the reference lists. After removing duplicates, the titles and abstracts of 5646 articles were screened in which 5604 studies records were excluded. The full-text of the remaining 42 papers was assessed and 37 articles were excluded. Five publications were included in the review (Figure 1) including four quantitative studies and one qualitative study.

Excluded studies

5642 studies were excluded because they did not meet the inclusion criteria. The reasons for exclusion were: not an intervention, not conducted in a LLMICs, intervention not for PSMI, and intervention not provided by an ICCP.
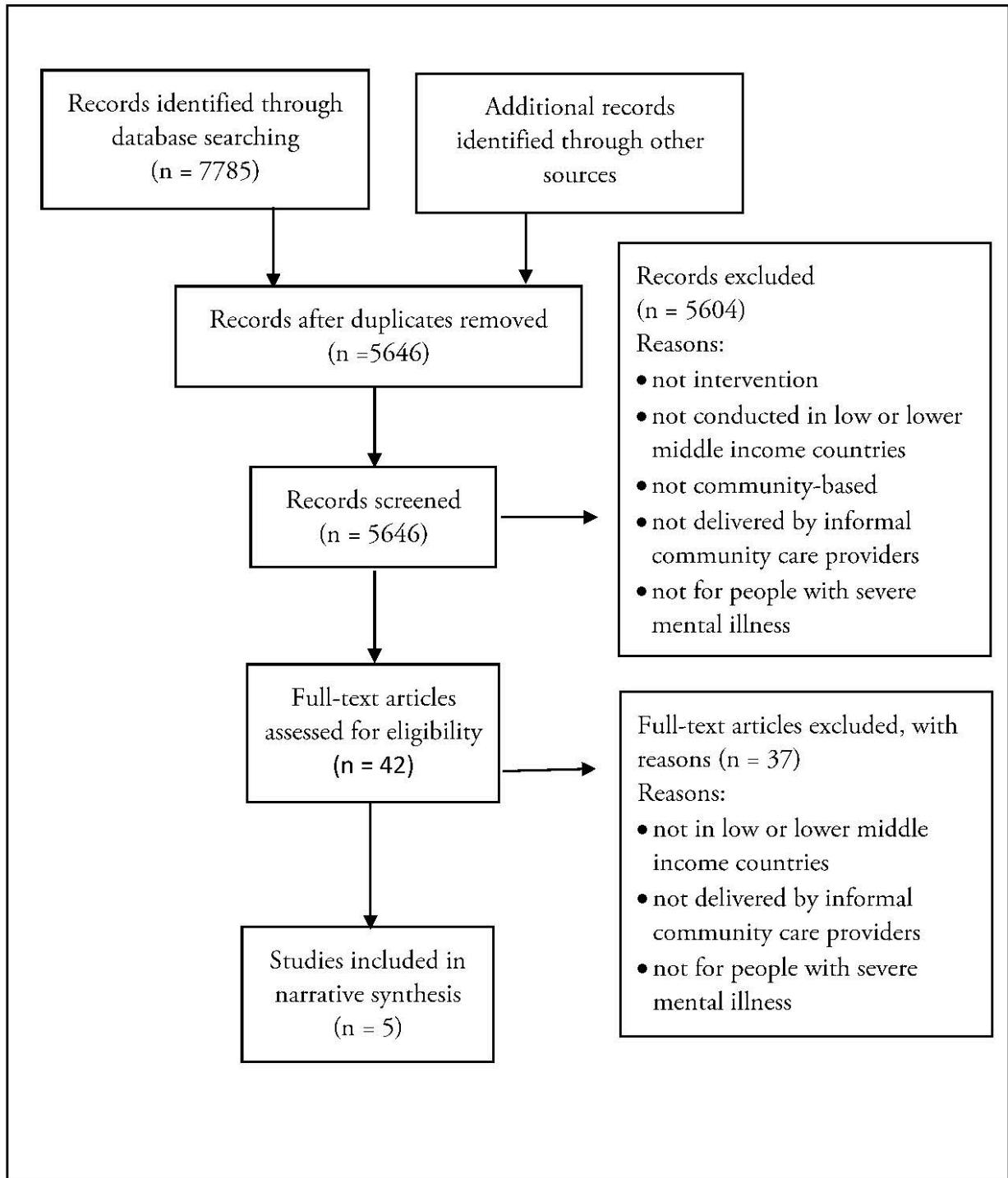
Figure 1 – Study flow diagram

Quality assessment

The summary scores ranged from 0.64 to 0.89 for the quantitative studies and was 0.45 for the qualitative study (Tables 1 and 2). Of the five studies, four did not provide a sufficiently detailed description of the ICCP, assessment tools used to measure the outcomes, methodology or the results.

Table 1 – Quality assessment of the quantitative studies

	Chatterjee et al, 2014 India	Lund et al, 2013 Kenya	Abbo, 2011 Uganda	Chatterjee et al, 2009 India
Question/objective sufficiently described?	2	2	2	2
Study design evident and appropriate?	2	1	1	1
Method of subject/comparison group selection or source of information/input variables described and appropriate?	2	1	1	1
Subject (and comparison group, if applicable) characteristics sufficiently described?	1	1	1	1
If interventional and random allocation was possible, was it described?	2	n/a	n/a	n/a
If interventional and blinding of investigators was possible, was it reported?	2	n/a	n/a	n/a
If interventional and blinding of subjects was possible, was it reported?	1	n/a	n/a	n/a
Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?	2	1	1	1
Sample size appropriate?	2	2	2	2
Analytic methods described/justified and appropriate?	2	1	1	1

Some estimate of variance is reported for the main results?	2	2	1	2
Controlled for confounding?	2	1	1	1
Results reported in sufficient detail?	1	1	1	1
Conclusions supported by the results?	2	2	2	2
Total score	25	15	14	15
Summary score	**0.89**	**0.68**	**0.64**	**0.68**

Table 2 – Quality assessment of the qualitative study

	Cohen et al, 2012 Ghana
Question / objective sufficiently described?	1
Study design evident and appropriate?	1
Context for the study clear?	1
Connection to a theoretical framework / wider body of knowledge?	1
Sampling strategy described, relevant and justified?	1
Data collection methods clearly described and systematic?	1
Data analysis clearly described and systematic?	0
Use of verification procedure(s) to establish credibility?	1
Conclusions supported by the results?	1
Reflexivity of the account?	1
Total score	9
Summary score	**0.45**

Methodological characteristics and main findings

Study location, method, and design

Overall, the nature of five included interventions mainly focused on medical treatment (Chatterjee et al., 2014; Chatterjee, Pillai, Jain, Cohen, & Patel, 2009), traditional healing

(Abbo, 2011), rehabilitation (Chatterjee et al., 2014; Chatterjee et al., 2009), and self-help groups (Cohen et al., 2012; Lund et al., 2013). All studies aimed to improve the outcomes of PSMI by increasing: adherence to medical treatment (Abbo, 2011; Chatterjee et al., 2014; Chatterjee et al., 2009; Cohen et al., 2012; Lund et al., 2013) or participation in rehabilitation programs (Chatterjee et al., 2014) provided by formal health care services; family knowledge and engagement in caring for mentally ill members (Chatterjee et al., 2014; Cohen et al., 2012); social inclusion (Chatterjee et al., 2014; Chatterjee et al., 2009; Cohen et al., 2012); access to micro-credit or financial aid (Chatterjee et al., 2014; Cohen et al., 2012); and reducing social stigma (Chatterjee et al., 2014); and financial difficulties of the families through livelihood programs (Lund et al., 2013).

Of the five included studies, three were before and after designs, one was a qualitative study, and one was a randomized control trial. The randomized controlled trial compared facility-based care with facility-based plus community – based care (Chatterjee et al., 2014). The three quantitative studies did not have a control or comparison group (Abbo, 2011; Chatterjee et al., 2009; Lund et al., 2013).

Among the five studies that met inclusion criteria, all were community-based. Two studies were conducted in India (Chatterjee et al., 2014; Chatterjee et al., 2009), and one each in Ghana, Uganda, and Kenya (Abbo, 2011; Cohen et al., 2012; Lund et al., 2013). Uganda is a low-income country, an all the other studies were conducted in lower-middle income countries. All studies were implemented in local government administrative areas such as districts, and regions, all with populations of at least 100,000 people. In most settings there were no existing psychiatric services (Chatterjee et al., 2009) or services were very sparse (for example one psychiatric clinical officer per three million population) (Abbo, 2011; Cohen et al., 2012; Lund et al., 2013).

All five studies focused on people who were 16 years and older (Abbo, 2011; Chatterjee et al., 2014; Chatterjee et al., 2009; Cohen et al., 2012; Lund et al., 2013). Severe mental illness in four of the studies included schizophrenia, mania, bipolar disorder, psychotic depression and other psychotic/neurological disorders. The other study in India recruited only people with schizophrenia (Chatterjee et al., 2014). The sample sizes ranged from 146 to 4791 PSMI

(Abbo, 2011; Chatterjee et al., 2014; Chatterjee et al., 2009; Cohen et al., 2012; Lund et al., 2013).

Two studies reported economic evaluations. Chatterjee et al. (2014) conducted an cost effectiveness and cost utility studies alongside the intervention to compare with the usual standard of care (Chatterjee et al., 2014). Lund et al. undertook a "cost analysis" which measured participants' quality of life including individual items (overall quality of life and health satisfaction) and four domain scores (physical health, psychological health, social relationships, and environment); and economic well-being including family income and income generation (Lund et al., 2013).

Study characteristics

Characteristics of the ICCP

Of the five included studies, three recruited community-based health workers, one employed traditional healers and one used local Basic Needs staff (Chatterjee et al., 2014; Chatterjee et al., 2009; Lund et al., 2013). Basic Needs is a non-government organization (NGO) in Kenya with the mandate of promoting social and economic development in mental health care. Among the three studies which recruited community health workers, two studies included community health workers who had at least secondary school level education and good interpersonal or communication skills (Chatterjee et al., 2014; Chatterjee et al., 2009); while the other study included community health workers who could read and write in the local language in Kenya, and had experience in community voluntary work (Lund et al., 2013). However, two studies did not provide specific details about the pre-service training and other related skills of the community health workers. Cohen et al.'s intervention was implemented by local NGO staff who collaborated with Basic Needs in Ghana. However, only limited characteristics of the direct workforce who organized and supported the self-help group were reported (Cohen et al., 2012). Abbo's study employed traditional healers who were local residents, had a close relationship with the community, and shared similar cultural beliefs about health and illness. Their roles included the diagnosis of specific mental illnesses and

providing various treatments for psychotic disorders using herbs and appeasing the spirits (Abbo, 2011).

Workforce training

Three articles outlined the training provided for the ICCP to conduct the intervention (Chatterjee et al., 2014; Chatterjee et al., 2009; Lund et al., 2013), one intervention did not provide any training (Abbo, 2011) and the other paper did not include any details about training (Cohen et al., 2012). Two Chatterjee et al.'s studies conducted in India provided a 4 or 6 week training about the recognition, management, and treatment of people with mental disorders/schizophrenia (Chatterjee et al., 2014; Chatterjee et al., 2009). Lund et al in addition to the mental health training, provided the community health workers with 5 days of training about self-help group facilitation (Lund et al., 2013). Only a limited description of the training provided for the local NGO staff in the self-help group study of Cohen et al. was included (Cohen et al., 2012). In Abbo et al's study, the traditional healers did not receive any training as part of the study intervention (Abbo, 2011).

Supervision/on-going technical support

Two studies reported that continued supervision was provided to the ICCP, while the remaining studies did not provide specific details about it. In Chatterjee et al.'s study (2009), the ICCP were supervised by cluster coordinators every week and program psychiatrists every month; and received continuing supervision from the outreach psychiatrists (Chatterjee et al., 2009). Similarly, community workers were supervised by trained intervention coordinators and psychiatrists in the other study by Chatterjee et al. (2014), and provided with on-going education and training (Chatterjee et al., 2014). Details were not provided about any on-going support for the ICCP in the two self-help group interventions conducted by Cohen et al. and Lund et al. (Cohen et al., 2012; Lund et al., 2013). Abbo reported in her paper that the traditional healers worked independently without any professional support from the formal system (Abbo, 2011).

Effect of the interventions on the primary and secondary outcomes

Instruments used

The four quantitative studies used several psychometric instruments to assess mental health outcomes including the Indian Disability Evaluation Assessment Scale (IDEAS) (Chatterjee et al., 2014; Chatterjee et al., 2009), Positive and Negative Symptoms for Schizophrenia Scale (PANSS) (Abbo, 2011; Chatterjee et al., 2014), General Health Questionnaire 12 items (GHQ12) (Lund et al., 2013), Global Assessment of Functioning scale (GAF) (Lund et al., 2013), Young Mania Rating Scale (YMRS) (Abbo, 2011), and Montgomery-Asberg Depression Rating Scale (MARDS) (Abbo, 2011). Among these instruments, only the IDEAS was validated in India. However, methodology and results of the validation study were not reported in the papers (Chatterjee et al., 2014; Chatterjee et al., 2009). Psychiatric symptoms were measured by PANSS, GHQ12, YMRS, and MADRS (Abbo, 2011; Chatterjee et al., 2014; Lund et al., 2013). IDEAS and GAF were designed to assess the disability and functioning of people with a mental illness (Chatterjee et al., 2014; Chatterjee et al., 2009; Lund et al., 2013). Three out of the four interventions used at least two instruments to assess changes in mental health outcomes (Abbo, 2011; Chatterjee et al., 2014; Chatterjee et al., 2009; Lund et al., 2013). The WHO Quality of Life Brief version (WHOQOL-BREF) consisting of 26 items was used in the Kenyan study to assess the quality of life of people receiving the intervention across individual items and four broad domains (Lund et al., 2013). Only Chatterjee et al. (2014) reported the randomization process in allocating participants in the intervention and control groups, and masking procedure in assessing the outcomes of the study (Chatterjee et al., 2014). The remaining studies did not provide specific information about whether the outcomes were assessed blind (Abbo, 2011; Chatterjee et al., 2009; Cohen et al., 2012; Lund et al., 2013).

Reference period

The duration of the interventions ranged from 6 months to 46 months. The assessment of the self-help groups in Ghana occurred three years after implementation (Cohen et al., 2012). Three studies assessed outcomes at different time points: baseline (Abbo, 2011; Chatterjee et al., 2014; Chatterjee et al., 2009; Lund et al., 2013); midpoint (three months (Abbo, 2011),

twelve months (Lund et al., 2013); endpoint (six months (Abbo, 2011), twelve months (Chatterjee et al., 2014), 24 months (Lund et al., 2013). Chatterjee et al.'s community-based rehabilitation programme in rural India (2009) implemented two surveys: baseline and endpoint (46 months)(Chatterjee et al., 2009).

Improvement in primary outcomes

All five studies reported significant improvements in terms of disability scores, psychotic symptoms and personal functioning (Abbo, 2011; Chatterjee et al., 2014; Chatterjee et al., 2009; Cohen et al., 2012; Lund et al., 2013). Psychotic symptoms reduced significantly as a result of the interventions implemented in India after 12 months follow-up (Chatterjee et al., 2014), and in Uganda after 3 months and 6 months (Abbo, 2011). Symptoms of mania and depression, measured by the YMRS and MADRS, also improved in the intervention implemented in Uganda (Abbo, 2011). Similarly, GHQ12 scores significantly decreased over two years in the study in Kenya suggesting an improvement in mental health status (Lund et al., 2013). The study conducted by Cohen et al. only reported qualitative description of the outcomes (Cohen et al., 2012).

The IDEAS scores in both studies conducted in India were higher among the intervention groups compared to the control groups (Chatterjee et al., 2014; Chatterjee et al., 2009) which indicate an improved status in self-care, interpersonal activities, communication and understanding, and work. Lund et al.'s study also reported an increase in GAF scores which suggests an improvement in the functioning of the intervention participants (Lund et al., 2013).

Improvement in secondary outcomes

Access to health service/treatment adherence

Among the five studies, four reported a positive effect on pharmacological treatment adherence such as attendance at rehabilitation sessions and consistently/regularly taking medications. Abbo and Chatterjee et al.'s studies reported the specific adherence rate to the medical treatment or rehabilitation (Abbo, 2011; Chatterjee et al., 2014; Chatterjee et al.,

2009). However, measurements of the adherence varied among studies. Chatterjee et al. (2014) utilized a 5-point ordinal scale rating which ranged from non-adherent to fully adherent to the antipsychotic medication(Chatterjee et al., 2011; Chatterjee et al., 2014). Chatterjee et al. (2009) defined the adherence using two categories: complete adherence (total duration of non-adherence is less than 90 days in a year) and non-adherent (total duration of non-adherence is more than 90 days in a year) (Chatterjee et al., 2009). Abbo assessed the treatment adherence in terms of the use of both medical services and traditional healing practice at three and six month follow-up. However, the definition of adherence was not provided. Chatterjee et al. (2014) provided reasons for non-adherence which included the lack of money (Chatterjee et al., 2009).

Family knowledge/ engagement

Three studies reported the effect on family knowledge about mental disorders and engagement in supporting their mentally ill family member. Chatterjee et al. (2009) reported that 83.5% of families met at least three criteria of engaging with the intervention such as attending psycho-education sessions, partnership in the care plan provided by the community-based rehabilitation workers, and supervising adherence to medications (Chatterjee et al., 2009). Chatterjee et al. (2014) reported an improvement in family knowledge about schizophrenia (Chatterjee et al., 2014). Cohen et al. described the specific actions that families took to support PSMI including encouragement and monitoring medication adherence (Cohen et al., 2012).

Family caregiving burden

Two studies reported a reduction in the caregiving burden of families having PSMI such as receiving physical support and advice from peers in terms of caring for PSMI or for the whole family (Cohen et al., 2012), and a significant reduction in the need for receiving help from carers among PSMI after the intervention so that their caregivers were more able to undertake paid employment outside of the home (Lund et al., 2013).

Social exclusion/ stigma

Three of the five studies discussed the impact of the intervention on the social exclusion or discrimination and experiences of stigma among PSMI. Chatterjee et al. (2014) reported no significant improvement in the stigma that families and PSMI experienced, however, families in the intervention group were more likely to disclose that their family member had a mental health problem to mental health professionals or to the community (Chatterjee et al., 2014). Chatterjee et al. (2009) reported an increase in social inclusion with greater proportions (more than 80%) of PSMI participating in community activities (Chatterjee et al., 2009). Cohen et al. reported an increase in social inclusion such as being allowed to use the same water vessels, to share meals and to lead community prayers (Cohen et al., 2012).

Financial support/ income generation

Three studies reported an improvement in the financial status of families having PSMI. Among those, one described that the self-help group in Ghana provided financial support for medication, food, and other items when the families were experiencing financial difficulties (Cohen et al., 2012). One identified an improvement in the economic status of families in terms of their assets gained during the intervention such as access to local funds for livelihood programs (Chatterjee et al., 2009). One study reported an increase in families' monthly average income after the intervention as a result of the engagement of their mentally ill family members in income generation or productive work (such as housework, studying) (Lund et al., 2013).

Economic evaluation

Chatterjee et al. (2014) undertook a cost-effectiveness evaluation of the intervention to identify the amount required to achieve a point reduction in the score measured by PANSS and IDEAS in the intervention compared to the usual standard of care. The cost of a one point reduction in psychotic symptoms measured by IDEAS was INR 9923 (approximately US$142). The cost of a one point improvement in disability measured by PANSS was INR 2514 (US$36) (Chatterjee et al., 2014). These findings suggest that the combination of community-based and facility based care had a higher cost but greater effectiveness in the intervention group than the facility-based care alone (usual standard of care) in the control

group. Lund et al. reported that the intervention was associated with an increase in the summed quality of life score of PSMI as measured by the WHOQOL-BREF. The intervention also led to increases in the average monthly income of families having PSMI (Lund et al., 2013).

Discussion

This is the first review of evidence about the use of ICCP such as family members and lay health workers to deliver interventions for PSMI in the community in LLMICs. Only five studies were identified from 4 countries and included in the review. Although, there was a variation in the implementation and evaluation of the interventions between the studies included in the review, the findings provide consistent evidence that interventions for PSMI delivered by ICCP in LLMICs are effective.

Several limitations should be acknowledged. First, the review only included papers published in English and therefore relevant papers published in other languages were missed. Second, all interventions included in this review (one qualitative and four quantitative studies) were not heterogeneous with outcomes assessed using different instruments, precluding meta-analyses.

Quality of the evidence

Five interventions for PSMI in four LLMICs met inclusion criteria for this review. Apart from Chatterjee et al's 2014 study which yielded (Chatterjee et al., 2014) good quality of evidence, the quality of evidence was low to moderate. All authors acknowledged the main limitations of their studies, including lack of a control group or other comparator, and assessment instruments for which local psychometric properties had not been established. These contributed to the lower quality ratings of the studies. They might be attributable to the relative lack of research capacity and the limited research funding available in these settings. This finding is consistent with the assessment of studies included in a Cochrane review about non-specialist health worker interventions for mental, neurological and substance-abuse disorders in low and middle-income countries. The Cochrane review found that the quality of evidence among the included studies was also low and moderate due to the lack of specific

details of sequence generation and allocation concealment, not controlling for the difference in the baseline characteristics, lack of local reliability of the outcome assessment tools, insufficient description of study outcomes, and small sample sizes, each of which could increase risk of bias (Ginneken et al., 2013).

Intervention effectiveness

The interventions addressed the mental health, and social and economic well-being of PSMI living in the community. The findings indicate the effectiveness of such interventions in both the short-term (within one year) (Abbo, 2011; Chatterjee et al., 2014) and longer-term (more than one year) (Chatterjee et al., 2009; Cohen et al., 2012; Lund et al., 2013). These interventions provided a comprehensive approach with a combination of components to improve physical health, pharmaceutical treatment, social inclusion, self-care, and work ability (Abbo, 2011; Chatterjee et al., 2014; Lund et al., 2013). Therefore, it contributed to improve the primary outcome (the psychotic symptoms, disability and personal functioning) among intervention participants.

These interventions also contributed positively to the secondary outcomes: improved adherence to medical treatment by PSMI (Abbo, 2011; Chatterjee et al., 2014; Chatterjee et al., 2009; Cohen et al., 2012), enhanced family support and engagement in providing care for PSMI (Abbo, 2011; Cohen et al., 2012; Lund et al., 2013), improved social inclusion of PSMI (Chatterjee et al., 2009; Cohen et al., 2012) and reduced financial burden on families (Chatterjee et al., 2014; Chatterjee et al., 2009; Cohen et al., 2012; Lund et al., 2013) .

Informal community care providers' capacity and training needs

All included interventions were developed and designed by the mental health professionals with the main focus on adherence to medical treatment. ICCP were the implementing workforce to deliver the interventions in the community. The findings suggest that this approach is feasible to support PSMI in LLMICs. After receiving training courses of basic mental health symptoms and treatment, and supportive supervision, ICCP were able to provide a wide range of activities such as rehabilitation (Chatterjee et al., 2014), livelihoods

programs such as training in agricultural or business skills (Lund et al., 2013), medical treatment adherence (Abbo, 2011; Chatterjee et al., 2014; Chatterjee et al., 2009; Cohen et al., 2012; Lund et al., 2013), promoting social inclusion (Cohen et al., 2012; Lund et al., 2013), reducing social stigma (Chatterjee et al., 2014), and access to micro-credit or financial aid (Chatterjee et al., 2009; Cohen et al., 2012; Lund et al., 2013). It appears that ICCP are able to provide mental health support and services that are not currently available or able to be provided by formal health care services in many resource-constrained settings. Chatterjee et al. (2014) reported that this approach was sustainable in the long-term and suitable to the WHO's mhGAP intervention (Chatterjee et al., 2014).

Economic impact

Findings from Chatterjee et al.'s study (2014) suggest that the combination of facility-based and the community – based care was more costly than the facility-based care alone (usual standard of care), however, the improvement in health outcomes was greater. The costs to implement the intervention mainly resulted from supportive supervision activities (Chatterjee et al., 2014). Although the evidence is limited (only one out of five studies), it still provides promising evidence of the economic impact of the intervention delivered by the ICCP.

Implications for mental health policy, service delivery organization, and workforce

Mental health policy and service delivery organization

The findings of this review also suggest that strengthening the ICCP in addition to formal mental health services may be a sustainable approach to address severe mental illness in LLMICs. This approach is consistent with Rathod et al.'s discussion on the provision of mental health services in LLMICs. The authors mentioned that community and family care are the most significant opportunities in providing support and care to people with mental disorders in these countries (Shanaya et al., 2017).

Training of mental health workforce

The findings of this review indicate the importance of providing the ICCP with basic knowledge about mental illness and associated treatment can contribute to address the mental

health workforce gap to deliver support and services to PSMI in the community (Bruckner et al., 2011). Such training could be provided through a combination of pre and on-the-job short-term courses with well-defined content materials.

Conclusion

The findings of this systematic review suggest the potential effectiveness of trained ICCPs in improving mental health, and social and economic well-being of PSMI in the community in LLMICs. Nevertheless, due to the small number of studies reviewed, further research about the role of the ICCP in providing mental health support and services in this setting is vital.

Declaration of Conflicting Interests

The author(s) declare no potential conflicts of interests with respect to the research, authorship, and/or publication of this article.

Supplementary material

Supplementary material is available for this article online.

Table 3 – summary of included studies

Country Author Year	Aims	Study design	Participants	Direct workforce	Training & supervision of the direct workforce	Nature of interventions
India (Chatterjee et al, 2014) (Chatterjee et al., 2014)	To compare the clinical effectiveness of two models for people with schizophrenia: Combination of facility –based care and collaborative community-based care, and the facility-based care alone.	Randomised controlled trial	Participants having the primary diagnosis of schizophrenia aged 16-60 years old 187 participants - intervention group 95 participants– control group	Community health worker	6 weeks covering three modules of schizophrenia and treatment.	Needs assessment & individualized treatment plans Clinical reviews Psychoeducation Adherence management strategies Promotion of physical health Dealing with stigma & discrimination Individualised rehabilitation strategies Linkage to self-help groups and local supports Networking with community agencies
Kenya (Lund et al, 2013) (Lund et al., 2013)	To evaluate mental health, economic and quality of life outcomes of	Pre and post design	203 people with a severe mental or neurological disorder - Age ≥18 years	Community-based health worker	- Mental health training - 5 days training in self-	Identifying the symptoms of mental disorders Refer individuals to local primary care psychiatry clinics

	intervention participants				help group facilitation	Facilitate self-help groups
Uganda (Abbo, 2011) (Abbo, 2011)	To investigate the treatment outcomes of traditional healing practice for severe mental illness	Pre and post design	146 patients having psychotic illness	Traditional healer	No training	Diagnosis of mental disorders Treating psychosis using herbs, appeasing the spirits and divination
India (Chatterjee et al, 2009) (Chatterjee et al., 2009)	To describe the functional outcomes of the intervention participants and its determinants	Pre and post design	236 people with psychotic disorders - 79 people < 30 years old - 87 people from 31-40 years old - 70 people ≥ 41 years	Community-based rehabilitation worker	4 weeks training in the recognition and management of people with mental disorders	Medical review Need assessment & individual care plan Psychoeducation Rehabilitation Community awareness Networks to promote reintegration
Ghana (Cohen et al, 2012) (Cohen et al., 2012)	To explore the effectiveness of the self-help groups to the clinical, social, and economic well-being of the intervention participants	Qualitative research after the intervention	71 Self-help groups consisting of families with a member who has severe mental illness (4791 patients)	Local NGO staff	Not specified	Social and financial support: loan program financial support for families with acute financial needs physical assistance in caring for patients while their caregivers were busy

Table 4. Main findings of 5 included interventions for people with severe mental illness

Study	Baseline assessment and outcome measures	Main findings
Chatterjee et al., 2014 (Chatterjee et al., 2014)	Baseline: Sociodemographic characteristics, treatment status, and duration of illness. Outcome (assessed at 12 months after recruitment): Primary outcome: Psychiatric symptoms using PANSS (positive and negative symptoms, and general psychopathology) Disability using locally validated IDEAS (self-care, interpersonal activities, communication, and work). Secondary outcome: Adherence to the intervention: a 5-point scale developed for the study Discrimination and stigma: Discrimination and stigma scale Caregiver knowledge and attitude: The knowledge about schizophrenia interview scale Family burden of caring: The burden assessment schedule Caregiver experiences of stigma and discrimination: a modified version of the item willingness to disclose the illness Cost of illness schedule: health economic outcomes	Primary outcomes: Total PANSS score was lower at 12 months in the intervention group than those in the control group. More people had improved IDEAS scores in the intervention group than in the control group (75 [48%] vs 28 [35%], adjusted odds ratio [OR] 1.84, 95% CI 0.97–3.46; p=0.06). Secondary outcomes: Adherence: participants reported complete adherence to drugs (61%), participants reported adherence most of the time (23%). Stigma and discrimination: Clinically and significantly reductions in reported experiences of stigma and discrimination in both groups (p=0.004). Caregiver knowledge and attitude: Mean total score on the knowledge about schizophrenia interview scale (adjusted mean difference 0.34, 95% CI –0.28 to 0.96) Family burden of caring: Mean total score on the burden (–0.04, –0.18 to 0.11) Caregiver experiences of stigma and discrimination: No effect of the intervention on the mean score. Cost of illness schedule: The ICER* based on the PANSS is INR 2514. The ICER based on the IDEAS is INR 9365.
Lund et al., 2013 (Lund et al., 2013)	Baseline: Sociodemographic characteristics Outcome (assessed at 12 months and 24 months after recruitment) Primary outcome:	Primary outcome Mental health status: Significant improvement in GHQ score (21.5 [95% CI: 20.2–22.8] to 6 [95% CI: 4.8 – 7.2], (p = 0.01).

	Mental health status using GHQ-12 Functioning using GAF scale Secondary outcome Quality of life: WHOQOL- BREF Engagement in income generation or productive work: Productive work was defined as any work without monetary benefit and included household work, studying or other work without remuneration. Income generation of the family Requirements for care in the home	Functioning: Significant improvement in GAF score (78 [95% CI: 75.5–80.3] to 94 [95% CI: 90.7–97.3], (p = 0.01). Secondary outcome: Quality of life: Significant improvement in the summed WHOQOL scale (39.5 [95% CI: 38.6–40.4] to 57.2 [95% CI: 56.2–58.3] (p = 0.01) Engagement in income generation or productive work: 45.3% to 64.0%, p<0.01). The average monthly income increased from a median of 700 Kenyan Shillings (Ksh700) (95% CI: 589–811) to Ksh2000 (95% CI: 1821–2178) (p = 0.01) over 2 years A significant reduction in receiving help from caregivers in the home, from 37.0% at baseline to 8.0% at 12 months, and 7.5% at 24 months. A significant reduction in the caregivers who left their jobs to care for the mentally ill members from 13.8% (baseline) to 2.0% (12 months), and 0.6% (24 months).
Abbo, 2011 (Abbo, 2011)	Baseline: Sociodemographic characteristics Outcome (assessed at 3 months and 6 months after recruitment) Primary outcome: Psychiatric symptoms using PANSS for schizophrenia, YMRS for mania, MADRS for depression. Secondary outcome: Traditional healing and medical services use	Primary outcome Psychiatric symptoms: Reduction at the 3- and 6-month follow- ups. The percentage reduction was greatest for PANSS[2] (30%, 40%), YMRS[6] (21%, 28%), MADRS[7] (29%, 20%). Secondary outcome: Traditional healing and medical services use concurrently by over 80% of the subjects
Chatterjee et al., 2009	Baseline: Diagnosis of mental disorders using ICD-10, duration of illness, historical information, treatment	Primary outcomes:

(Chatterjee et al., 2009)	discontinuation, and support provided to the study participants by their families. Outcome (assessed at 5 years after recruitment): Primary outcome: Disability score – locally validated IDEAS including four domains: Self-care, interpersonal activities, communication and understanding, and work. Secondary outcomes: Social activities participation Assets acquired including livestock, farming equipment, home appliances and home improvement activities. Process indicators: Adherence to medication and membership of the SHGs	Improved IDEAS scores: 50% of participants had marked improvement, 40% showed moderate improvement, and 10% showed minimal improvement. Secondary outcome: Social activities: Majority of participants took part in normative community activities (more than 80%). Economic assets: Additional livestock (63%), home appliance (26%), secured employment (68.2%). Process indicators: Engagement with the intervention (83.5%), members of SHGs (65.7%)
Cohen et al., 2012 (Cohen et al., 2012)	Baseline: No assessment Outcomes (assessed at approximately 3 years after the first self-help group (SHG) was established). The outcomes were reported in qualitative data. Outcomes: Results of medical treatment Number of membership in 10 self-help groups Operation of the SHGs: Activities, frequency of meetings Loan program Social supports Social inclusion	Outcomes: Improved self-care Fewer psychotic symptoms Improved sleep Seven SHGs had large increases, two had more families about to join, and one had a decrease in members SHG operation: Meeting once a month, dues collection every month, financial support to families having acute financial needs (bereavement, births, weddings). Loan program: Loan ranged from US$ 60 to 120, repayment rate was one-third Social supports: SHG members shared the burden on looking after ill members, cooking for families; shared advice and experience in taking care of mentally ill members

		Increased social inclusion: Greater understanding of mental disorders among the community, one SHG member was allowed to lead community prayers, less SGH members suffering from stigma from their own families (using the same water vessels and sharing meals). Other results of biomedical treatment: Improved adherence to taking medications; family encouraged ill service users to take medications; caregivers to monitor the care of their ill family members

SHG, self-help group; IDEAS, Indian Disability Evaluation Assessment Scale; PANSS, Positive and Negative Symptoms for Schizophrenia Scale; GHQ12, General Health Questionnaire 12 items; GAF, Global Assessment of Functioning scale; WHOQOL, WHO Quality of Life Brief version; YMRS, Young Mania Rating Scale; MADRS, Montgomery-Asberg Depression Rating Scale; ICER, Incremental cost-effectiveness ratio.

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Supplementary Table 1 - Search strategy

Concept 1	OR	psychiatr*/psychotic disorders/psychosis disorders
		schizophrenia/ bipolar/ mania/ manic/ paranoid
Concept 2	OR	voluntary workers/ caregivers/ volunteer/ community network
		lay health worker/ lay person/ helper
		nonprofessional worker/ non medical worker/ non health worker
		community worker/ village health worker
		informal carer/ self help group/ support group/ teacher/ school trainer
Concept 3	OR	developing/ underdeveloped/ under-developed/ emerging/ less-developed/ least developed/ less-economically developed/ least-economically developed/ less-affluent/ least-affluent
		countr*/ nation*/ region*/ econom*) OR (third-world*/ thirdworld*/ 3rd-world*
		Afghanistan* orAngola* or Armenia* or Bangladesh* or Benin* or Bhutan* or Bolivia* or Burkina* or Burundi* or Cabo Verde* or Cape Verde* or Cambodia* or Cameroon* or Central African or Chad* or Comor* or Congo* or Cote d'Ivoir* or Djibouti* or Egypt* or El Salvador* or Eritrea* or Ethiopia* or Gambia* or Georgia* or Ghana* or Guatemala* or Guinea* or Guyan* or Haiti* or Hondura* or India* or Indonesia* or Kenya* or Kiribati* or Korea* or Kosov* or Kyrgyz Republic or Lao* or Lesotho* or Liberia* or Madagascar* or Malawi* or Mali* or Mauritania* or Micronesia* or Moldova* or Mongolia* or Morocc* or Mozambi* or Myanma* or Burmese or Nepal* or Nicaragua* or Niger* or Nigeria* or Pakistan* or Papua New Guinea* or Paraguay* or

		Phillipines or Filipino or Rwanda* or Samoa* or Sao Tome* or Senegal* or Sierra Leon* or Solomon Island* or Somalia* or Sudan* or Sri Lanka* or Swazi* or Syria* or Tajikistan* or Tanzania* or Timor* or Togo* or Uganda* or Uzbekistan* or Vanuatu* or Vietnam* or Viet Nam or West Bank or Gaza or Yemen* or Zambia* or Zimbabwe*
Concept 4		intervention study/intervention*/trial/ case-control studies/ cohort studies/ controlled before-after studies/ feasibility studies/ intervention studies/ pilot projects/ randomized controlled trial/qualitative studies
AND		Concept 1 AND concept 2 AND concept 3 AND concept 4

CHAPTER 3 – CHALLENGES IN INTEGRATING MENTAL HEALTH INTO PRIMARY HEALTH CARE

Manuscript 2: Challenges in integrating mental health into primary health care

The manuscript describes the mental health system in Vietnam in terms of policy and plans, workforce, and service provision system. This chapter also highlights the challenges of integrating mental health into primary care in Vietnam. The chapter reveals policy evidence gaps that provide a rationale for this PhD research. Manuscript two is a book chapter which is under review with *Innovations in Global Mental Health*.

Challenges in Integrating Mental Health into Primary Care in Vietnam

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Abstract

In order to alleviate the burden of mental health problems in low and middle-income countries, the World Health Organization has developed a guideline to integrate mental health into primary health care. The framework was used to assess the Vietnam mental health system and the progress of integrating mental health into primary care. Vietnam has a weak mental health system governance with no mental health policy and legislation and an ineffective action plan. Like other developing countries, Vietnam has also facing custodial institution approach in providing mental health services. Formal mental health services provided by the health and social sectors were dominant. Informal services including community, family, and self-care were ignored by the public sector. In addition, the shortage of mental health workforce in terms of the quantity and the quality is one of the main concerns of the government.

Based on the context, four main key challenges were discussed including the lack of mental health policy and legislation; inappropriate service organization and planning; human resource shortage; and lack of evidence-based interventions. Recommendations are raised to address these challenges to promote the implementation of the primary mental health care in Vietnam.

1. Introduction

Mental health problems among people living in low and middle-income countries (LMICs) have become a concern for global health because they contribute to around 75% of the global burden (1, 2). In the total burden of disease in LMICs, neuropsychiatric disorders make up to nearly 10% (2). However, these countries face a wide range of challenges including resource scarcity, mental health workforce shortages, hospital- rather than community-based services, and serious human rights violations (3). Consequently, approximately 80% of people with severe mental disorders cannot access treatment or health services (4). A survey conducted in 17 countries by the World Health Organization (WHO) reported that the proportions of people using mental health services in the last 12 months due to mental health problems in LMICs were 8.3% in Nigeria and 16.3% in South Africa (5). Similarly, among people with severe mental disorders, the prevalence of people who did not receive treatment within the prior 12 months ranged from 76% to 85% in LMICs. This proportion of people with mild mental disorders was from approximately 90%-99.5% in less developed countries (6).

In order to address the huge treatment gap in LMICs, there were substantial efforts in the global context to alleviate the mental health burden such as the WHO's Mental Health Gap Action Program (1), Global Mental Health program of Grand Challenges Canada (7), Collaborative Hubs for International Research in Mental health established by the National Institute of Mental Health USA (8), the Programme for Improving Mental Health Care (PRIME) (9), the APEC Digital Hub for Mental Health (10), and the Emerging mental health system in low and middle income countries program (Emerald) (11). All these endeavors have focused on strengthening the mental health

system by integrating the mental health system into general health care and encouraging local mental health innovations to address the treatment gap in LMICs. Among these efforts, in 2008, WHO and the World Organization of Family Doctors (WONCA) developed the approach of integrating mental health into primary care which has shown a potential effectiveness for the mental health problems in LMICs. The publication provided an evidence-based model, the "pyramid for an optimal mix of services for mental health". The model was expected to provide adequate mental health services to address those challenges in LMICs (12). The purposes of the model are to ensure that the population in need receives adequate and affordable treatment in a cost-effective manner, to protect human rights and to alleviate stigma and discrimination against people with mental disorders. The model divided the mental health service system into two main components: formal and informal health system. The formal health system is defined as all services delivered by health professionals such as community health workers, psychologists, social workers and psychiatrists. The informal health system includes informal community services and self-care which were provided by community care providers who are not part of the formal health and welfare system (for examples: traditional healers, teachers, non-government organization, lay people, and user and family associations. This model provides potential advantages for LMICs which are moving towards community-based models of mental health care.

Nearly 60% of LMICs have insufficient mental health professionals to respond effectively to the mental health burden, where the shortage of psychiatrists, nurses and psychosocial care was 67%, 95% and 79%, respectively (13). To alleviate the problem, informal services provided by non-professional staff

who do not work in formal health and welfare systems were developed in LMICs (12). In this approach, there is a task-shifting process from professional staff to non-professional workers such as traditional healers, teachers, non-government organizations, user and family associations, and lay people. Task-shifting was advocated and recommended by WHO to tackle the shortage of health workers (14). Although there are still different opinions of the acceptability and feasibility of this approach (15), it cannot be denied that non-specialist interventions contribute to the prevention and treatment of common and severe mental disorders in LMICs, with promising emerging evidence of their impact (16).

2. Socioeconomic characteristics of Vietnam

Vietnam has a population of 90.493.400 - the second highest population in Southeast Asia (17). Vietnam is an area of approximately 330.991 square kilometers and borders to China, Laos, and Cambodia. More than 70% of the population live in rural areas and 80% of the population speaks Vietnamese. Among 54 ethnic groups, Kinh is the largest. In 1975, after the reunification of the North and South of Vietnam, the social and economic systems were managed by the communist government. The new government had worked hard to alleviate the damages of the War. Vietnam was significantly influenced by the Soviet Union, as illustrated by the Soviet-style central planning for the economy. The government directly controlled the economy and businesses. The economy depended heavily on agriculture and publically-funded factories. Trade with foreign countries was limited and the private sector was scarce. Due to the development of the global economy, in 1986 there was a political and economic reform, called Doi Moi. This reform

changed the economy from central planning to a competition–led market. Doi Moi boosted the national economy and social system. Since applying the market-driven socialist theme, the living standard of people has improved significantly.

Currently, Vietnam is categorized by the World Bank Group as a lower middle-income country (18, 19). The total fertility rate is 2.09 (2014) and the proportion of health expenditure to GDP is 6.0 (2013). Private businesses have been established and grown considerably. On the other hand, the reform has widened the gap between the rich and the poor and there have been negative effects on the people in the lowest socioeconomic positions. Before the reform, the government distributed essential living items such as food, clothes and access to education and healthcare services equally. Therefore, the majority of the population had similar incomes and were able to access the same health and social services for free (20). After Doi Moi, income inequalities between urban and rural areas increased and led to greater disparities in access to social and health services. Poor people have limited access to fee-based services. Private sector services are profit-oriented, and private health services are more prevalent in urban areas where people can afford to pay.

3. Vietnam's health system

Along with the economic renovation, in 1989 there was a major health care reform which included both public and private sectors. The free medical care system changed to become a user-fee based system. It directly impacted on the improvement of treatment quality and on health infrastructure. It also contributed to reducing the financial burden carried by the government. However, the introduction of user-fee services has had a negative impact on

the most economically disadvantaged groups. The financial autonomy policy for hospitals has forced them to increase the price of health services.

In 2015 70% of the population were covered by health insurance, but it only paid for limited health services. Although there has been an increase of health insurance coverage, out-of-pocket payments have also increased to a high level. There are several reasons for this problem. First is the weakness of primary health care, which leads healthcare users to go to higher level services or to private clinics or hospitals for a better quality of treatment. Users have to pay out of pocket for these services. Second is that the health insurance company does not fully cover the expenses of the health care providers, so that the providers have to collect a service fee from users to balance their own costs. The final reason is that health service users and providers avoid using the health insurance system because of its very complicated guidelines and administrative requirements, which incur long delays in claiming money (21).

The administrative health system in Vietnam is categorized into four levels (central, provincial, district and commune). From the provincial to commune level, all health agencies are under the management of the local authority – the People's Committee.

The central level includes the Ministry of Health (MOH), and other national agencies which are managed directly by the MOH such as national hospitals and institutes (22). The MOH is in charge of developing national health laws, policies, and plans to shape the health services and strategies. National hospitals often collaborate with medical universities and are responsible for providing medical treatment. National institutes mainly focus on medical

research and the direction of health care activities at sub-national levels. The MOH manages and supervises all operations at the provincial level (23).

The provincial level is the main level for the implementation of national plans and regulations. The provinces are encouraged to be fiscally self-sufficient and the provincial People's Committee is the chief agency. Hence, the provincial Department of Health (DOH) has a responsibility to support the People's Committee in implementing national health policies and plans. In return, the People's Committee has the role of allocating funds for health activities. Under the provincial DOH, there are sub-departments in terms of population and family planning, food hygiene-safety, health prevention (Centre for Preventive Medicine/ Centre for Disease Control); medical service administration and rehabilitation (provincial hospital, traditional medicine hospital, other specialist hospitals), forensic medicine (Centre for inspection on forensic medicine), medical quality control (Drug, Cosmetic and Food Quality Control Centre), Centre for Medical Review, medical education (Medical University, medical colleges, medical school), and district health centres (24).

Primary health care is a combination of district and commune level services. Before 2016, there were three main health agencies at the district level, including the health division, general hospital, and the centre for preventive medicine. Since 2016, the district health centre is the managing agency of the district hospital and centre for preventive medicine. In addition, the district health centre is in charge of providing technical support to the commune health stations. Some districts may not have a district general hospital (25).

Commune health stations are at the grassroots level and are the first service that people can access in the health system. Each commune has a commune health station which is responsible for providing basic health treatment and conducting national programs (such as maternal and child care, family planning, immunization, food safety, nutrition, reproductive health care) directly to the population. This level is supported by village health workers in delivering health communication, health surveillance, and other national program activities to families and individuals in the commune (26).

4. Mental health governance

Mental health legislation is the legal framework to support the implementation of mental health policy. The aims of the legislation are to promote the human rights of people with mental disorders, to improve the quality of mental health services, and to strengthen the informal mental health services. In general, a lack of mental health legislation leads to many negative consequences on both the mental health system and service users, such as low quality mental health services, unaffordable mental health care costs for people in need, human rights violations, severe stigma and discrimination against mental disorders, lack of mental health prevention, and social exclusion of people with mental disorders (27).

Although there have been advocacy efforts to develop local mental health law, Vietnam is one of 35 countries that do not have any mental health laws (28). Mental health legislation was covered partially in related laws such as the disability law (2010), the law on health examination and treatment (2009), the law on the elderly, law on children (2016), law on health insurance (2014), and law on pharmacy (2016). However, these laws do not provide a specific legal

framework for mental health care. Therefore, there is still an urgent need of developing a mental health law for Vietnam.

After reviewing all official documents issued by the Ministry of Health and the Ministry of Labour, Invalids and Social Affair (MOLISA), there is no document that meets the requirements of a mental health policy as defined by WHO in terms of providing "a vision, values, principles, objectives and a broad model for action" (29). A mental health plan was reported to be established in 1999 and revised in 2010. The plan consists of timelines, details of funding, services, resource organization and of integration into primary health care (30). The primary mental health care model is also included in the Mental Health Protection for Community and Children project which is a component of the National Target Programs on Health. It is clear that, without a mental health policy, the plan does do not provide specific information about the overall organization of mental health services towards the primary integration approach. Mental health promotion and the prevention of common and severe mental disorders were not mentioned in the plan (31). Due to the recommendations from local and international NGOs working in the mental health area, and the support from WHO, a draft of the Mental Health Strategy for the period of 2016-2025 was developed by MOH in consultation with other ministries such as MOLISA, the Ministry of Education and Training, the Ministry of Finance, and the Ministry of Justice (32). The recent version of the draft, published on the MOH website, has shown that the strategy focuses on socialization and improving mental health hospitals and training human resources. The primary integration approach was not emphasized in the draft.

There are around 19 official documents related to mental health issued by government agencies including laws, decrees, and decisions (33). Most documents focus on treatment and caring for people with severe mental illness. Mental health promotion and mental disorder prevention are rarely mentioned. Since 2009, there was a noticeable change in government. Two important documents were issued by the Prime Minister that directly impacted the mental health system in Vietnam. The first document was Decree 930, which concerned the building and upgrading of psychiatric hospitals in disadvantaged areas using government funding. This Decree was managed for implementation by the MOH (34). The second one was Decision 1215, which addressed the social support and rehabilitation of people with mental illness and people with mental disorders via a community-based program. The Decision aimed to support 90% of mentally ill patients then being cared for by inpatient mental health facilities and their families, to provide psychological counselling and social services to 90% people with common mental disorders, and to assist all families with a mentally ill member via a community-based model. The term "people with mental disorders" refers to people suffering from both common mental disorders (depression, anxiety) and severe mental illness (35). This Decision was managed by MOLISA. It is clear that there was a different vision between MOLISA and MOH, the two main ministries providing mental health support and services to the population. MOH aims to improve and strengthen their mental health hospitals, while MOLISA has shown its vision in providing social support towards the community-based approach. Decision 1215 is a clear movement of mental health policy in Vietnam towards the WHO recommendations.

There is no self-help organization or advocacy group for people with mental disorders, psychosocial disabilities and their families or carers in Vietnam. Just a small proportion of service users receive information related to mental health care and its services. Thus, there is limited involvement of them in the mental health policy-making procedure (Kelley Lee, 2015).

5. Mental health service delivery

As according to the optimal mix of services developed by the WHO, the mental health service system in Vietnam is divided into two main components: Formal and informal health components (figure 1).
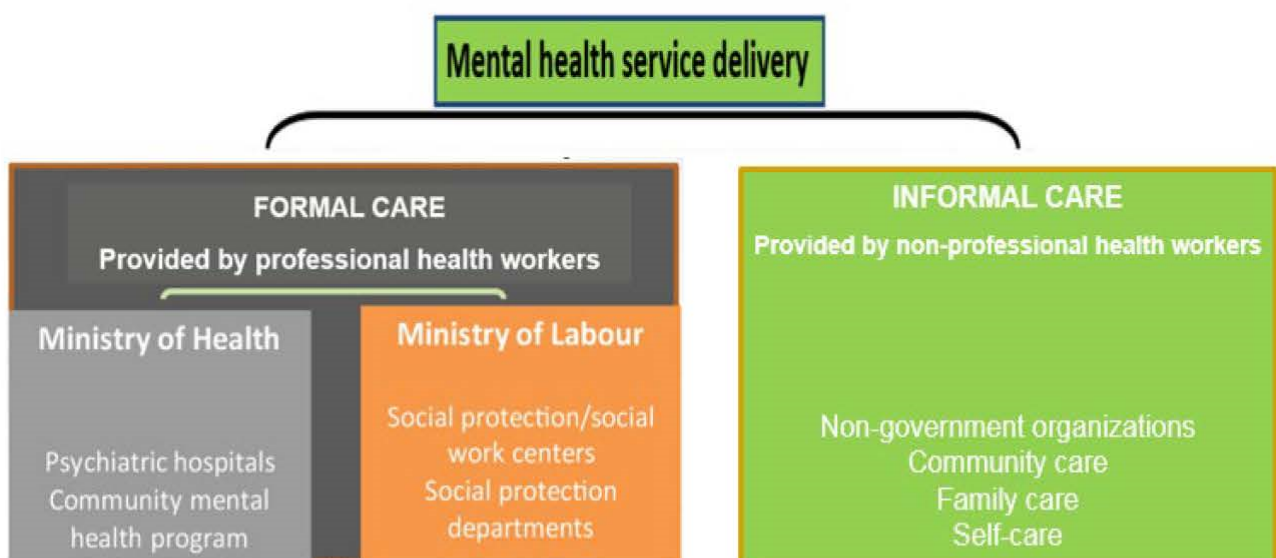
Figure 1: Mental health service delivery in Vietnam

The formal health system is managed by MOH and MOLISA. MOH is responsible for the prevention and treatment of mental disorders. MOLISA has a responsibility for rehabilitation and social services for vulnerable populations, including people with a mental illness.

5.1 Health sectors

In general, mental health services are provided by MOH through mental health facilities and the national community-based mental health project.

5.1.1 Mental health facilities

Similar to the health system, the mental health system is also divided into four levels. At the central level, under the management of the Medical Services Administration Department (MOH), there are two national psychiatric hospitals: the National Institute of Mental Health and the National Institute of Forensic Psychiatry. Of these national hospitals and institutes, the National Psychiatric Hospital No. 1 is based in Hanoi and is in charge of drafting national mental health policies to submit to the MOH. In addition, the hospital also provides technical support and supervision to other mental health inpatient facilities in Vietnam. The National Psychiatric Hospital No.2 has the responsibility to provide technical services to Southern provinces in Vietnam. The National Institute of Mental Health, located in Bach Mai General Hospital in Hanoi, is a unit that conducts training for the postgraduate degree and implements research projects. This institute also provides treatment to the people living in the inner Hanoi city. The National Institute of Forensic Psychiatry is responsible for judicial forensic psychiatry. In addition, the Institute is in charge of providing treatment for patients who commit a crime or other voluntarily admitted patients with mental disorders.

The provincial level is an important level to implement the mental health action plans and guidelines issued at the national level. There are 36 provincial psychiatric hospitals with more than 60000 beds in 63 provinces in Vietnam. Therefore, in provinces that do not have mental health hospitals, mental health services are provided by psychiatric departments within the

provincial general hospitals or the provincial centres for social disease prevention or provincial centres for preventive medicine. These mental health facilities are responsible for providing inpatient and outpatient treatment, participating in the forensic examination as requested, and implementing the community mental health programs (36).

The Research and Training Centre for Community Development (RTCCD) - a local non-government organization, conducted a cross-sectional study in two randomly selected provinces (one from the Northern provinces, one from the Southern provinces) in 2014 in order to provide evidence for the implementation of Decision 1215. The survey included three components: mental health service providers, mental health policy, and mental health service users. A mixed method was employed. The components of service providers and policy used qualitative methods (focus group discussions, in-depth interviews) and secondary data analysis. The component of mental health service users was a population-based survey on general population and people with severe mental illness. Information was collected by the RTCCD's research team and trained staff of Department of Invalids, Labour and Social Affairs in the two selected provinces. The evaluation component of mental health service providers conducted by RTCCD included a section of inpatient mental health facilities. The quality of service provided by the health sector was assessed using the five basic themes of the WHO QualityRights Tool Kit. This toolkit was developed to support countries in assessing basic human rights standards in inpatient facilities (37). In general, the results of this survey reflected that the quality of inpatient services in health sectors of Vietnam has only limited achievements against international standards. The infrastructure of these facilities had been improved to meet the basic living

standard. Other themes did not meet appropriate standards of service provision (33).

i. *Standard of living environment and social protection*: Inpatient rooms meet basic living standards such as having sufficient lights, openable windows, good hygiene and suitable temperature. Separate toilets for male and female patients are provided. Patients are given meals regularly and uniforms of the inpatient facility and are allowed to meet their families. However, there is no function room for patients. The buildings do not meet safety requirements in terms of emergency exits in case of fire. Personal items such soap, toothpaste, sanitary pads for women are insufficient to meet patients' needs. These items are therefore contributed mainly by the families. The structural design of the treatment and living rooms for patients is unfriendly for users and does not support the interaction between patients and health staff. It is designed for the convenience of the service providers, rather than service users. Access to private rooms in which patients can spend time or have meetings with their families is limited. No community or entertainment activities for patients are provided.

ii. *Standards of physical and mental health*: The hospitals provide essential treatments to all patients having severe mental illness regardless of their financial difficulties, religious and cultural difference. Pharmaceutical therapy is the predominant treatment in inpatient services. Psychological and occupational therapies are not employed. Only severe physical problems are treated. An approach based on ascertainment of patient's needs for rehabilitation and management is not mentioned in any documents and is not implemented in these facilities.

iii. *Legal capacity and the right to personal liberty and the security of person*: The most common problem is patients were not asked for permission to receive the mental health treatment by both their families and health staff. Patients and their families are not involved in planning treatment. Medical records are not shared with the patients.

iv. *Freedom from torture or cruel, inhumane or degrading treatment or punishment and from exploitation, violence, and abuse*: There is no mechanism to monitor abuse cases against mentally ill patients in these facilities. Therefore, no violation case is recorded. Chaining and confinement are employed for patients whose behaviours are disturbed or difficult to manage. A "Calming room" has been introduced in some hospitals in the South of Vietnam.

v. *Live independently and be included in the community*: This theme is totally new to psychiatric hospitals. Health staff do not provide any information to support patients re-integrate into the community.

In the mental health system, the district level does not play a major role in providing mental health services because district general hospitals do not have mental health departments. Its role is to refer possible cases of mental disorders to the provincial level.

5.1.2 Primary mental health care - Community mental health program

The commune level is associated with the community mental health program. With the success of the National Target Programs on Health and the policy advocacy activities of mental health experts, in 1998, the Community Mental Health Program was established as a component of the National Target Program to combat and prevent what are deemed 'social' and 'dangerous'

diseases. Schizophrenia was chosen as the first mental disorder to be addressed in the program (38). Reasons for choosing this severe mental illness were that it can be episodic and have a relapsing course, symptoms are severe and commonly lead to disability requiring long-term treatment. These led to the overload of psychiatric hospitals and financial burden on the families. In 2001, epilepsy and depression were added to the program by Decision No. 77/2002/QD-TTg (39). Although epilepsy is a neurological disorder, it was labeled as a social disease. After discharge from the intensive treatment in hospitals, people with this condition require management in the community. Therefore, it was included in the national community mental health program. Since then, the program has been implemented for schizophrenia and epilepsy in up to 64% of a total of 11.000 communes in Vietnam (40). The program for depression has only been implemented in pilot projects and there is no plan for scaling up, due to human resource shortages and lack of financial resources (36, 41).

The program is mainly conducted by staff of provincial psychiatric hospitals. When the program is introduced to a new commune, the provincial team will go to the commune to diagnose possible cases of severe mental illness identified by commune health staff or the community. Then, people with schizophrenia will have medical care managed at the commune health station with the prescription of medications. Based on the prescriptions provided, the amount of medication needed will be calculated and submitted to the provincial level. Provincial psychiatric hospitals will order the medication from the pharmaceutical companies. Medications will be distributed to commune health stations every month or every three months. Patients or their

family members will go to the commune health stations to collect medications every month or every two weeks.

There is limited access to updated results of the program. After around 6 years of implementation, from 2000 to 2006, it was reported that the program covered 90% of patients in the Northern provinces and 70% of patients in mountainous areas (36). A program evaluation in 2007 showed that communes receiving the program had increased the percentage of possible cases of people with a severe mental disorder seeking medical services (91%) in comparison with the communes without the program (87%) (41). The obvious benefit of the program is to provide medication to people with schizophrenia and epilepsy at commune level. Without the program, due to the policy of free medication for these conditions, patients are required to go to the provincial psychiatric hospital to collect medication every month. It cannot be denied that the program has a crucial role in improving the mental health system due to its linkages from the national to the grassroots level. Commune health staff were trained to identify possible cases of schizophrenia and epilepsy.

However, it is clear that the program is just an extension model of the provincial psychiatric hospitals rather than being a comprehensive community-based program. In fact, the project totally depends on psychiatrists of provincial hospitals to identify a person with a psychotic illness and develop a treatment plan. Commune health stations have the responsibility to follow-up and distribute medication to people with schizophrenia and epilepsy. The main emphasis of the program is on medication management and distribution. Therefore, it has been recommended that the program is renamed as "the care model for patients

with schizophrenia and epilepsy at the commune level" (41). In addition, poor monitoring and supervision is a considerable problem. Evidence from an evaluation suggested that the number of patients managed by the commune health stations may be higher than the actual number. Moreover, the medications provided by the program were "the first generation" and some of them were out of date, therefore, some patients did not take them, and their families buy the "second-generation" antipsychotics at the pharmacy outlets (42).

5.2 Social sectors

5.2.1 Social protection centres

In terms of mental health service providers, MOLISA is also in charge of providing social support and rehabilitation services to people with mental disorders through the centres for social work services and social protection centres. Up to date, 26 provincial centres for social work services were established in the period 2011 - 2013 because of the introduction of the social work profession in Vietnam. These centres have the responsibility to provide social work services such as psychological support, social resources mobilization, need assessments and referral to related services to people with mental disorders in the community. However, due to its recent establishment, mental health services are limited (43).

There are four national and seventeen provincial social protection centres managed by MOLISA. These centres are the key component to provide inpatient services such as treatment and rehabilitation to people with severe mental illness who may be dangerous to the community or have no relatives or whose family members cannot afford to care for them (44). Therefore, these

mentally ill patients are sent to the social protection centres by their families or local authorities. Those who recover from the mental disorders can return to the community if they can live independently or with minimum support from their relatives or family members. Those who do not recover will remain in the facilities for the rest of their life. Therefore, the functioning of the social protection centres is different from the psychiatric hospitals managed by the health sector. The social protection centres are located in 16 out of 63 provinces. In fact, the centres can meet only one-third of the population needs in the province that they located (35). It is explained that most of the families having mentally ill members are poor, hence taking care of the patients are their huge burden. Sending the patients to the centres without paying any fee is a solution for the families. As mentioned above, these centres are more likely to focus on rehabilitation rather than treatment. The evaluation report of the social protection centres in two provinces in 2014 clearly illustrated the quality of care in these settings. The findings in this report described the common problems of other centres managed by the social sector. Using the WHO QualityRights Tool Kit, the results showed that services provided by these centres are poor and not based on scientific evidence. They mainly focused on keeping the patients away from the general community rather than treatment and rehabilitation. The quality of care was analysed in five themes using the toolkit.

i. *Standard of living environment and social protection*: The centres have good infrastructure with specific functioning areas. However, the structural design is not intended to be "patient-centered". It is designed for the convenience of management of the service providers. Safety requirements in emergency circumstances are not considered. Personal items (soap,

toothpaste, and toothbrush) are provided by the centres and it is given to the patients when they need. Patients do not need to wear uniforms but can wear clothes provided by their families. Patients are encouraged to meet their families in private rooms. However, letters between patients and their families are supervised in terms of content for safety reasons. There are rooms for entertainment and exercise, but these are not used frequently. The centres have started to organize some social events with the involvement of patients and their families.

ii. *Standards of physical and mental health*: Due to the lack of psychiatrists, in some centres, medications are provided by general health nurses without consultation with mental health professionals or a medical prescription. Staff are not trained in terms of patients' support and management. Rehabilitation plans are offered to people who have recovered from an episode of psychiatric illness. The main rehabilitation method is gardening therapy. Patients who are acutely ill are accommodated in locked areas under the close supervision of staff. Routine health care checks have been initiated, but reproductive health checks are not included, including for female patients. Therefore, although there are separate living areas for male and female patients, unintended pregnancies occur, and it is not documented whether these followed forced sex.

iii. *Legal capacity and the right to personal liberty and the security of person* and *Freedom from torture or cruel, inhumane or degrading treatment or punishment and from exploitation, violence, and abuse*: There is limited effort conducted to meet the criteria of these themes. The patients are sent involuntarily to the centres. Both the patients and their families are not involved in planning treatment. There is a serious violation of human rights in these centres. In

order to keep the hygiene of the patients' living area, privacy concerns of patients are totally ignored. All patients are forced to go outside for the whole day and are allowed to go back to their rooms in the afternoon. No individual bathroom is provided, there are communal pools for all female or male patients. Chaining and confinement are common for those having difficult behaviours. Detailed guidelines are urgently needed to support these centres to implement the basic standards of WHO (33).

iv. *Live independently and be included in the community*: This is partially implemented. Gardening therapy is used for those who recover from mental disorders. Those patients can live a separate area with limited management and supervision of the staff. They have common rooms with televisions for entertainment activities. However, there is no additional effort of the facilities to link them to the community resources to prepare for the re-integration into the community of the patients.

5.2.2 Financial support

MOLISA is responsible for providing social services to people with a mental illness. One of the key mandates is to provide monthly financial allowances and health insurance cards to people with severe mental illness in the community. The minimum subsidy is around US$14 per month. In addition, people who are admitted to the social protection centres are provided approximately US$22 per month. Different provinces may have additional support due to their financial capacity (45).

This Decree has had a significantly positive impact on both people with psychotic disorders and their families, and service providers (social protection centres). Most people with severe mental disorders and their families in the

community are poor. Although the allowance is limited, it and the health insurance cards still contribute to reducing the burden on the patients and their families. However, some problems happened occurred during the implementation of this Decree. In order to meet the criteria to get the support under this Decree, several supporting documents are required to demonstrate eligibility. One of these requirements was a formal diagnosis of a severe mental illness provided by a psychiatric hospital. This requirement is not affordable for poor families, especially those living in the mountainous areas where there are no psychiatric hospitals and transportation is difficult. Consequently, many people who could not obtain the diagnosis of psychiatric hospitals would have no access to this essential financial support (35).

5.3 Informal mental health services

The informal mental health system is defined by WHO as consisting of informal community services and self-care without inputs from a health professional. Informal community care is provided by the community or agencies that are not part of the health or welfare systems, including non-governmental organizations, family care and self-care.

5.3.1 Non-government organizations

Non-government organizations (NGOs) play an important role in providing mental health services and interventions to the population in need. An evaluation was conducted by RTCCD in 2011 as a report to the UNICEF and the WHO office in Vietnam. The assessment had sent emails to approach 80 local and international NGOs in Vietnam to identify those providing mental health activities. It is reported that there were 6 out of 80 NGOs engaged in the mental health area in Vietnam. Although their services were not on   large

scale, the nature of services was flexible and creative. Their activities included epidemiological research surveys, training courses, policy advocacy activities, interventions to primary health care and outpatient services for mothers and children with mental disorders and behaviour disorders; people with HIV/AIDS, and the elderly (46). There were two international NGOs involved in mental health care. They aimed to renovate the health care system at the provincial level by conducting pilot models. The first model was to integrate mental health care of common mental disorders (depression and anxiety) and severe mental illness (schizophrenia and epilepsy) into the commune health stations. The second model was to include mental health care in the outpatient clinics for people living with HIV (46).

There were four local NGOs providing mental health care services directly to the community using the fee-based mechanism. Their scale is smaller than interventions conducted by international NGOs. The services were mainly focused on delivering counselling, screening, treatment, and rehabilitation to women and children through mental health clinics, pilot interventions, and epidemiological surveys. It is clear that their services could approach a limited population, however, the services contributed to addressing basic needs of one of the most vulnerable groups in the population (women and children). Instead of focusing on treatment and management of mental disorders like international NGOs, local NGOs emphasized on prevention, early identification and psychosocial therapy of common mental disorders during the perinatal period.

In general, NGO players contributed to providing research evidence of the burden of mental disorders and potential models to address the burden that were appropriate to the specific context of Vietnam and aligned with the

WHO recommendations. However, although there was an effort in policy advocacy, the involvement of NGOs in the policy-making procedure was still limited, such as providing technical consultations to MOH or MOLISA by some well-known experts of NGOs (47). There was no mental health policy or government documents issued due to the technical advice of NGOs in Vietnam (31).

5.3.2 Family care and self-care

Vietnamese culture is influenced heavily by the Chinese tradition. Multi-generational families are common in rural areas, but nuclear families are more widespread in urban areas. Family plays a crucial role in health care that directly affects the health-seeking behaviours of family members. Therefore, health care for an ill member is commonly conducted by or sought on the person's behalf by other family members. It is reported in the RTCCD's assessment on the service user component in two provinces in 2014 that compared to the number of people with mental disorders, approximately 1.5% of them were cared by mental health facilities of both health and social sectors. More than 98% of them lived in the community. In addition, nearly 80% of people with severe mental illness are cared for by their family members such as parents, a spouse, or their children (33). It clearly showed that the role of informal care services including family and self-care is crucial in the community.

There is limited evidence of the quality of care provided by the family in Vietnam. To date, only one survey has been conducted to investigate this aspect of the care of people with a severe mental illness. The report of this survey showed that almost 50% of people with severe mental illness did not have a private or clean bedroom. Only 60% of them had access to warm water

for washing and bathing in winter. Around 20% of women of reproductive age did not have access to menstrual pads for menstrual management. Having access to entertainment activities such as reading newspapers, listening to music or radio, watching television was only available to fewer than 59% of patients. More than 70% of patients were however enabled to participate in family events such as funerals and weddings, and around 30% of them were allowed to participate in other community events such as festivals, or cultural meetings. In addition, while the rates of patients being provided with nutritious meals, clean drinking water, and clean clothes were high (approximately 90%), nearly a quarter of patients did not have basic personal items such as soap, toothbrush, and toothpaste for use at home. Therefore, the most common physical problem they experienced was dental diseases (33). The results suggested that family care focused on meeting some basic needs, by providing sufficient foods and clothes. Other factors such as the participation in community events, physical health, personal items and living condition of people with mental disorders were not considered necessary or addressed.

In terms of mental disorders' management, nearly one-third of families did not know how to deal with the acute episodes of illness. While more than half of patients had routine mental health checks, their physical health was generally ignored by their families. The study also found that reach of treatment was quite wide and that more than 60% of patients had received mental health treatment. Among those receiving treatments, however, 40% of them did not have an adjustment in their prescription such as change of medications when they experienced side effects or the treatment was

ineffective. It was concluded that, although a community mental health program does exist, family care is still based on traditional experiences and lacks specialist support (33).

6. Human resources for mental health

The training system for the mental health workforce was provided primarily within the health sector. Compared to the health sector, the training system in the social sector has only been developed very recently. Psychiatrists are trained by the Department of Psychiatry in Medical Universities. In 2015, three faculties of the non-medical university were approved to train general doctors and psychiatrists. In total, there are eleven faculties providing psychiatric training. Medical students need to study for six years to be a general doctor. A six-month psychiatric orientation training and eighteen-month clinical training are required for medical graduates to be a psychiatrist. Up to date, there is no data on the number of psychiatrists trained by the three non-medical universities. Hence, it is difficult to assess the training quality of the non-medical universities compared to the medical counterparts. In terms of postgraduate training, medical universities and the National Institute of Mental Health provided doctoral, master and specialist degrees. General nurses can be trained in Medical Universities and some Nursing Colleges. To be a mental health nurse, a general nurse must be trained for an extra six months' specialism in mental health. Then, they can work in mental health facilities. General psychologists are trained in several universities including Hanoi University of Pedagogy, Ho Chi Minh University of Pedagogy, University of Humanities and Social Sciences. It requires four years for bachelor degree and two years for the master degree in these universities.

The profession of social work has just been introduced to Vietnam in 2010, hence social workers are rare. The first social work bachelor degree was launched in the public Open University in Ho Chi Minh city (in the south of Vietnam). Then, after the approval of the Ministry of Education and Training in October 2014 for the social work profession, currently, there are around 30 universities and 10 vocational schools providing on-the-job training, vocational training, bachelor and postgraduate degrees. There are only four training institutes providing post-graduate degrees, including the Vietnam Academy of Social Science, University of Social Sciences, Thang Long University and the University of Labour and Social Affairs) (36, 48).

Vietnam is facing a similar problem of mental health workforce shortage to other LMICs (13). It is reported that there were only 286 psychiatrists within MOH system in 2004 and 900 psychiatrists in 2017 (36). It means that proportion of psychiatrists per 100.000 population is 0.35, much lower than 11.0 in the United Kingdom and 13.7 in America (31). These rates are slightly lower than other Asian developing countries such as Thailand and Philippines (0.66 and 0.42, respectively) (49). Psychologists, social workers, occupational therapists and psychiatric nurses are rare in Vietnam. In 2011, there was an improvement in the proportion of mental health staff per 100.000 population. It was 1.01 for psychiatrists, 0.003 for psychologists (36). According to a report from MOH, the number of psychiatrists has been declining in recent years (23). Psychiatry is the least preferred specialty for medical students due to severe stigma and discrimination against the mental health area, for example, there was no graduate in psychiatry nationally in 2004 (49). Other reasons for the shortage were the high workload and low salary for mental health staff (35).

The quality of the mental health workforce is also a considerable issue of the system. There is limited evidence in this area. Psychiatry graduates are trained in pharmaceutical therapy only- training in psychological therapies, psycho-education, social support programs and environmental change is not provided to medical students. Psychologists receive undergraduate education in general psychology but have no clinical experience or clinical training. Therefore, in order to work in mental health facilities, these graduates need to have extra training and clinical supervision, which is difficult to acquire as there are few training institutions (31). Staff working in the social protection centres have diverse backgrounds, and limited education, few of them have a social work degree. In addition to limited to pre-service education, there are few opportunities for professional development or in-service training, and few people have any access to training materials for up to date approaches to treatment rehabilitation for people with a mental illness (33, 35).

7. Burden of mental disorders in Vietnam

Due to the social and economic development, there is a transition from communicable disease to non-communicable disease in Vietnam. Mental health problems are a hidden burden that is not yet understood properly. Based on existing evidence, Vietnam experiences a high population burden of both common disorders (depression, anxiety) and severe mental illness (schizophrenia, bipolar disorders). Common mental disorders are less severe but are more prevalent and occur among people at different stages of the life course Around 20% of eight-year-old children have been shown to experience a neurological or psychological disorder (5) and nearly 30% of women who are pregnant or who have recently given birth meet diagnostic criteria for a

common mental disorder (6). Other psychotic disorders such as schizophrenia and epilepsy occur among about 0.5% of citizens. Alcohol abuse and major depression are the most common mental disorders among the population (5.3% and 2.8% respectively) (7). However, due to the severe stigma against mental disorders, this prevalence may be underestimated in the efforts to establish the actual burden among Vietnamese.

8. Stigma against mental disorders in Vietnamese Culture

Stigma in mental health is a significant problem in Vietnam. Not only about people with mental disorders and their families but mental health professionals also experience stigma. The definition of "mental health" itself is neutral and is used to differentiate it from "physical health". However, in Vietnamese, this term is understood to refer to severe psychotic disorders and people with them are seen as dangerous to the community. Therefore, the definition itself is also discriminatory. Consequently, this prevents people with mental health problems from disclosure and seeking mental health services. The term "mental illness" is associated with images of "mad or crazy" persons. In addition, psychiatric science conceptualises mental illness as a consequence of individual and family factors (individual characteristics, negative family environment), rather than a reflection of broader contextual factors beyond individual control (e.g. rapid social change, poverty, mental health policy). As a consequence, people with mental disorders and their families are facing severe stigma in the community (50).

According to the evaluation report, nearly 30% of families with mentally ill members were stigmatized frequently by the community. Among those suffering from stigma, more than 20% reported the serious negative effect on

their relationships with friends and colleagues, and around 40% claimed that this problem has a harmful impact on their family relationships (51). In this context, having members with mental disorders is a source of shame for families, hence they are more likely to confine and hide their family member, instead of taking them to doctors.

Regarding the mental health workforce, psychiatrists are referred to as doctors who are involved with crazy and mad people. Therefore, psychiatry is the least preferred specialty for medical students. Some psychiatric graduates change their specialization when seeking a job or do not disclose their training as a psychiatrist to their friends or relatives.

9. Challenges of integrating mental health into primary health care

There are many influencing factors that affect the progress of integration into primary mental health care. The WHO Service Organization Pyramid of an optimal mix of services for mental health provides an accessible and comprehensible framework for the key challenges: legislation and policy; human resources; service organization and evidence-based interventions (12).

9.1 Challenge 1 – Mental health legislation and policy

Like other LMICs, Vietnam lacks mental health policies and laws to provide an integrating framework for the whole mental health system (52). Although there is increasing awareness of mental health problems in the National Assembly and the Communist Party, Vietnam still does not have clear goals to achieve improvements in this area nationally. There are several negative consequences of this challenge. The most obvious example is the different orientations of the Ministry of Health and Ministry of Labour, Invalids and

Social Affairs have hindered the progress of the embedding of mental health care into primary care. MOH keeps following the custodial institution approach by upgrading and constructing new psychiatric hospitals. This approach was used in Europe in the 19th century, then exported to Africa, the Americas, and Asia later. Mentally ill patients were isolated and kept in large custodial psychiatric hospitals which have been shown to be inadequate modes of treatment and to fail quality assurance procedures. Such facilities hindered rather than facilitated recovery and the community integration of patients. Due to these failures, many countries moved to the community mental health care model, which is more respectful to the human rights of people with mental disorders (53).

In contrast, MOLISA has demonstrated its vision of community-based mental health care by providing social support in the community. Common mental disorders, which have been shown to be a great burden on the population are also emphasized. This vision was supported by WHO that people with mental disorders can and should be able to access specialist services in community and inpatient facilities. Informal community care and self-care should be promoted adequately to address the frequency of need and the treatment costs (12).

In addition, lack of mental health law leads to violations of the human rights of people with mental disorders in both inpatient facilities and in the community. In general, according to the five themes included in the WHO quality right toolkit, the standards of care for people with severe mental illness did not meet the right to enjoyment of the highest attainable standard of physical and mental health; the right to exercise legal capacity and to personal liberty and security of the person; the right to freedom from torture

or cruelty, inhuman or degrading treatment, or punishment by exploitation, violence and abuse; and the right to live independently and be included in the community. The right to an adequate standard of living and social protection was partially addressed (37).

9.2 Challenge 2 – Human resource

The mental health system in Vietnam has a major shortage of qualified and experienced mental health professionals. The proportion of psychiatrists per 100.000 population is lower than in neighbouring countries such as Thailand, Mongolia, Philippines (13). In addition, psychiatrists often work in the hospitals in big cities such as Hanoi, and Ho Chi Minh City and not in the rural services. They also experience stigma from their colleagues and the community. Also, the number working in rural areas is much lower than the estimated requirement.

Psychiatrists are trained in medical universities where the main information source is dated textbooks, mostly translations from Russian or Eastern European countries that are at least two decades old, when Vietnam only engaged with other Communist nations, including for medical training. Therefore, modern treatment approaches are poorly understood, including in the medical universities.

Psychologists and social workers specialized in mental health are rare in Vietnam. The training curricula for both these professions are regarded as theoretical rather than practical. Most textbooks were translated directly from those used in high-income countries such as Australia and America. They have not been adapted to the culture and real situation in Vietnam. Therefore, graduates of these professions experience major difficulties in meeting the

practical requirements of providing allied health services in the mental health facilities and in the community (54).

9.3 Challenge 3 - Service organization and planning

Rathod et al mentioned that service organization and planning was one of the key challenges in mental health services in LMICs. One challenge was the limited access to mental health services in rural areas while primary mental health care was weak in addressing community needs (52). In terms of the WHO service organization pyramid, Vietnam has a reverse model, with formal services as the predominant component. Vietnam shares a similar problem to other LMICs of spending about 80% of its budget on mental health hospitals (55). Therefore, resources for primary mental health care are limited (23).

It is clear that the foundation layers that have been named "informal health services" should be strengthened to fill the gap between mental health services and the community. Community and family care are seen as one of the key opportunities to improve mental health services in the resource-constrained contexts of LMICs (52). There has been evidence of the clinical effectiveness and cost saving of interventions in these settings delivered by the informal community workforce, such as lay health workers, non-government organization staff and traditional healers (32, 56-58). However, this component has not been adequately explored and publicised by the government. Although the national community mental health program is operating, in fact it consists of medication management for schizophrenia and is provided by psychiatric hospitals. There is still lack of family and community care. Their role remains unempowered and unsupported by the community mental health program. This is also despite ongoing evidence by

international and local non-government organizations (NGOs) that suggests it is a key positive contribution to addressing the mental health problems in Vietnam. NGOs did not use the state budget, but provided a high quality of scientific evidence-based initiatives to meet the needs of the community (46). Although there is evidence of a making a successful case in advocating change via research evidence to policymakers, generally the voice of NGOs is not heard by the public sector (47).

Research evidence in Vietnam has shown that common mental disorders are a huge burden on the population, however the current mental health services predominantly focus on psychotic disorders (schizophrenia, bipolar disorders. Common mental disorders such as anxiety and depression are not addressed properly. After nearly 20-years of implementation of the national community mental health program, depression research was conducted on a pilot scale, not nationwide (36). With respect to the treatment approach, compared to the pharmaceutical therapy, psycho-social therapy, as recommended by the WHO, has not been implemented. No mental health promotion and stigma awareness activities were run at the community level by the public sector.

9.4 Challenge 4 - Evidence-based interventions

In order to implement Decision 1215 with the financial support of the Atlantic Philanthropies, a Mental health Taskforce Group was established with the involvement of MOLISA, MOH, international and local NGOs in 2013 (59). The aim of the task force group is to develop a community-based model to address common and severe mental disorders at the provincial level. However, since the announcement of the Decision in 2010, limited achievements were reported. The two ministries still manifested confusion about the integration of mental health into primary care in Vietnam. It was

reported that the adaptation of an intervention to a different cultural context was challenging due to the dissimilarity of cultural background, service organization and policies. Interventions should be assessed in terms of feasibility, acceptability, alignment with strategic context, cost, and effectiveness (52, 60). Thus, the lack of appropriate scientific evidence-based interventions is one of the most challenging issues for the government in Vietnam.

10. Conclusion

Since 1997, there has been a reform of state-funded public services, especially after the economic renovation - Doi Moi. The National Assembly has introduced the policy of the Socialisation of Public Services Supply. The policy allows the private sector to be involved in providing health care services to address community needs (20). Due to the lack of mental health policy and legislation, the shortage of human resources, and the predominantly custodial institutional approach, several actions are needed to align the country with international standards and recommendations. The first action to be prioritized is to develop and issue suitable mental health policy and legislation. This will provide a framework for the whole mental health system and delineate the involvement of related stakeholders in providing mental health care in the long-term. Such policy would regulate the transition from the custodial institutional to the community-based approach. Informal community services should be acknowledged and promoted. In addition, common mental disorders should be addressed properly as they are a huge burden on the community.

Evidence-based interventions should be conducted at pilot level to provide potential comprehensive models for the implementation of policy and action plans. Various interventions have been established by NGOs that have shown potential impacts on the feasibility and cost-effectiveness on a small scale. These need reviewing by a team of mental health professionals, researchers, and policymakers to identify suitable models to scale up at provincial and national levels.

In terms of the quality of the mental health workforce, the education system should be revised to develop learning about community needs via practical experience. Updated information on mental health promotion and treatment should be provided to mental health professionals through on-the- job training. With respect to the workforce shortages, new mental health professionals should be trained, including psychiatrists, mental health nurses, psychologists and social workers. A varied mental health workforce is essential to provide comprehensive services.

Regarding policy advocacy, therefore, participation by the community, mental health service users and civil society organizations should be encouraged to have a voice in the decision-making process as well as in service provision (61). This approach fits the policy of the National Assembly and the WHO recommendations well.

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Additional information

The section 5.1.2 Primary mental health care – Community mental health program was revised in the fifth paragraph on page 88 was: "In 1998, the Community Mental Health Program was established as a component of the National Target Program. The National Target Program is an effort of the Vietnam government to target some priority areas which are important to social and economic development. This program on health is approved by the Prime Minister to control and prevent what are deemed "social" and "dangerous" diseases in the community such as tuberculosis, leprosy, malaria, cancer, HIV/AIDS, child malnutrition, reproductive health, and national immunization program."

The first paragraph of section 5.3.1 Non-government organizations, page 95 was revised. It reads: "There were three NGOs involved in mental health care. They aimed to renovate the health care system at the provincial level by implementing and evaluating pilot models of care. The first and second models were to integrate mental health care of common mental disorders (depression and anxiety) (Murphy, Goldsmith, Jones, Oanh, & Nguyen, 2017; Murphy, Oanh, Goldsmith, & Nguyen, 2018) and SMI (schizophrenia and epilepsy) into the commune health stations (Vietnam Veterans of America Foundation, 2019). The third model was to include mental health care in the outpatient clinics for people living with HIV (Research and Training Center for Community Development, 2012)."

CHAPTER 4 – METHODS

The shortages in services and human resources to provide care for people with severe mental illness (SMI) in Vietnam have led to the recommendation that mental health care should be integrated into primary care. However, there are major gaps in policy to inform the development of the mental health system in Vietnam, in particular the strengthening of informal services to meet the basic needs for mental health care in the community.

4.1 Research aims

The aim of this research is to contribute evidence about informal interventions for people with severe mental illness in rural Vietnam in order to address the national policy gaps.

The specific objectives of the study are:

1. To review the available evidence about informal mental health interventions for people with severe mental illness in low- and lower-middle-income countries.

2. To determine the burden of common and severe mental disorders among adults in Vietnam.

3. To describe the delay to diagnosis and costs of informal care for people with severe mental illness in rural Vietnam.

4. To describe the development and proof of concept of a psycho-educational community-based intervention for people with severe mental illness in rural Vietnam.

4.2 Conceptual framework

In order to respond to the mental health burden and address the weak mental health system in lower-middle-income countries (LMICs), the World Health Organization (WHO) and World Organization of Family Doctors (WONCA) developed a "pyramid for an optimal mix of services for mental health". The model provides guidance about how LMICs can provide adequate mental health services to address

these challenges. The purposes of the model are: to enable the population in need to receive adequate treatment at low cost; to protect human rights; and to alleviate stigma and discrimination against people with mental disorders (Figure 1). The model describes clearly the role and parameters of informal services (informal community care and self-care) in terms of the magnitude of need and costs. In the model, there are more informal services (community care and self-care) and these are available at lower cost, compared with formal services. This model is argued to be a good fit in the context of LMICs which are seeking to build community-based mental health care (World Health Organization & World Organization of Family Doctors, 2008).
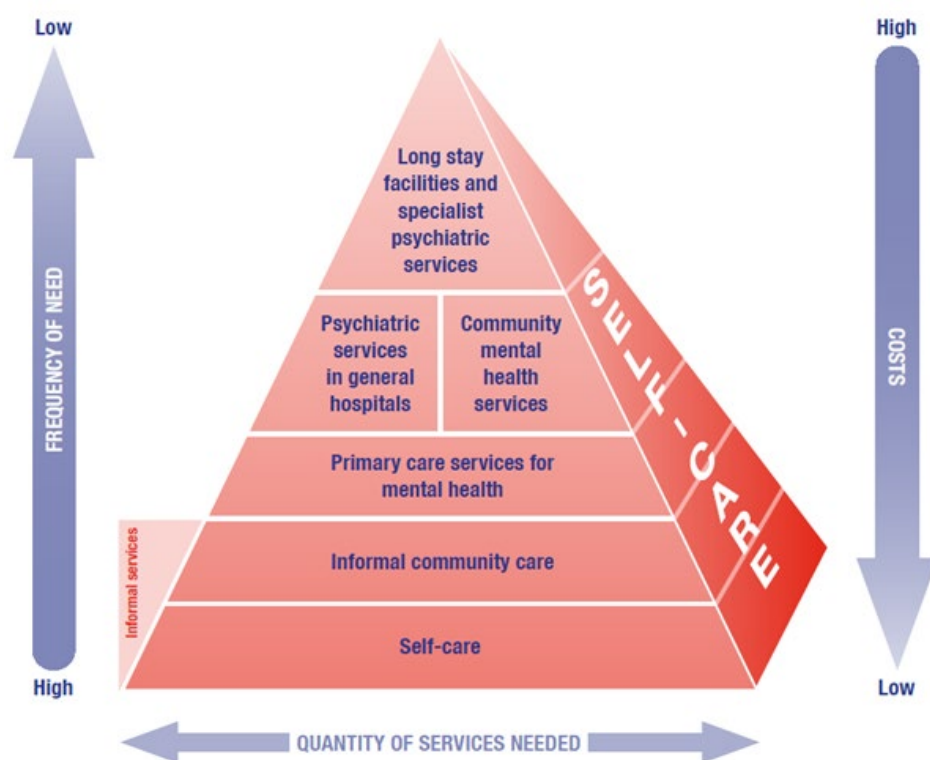
Figure 1: WHO service organization pyramid for optimal mix of services for mental health (World Health Organization & World Organization of Family Doctors, 2008)

4.2.1 Formal health system

The formal health system includes all services provided by mental health professionals such as psychiatrists, psychiatric nurses, social workers, and psychologists. These formal human resources work at various mental health levels

including psychiatric hospitals, psychiatric departments within general hospitals, long-stay facilities, community mental health settings, and specialist psychiatric services. Formal services deliver professional mental health services which are costly and can serve only a small fraction of the population with needs for mental health care (World Health Organization & World Organization of Family Doctors, 2008).

4.2.2 Informal health system

Informal mental health care includes community care, family care, and self-care. These services are provided by non-professional people who do not work in the formal health and welfare system. These informal human resources include laypeople, traditional healers, village health workers, professionals in other sectors (such as teachers and members of the police force), peer-support groups, family members, and staff of non-government organizations (NGOs). This system serves a large population at low cost. It is more accessible and acceptable because it is provided locally by known members of the general community. Self-care is encouraged, as people with mental disorders may be better able to manage their mental health problems themselves with support from family members, the community, and the staff of the formal services. Self-care is promoted as the foundation of the pyramid, which encourages the autonomy of people with mental disorders (World Health Organization & World Organization of Family Doctors, 2008).

4.3 Research design

The research methods for this project have been described in each of the papers (see Chapters 5, 6, and 7). In this chapter, the generation and content of the datasets that the papers were drawn from are described.

This study includes secondary analyses of data generated in two population-based surveys, along with formative and proof-of-concept research for a community-based intervention. The first was a cross-sectional survey to investigate the prevalence of

common and severe mental disorders among members of the general population aged more than 16 years. The second was another cross-sectional study examining the delay to diagnosis among people with SMI in Vietnam. The last part of the study included community consultations and a before-and-after evaluation of an intervention for people with SMI in a rural commune in Vietnam.

4.3.1 Study 1: Cross-sectional survey investigating the burden of clinically significant symptoms of common and severe mental disorders among adults in rural Vietnam

4.3.1.1 Sampling method and sample size

A multi-stage cluster sampling method implemented by an independent statistician was used. A list of all provinces in the North and the South of Vietnam was prepared. One province in the North and one province in the South were selected using a simple random sampling method. In each province, all communes were listed and 30 communes were randomly selected from each list for the survey using systematic sampling.

In each selected commune, a list of all households was provided by the Communal People's Committee. From the household list, 10 households were picked for the interview using the same method of random sampling. Consequently, 300 households were selected in each province and 600 households in total were included in the survey across the two provinces. The survey was implemented in May and June 2013.

4.3.1.2 Setting

Vietnam is located in Southeast Asia and is an LMIC with a population of more than 96 million people (Vietnam General Statistics Office, 2017). Over its long history, the country has mainly been divided into two socio-political areas: the North and the South. In the 18th century, the Northern part of Vietnam was influenced by China, while the Southern part was influenced more by Indian culture. From the 17th to the

19th centuries, there were two hostile dynasties in Vietnam, the Nguyen Dynasty in the South and the Trinh Dynasty in the North. These two dynasties were at war with each other over the long term. During the French colonization of Vietnam from 1887, the country was controlled and influenced by French culture, especially the North. From 1954, with Independence and the victory of the Vietnam War led by Ho Chi Minh, the North was ruled by a communist government which was significantly influenced by other communist countries, in particular China and the Soviet Union. Meanwhile, the South of Vietnam was ruled by a quasi-democratic government which was controlled by the United States. The North and the South of the country were united in 1975. However, due to the history, differences between the North and the South in terms of culture, language, accents, traditions, living standards, and ways of life, differences persist. People living in the South are more likely to be flexible, and open minded to new concepts, including about mental health from Western countries. Hence, stigma and discrimination against mental illness among people in the South are less severe than among their counterparts in the North. In addition, the South has more advantages in agriculture because of the favourable natural environment than in the North. Consequently, the living standard in the South is higher than that in the North.

Thanh Hoa and Ben Tre provinces were selected to represent the North and the South of Vietnam, respectively. Thanh Hoa is a Northern province with a population of nearly 3.5 million people in 27 districts. The average income per capita per month was approximately 1.6 million Vietnamese dong (around USD82) in 2013 (Thanh Hoa Portal, 2017). Ben Tre is a Southern province with a population of around 1.26 million people in one city and 8 districts. The average income per capita per month was almost 2.2 million Vietnamese dong (approximately USD100) in 2013 (Ben Tre Portal, 2017).

4.3.1.3 Data collection tools and sources

Two forms of data were collected, one at the household level and the other at the individual level.

4.3.1.3i Household level: Structured interviews were conducted with the household heads. Household characteristics consisted of demographic characteristics, household economic status, alcohol abuse, family violence, household social capital, and specific adverse life events.

Table 1: Data collection tools at household level

Variable	Tool	Description
Demographic variables	Study-specific questions	The questions were about the province, the commune, and the village where the interviewees were living at the time of the survey.
Economic status	A single study-specific question	This was the household head's subjective self-assessment of the wealth of their household in comparison to their neighbours in their commune.
Alcohol abuse	A single study-specific question	This asked about any household member who had abused alcohol in the last 12 months.
Family violence	Adapted Short-form Domestic Violence Screening Tool (HITS)	This used the Short-form Domestic Violence Screening Tool (HITS), which has 4 domestic violence items: "How often does your partner: physically hurt you, insult you or talk down to you, threaten you with harm, and scream or curse at you?" It was designed for screening of domestic violence by family practitioners. The

Variable	Tool	Description
		scale was validated in America with two phases: Phase 1 for reliability and concurrent validity with a sample of 160 female patients who visited a family practice clinic, and Phase 2 for construct validity among 99 women who disclosed having experienced domestic violence. The authors reported that HITS has a Cronbach's alpha value of 0.80 and a correlation score of 0.85. The instrument was reported to have good internal consistency, and concurrent and construct validity (Sherin, Sinacore, Li, Zitter, & Shakil, 1998). This scale was not validated in Vietnam. It was translated and adapted in this survey to ask whether any household members were experiencing domestic violence.
Social capital	A short version of the modified Adapted Social Capital Assessment Tool (SASCAT)	The scale has 9 items divided into two subscales: structural and cognitive social capital. Construct and cognitive validation were completed in Vietnam and Peru. Regarding construct validity, it was reported that the scale has credible face validity and good content validity. The SASCAT also has good discriminant validity with the same three independent factors of 56% and 57% of the total variance variables in the results from Peru and Vietnam, respectively. Re cognitive validity, the scale had a "correct interpretation"

Variable	Tool	Description
		rate of 77% in Vietnam (Tuan, Harpham, & Huong, 2003). Therefore, the scale was reported to be a valid tool to measure social capital in quantitative surveys in LMIC countries (Silva et al., 2006).
The specific adverse life events	A single study-specific question	One question addressed the following events occurring in the previous three years: household items stolen, threatened loss or lost rights of inheritance, threatened or lost land/property ownership.

4.3.1.3ii Individual level: All adults who were older than 16 years in the selected households were invited to provide individual demographic information (age, gender, level of completed education) and to self-administer the WHO Self-Reporting Questionnaire's (SRQ) 24 items (World Health Organization, 1994).

This screening tool consists of 20 questions describing symptoms of common non-psychotic mental disorders and 4 questions describing psychotic symptoms. Each item is scored either 0 (the symptom is not being experienced) or 1 (the symptom was experienced in the past month). The maximum scores are 20 for the first 20 items and 4 for the 4 psychotic items (World Health Organization, 1994).

The 24-item SRQ was formally validated in two separate projects in Vietnam (Giang, Allebeck, Kullgren, & Tuan, 2006; Tuan, Harpham, & Nguyen, 2004). The first validation was implemented in Ba Vi district – a rural district in the North. The study had a clinical sample of 52 patients at the district hospital and a community sample of 500 people from three communes, all aged from 18 to 60 years. The SRQ was validated against the Composite Internal Diagnostic Interview (CIDI) administered by a qualified psychiatrist from the National Institute of Mental Health in Vietnam.

In the district hospital sample, the cut-off point to detect clinically significant symptoms of common mental disorders was 5/6 with a sensitivity of 85% and a specificity of 46%. In the community sample, the cut-off point to detect clinically significant symptoms of common mental disorders was 6/7 with a sensitivity of 85% and a specificity of 61% (Giang et al., 2006). The second validation was conducted in a community sample of 200 women aged 19 to 62 years living in three communes in Hung Yen province. The SRQ was validated against a clinical diagnosis made by a paediatric psychiatrist. The cut-off point to detect clinically significant symptoms of common mental disorders was 7/8 with a sensitivity of 72% and a specificity of 77% (Tuan et al., 2004).

This survey used the cut-off point of 6/7 to calculate clinically significant symptoms of common mental disorders of adults, due to the similarity of the survey participants to those in the study of (Giang et al., 2006).

4.3.1.4 Procedure

Staff of the Thanh Hoa and Ben Tre provincial departments of Health and departments of Labor, Invalids, and Social Affairs were chosen due to their familiarity with local accents, customs, and access to communes, and were trained for three days. Only staff who met the criteria of understanding of the interview schedules, protection of confidentiality, and ensuring data integrity were selected to collect the data.

Selected households were informed about the time and content of the interviews by local authorities in a local meeting. On the day of the interview, a village head guided the data collectors to the selected households. A verbal or written plain language description of the survey was provided to all study participants. The household heads and household members were each given consent forms to sign. Those who could not write provided thumbprints or verbal consent witnessed by an independent observer. After completing the interview with the household head, all

members who were older than 16 years were assigned to different private rooms to self-administer the SRQ 24 items. The questionnaire was completed by interview for participants who could not read.

The research team had responsibility for supervising the data collectors and selecting 5% of completed interview schedules to re-interview for quality assurance using the same method. Completed consent forms and paper-based interview schedules were returned to the research team at the end of the each working day to be store in a locked cabinet at the provincial Department of Labor, Invalids, and Social Affairs office. Then they were transported in a locked bag with the research team for secure storage and data entry at the Research and Training Center for Community Development (RTCCD) office in Hanoi.

4.3.1.5 Data management and data analysis

All names and identifying information were numerically coded for data entry and data analysis. Each individual's unique code was a combination of the codes for the province, the commune, the household, and the individual. Household members shared the same household code, but had different personal codes. Data entry was implemented using Microsoft Access 2013 (Microsoft Corp, USA). Data were analyzed using Stata Version 13.0 (StataCorp LP, College Station, USA) in three steps. Step 1 was a descriptive analysis to calculate community prevalence and its 95% confidence intervals. Clinically significant symptoms of common mental disorders (CMDs) were classified as those having a total SRQ 20 score of at least 7. Clinically significant symptoms of severe mental disorders (SMDs) were classified as those having at least 1 of the SRQ 4 psychotic items. People who reported both clinically significant symptoms of CMDs and any psychotic symptoms were classified in the SMD group (American Psychiatric Association, 2013). The prevalence of clinically significant symptoms of CMDs and SMDs were weighted using the standard

proportions of age and gender groups among the Vietnamese population in 2013 (General Statistics Office of Vietnam, 2013).

In Step 2, univariate analyses were implemented to compare household characteristics between those with or without a member with clinically significant symptoms of CMDs or any symptom of SMDs. The same method was also used to identify differences in individual characteristics between groups of people with and without clinically significant symptoms of CMDs or SMDs.

In Step 3, two-level mixed-effects logistic regression models were used to investigate the associations between the CMDs or SMDs and social factors. The data from this survey had two levels, with individuals being nested within households. All people in the same household shared common socioeconomic characteristics (Austin & Merlo, 2017). The binary outcome was assigned a value of either 0 (having no clinically significant symptoms of CMDs or SMDs) or 1 (having clinically significant symptoms of CMDs or SMDs).

4.3.2 Study 2: Cross-sectional survey examining the delay to diagnosis among adults with severe mental illness in rural Vietnam

4.3.2.1 Sampling method and sample size

In each of the 60 communes which were selected in Thanh Hoa and Ben Tre provinces in Study 1, a list was made of all households with a member experiencing an SMI that was being managed by the commune health station. People with SMI managed by the commune health station were defined as people with a formal diagnosis of schizophrenia or a bipolar affective disorder diagnosed by a clinician from a public psychiatric hospital. Ten households per commune were selected from this list using the same method of systematic sampling used in Study 1 by the research team. Among the ten selected households, six were selected for interview, and four were used for replacement purposes if any of the six households were not available or refused to participate in the study or had already been surveyed in the

first study. Therefore, the households included in Study 2 were separate from those that were surveyed in Study 1. Overall, 180 households in each province (360 households in total) in which there was a member experiencing an SMI were included.

4.3.2.2 Setting

Study 2 was conducted in the same 60 communes that were the site for Study 1. Therefore, the characteristics of the setting of the two surveys are the same.

In each commune, there is one commune health station which is responsible for managing people with SMIs under the community mental health program. The program is conducted by one mental health staff member of the commune health station with two main responsibilities: (1) identifying people who might be experiencing an SMI and referring them to the provincial psychiatric hospital for assessment and potential formal diagnosis; and (2) distributing free antipsychotic medications to those with a formal diagnosis of SMI. The program was first implemented in Vietnam in 2000 and rolled out progressively to cover more than 7000 out of 11,162 communes in Vietnam (Tran, 2017). The program was implemented in Thanh Hoa and Ben Tre provinces over the period 2000–2003.

4.3.2.3 Data collection tools and sources

Two types of interview schedule were used: one about the household and one about the individual with SMI. Both interview schedules were completed by the main caregiver, because the project leaders were advised by a mental health expert in the provincial departments of Health that people with SMI would be unlikely to have the cognitive capability to complete the interview. The household schedule assessed demographic characteristics, household economic status, household social capital, and household size. Household economic status was measured using one question which asked the main caregivers to subjectively self-assess their economic status in comparison to their neighbours in the commune. This question had five options: very

poor, poor, average, better off, and rich. The household size was calculated by the number of people who had been living and having meals together for at least the prior six months. Household social capital was measured using the short version of the modified SASCAT which was used in Study 1 and had been validated in Vietnam and Peru (Silva, Huttly, Harpham, & Kenward, 2007; Tuan et al., 2003).

The interview schedule to collect information about people with SMI included the delay to diagnosis, personal functioning, personal income, and expense. First, the delay to diagnosis was assessed by two questions to identify the interval (in months) between the first symptoms of abnormal thinking or behaviour being noticed by family members and the first formal diagnosis of a psychotic illness. Second, personal functioning was measured using the adapted version of the Specific Level of Functioning Scale (SLOF) (Schneider & Struening, 1983). The original scale had six sub-scales: physical functioning (5 items); personal care skills (7 items); interpersonal relationships (7 items); social acceptability (7 items); activities (11 items); and work skills (6 items). Each item is rated using a 5-point Likert scale from 1 (poorest function) to 5 (best function) (Mucci et al., 2014). The scale was adapted using four sub-scales (interpersonal relationship, social acceptability, activities, and work skills) and was translated into Vietnamese for this study. Higher scores indicate more independent functioning of people with SMI.

Third, the personal annual income of people with SMI was calculated by including income from any paid work, government financial support, and other sources (for example, donations from humanitarian organizations and gifts from relatives). The incomes from paid jobs and government support were measured per month. The income from other sources was measured per year. Finally, the personal annual expenses of people with SMI comprised all costs related to living expenses, productivity losses incurred by household members because of caring for people with SMI, health service use (outpatient and inpatient services), and other expenses

(for example, fees to find people when they wandered away, property destroyed by people with SMI). Living expenses included costs paid for food, clothes, and bills in a month. Productivity loss was measured in hours per day that adults (those older than 16 years) spent to care for people with SMI. The cost of using outpatient services was measured per month, while the inpatient service cost was measured per year.

4.3.2.4 Procedure

The trained data collectors from Study 1 also worked on this survey after being given an additional one day of training to administer the Study 2 interview schedule. Village heads invited all main caregivers in the selected households to an information session in each commune. The study description and consent forms were given to the main caregivers. On the day of the interview, the village head guided the data collectors to the selected households.

At the household, the consent form for collecting the household characteristics was collected, followed by the interview about the household characteristics. When the household interview schedule had been completed, another consent form was given to the main caregivers to collect information about the person with SMI for whom they were responsible. All interviews were conducted in a private room to ensure confidentiality.

Quality assurance involved selection of 5% of the completed paper-based interview schedules for re-interview by a member of the research team using the same method. All data collectors were supervised by field supervisors, who were trained staff from RTCCD, to minimize missing data through immediate checks of the schedules and returning to the informant to check any incorrectly recorded or missing items while in the field.

All signed consent forms and completed interview schedules were collected by the research team at the end of each working day. They were stored in a locked cabinet

at the office of the Department of Labor, Invalids, and Social Affairs. These materials were transported to the RTCCD office with the research team in a sealed box.

4.3.2.5 Data management and data analysis

Data entry was implemented using an Access database and analyzed using Stata Version 13.0 (StataCorp LP, College Station, USA). All identifiable information such as province, commune, name of household head, and individual name were coded to ensure confidentiality. Individual codes consisted of the codes for the province, commune, and household.

The delay to diagnosis was defined as the interval between the first psychotic symptoms being observed by family members and the first diagnosis of a psychotic disorder being made by a mental health professional. The interval was analyzed as a continuous variable (in months) and a categorical variable of more than or up to one year.

All incomes and costs were collected in Vietnamese dong and converted to US dollars using the exchange rate on 30 June 2013 (USD1 = 20,858 Vietnamese dong). Productivity loss was estimated by using the human capital method of measuring the total hours spent per year by adult household members and the productivity cost of USD7.67 for eight working hours in Vietnam. All monthly incomes and costs were multiplied to estimate costs for the year. The financial burden of people with SMI on their families was estimated by deducting the personal annual expense from the personal annual income.

Three steps were used in the data analysis. The sample had two levels (households and individuals). Some households had more than one member with an SMI. The commune level was not included due to there being no differences among the communes in the study. The first step was a descriptive analysis, followed by the second step, a univariate analysis. The third step was a two-level logistic regression to examine the associations between the delay to diagnosis and relevant social

factors, including household characteristics (household size, economic status, residence in urban or rural area, social capital) and individual characteristics (age, gender, education, free medication received from the national mental health program, main caregiver, marital status, comorbid chronic physical health problems, functioning scale, time of having psychotic diagnosis, financial burden on the family). The dependent variable (delay to diagnosis) is binary, with a value of 0 indicating a delay to diagnosis within 1 year, and a value of 1 indicating a delay to diagnosis of at least 1 year.

4.3.3 Study 3: Community-based intervention for adults with severe mental illness in rural Vietnam

4.3.3.1 Setting

Northern provinces were used for selection of the intervention site due to the limited fund received for pilot studies. Hanam province was chosen by a simple random selection process from the list of Northern provinces in Vietnam. A list of all communes in Hanam province was provided by the provincial Department of Health for a random selection of one intervention commune. This was a typical Northern commune with a population of approximately 5000 people located in 1391 households in 2013. Most of the population were rice farmers.

Regarding government administration, the commune has a local authority called the Communal People's Committee which provides overall management of all health, labour, and social sectors. There is one commune health station, which provides basic health treatments and implements national programs such as maternal and child health, family planning, immunization, reproductive health care, food safety, nutrition, and community mental health. There is one Department of Labor, Invalids and Social Affairs, which is responsible for providing social and financial support to disadvantaged groups such as people with SMI, people who contributed to the American War, people with disabilities, and poor households. In addition, there are

several social organizations which have significant activities to improve the standard of living in the community including the Farmers' Union, Youth Union, Women's Union, Veterans' Union, and Seniors' Union.

4.3.3.2 Stage 1 – Formative research

Stage 1 had two steps: Identification of the treatment gap for people with SMI and development of the intervention framework.

4.3.3.2.1 Stage 1 – step 1: Identification of treatment gap for people with SMI

4.3.3.2.1i Sample size: All people who were involved in activities related to people with SMI in the commune were invited for in-depth interviews, including: one deputy head of the Communal People's Committee who was in charge of health social activities, one mental health staff member of the commune health station, one social work staff member of the Department of Labor, Invalids and Social Affairs, and the heads of the Women's Union and Farmers' Union. In addition, the research team consulted with the commune health station to obtain the list of people with SMI in the commune. In the list, five main caregivers were selected randomly for in-depth interviews.

4.3.3.2.1ii Data collection tools: The guiding questions for the in-depth interviews included: the main activities to support people with SMI, the challenges of implementing these activities, and recommendations to improve the quality of the activities. The structured interviews with the main caregivers consisted of the living standard, self-care, and family care of people with SMI.

4.3.3.2.1iii Procedure: An official meeting was conducted with the Hanam provincial Department of Health to obtain its approval to conduct the project activities in Tien Ngoai commune. A letter was sent by the Department to the local authority of Tien Ngoai commune to introduce the research team. Then the research team had an official meeting with the Tien Ngoai authority and representatives of the health and labour sectors and other social organizations, to describe all project activities. The

schedule for the in-depth interviews was developed by the research team in consultation with the interviewees. At the meeting in the intervention commune, written explanatory forms and consent forms were given to the interviewees. All questions related to project activities and the interviews were answered by the research team. On the day when the in-depth interviews were conducted, completed consent forms were collected and the interviews were conducted in private rooms at the local authority office and the commune health station.

Regarding the structured interviews with the main caregivers of people with SMI, a letter of invitation was sent by the local authority to the main caregivers, followed by a meeting to provide the explanatory form and the consent form. During the meeting, any concerns related to the interviews were explained by the research team. The research team also consulted with the caregivers about the timeframe that would be suitable. On the day of the interviews, consent forms were given to the main caregivers to sign.

<u>4.3.3.2.1iv Data management and analysis</u>: All written field notes were transcribed by the research team. A deductive approach was used to analyze the qualitative data. Information was allocated into three main themes: (1) the gap in care provided by formal health and social sectors; (2) the gap in care provided by informal community care providers (community, family, self-care and other lay providers); and (3) the delayed diagnosis and treatment among people with SMI. The structured interview data were analyzed in terms of living conditions, self-care, and family care.

<u>4.3.3.2.2 </u>Stage 1 – step 2: Developing the intervention framework

The research team conducted a group discussion with four local experts in community mental health and community development in both the government and non-government sectors. The guiding questions for the in-depth interviews were common methods used in community-based interventions in mental health projects, along with challenges and enablers of these methods. The group discussion was

recorded with the permission of the participants. The audiotape was transcribed by the research team. The method of delivering the intervention was decided in consideration of its acceptability and feasibility in the rural community.

In order to improve the quality of life for people with SMI in the community, their basic rights must be respected. However, there is no mental health law in Vietnam. The rights of people with mental disorders are mentioned separately in some related laws, such as the law on health examination and treatment (2009), the law on the elderly, and the law on health insurance (2014). But there was no standard source for the research team to refer to. Therefore, after reviewing existing international human rights documents, the research team decided to use the *Convention on the Rights of Persons with Disabilities* developed by the United Nations to identify the key basic rights of people with SMI for the intervention. The Convention was published by the UN in 2006 and has been signed by 161 countries. It includes 50 articles which aim to promote, protect, and ensure the human rights and freedom of people with disabilities (United Nations, 2006). Among the 50 articles, key human rights were selected using two criteria: feasibility and necessity. Each research team member worked independently to select the key rights for the intervention. Then a discussion was organized to establish consensus among the team members. The list of key human rights proposed by the research team was used to develop the content of the intervention.

4.3.3.3 Stage 2 – Proof of concept of participant-informed psycho-educational community-based intervention

The proof of concept included qualitative assessment, impact assessment, and cost analysis using a before-and-after design. The qualitative assessment provided evidence of the intervention's acceptability, feasibility, and alignment with the strategic context. The impact assessment aimed to provide quantitative evidence of

the effectiveness of the intervention. The cost analysis included the implementation costs of the intervention and costs related to participants receiving the intervention.

4.3.3.3.1 Participants and recruitment for the intervention

People with SMIs including schizophrenia, schizoaffective disorders, and bipolar disorder were recruited to participate in the intervention from two sources. The first source was the list of people with a mental illness managed by the community mental health program at the commune health station. Participants from this source had been diagnosed by the provincial psychiatric hospital staff and were receiving free medications from the program. Second, a meeting was organized with a mental health staff member of the commune health station to identify people whose behaviours suggested psychotic symptoms, but whose families could not afford to bring them to the mental health facility for diagnosis and treatment. The main caregivers of these people were encouraged to go to the provincial psychiatric hospital by commune health station staff and were given travel support by the research team. People who then received a formal diagnosis of SMI from the psychiatric hospital and began management by the commune health station were invited to participate in the intervention.

4.3.3.3.2 Qualitative assessment

4.3.3.3.2i Data sources: Several methods were used to gather data for the qualitative assessment. Group discussions with the Women's Union staff who were the facilitators of the intervention; intervention participants and their family members, and with representatives of community and other social organizations such as the Farmers' Union, Youth Union, and Seniors' Union were conducted to collect information on the acceptability and feasibility of the approach (Peters, Tran, & Adam, 2013). In-depth interviews with local authorities and critical analysis of mental health–related strategies and polices were employed to assess the alignment with the strategic context (Peters et al., 2013).

4.3.3.3.2ii Sample size: Maximum variation purposive sampling was used for the group discussions to recruit outliers whose experiences were diverse, in order to maximize the variety of perspectives among the people contributing data.

4.3.3.3.2iii Data collection tools: For the group discussions, probe questions included their experiences and views when participating in/facilitating the mental health support group, along with advantages, difficulties, and unexpected outcomes.

Regarding the in-depth interviews, the question guide included open-ended questions on the strategies, regulations, and vision of the local authority in terms of mental health areas or disadvantaged groups.

4.3.3.3.2iv Procedure: Invitation were sent by the research team to the interviewees and group discussion participants with an explanatory form and a consent form. Completed consent forms were collected before the interviews/discussions. The in-depth interviews and group discussions were conducted in private rooms and were audio recorded with the permission of the interviewees.

4.3.3.3.2v Data analysis: Audio recordings were transcribed verbatim by the research team. Qualitative data were analysed thematically (Castleberry & Nolen, 2018) using the broad thematic categories of acceptability, feasibility, and alignment with the local context.

4.3.3.3.3 Impact assessment

4.3.3.3.3i Data collection tools: The effectiveness of the intervention was measured in terms of changes in functioning scores and psychotic symptoms of the participants, and the stigma against these people and their families between the baseline and endline. The functioning score was measured using the adapted version of the SLOF which was used in Study 2.

Psychotic symptoms in the previous month were assessed using a list of common psychotic symptoms devised by a local psychiatrist. The symptoms were: seeing a

vision that other people who were there could not see; hearing voices that other people could not hear; believing that some mysterious force was inserting many different strange thoughts into their mind; feeling that their mind was being taken over by strange forces that were making them do things they did not choose to do; believing that some strange force was trying to communicate directly with them by sending special signs or signals that they could understood but no-one else could understand; and believing that there was an unjust plot going on to harm them or to have people follow them that their family and friends did not believe was true.

The stigma and discrimination that the families and/or their members with SMI experienced was also measured. Having at least one of these options was considered to be having stigma and/or discrimination in this study. The data were obtained using four questions to ask whether the participant or their family member had ever experienced stigma or discrimination.

4.3.3.3.3ii Procedure: The purpose of the pre- and post-surveys was explained by the intervention facilitators to the intervention participants. An explanatory form and a consent form were given to the participants before each survey. The research team had trained five staff of RTCCD who were not involved in any intervention activities to collect information using the paper-based interview.

On the survey day, the facilitators of the intervention guided the data collectors to the households having members with SMI who participated in the intervention. Completed consent forms signed by the main caregivers for permission to collect information about the people with SMI were collected before the interviews. Each interview was undertaken in a private room.

The completed consent forms and interview schedules were gathered and stored in a locked cabinet at the provincial Women's Union office. They were transported to the RTCCD office with the data collectors in a sealed box.

4.3.3.3.3iii Data management and analysis: Data entry was implemented using an Access database with double entry. A dataset without identifiable information was sent to Monash University for storage in a secured cloud-based storage system. The data were analyzed using Stata Version 13.0 (StataCorp LP, College Station, USA). The functioning scores and psychotic symptoms were analyzed using paired t-tests because these primary outcomes were normally distributed continuous variables. The McNemar's test was employed for the paired binary variables of stigma.

4.3.3.3.4 Economic impact

The cost analysis collected project- and participant-related costs. Therefore, the data sources were obtained from two corresponding sources: the project officers; and the main caregivers of the intervention participants.

4.3.3.3.4i Data collection tools: The project implementation costs included: start-up phase; ongoing central management activities; and ongoing program activities. The start-up phase included all costs related to designing the intervention, research activities, workshops, and meetings to prepare for the intervention implementation. The ongoing central management activities were the salaries of the project coordinator and project officers, and the administration costs in the Hanoi office. The ongoing program activities comprised the salaries of the intervention facilitators, supportive supervision and in-service training provided by the research team, program resources (such as materials for the club meetings and actitvites), and knowledge sharing (the participants' manual, DVD, and wall paintings) (Gustafsson-Wright & Boggild-Jones, 2018; Johns, Baltussen, & Hutubessy, 2003). All costs were measured on an annual basis.

The participant-related costs were calculated by estimating the actual incomes and expenditures of people with SMI. The income per month consisted of job incomes that the mentally ill people could generate, financial support from the government, and other sources such as donations from relatives or humanitarian organizations. The

monthly expenditure included the living costs (for food, clothes, and other basic living costs), total hours per day that adult family members spent caring for the mentally ill member, inpatient costs per year and outpatient costs per month, and the costs that the family had to pay to find the mentally ill member when they wandered away or to compensate for what the mentally ill member destroyed per year.

<u>4.3.3.3.4ii Procedure</u>: The cost analysis was combined with the impact evaluation using face-to-face paper-based interview schedules. Therefore, the procedure for this cost analysis was similar to the procedure presented in the impact assessment. The data collectors trained for the impact assessment were trained for one additional day in how to enable the main caregivers to estimate the costs and how to encourage them to recall costs incurred in the past.

<u>4.3.3.3.4iii Data management and analysis</u>: The costs were collected and calculated in Vietnamese dong and then converted to annual costs in USD. The intervention was conducted for one year (2013); therefore, no adjustment to the cost data was needed. The human capital approach was used to value the productivity costs of informal care (Gray, Clarke, Wolstenholme, & Wordsworth, 2011). The local rate of farming labour was 160,000 Vietnamese dong (USD7.67) for an eight-hour working day. The contemporaneous exchange rate was 20,858 Vietnamese dong to USD1 (June 2013). The Wilcoxon matched pairs signed-rank test was used to identify the difference between the costs (which were not normally distributed) before and after the intervention.

4.4 Ethics

Mental health is a sensitive topic in Vietnam. In these three sub-studies, individual information was not ascertained directly but collected from the household head or the main caregiver. This method is not precisely aligned with the recommendations of the *Australian National Statement on Ethical Conduct in Human Research 2007* (National Health and Medical Research Council & Australian Research Council,

2018), but was culturally congruent with the norms and values of Vietnam at the time of the study. In Survey 1, it was culturally appropriate for the Vietnamese household head to report information about other household members, because they are the people who know the overall information about the household as well as about the household members. The household head is the person who reported to the local authorities about civic responsibilities and is the identified representative of the household members to provide information for national surveys. However, more than 80% of the household heads in this survey were men, and they might have been unlikely to disclose their own perpetration of family violence or alcohol abuse. Hence, it may underestimate these risks. In Study 2 and Study 3, we were advised by local mental health experts that people with SMI were unlikely to have the cognitive capacity to complete the interviews and, therefore, that their main caregivers should be asked to provide consent and information on their behalf.

A thorough procedure was followed by the research team in order to meet the ethical requirements. First, meetings with the study participants were held to provide information about the study and distribute an explanatory form in plain language. Any concerns about the study were addressed by the research team at the meetings. The meetings also emphasized the voluntary nature of participation and that the interviewees could withdraw from the study at any time. This was also reminded before the interviews and the group discussions. Second, information about people who met the criteria of having clinically significant symptoms of common or severe mental disorders in Survey 1 and any concerns of the main caregivers in Survey 2 and Sub-study 3 were noted by the data collectors. Then, with consent, these were reported to the mental health staff of the commune health stations or the social work staff of the Department of Labor, Invalids, and Social Affairs at the commune level, or to the local authority, so that further support could be provided. Third, no identifying information was written on the paper-based interview schedules or the

field notes. This information was coded to ensure confidentiality. The data were sent to and stored in a secure cloud-based storage system at Monash University, Australia. Only authorized researchers could access the data.

This thesis project was given ethical approval by the Vietnam Medical Association (Decision No. 25/12/QD-RTCCD) and the Monash University Human Research Ethics Committee (certificate number: 9515).

CHAPTER 5 – BURDEN OF MENTAL DISORDERS AND ASSOCIATED FACTORS AMONG ADULTS IN VIETNAM

Manuscript 3: The burden of clinically significant symptoms of common and severe mental disorders among adults in Vietnam: a population-based cross-sectional survey

The manuscript illustrates the prevalence of common and severe mental disorders among the general population. In addition, the chapter also examined the association between common or severe mental disorders and social determinants at individual and household levels. These findings were described in manuscript three which was under review by the *BMC Public Health*.

The burden of clinically significant symptoms of common and severe mental disorders among adults in Vietnam: a population-based cross-sectional survey

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Abstract

Background

Vietnam has limited evidence about the burden of common and severe mental disorders among adults to inform policy. The aim of this paper was to estimate the prevalence of common and severe mental disorders among adults and factors associated with them in Vietnam.

Methods

We conducted a cross-sectional household survey among people aged at least 16 years in Thanh Hoa and Ben Tre provinces which are nationally representative of the North and the South of Vietnam. The World Health Organization Self-Reporting Questionnaire 24 was used to screen for clinically significant symptoms of common and severe mental disorders at the individual level. Household characteristics were obtained in face-to-face interviews with the household heads. A multilevel mixed-effects logistic regression model was used to identify associated factors of the common and severe mental disorders.

Results

Among 611 households which included 1528 adults, the point prevalence of clinically significant symptoms was 14.4% for common mental disorders and 8.2% for severe mental disorders after weighting by age groups. Common mental disorders were associated with social factors including lived in a Northern rather than a Southern province, disadvantaged household economic status, in which a family member(s) misused alcohol, the family lacking links to social organisations able to provide instrumental support, and the individual not having completed primary school. Severe mental disorders had fewer associations with social factors compared to common mental disorders, but were associated with living in the Northern province,

disadvantaged household economic status, family violence and being older than 50 years.

Conclusions

The prevalence of clinically significant symptoms of common and severe mental disorders among adults in Vietnam was higher than in high income countries and had a strong association with household characteristics. The result indicates that a community-based approach to reduce household risk factors and to provide instrumental support might be an effective strategy to alleviate the burden of mental health problems in Vietnam.

Keywords

Common and severe mental disorders, risk factors, Vietnam, adults

Background

Mental disorders in low and middle-income countries (LMICs) are becoming more widely recognized due to its burdens and associating factors (1). Mental disorders contributed to more than 30% of years lived with disability (YLDs) and nearly 15% of disability-adjusted life years (DALYs) globally (2). The term common mental disorders (CMDs) is the widely-accepted descriptor for non-psychotic anxiety, depressive, adjustment and somatic disorders which are potentially detectable in primary care (3). Severe mental disorders (SMDs) include disorders characterised by psychotic symptoms such as schizophrenia and bipolar affective disorder (4). The World Health Organization (WHO) classifies psychotic symptoms as abnormalities in thinking or disorganized behaviour: delusions, hallucinations, neglect of self-care, inability to complete usual responsibilities and either lack of volition or the excessive drive revealed in manic states (5).

Depressive and anxiety disorders were reported to contribute nearly 45,000 and 27,000 thousands DALYs in 2016, respectively (6). It is estimated that 80% of the people experiencing both these conditions live in LMICs (7). Steel et al's (2014) recent systematic review of 174 population-based studies from 63 countries, reported a pooled 12-month period prevalence of anxiety and depression of 20%. The review concluded that the prevalence was similar in LAMICs and high income countries (HICs), and that approximately one in three people experience a CMD at some point during their lifetime. Lifetime prevalence in LMICs was estimated to be lower than that in HICs (8). However, there are some influential limitations in this review that warrant consideration in interpreting these conclusions. First, there was no critical engagement with whether the data collection tools (including diagnostic interviews) had been appropriately culturally verified or formally validated

for the cultural contexts in which they were administered (9). Second, there was also no consideration of cultural differences in emotional literacy or the impact on disclosure of severe stigma against people with mental disorders. It was not clear whether strategies to enable the participation of people with low literacy had been considered in evaluating study methodologies. If questions are not comprehensible people are likely to answer no and this leads to underestimates of prevalence.

Establishment of the prevalence of severe mental disorders in resource-constrained settings has been difficult due to insufficient mental health specialists and lack of research capacity in psychiatric epidemiology. The prevalence has most commonly been established by ascertainment of psychotic symptoms rather than diagnoses of disorders (10, 11). In 2012 Nuevo et al analysed data contributed by 256, 445 participants in 52 countries to the World Health Survey to establish the prevalence of psychotic symptoms. The cross-national survey employed the Composite International Diagnostic Interview (CIDI) administered trained by non-mental health professionals to detect specific psychotic symptoms, but not to form clinical diagnoses. The prevalence of having at least one psychotic symptom varied widely from 0.66% to 45.84%. The authors suggested that the potential reason for this wide range was cultural differences among countries. However, the publication did not mention the procedure of adapting the CIDI for specific countries. In addition to the cultural difference, the lack of formal validation might contribute to the wide variation of the prevalence of psychotic symptoms in the multi-national survey(12).

Burden of mental disorders in Vietnam

There have been five investigations reported to date of the burden of CMDs and SMDs among adults in the general population in Vietnam in international peer-reviewed journals in English. Among these, one summarised the main

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findings of a Ministry of Health report, but did not include any information about method, sample and data analysis (13). Four papers described four original research studies. One survey was conducted in a Southern province (Hau Giang) applying a multistage probabilistic cluster sampling frame with the commune or hamlet as the sampling unit. The investigators conducted interviews with 3039 people who were older than seventeen years. Data collectors were mental health physicians, mental health nurses and general staff. The CIDI was culturally adapted in several stages including a comprehensive review of emotional states in Vietnamese ethnographic studies, and psychometric tests with high internal consistency (r= 0.87-0.95) and reliability (r=0.81-0.89). The data collection tool consisted of a depression scale (26 items), an anxiety scale (13 items), and a somatisation scale (14 items) to measure the prevalence of depression and anxiety (14). The household cross-sectional survey in two southern provinces (Da Nang and Khanh Hoa) used a four-stage cluster sampling strategy. The investigators included 4981 adults who were 18 or older. The face-to-face interviews were implemented by trained lay data collectors. The SRQ20 validated in Vietnam with the cut-off of 6/7 was used to screen for CMDs among the study population (15). Another paper in Vietnam was a pre- and post Xangsane typhoon survey with 797 adults (18+) in Da Nang – a southern province. Data were collected by trained interviewers using validated SRQ20 with cut-off of 7/8 for CMDs (16). Finally, the WHO survey was conducted in 52 countries including Vietnam. The CIDI was used by trained staff to screen for SMDs among 4174 adults (18+). This data collection tool was translated into Vietnamese using a specified protocol. There was lack of information about which province the study was conducted in (12).

The Ministry of Health reported that the prevalence of depression and anxiety among the population were 2.8% and 2.6% respectively (13). The two peer-

review articles revealed a wide variation of depression and anxiety prevalence. A survey among adults in the Southern Hau Giang province found that the prevalence was 1.2% (Standard Error: 0.7) for depression, 4.0% (Standard Error: 0.2) for anxiety (14). The study in Da Nang and Khanh Hoa provinces reported that around 20% of adults have clinically significant symptoms of CMDs (15). The prevalence in another study in Da Nang was 20.7% before the typhoon (16). These findings suggest that the prevalence of CMDs among adults in Vietnam was estimated by screening instruments to be higher than among those using diagnostic tools.

The Ministry of Health reported the prevalence of schizophrenia to be 0.5% but means of ascertaining this was not clear (13). The WHO survey found that the prevalence of having at least one psychotic symptoms in Vietnam was 0.66% (Standard Error: 0.20) at the population after weighted and sex-age standardization (12).

In general, the burden of CMDs and SMDs in Vietnam were estimated from sub-populations such as some provinces in the south of Vietnam, or from women during the perinatal period in the northern rural area. Methodologies used were inconsistent among these studies.

The four original studies in Vietnam reported a limited set of protective and risk factors such as age, gender, marital status, education, occupation (12-15). In general, especially in rural areas, most families live in multi-generation arrangements where family members are strongly connected, share social capital, economic status, supports from government or resource groups, and co-experience adverse events. In addition, most people with psychotic disorders are cared by their family members. Therefore, mental health problems have to be understood within the family environment.

In order to address the policy need and limitation of the existing evidence in Vietnam, the aim was to estimate the burden of CMDs and SMDs among

adults in Vietnam. In particular, this study aimed to (1) estimate the prevalence of clinically significant symptoms of CMDs and SMDs among adults in Vietnam; and (2) identify factors at both individual and family levels associated with CMDs and SMDs among adults in Vietnam.

Methods

Study design

The study was a cross-sectional household survey completed in May and June 2013.

Setting

Vietnam is a World Bank classified lower-middle income country, with a population of more than 90 million people in Southeast Asia (17). Vietnam was divided into two socio-political areas: the North and the South. The two areas had been ruled by different Kings for a long history. Then, the South area was more influenced by the French and the United States' colonialism, whereas the North of Vietnam was affected by the Soviet Union and China. Therefore, there significant differences between the two areas in terms of culture, linguistic, living standard, and people characteristics. The survey was conducted in two provinces which represent the north and the south of Vietnam. Thanh Hoa is the Northern province with the third highest population in Vietnam with 3.496.600 people living in 27 districts. The province has 6 coastal, 11 mountainous and 10 plain land districts and a capital city. At the time of the survey the average income per capita per month was approximately 1.6 million Vietnam dong (approximately USD 82) (18). Ben Tre – a southern province has a population of approximately 1.26 million people living in one city and eight districts. All city and districts are in the plain land. The average income per capita per month was nearly 2.2 million Vietnam dong (more than USD 100) (19).

Random selection of households and sample size

A cluster sampling method was used. At the provincial level, 30 communes were randomly selected from the list of communes provided by the provincial level Departments of Health and Labour, Invalids and Social Affairs. In each selected commune, a list of households was made by the commune administrators and 15 households were selected randomly from it. Ten households were visited and, if no-one was at home, a household was selected from the replacement list. All adults who were older than 16 years in the households were invited to participate in the survey. Household members were defined as members who have had meals together for at least 6 months. The household head was defined by the local authority. Commonly the household head is the most powerful decision-maker in the family.

Data collection tools and sources

The structured interview schedules included standardised instruments and study-specific questions. Two forms of data were collected: (1) Individual-level information was collected by self-reported questionnaires. The questionnaires included the SRQ and other background information such as age, education, and gender; (2) Household socio-economic characteristics were ascertained by interviewing the head of the household. Specific tools and information used in this survey were described in table 1.

Table 1: Tools used for data collection

Variable	Tool	Description
Individual level		
Symptoms of common and severe mental	WHO Self Reporting Questionnaire (SRQ)	The screening tool consists of 20 questions related to common non-psychotic mental disorders and four questions related to psychotic symptoms (11). There are two

disorders		formal validity studies of SRQ 20 items in Vietnam. The first study (2004) was conducted in a Northern province among 2000 female caregivers to validate the SRQ20 against the diagnosis of a professor of paediatric psychiatry. The cut-off point was 7/8 (20). The second study in 2006 included a community sample of 500 people aged from 18 to 60 in a rural northern province presented an optimal cut-off point of 5/6. SRQ 20 items was validated against psychiatrists (21). This study used the cut-off point of 6/7 to calculate the prevalence of clinically significant symptoms of CMDs among adults in Vietnam due to the similarity of the study participants. The SRQ includes 4 items assessing symptoms of severe mental disorders including (1) has somebody been trying to harm you in some way, (2) are you a much more important person than most people think, (3) have you noticed any interference or anything else unusual with your thinking, (4) have you ever heard voices without knowing where they come from or which other people cannot hear (11).
Household level		

Household economic status	One question addressing household economic status	Subjective self-assessment of household heads in terms of their household economic status compared to other neighbours in their commune (22).
Alcohol abuse	One question addressing whether any household member abused alcohol	The household heads identify whether a household member was abusing alcohol.
Family violence	Short form of domestic violence screening tool (HITS) (23).	The original four-item scale was developed to identify domestic violence in term of Hurts, Insults, Threatens and Screams (HITS) with 5-point frequency format at individual level. The score ranges from 4 (no family violence) to 20 (frequent family violence) (23). This scale was adapted to screen the family violence by asking whether any household member suffering from such domestic violence.
Social capital	Short version of the modified Adapted Social Capital Assessment Tool (SASCAT) (24)	The SASCAT comprises nine items divided into two subscales: structural and cognitive social capital. The structural social capital reflects the connectedness of the household with the community such as participation in organizations, degree of citizenship (the involvement in voting, campaign activities

		at commune or provincial levels), specific collective action (together with other neighbour to address a specific problem in the community) and links to groups with resources (such as local government or aid agencies). The cognitive social capital describes the feelings of sense of community such as reciprocity, and sharing. It consists of emotional support, instrumental support (food, money, etc), trust, social harmony (getting along with others in the community), sense of belonging (attachment to the community), and perceived fairness (whether others in the community take advantage of people) (25). This tool was validated in Vietnam with nearly 80% of accurate interpretation of all questions among caregivers and data collectors. SASCAT was also reported as a valid tool in terms of psychometric and cognitive validation (26, 27).
Specific adverse life event	One question assessing experiences of adverse life events	Have the following events occurred in the previous three years: household items stolen/robbed, threatening of losing or lost rights of inheritance, threatening or lost land/property ownership.

Procedure

Local staff of the provincial level Department of Health and Department of Invalids and Social Affairs were employed as data collectors due to their familiarity with local accents, customs, and access routes to communes. They were trained for three days by the research team from the Research and Training Centre for Community Development (RTCCD) in Hanoi. Only staff who fulfilled all requirements in terms of communication skills and understanding of the questionnaire, protection of confidentiality and ensuring data integrity were employed as data collectors.

All potential participants were informed by local authorities that they were to be invited for interviews. At the day of the interview, village heads guided the data collectors to the selected households. All household members who were adults were given separately an oral or written plain language description of the study and were asked to sign a consent form. Those who could not write provided a thumbprint or verbal consent witnessed by an independent observer. After interviewing the household heads to collect household characteristics, all members who were older than 16 years old were assigned into different private rooms to complete the written self- report the SRQ with 20 items for symptoms of CMDs and 4 items for psychotic symptoms. For those who had low literacy, interviews were conducted by the data collectors.

The research team supervised all data collectors and selected randomly 5% of the completed questionnaires to reinterview participants for quality assurance. In addition, questionnaires were checked by supervisors in the field for missing values and inconsistent responses, to enable data collectors to go back to the household to amend possible errors.

Completed consent forms and paper-based questionnaires gathered by the data collectors were returned to the research team at the end of each working day for secure storage in a locked cabinet at the provincial level Department

of Labour, Invalids and Social Affairs office. Then it was transported in a locked bag with the research team for secure storage and data entry at the RTCCD office.

Data management and analysis

No name was recorded in the questionnaires, only the codes of provinces, communes and households were used for data entry and data analysis. Family members shared the same family code, but different personal codes to allow the researchers to identify data of individual and household levels

A double data entry method was conducted using the Microsoft Access 2013 (Microsoft Corp, USA). The paper records were stored securely at RTCCD office and only researchers had access to the original data.

Data analyses were completed in two steps using Stata, Version 13.0 (StataCorp LP, College Station, Texas, USA), with statistical significance set at p-value less than 0.05. Step 1 used descriptive analyses to calculate the community prevalence and 95% confidence intervals. A score of 6 and above in the SRQ20 was used as the indicator of clinically-significant symptoms of CMDs. The cut-off score of 6/7 was reported in the validity study of SRQ-20 with a sensitivity of 85%, and a specificity of 46% (21). Participants who reported at least one psychotic symptom were classified as having a clinically significant symptom of an SMD. People who reported both clinically significant symptoms of CMDs and any psychotic symptoms were classified in the SMD group (28). The prevalence of CMDs and SMDs were weighted using the standard proportion of age and sex groups among the Vietnam population in 2013 (29).

Step 2, univariate analyses were used to compare individual characteristics between groups of people with and without clinically-significant symptoms of CMDs or SMDs. The same method was also employed to identify the association of household characteristics with groups of households having or

not having at least a member with clinically significant symptoms of CMDs or SMDs.

In step 3, the binary outcome (CMDs or SMDs) had a value of 0 referring to having no clinically significant symptoms of CMDs or SMDs, and a value of 1 indicating otherwise. The data of this study had two levels, with individuals nested within households. All people in the same household shared common socio-economic characteristics. Therefore, two-level mixed-effects logistic regressions with random intercepts and fixed coefficients included both household and individual characteristics were used (30).

Results

In total 643 households were approached, among which 32 households were not included either because the household heads were not at home at the time the study team visited or declined participation. In total, 611 households accepted the invitation to contribute data, giving a recruitment fraction of 95%. Overall, 1528 individual household members aged more than 16 years contributed data.

Socio-economic characteristics of the study sample

Most households were of mid-level or disadvantaged economic status (72.6%) and had experienced specific adverse events in the previous three years. Regarding the cognitive social capital, a majority of households reported experiencing emotional support, trust, social harmony, and sense of belonging. Insignificant numbers reported any experiences of family violence. Among 1528 participants, most were aged over 24 years and less than 10% had completed tertiary education. More women than men contributed data (see Table 2).

The prevalence of clinically significant symptoms of CMDs and SMDs

Among the 1528 participants, 251 (16.4% (95% Confidence Interval: 14.65% - 18.37%)) had SRQ20 scores greater than 6/20, and 132 (8.6% (95% Confidence Interval: 7.32% - 10.16%)) reported at least one psychotic symptom. After weighting for age and sex, the population point prevalence was 14.2% (95% Confidence Interval: 14.16 % - 14.18) for CMDs, and 8.1% (95% Confidence Interval: 8.12% - 8.14%) for SMDs.

Factors associated with CMDs

In the uncontrolled univariate analyses, individual characteristics including gender, age, and education were significantly associated with CMDs (see Table 3). The household factors which were significantly associated with CMDs were province, residence of urban or rural area, economic status, and some social capital items (specific collective actions, links to groups with resources, instrumental support, and social harmony) (see Table 4).

After conducting the multilevel mixed-effects logistic regression, participants who were younger than 24 years old versus 50+ group, male and had completed tertiary education were less likely to experience clinically significant symptoms of common mental disorders when comparing with the reference groups. Households in the southern province, having advantaged economic status, having no member experiencing alcohol abuse, having links to groups with resources and receiving instrumental support were protected against CMDs among their family members when comparing with the reference groups (see table 5).

Associated factors of SMDs

In the uncontrolled univariate analyses, at individual level, gender, age, and education were not significantly associated with symptoms of SMDs (see table

6). Household's factors associated with any psychotic symptom were province, residence, and economic status (see table 7).

The multilevel mixed-effects logistic regression analysis revealed that, people aged at least 50 years were more likely to report symptoms of SMDs than those in the 17-24 years old group when comparing with the reference groups. Households in the southern province, having mid-level or advantaged economic status and having no family violence were less likely to have family members with any psychotic symptom when comparing with the reference groups. (Table 8).

Table 2: Social characteristics of households and individuals in Vietnam which contributed data

Variables	Thanh Hoa n (%)	Ben Tre n (%)	Total N (%)
Household level			
Number of households	294 (48.1)	317 (51.9)	611 (100%)
Economic status			
Disadvantaged	51 (17.3)	50 (15.8)	101 (16.5)
Mid-level	181 (61.6)	174 (54.9)	355 (58.1)
Advantaged	62 (21.1)	93 (29.3)	155 (25.4)
Residence			
Urban	50 (17.0)	169 (53.3)	219 (35.8)
Rural	244 (83.0)	148 (46.7)	392 (64.2)
Alcohol abuse in the family			
Yes	23 (7.8)	52 (16.4)	75 (12.3)
No	271 (92.2)	265 (83.6)	536 (87.7)
Family violence			
Yes	9 (3.1)	5 (1.6)	14 (2.3)
No	285 (96.9)	312 (98.4)	597 (97.7)
Structural social capital			
Participation in organizations	72 (24.5)	145 (45.7)	217 (35.5)
Degree of citizenship	204 (69.4)	227 (71.6)	431 (70.5)
Specific collective actions	90 (30.6)	136 (42.9)	226 (37.0)
Links to groups with resources	92 (31.3)	196 (61.8)	288 (47.1)
Cognitive social capital			

Emotional support	263 (89.5)	226 (71.3)	489 (80.0)
Instrumental support	203 (69.1)	180 (56.8)	383 (62.7)
Trust	271 (92.2)	269 (84.9)	540 (88.4)
Social harmony	286 (97.3)	301 (95.0)	587 (96.1)
Sense of belonging	289 (98.3)	303 (95.6)	592 (96.9)
Perceived fairness	275 (93.5)	301 (95.0)	576 (94.3)
Specific adverse events within the last 3 years			
Yes	240 (81.6)	248 (78.2)	488 (79.9)
Household size (Mean ± SD)	3.5 ± 1.4	3.5 ± 1.4	3.5 ± 1.4
Individual level			
Number of participants	646 (42.3)	882 (57.7)	1528 (100%)
Age			
17-24 years old	80 (12.4)	108 (12.2)	188 (12.3)
25-49 years old	251 (38.8)	434 (49.2)	685 (44.8)
50+ years old	315 (48.8)	340 (38.6)	655 (42.9)
Gender			
Male	288 (44.6)	389 (44.1)	677 (44.3)
Female	358 (55.4)	493 (55.9)	851 (55.7)
Education			
Up to completed primary school	159 (24.6)	464 (52.6)	623 (40.8)
Completed secondary school	439 (68.0)	334 (37.9)	773 (50.6)
Any post-secondary qualification	48 (7.4)	84 (9.5)	132 (8.6)

Table 3: Univariable comparison of characteristics of people with or without a SRQ20 score >6

	People without clinically significant symptoms of CMDs n (%)	People with clinically significant symptoms CMDs n (%)	Total n (%)	p-value
Sex				
Male	588 (46.1)	89 (35.5)	677 (44.3)	0.002
Female	689 (53.9)	162 (64.5)	851 (55.7)	
Age				
17-24 years old	176 (13.8)	12 (4.8)	188 (12.3)	<0.001
25-49 years old	610 (47.8)	75 (29.9)	685 (44.8)	
50+ years old	491 (38.4)	164 (65.3)	655 (42.9)	

Education				
Up to completion of primary school	502 (39.3)	121 (48.2)	623 (40.8)	<0.001
Completion of secondary or high school	648 (50.7)	125 (49.8)	773 (50.6)	
TAFE/ bachelor/postgraduate	127 (10.0)	5 (2.0)	132 (8.6)	

Table 4: Univariable comparison of characteristics of households with or without a member with SRQ20 scores > 6

	Household with no members having clinically significant symptoms of CMDs n (%)	Household with members having clinically significant symptoms of CMDs n (%)	Total n (%)	p-value
Province				
Thanh Hoa (north)	230 (45.9)	64 (58.2)	294 (48.1)	0.02
Ben Tre (south)	271 (54.1)	46 (41.8)	317 (51.9)	
Residence				
Urban	189 (37.7)	30 (27.3)	219 (35.8)	0.01
Rural	212 (62.3)	80 (72.7)	392 (64.2)	
Household size (Mean ± SD)	3.5 ± 1.4	3.3 ± 1.4	3.5 ± 1.4	0.08
Economic status				
Disadvantaged	73 (14.6)	28 (25.5)	101 (16.5)	0.03
Mid-level	296 (59.1)	59 (53.6)	355 (58.1)	
Advantaged	132 (26.3)	23 (20.9)	155 (25.4)	
Alcohol abuse	53 (10.6)	22 (20.0)	75 (12.3)	0.06
Family violence (Mean ± SD)	4.0 ± 0.2	4.0 ± 0.2	4.0 ± 0.2	0.3
Structural social capital				
Participation in organizations	185 (36.9)	32 (29.1)	217 (35.5)	0.1
Degree of citizenship	351 (70.1)	80 (72.7)	431 (70.5)	0.5
Specific collective actions	195 (38.9)	31 (28.2)	226 (37.0)	0.03
Links to groups with resources	246 (49.1)	42 (38.2)	288 (47.1)	0.003
Cognitive social capital				
Emotional support	398 (79.4)	91 (82.7)	489 (80.0)	0.4
Instrumental support	327 (65.3)	56 (50.9)	383 (62.7)	0.005
Trust	446 (89.0)	94 (85.5)	540 (88.4)	0.2
Social harmony	485 (96.8)	102 (92.7)	587 (96.1)	0.04
Sense of belonging	485 (96.8)	107 (97.3)	592 (96.9)	0.7
Perceived fairness	475 (94.8)	101 (91.8)	576 (94.3)	0.2
Adverse events within the last 3 years	99 (19.8)	24 (21.8)	123 (20.1)	0.6

Table 5: Adjusted odd ratios of household and individual characteristics of adults with and without SRQ20 scores> 6 in Vietnam

Factors	Adjusted OR	95% CI	P-value
Age			
0 – 17-24 years old (reference group)	1.00		
25-49 years old	1.69	0.83-3.43	0.1
50+ years old	4.64	2.27-9.47	<0.001
Gender			
Male (reference group)	1.00		
Female	1.59	1.14-2.21	0.006
Education			
TAFE/bachelor/postgraduate (reference group)	1.00		
Completion of secondary or high school	3.73	1.35-10.38	0.01
Up to completion of primary school	4.57	1.61-13.0	0.004
Province			
Thanh Hoa (northern Vietnam) (reference group)	1.00		
Ben Tre (southern Vietnam)	0.48	0.30-0.75	0.002
Economic status			
Disadvantaged (reference group)	1.00		
Mid-level	0.62	0.38-1.01	0.06
Advantaged	0.53	0.29-0.98	0.04
Residence			
Urban (reference group)	1.00		
Rural	1.02	0.66-1.59	0.9
Household size	1.01	0.89-1.15	0.8
Alcohol abuse			
No (reference group)	1.00		
Yes	1.80	1.06-3.06	0.03
Family violence			
No (reference group)	1.00		
Yes	1.99	0.71-5.58	0.1
Structural social capital			
Participation in organizations			
Yes (reference group)	1.00		
No	1.08	0.70-1.65	0.7
Degree of citizenship			

Yes (reference group)	1.00		
No	1.02	0.67-1.57	0.9
Specific collective action			
Yes (reference group)	1.00		
No	0.77	0.50-1.19	0.2
Links to groups with resources			
Yes (reference group)	1.00		
No	1.83	1.16-2.88	0.009
Cognitive social capital			
Emotional support			
Yes (reference group)	1.00		
No	1.45	0.85-2.49	0.1
Instrumental support			
Yes (reference group)	1.00		
No	1.56	1.04-2.34	0.03
Trust of community			
Yes (reference group)	1.00		
No	1.23	0.65-2.33	0.5
Social harmony			
Yes (reference group)	1.00		
No	1.75	0.62-4.90	0.2
Sense of belonging			
Yes (reference group)	1.00		
No	1.01	0.32-3.22	0.9
Perceived fairness			
Yes (reference group)	1.00		
No	1.88	0.91-3.85	0.08
Adverse life events in the last three years			
No (reference group)	1.00		
Yes	1.00	0.64-1.58	0.9

Table 6: Univariable comparison of characteristics of people with or without any psychotic symptoms

	People without any psychotic symptoms n (%)	People with any psychotic symptoms n (%)	Total n (%)	p-value
Gender				
Male	628 (45.0)	49 (37.1)	677 (44.3)	0.08
Female	768 (55.0)	83 (62.9)	851 (55.7)	
Age				
17-24 years old	178 (12.8)	10 (7.6)	188 (12.3)	0.08
25-49 years old	630 (45.1)	55 (41.7)	685 (44.8)	
50+ years old	588 (42.1)	67 (50.8)	655 (42.9)	
Education				
Up to completion of primary school	576 (41.3)	47 (35.6)	623 (40.8)	0.4
Completion of secondary or high school	701 (50.2)	72 (54.6)	773 (50.6)	
TAFE/ bachelor/postgraduate	119 (8.5)	13 (9.8)	132 (8.6)	

Table 7: Univariable comparison of characteristics of households with or without a member with at least one psychotic symptom

	Household with no members having any symptom of SMDs n (%)	Household with members having any symptom of SMDs n (%)	Total n (%)	p-value
Province				
Thanh Hoa (north)	260 (46.9)	34 (60.7)	294 (48.1)	0.04
Ben Tre (south)	295 (53.1)	22 (39.3)	317 (51.9)	
Residence				
Urban	207 (37.3)	12 (21.4)	219 (35.8)	0.01
Rural	348 (62.7)	44 (78.6)	392 (64.2)	
Household size (Mean ± SD)	3.5 ± 1.4	3.3 ± 1.4	3.5 ± 1.4	0.08
Economic status				

Disadvantaged	83 (14.9)	18 (32.1)	101 (16.5)	0.002
Mid-level	325 (58.6)	30 (53.6)	355 (58.1)	
Advantaged	147 (26.5)	8 (14.3)	155 (25.4)	
Alcohol abuse	71 (12.8)	4 (7.1)	75 (12.3)	0.2
Family violence (Mean ± SD)	4.0 ± 0.2	4.1 ± 0.04	4.0 ± 0.2	0.1
Structural social capital				
Participation in organizations	200 (36.0)	17 (30.4)	217 (35.5)	0.3
Degree of citizenship	393 (70.8)	38 (67.9)	431 (70.5)	0.5
Specific collective action	204 (36.8)	22 (39.3)	226 (37.0)	0.7
Links to groups with resources	267 (48.1)	21 (37.5)	288 (47.1)	0.1
Cognitive social capital				
Emotional support	442 (79.6)	47 (83.9)	489 (80.0)	0.4
Instrumental support	354 (63.8)	29 (51.8)	383 (62.7)	0.07
Trust	489 (88.1)	51 (91.1)	540 (88.4)	0.5
Social harmony	533 (96.0)	54 (96.4)	587 (96.1)	0.8
Sense of belonging	538 (96.9)	54 (96.4)	592 (96.9)	0.8
Perceived fairness	522 (94.1)	54 (96.4)	576 (94.3)	0.4
Adverse events within the last 3 years	113 (20.4)	10 (17.9)	123 (20.1)	0.6

Table 8: Adjusted odd ratios of household and individual characteristics of adults with and without any psychotic symptom 6 in Vietnam

Factors	Adjusted OR	95% CI	P-value
Age			
17-24 years old (reference group)	1.00		
25-49 years old	2.15	0.98-4.71	0.06
50+ years old	2.83	1.26-6.38	0.01
Gender			
Male (reference group)	1.00		
Female	1.42	0.94-2.14	0.09
Education			
TAFE/bachelor/postgraduate (reference group)	1.00		
Completion of secondary or high school	0.69	0.32-1.49	0.3
Up to completion of primary school	0.47	0.20-1.09	0.07
Province			
Thanh Hoa (northern Vietnam) (reference group)	1.00		

Ben Tre (southern Vietnam)	0.54	0.31-0.95	0.03
Economic status			
Disadvantaged (reference group)	1.00		
Mid-level	0.50	0.27-0.91	0.02
Advantaged	0.35	0.16-0.75	0.007
Residence			
Urban (reference group)	1.00		
Rural	1.25	0.72-2.16	0.4
Household size	1.00	0.85-1.18	0.9
Alcohol abuse			
No (reference group)	1.00		
Yes	0.58	0.26-1.30	0.1
Family violence			
No (reference group)	1.00		
Yes	3.50	1.08-11.31	0.03
Structural social capital			
Participation in organizations			
Yes (reference group)	1.00		
No	1.02	0.60-1.72	0.9
Degree of citizenship			
Yes (reference group)	1.00		
No	1.00	0.57-1.71	0.9
Specific collective action			
Yes (reference group)	1.00		
No	1.12	0.65-1.92	0.6
Links to groups with resources			
Yes (reference group)	1.00		
No	1.01	0.58-1.75	0.9
Cognitive social capital			
Emotional support			
Yes (reference group)	1.00		
No	1.27	0.65-2.49	0.4
Instrumental support			
Yes (reference group)	1.00		
No	1.54	0.93-2.56	0.09
Trust of community			
Yes (reference group)	1.00		
No	1.37	0.63-2.98	0.4
Social harmony			
Yes (reference group)	1.00		

No	1.10	0.28-4.35	0.8
Sense of belonging			
Yes (reference group)	1.00		
No	0.87	0.18-4.24	0.8
Perceived fairness			
Yes (reference group)	1.00		
No	0.55	0.18-1.65	0.2
Adverse life events in the last three years			
No (reference group)	1.00		
Yes	1.06	0.60-1.87	0.8

Discussion

To our knowledge, this is the first household survey conducted in both southern and northern provinces to estimate the burden of common and severe mental disorders among adults in Vietnam. A rigorous random selection method was used in each implementation step and there was a high recruitment fraction (95%). The data were collected by local language speakers to maximize the likelihood that participants could comprehend the questions. The data sources were developed in Vietnam and the indicator of the primary outcome of the SRQ20 had been formally validated to establish the local cut-off scores for clinically significant symptoms with high sensitivity and specificity in the country.

In rural provinces in Vietnam, it is common for people to migrate internally to secure income-generating work. Elderly and young people are more likely to stay at home to farm while people of working age migrate to urban centres for paid employment. In order to take this into account, prevalence estimates were weighted by age group according to the national household survey conducted in the same year. No previous comparable studies in Vietnam have made this adjustment.

Nevertheless, we acknowledge some limitations in the study.

Relevant information about individuals was not ascertained directly, but was sought from household heads. This practice, while common in household surveys in LMICs introduces potential biases, which might reduce precision of prevalence estimates and accuracy of associations with risk and protective factors. There is a likely gender bias in that most household heads are men and might have limited understanding or appreciation of the experiences of women. Additionally, household heads may have been unlikely to disclose their own perpetration of family violence or alcohol abuse. These risks are therefore most likely to be underestimated.

Alcohol abuse was not fully investigated. It was addressed by asking one question to the household heads to ascertain whether any family member was misusing alcohol. The definition of alcohol abuse was likely to have varied among household heads and was not defined clearly by the research team (14)..

Finally, SRQ is a psychometric tool which was used to identify probable cases of clinically significant symptoms of CMDs and SMDs in community (11). In other words, this tool indicates that it cannot provide a diagnosis as a diagnostic instrument. Therefore, SRQ results can only suggest potential burden of mental disorders in a population.

Despite these limitations which we believe are more likely to have led to under rather than overestimates of prevalence, we believe the data provide a generalizable indication of the burden and potentially modifiable risks for mental disorders in Vietnam.

Prevalence of clinically significant symptoms of CMDs and SMDs in Vietnam and other countries

Overall, the prevalence of clinically significant symptoms of CMDs and SMDs among people who are aged at least 16 years old in this study was more than 22% after age standardization. The raw prevalence of clinically significant

symptoms of CMDs was around 20%, which is similar to other studies using SRQ20 (15, 16). However, there were people who had both clinically significant symptoms of CMDS and SMDs which was included in the group of having CMDs. The DSM-5 reported that people with psychotic disorders may sometimes experience several depressive and anxiety periods during their lifetime (28). Therefore, after excluding those people in the CMDs' group, the prevalence reduced from around 20% to just over 14%.

The rate of clinically significant symptoms of CMDs is lower than other studies using SRQ20 among adults in southern provinces (15, 16). There are several factors contributing to the difference. First, due to the deduction of people having both CMDs and SMDs symptoms. Second, the difference may be due to the different cut-off point (7/8) and lack of age standardization. However, the result of this study is higher compared to other three studies (13, 14, 31). The study conducted by Kim Bao Giang et al. reported a low prevalence (5.4%) using the same screening tool (SRQ20). Differences in age distribution and geographical area may be the possible explanations. The study was implemented among adults from 18 to 60 years old and was not weighted with the standard age distribution of Vietnam. In addition, Ba Vi is a northern district of Hanoi city, which is around 60 kilometers from the centre of Hanoi. Therefore, the socio-economic status may be more advantaged compared to our study population which may lead to the lower rate of CMDs than our study (31). Different psychometric instrument used for identifying the burden of mental health problems is also considered as a reason of the difference. The study conducted by Steel et al. in a southern province use CIDI – a diagnostic tool with cultural adaptation (14). The rate of depression and anxiety reported in the Vuong et al. paper did not provide sufficient details for discussion of the difference (13).

Our finding of 8.6% of SMDs was higher than the result in Vietnam (0.66%), but lower than the prevalence of low and middle income countries (12.9%) which were reported by a WHO multi-country study using CIDI (12). The rate of respondents having one or more psychotic symptoms in this survey is higher than the prevalence of schizophrenia published by the Ministry of Health (0.5 %) (13). The World Health Survey used CIDI – a diagnostic tool and the Vietnam government's prevalence is believed to employ diagnostic instruments because it was estimated by the public mental health hospitals which may explain the different findings. However, due to the limitation to access to full report of the Ministry of Health's report, therefore, it is hard to provide further evidence for the difference.

Determinants of CMDs among different demographic groups

Regarding individual factors, there was a larger proportion of people with CMDs among women than man which was consistent with other studies (31, 32). It may due to gender inequity which creates a significant burden on women in Vietnam. In this study, people who are older than 50 years old faced a significant higher risk of both CMDs and SMDs compared to the 15-24 years old while others presented that CMDs were even less than in elderly or no association (4, 31, 33, 34). It can be explained that, in rural Vietnam, most study participants were farmers, therefore the older they were, the less probability to have a secure income from their farming. As a result, they were more likely to experience financial difficulties compared to younger participants. Illiteracy was found to be a risk factor for CMDs (31, 35). The reason may be that there is a strong link between education level and employment status. People with low literacy are less likely to get a job, they may have lower income. Therefore, less educated people had higher risk of experience CMDs.

In terms of determinants at the family level, living in Ben Tre (the southern province), and in a more economically advantaged household were found to independently protect adults from SMDs and CMDs. It can be seen that Ben Tre province is wealthier and has more natural resources compare to Thanh Hoa – a poor province in the north of Vietnam. Therefore, the hard-living condition in the north province contributed to the higher prevalence of both SMDs and CMDs. Similarly, households having more advantaged economic status compared to the disadvantaged group were less likely to have family members experience CMDs and SMDs. This result was confirmed by other studies in LMICs (31, 36, 37). It is also well known that there was a strong link between poverty and CMDs in LMICs by Lund and et al (35). Another household factor found to be associated with CMDs was at least one member experiencing alcohol abuse in the family. It may be that having at least one family member misusing alcohol increases the risk of both physical and emotional violence, and poverty. These risks, in turns, affect to the mental health of family members negatively (15, 38-41). However, due to the acknowledged limitation in examining the family violence in this study, hence, there was no association between CMDs and this factor.

It is believed that emotional support tends to be the most effective method when someone is experiencing depressive or anxiety symptoms (42). However, this analysis did not find this association. The data showed that having no instrumental support or no link to groups with resources was associated with CMDs. In this study, households having disadvantaged economic status were more likely to have family members experiencing CMDs. This may suggest that material support (for example: money, food) meets the basic needs of these households and alleviates their stress. In return, it may improve their mental health.

Determinants SMDs among different demographic groups

At individual level, people who are older than 50 years old were found to have more risk to develop psychotic symptoms. It may due to the three underlying reasons. First, it was reported in a recent population-based survey that among current drinkers, those aged around 50+ years old consumed the most alcohol (43). Alcohol abuse is believed to be associated with psychosis (28). Second, the prolonged delay to diagnosis and treatment which is common among older people is likely to have contributed to the higher prevalence among people in the 50+ age group. There is no mental health service which provides formal psychotic diagnosis available in the community in rural Vietnam. People who are suspected to have severe mental disorders must go to psychiatric hospitals for diagnosis. It was reported that most such people often cannot afford the travelling fee to go to psychiatric hospitals due to their disadvantaged economic status (44). Third, another reason may be the late – onset psychosis. Recent studies showed that psychosis is commonly diagnosed in young people (45, 46). However, there is not a small number of cases having psychotic symptoms in the late life (47). In addition, there was a strong link between people who were up to completion of primary school and psychotic symptoms. Substantial evidence of the association between school performance and psychotic disorders was established (48, 49). Early cognitive alteration was believed to hinder the education achievement.

At household level, similar to the associating factors of CMDs, residence and economic status had significant link to SMDs. At the time that the survey was conducted, the average income per capital per month in the Southern province was higher than that in the Northern province. In addition, the relationship between economic disadvantage and psychotic symptoms was well established in previous research studies (50, 51). People having psychotic symptoms are less likely to have stable incomes and more likely to live in

poverty due to their low productivity (52), limited educational level (53). Family violence was found as a risk factor of having psychotic symptoms in this study. A systematic review of 41 studies conducted by Trevillion et al. in 2012 found that people with SMDs were at risk of experiencing domestic violence (54). However, included studies were reported to have limited quality in terms of selection bias, sample representativeness, and impact of non-participation. In addition, domestic violence was measured using various methods such as different time periods, types of violence, and instruments. On the other hand, a study mentioned the burden of violent behaviour among caregivers of people with schizophrenia and bipolar disorders. With the sample of 243 schizophrenic patients and 200 bipolar patients recruited within one week of patient's admission to the mental health hospital, Zhou et al. found that caregivers of people with bipolar disorders experienced more violent burden than those of schizophrenic people (55). The findings was reported among recent admission patients, hence, the caregivers may experience higher burden than the people with SMI in the community due to the patients' acute symptoms. In addition, due to the domestic violence, people were more likely to admit the question of "somebody has been trying to harm you in some way". When examining this factor, we found that among 14 households reported of having family violence, only three household responded positively to this question. We acknowledge that it may contribute to the association between the family violence and SMDs.

Conclusion

The study found that among people who are older than 16 years old, around 14% of them experienced CMDs and approximately 8% had symptoms of SMDs. This burden indicates the need for early detection at primary health care. In addition, except for gender and age, most common influencing factors

related to family level. The result suggests that instead of focusing on the individual level, the community-based mental health model in Decision 1215 should focus on reducing family hazards such as family violence and providing instrumental support and access to resource groups to those in need.

List of abbreviations

LMICs	Low and middle-income countries
SRQ	Self-reporting Questionnaire
CMD	Common mental disorders
SMD	Severe mental disorders
WHO	World Health Organization
YLD	Years Lived with Disability
HICs	High income countries
CIDI	Composite International Diagnostic Interview
HITS	Hurts, Insults, Threatens and Screams
SASCAT	Short version of the modified Adapted Social Capital Assessment Tool
RTCCD	Research and Training Centre for Community Development

Declarations

Ethics approval and consent to participate

This survey was approved by an independent Ethics Committee in Vietnam (Decision No.25/12/QĐ-RTCCD) and the Monash University Human Research Ethics Committee (certificate number: 9515).

The study participants were given an oral or written plain language description of the study and were asked to sign a consent form. Those who could not write provided a thumbprint or verbal consent witnessed by an independent observer.

Consent to publish

Not applicable

Availability of data and materials

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

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

TT and HT designed the study and coordinated the data collection.TN analysed the data and drafted the manuscript. TT provided statistical support. JF provided detailed input to the reporting and interpretation of the data and revisions of the manuscript. All authors read and approved the final manuscript.

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Additional information

The definition of common mental disorders has been added to the Background section, in the first paragraph in page 141. "According to Goldberg and Huxley's rationale, depression and anxiety are not distinguishable in primary care and methods of assisting them are similar so single category is appropriate (Goldberg & Huxley, 1992; Huxley, 1996). Hence, in 2017, WHO has defined that "common mental disorders refer to two main diagnostic categories: depressive disorders and anxiety disorders. These disorders are highly prevalent in the population (hence why they are considered 'common'), and impact on the mood or feelings of affected persons; symptoms range in terms of their severity (from mild to severe) and duration (from months to years). These disorders are diagnosable health conditions, and are distinct from feelings of sadness, stress or fear that anyone can experience from time to time in their lives" (World Health Organization, 2017)".

A sentence was revised in the Methods section of Chapter Five, table 1 - Tools used for data collection, in page 149. "SRQ 20 is recommended to screen common mental disorders Vietnamese population by a scoping review conducted by Murphy et al. (Murphy et al., 2015)".

A sentence was added in the first row of the Methods section of Chapter Five on page 151. It reads: "The self-report question is a common method in public health surveys because all households are categorized in terms of household economic status by the local authority with updated regulations of the government."

The Discussion section of Chapter Five, in the first paragraph, on page 170 was revised as requested. "Alcohol abuse is believed to be associated with psychotic symptoms such as hallucinations, delusions, emotional and behaviour changes which is mentioned as "alcohol related psychosis" (American Psychiatric Association, 2013)."

CHAPTER 6 – DELAYS TO DIAGNOSIS OF PEOPLE WITH SEVERE MENTAL ILLNESS IN VIETNAM

Manuscript 4: Delays to diagnosis of people with severe mental illness in rural Vietnam, a population-based cross-sectional study

The manuscript presents the delay to diagnosis of people with severe mental illness who were managed by the national community mental health program, and the financial burden of these people on their families. The chapter also reveals the link between delay to diagnosis and associated factors at both individual and household levels. Manuscript four was submitted to the *BMC Psychiatry* for publication.

Delays to diagnosis among people with severe mental illness in rural Vietnam, a population-based cross-sectional survey

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Abstract

Objective

People with severe mental illness (SMI) living in low and middle-income countries can experience extended delays to diagnosis, which hinder access to medical treatment. The aims of this study were to describe the interval to diagnosis among these people in rural Vietnam and its associated factors.

Methods

A population-based cross-sectional study was conducted among people with SMI in two provinces in Vietnam. The delay to diagnosis was defined as the time between the first abnormal behaviour being observed by family members and the formal diagnosis of psychosis. A multilevel linear regression was used to examine the factors associated with the delay to diagnosis.

Results

Among 404 people with SMI from 370 households, the median delay to diagnosis was 11.5 months (IQR 0 – 168.0). Overall, 53.7% had a delay to diagnosis of less than one year (95% CI: 48.81 – 58.54). The financial burden of these people on their families was nearly USD 470/year. After adjusting for other factors at individual and household levels, living in a Northern province; older age, and having psychotic diagnosis before the implementation of the National Community Mental Health program (2003) were associated with a delay of more than twelve months to diagnosis.

Conclusions

These data indicate that the implementation of a national policy for community-based care has been effective in reducing the delay to diagnosis in rural Vietnam. Therefore, there is a need for strengthening the program and mental health policies, focusing on public communication to improve mental health literacy and reduce stigma against SMI.

Key words

Severe mental illness, delay to diagnosis, Vietnam, financial burden.

Introduction

Severe mental illness (SMI) is defined in three dimensions: clinical diagnosis, duration of the disorder, and the effect on social, family and workforce participation (1). This term is commonly used to describe people experiencing psychotic disorders (such as schizophrenia, or bipolar, or schizoaffective disorders) which compromise their personal and social life long-term; and require care from both health and social sectors (2).

Substantial evidence suggests that prolonged delay to diagnosis is associated with worse treatment outcomes and lower likelihood of long-term recovery (3). Therefore, identification of the onset of the first symptoms of SMI is critical to receiving an accurate diagnosis and to achieving optimal treatment outcomes (3-5). However, many people with SMI experience a delay to diagnosis. Most studies have examined the delay to treatment for psychoses (3, 6-8). There are limited research studies investigating nature of and reasons for the delay to diagnosis. Berk et al. recruited 240 adults with bipolar or schizoaffective disorders through public hospitals and the local print media in Melbourne and Geelong, Australia for a two-year prospective observational study (2006). The authors reported in the baseline data of this study that those who were aged 16-25 years received their first diagnosis of Bipolar I or Schizoaffective disorder around 6.5 years after their first experience of symptoms of mental illness. The delay decreased when the age of the study participants increased (9). The delay in Berk et al.'s study included the period of having other diagnoses such as depression prior to the final diagnosis of psychotic disorders which contributed to the long delay to the ultimate diagnosis. In 2015, Patel et al. conducted a retrospective study using electronic mental health records from the South London and Maudsley NHS Foundation Trust (SLaM). The study used data about 1364 adults with bipolar disorders in the period 2007 to 2012. The delay to diagnosis was defined as the interval between the first time that participants

presented to the SLaM and the time they received the diagnosis of bipolar disorders. The median delay was 62 days with a wide Inter Quartile Range from 17 to 243 days (10). This delay is short when compared with Berk et al.'s study because it measured only the period from when these people started to seek medical support. Patel et al.'s study did not provide information about the interval from when the first psychotic symptoms were identified to medical help-seeking

Several individual and family level factors have been associated with the delay to diagnosis among people with SMI. Spoorthy (2018) reported qualitative results of a hospital-based cross-sectional study in India of 25 people with SMI and their families. They concluded that individual level reasons such as unclear psychotic symptoms, onset coinciding with adverse life events, and impaired functioning influenced treatment seeking and interval to diagnosis. The influencing factors at household level were low mental health literacy, lack of social support, and financial constraints (11). Other studies found that, at individual level, age and gender were associated with the delay (8, 9, 12-14). Duration was greater among people who had first symptoms at a young age (9). Gender was also implicated, with females being diagnosed first at a higher mean age compared to males (12). Family-related factors such as financial burden on the family due to caring for a member with psychotic symptoms (8), lack of social support to the family (13), and lack of family awareness of the mental health problems of people with SMI and low mental health literacy (8, 13, 14) may increase the delay to diagnosis.

In comparison with high income countries, low and middle income countries are facing significant shortage of mental health professionals (15, 16), low mental health literacy, high stigma of mental illness (17) and huge treatment gap (18). The underlying causes of these problems are the lack of mental health polices (18), low expenditure on mental health (19, 20), inappropriate 82

organization and planning of mental health services (21), and lack of evidence based intervention and training (18).

In general, investigations of the delay to diagnosis have recruited participants from clinical facilities, not in the community or from the population at large and only limited individual and household factors have been examined. In addition, there was no consistency in the definitions of delays to diagnosis among these studies. Therefore, it may not represent the actual delay of people with SMI in the population. In order to address the gap, this study aimed to estimate the delay to diagnosis of people with SMI and its related factors at both individual and household level in a population-based sample in Vietnam.

Methods
Study design
The study used a population-based cross-sectional design with data collected in surveys of households with a member with SMI in rural provinces in the North and the South of Vietnam. The survey was conducted from May to June 2013.

Setting
Vietnam's socio-political and geographic situation is described mainly in terms of its having Northern and Southern areas. In Vietnamese history, the Northern and Southern areas were ruled by different Lords. During the periods of colonial occupation by France and the United States, Northern Vietnam was most strongly affiliated with the communist states of the Soviet Union and China. Southern Vietnam, allied with France and America developed a free market economy, and a quasi-democratic government. In 1975, the two areas were united, however, there are many differences between them in terms of culture, language-use, living standards, and common individual characteristics. The household survey was implemented in two provinces Thanh Hoa in the North and Ben Tre in the South which are representative of the Northern and

Southern areas. Thanh Hoa has the third highest population in Vietnam with approximately 3.4 million people living in 27 districts. The province has 6 coastal, 11 mountainous and 10 plain land districts and a city. The average annual income per capita was approximately 19 million Vietnam dong (about USD 980) in 2013 (22). Ben Tre province has a population of around 1,2 million people living in 1 city and 8 districts. All are located on plain land. The average annual income per capita was nearly 26 million Vietnam dong (more than USD 1300 in 2013) (23).

Vietnam's national community mental health program has two main activities. First, psychiatrists of provincial mental health hospitals assess whether people identified by the commune health staff or caregivers have diagnosable conditions, including schizophrenia, bipolar disorders, and epilepsy. Second, the program distributes free medications through community outreach to people meeting diagnostic criteria for one of these conditions (24). The program was initiated in 2000, to cover more than 7,000 communes in the 63 provinces in Vietnam. The program was scaled up in Thanh Hoa and Ben Tre provinces in the period 2000-2003.

Random selection of households and sample size

A cluster sampling method was used. At national level, lists of provinces in each of the Northern and Southern areas were developed. One province was selected using simple random sampling from each list. In each province, an independent statistician chose 30 communes randomly by systematic sampling. In each selected commune, 10 households were selected randomly from the list provided by commune health stations staff of households in which a person with a diagnosed SMI lived. People with SMI were defined as those who had been given a formal diagnosis of schizophrenia, or a bipolar affective disorder by a clinician from a public mental health hospital. They were managed by the national community mental health program at the local commune health

station (24). The household list included six households per commune for the interview, and four households to replace any of the six households if the person to be interviewed was not at home at the time the interviewers visited.

Data collection tools and sources

Data were gathered at household and individual levels by interviewing the main caregivers. At the individual level, information about the person with SMI was collected. At the household level, a structured schedule was used to ascertain household characteristics (table 1).

Table 1: Key information and data collection tools

Variable	Tool	Description
Individual level (people with SMI)		
Primary outcome		
Delay to diagnosis	Two questions: • Time when abnormal symptoms were first noticed by family members • Time of the first formal diagnosis of a psychotic illness	The interval was measured in months. This interval also included the time period of having prior diagnoses such as depression, or anxiety.
Associated factors		
Functioning scale	Adapted version of the Specific Level of	The SLOF is a multidimensional assessment instrument which is widely used to assess people with psychotic

	Functioning Scale (SLOF)	disorders (25). The instrument consists of six subscales and has a total of 43 items: Physical functioning (5 items), personal care skills (7 items), interpersonal relationships (7 items), social acceptability (7 items), activities (11 items), and work skills (6 items). Each item is rated using a 5-point Likert scale from 1 (poorest function) to 5 (best function). Higher scores indicate more independent functioning (26). In this study, an adapted version of this instrument with four subscales (interpersonal relationship, social acceptability, activities and work skills) was used. This tool was translated, cultural verification, back translation and pilot tested in Vietnam.
Income	Study-specific questions of personal income of people with SMI	The personal annual income of people with SMI included the income from the paid job, monthly financial support from the government, and other sources such as donations, or gifts from relatives. The income was measured by month.
Expense	Study-specific questions of personal expenses	The personal annual expense of people with SMI covered all costs related to daily living (food, clothes), productivity of household members lost because of caring

	of people with SMI	for people with an SMI, finding them when they wandered, compensation for any property that had been destroyed, and health service use (inpatients, and outpatient services). These costs of living expense were measured by month. The productivity loss was measured by day. Other costs were measured by year.
Household level (household having people with SMI)		
Economic status	Study specific single question about economic status	Subjective self-assessment of household heads in terms of their household economic status when compared to the local standard. There were five options: Very poor, poor, average, better off, and rich.
Household size	Number of people living in the family	Household members were defined as people living and having meals together at least 6 six months.
Social capital	Short version of the modified Adapted Social Capital Assessment Tool (SASCAT) (27)	The Short SASCAT was developed in a multi-country cohort study Young Lives. It is a quantitative tool used to measure the household social capital. The instrument consists of 20 items. This tool was validated in Vietnam and Peru with translation validity, criteirion validity, and cognitive validity. It was reported as a valuable tool with known constructs and

		internal links among variables (27). The response categories of yes/no.

Procedure

Local staff of the provincial Departments of Health and of Labour, Invalids and Social Affairs were employed for data collection due to their familiarity with local accents, customs, and transport access. They were trained for three days by the research team from the Research and Training Centre for Community Development (RTCCD) in Hanoi, which was the research implementing organisation. Staff members who were qualified in terms of interpersonal skills, comprehension of the schedule, and attention to details were selected as data collectors.

Village heads invited all main caregivers of people with SMI on the lists to attend an information session at the commune health station. Information about the research and an explanation that participation was voluntary were provided to caregivers before consent to participate in an interview was sought. On the scheduled day of the interview, village heads guided the data collectors to selected households in the list.

At the household, information about the household was collected first. All caregivers were given an oral or written explanatory form of the study and were asked to sign a consent form for the collection of the household characteristics and information of people with severe mental illness by the data collectors. Those who could not write provided a thumbprint or verbal consent witnessed by the village heads. The interview about household characteristics was conducted first, then it was followed by the interview to collect the information of people with SMI. All interviews were implemented a private room to ensure the confidentiality.

The research team from RTCCD selected 5% of the completed interview schedules to re-interview caregivers using the same schedule for quality checking. All schedules were checked onsite by field supervisors for missing values and logical mistakes for correction. No name was written on the paper-based schedule.

Consent forms and completed paper-based schedules were handed to the research team at the end of the data collection day by data collectors and were stored in a locked box at the provincial Department of Labour, Invalids and Social Affair. It was returned to the RTCCD office in Hanoi city with the research team in a sealed box.

Data management and analysis

Data from the completed paper-based schedules were manually double-entered into a password protected Access database at the RTCCD office in Hanoi. Each informant had a unique identification number that allowed the research team to distinguish individual and household characteristics. The paper records were stored in a locked cabinet and were accessible only to the research team.

Delay to diagnosis was defined as the period of time between the first symptoms of disturbed thinking or behaviour being observed by family members and the first diagnosis of a psychotic illness by a mental health specialist. As all study communes had implemented the national community mental health program by the end of 2003, comparisons were made between durations of delay to diagnoses prior to December 2003 and from January 2004 to when data were collected in 2013.

The financial burden of people with SMI on their families was calculated by deducting personal annual expenses of and costs of care from their personal annual government financial support. Among income sources of people with SMI, the monthly government financial support is a fixed and stable income.

Whereas, other income sources such as income from paid jobs and donations or gifts are unstable and may change over time. All costs were collected in Vietnam dong and converted to US dollars using the exchange rate in June 2013 (1USD = 20,858 Vietnam dong). The human capital method is a widely used approach among economic studies. It measures productivity costs by estimating earnings lost due to provision of informal care (28) This method was used to estimate the productivity costs of informal care valued at USD 7.67 for eight working hours in rural Vietnam.

We used Stata, Version 13.0 to analyse the data. A p-value less than 0.05 was set as the level of statistical significance. The sample had two levels (households and individuals). People in the same household shared similar household characteristics. First, we conducted a descriptive analysis at individual and household levels. Second, univariate analyses were implemented to identify factors associated with duration of delay to first diagnosis and the financial burden on the families having members with mental illness. Finally, a two-level logistic regression was performed. The dependent variable (delay to diagnosis) is binary, with a value of 0 indicating the delay to diagnosis within 1 year, and a value of 1 indicating otherwise.

Results

In total, 380 households were visited, and 370 caregivers gave consent and were included in the study. The recruitment fraction was 97%. The main reason for refusal to participate was the absence of the main caregiver from home at the time the data collectors visited. There was no difference in refusal rates between the northern and southern provinces. Overall, 370 caregivers of 404 people with SMI from 370 households provided information for the study.

The socio-economic characteristics of people with an SMI and their households are presented in Table 2. Most people with an SMI in the study were described as not having completed secondary school, being cared for by family members, not being married, and having no co-morbid chronic physical health problems.

Most of the households had disadvantaged and mid-level economic status; and were in rural areas.

Table 2: Socio-economic characteristics of people with SMI and their households in Vietnam

Variables	Thanh Hoa n (%)	Ben Tre n (%)	Total N (%)
Individual level			
Number of participants	191 (47.3)	213 (52.7)	404 (100%)
Age (Mean ± SD)	40.9 ± 16.2	41.1 ± 15.5	41.0 ± 15.8
Gender			
Male	100 (52.4)	113 (53.0)	213 (52.7)
Female	91 (47.6)	100 (47.0)	191 (47.3)
Education			
Not completed primary school	118 (61.8)	114 (53.5)	232 (57.4)
Completion of primary school	32 (16.8)	45 (21.1)	77 (19.1)
Completion of secondary school	26 (13.6)	38 (17.8)	64 (15.8)
Completion high school and higher	15 (7.8)	16 (7.6)	31 (7.7)
Receiving free antipsychotic treatment			
Yes	123 (64.4)	137 (64.3)	260 (64.4)
No	68 (35.6)	76 (35.7)	144 (35.6)
Main caregiver			
Husband/wife	60 (31.4)	19 (8.9)	79 (19.5)
Family members	127 (66.5)	175 (82.2)	302 (74.8)
Others	4 (2.1)	19 (8.9)	23 (5.7)
Marriage			
Married	68 (35.6)	25 (11.7)	93 (23.0)
Divorce/widow	21 (11.0)	24 (11.3)	45 (11.1)
Not married	102 (53.4)	164 (77.0)	266 (65.8)
Prior employment status			
Never employed	123 (64.4)	125 (58.7)	248 (61.4)
Previously employed	68 (35.6)	88 (41.3)	156 (38.6)

Having a comorbid chronic physical health problems			
Yes	52 (27.2)	48 (22.5)	100 (24.7)
No	139 (72.8)	165 (77.5)	304 (75.3)
Functioning status (Mean ± SD)	69.4 ± 20.8	86.6 ± 26.9	78.5 ± 25.7
Having psychotic diagnosis			
After 2003	97 (50.8)	129 (60.6)	226 (55.9)
Before 2003	94 (49.2)	84 (39.4)	178 (44.1)
Annual financial burden* (Mean ± SD)	442.0 ± 392.9	486.8 ± 452.3	465.6 ± 425.3
Annual income* (Mean ± SD)	262.8 ± 433.3	260.7 ± 323.6	261.7 ± 378.9
Annual Expense* (Mean ± SD)	606.8 ± 380.5	641.3 ± 450.4	625.0 ± 418.7
Household level			
Number of households	180 (48.7)	190 (51.3)	370 (100%)
Economic status			
Disadvantaged	108 (60.0)	73 (38.4)	181 (48.9)
Mid-level & advantaged	72 (40.0)	117 (61.6)	189 (51.1)
Residence			
Urban	29 (16.1)	102 (53.7)	131 (36.4)
Rural	151 (83.9)	88 (46.3)	239 (64.6)
Household size (Mean ± SD)	3.9 ± 1.5	4.0 ± 1.6	3.9 ± 1.5
Social capital (Mean ± SD)	4.1 ± 16.4	8.8 ± 35.4	6.5 ± 27.9

Unit: US dollars

The estimated delay to diagnosis

Among 404 study participants, the median delay to diagnosis was 11.5 months. The Inter Quartile Range was from 0 to 168.0 months. The distribution of the interval to diagnosis was skewed left. Given the date at which the National Community Mental Health program had been implemented, a binary variable was created to divide the sample into two groups: those who had been diagnosed within and those diagnosed more than one year after symptoms were first apparent. Overall 217 people (53.7%, 95% Confidence Interval: 48.81 – 58.54) had a delay to diagnosis of up to one year, and 187 people (46.3%, 95% Confidence Interval: 41.46 – 51.19) a delay to diagnosis of more than one year.

Table 3: Univariate comparison of individual factors and the delay to diagnosis

Variables	Delayed duration ≤ 1 year n (%)	Delayed duration > 1 year n (%)	Total	p-value
Province				
Thanh Hoa	85 (39.2)	106 (56.7)	191 (47.3)	<0.001
Ben Tre	132 (60.8)	81 (43.3)	213 (52.7)	
Economic status				
Disadvantaged	104 (47.9)	98 (52.4)	202 (50.0)	0.3
Mid-level & advantaged	113 (52.1)	89 (47.6)	202 (50.0)	
Gender				
Male	122 (56.2)	91 (48.7)	213 (52.7)	**0.1**
Female	95 (43.8)	96 (51.3)	191 (47.3)	
Education				
Not completed primary school	113 (52.1)	119 (63.6)	232 (57.4)	**0.1**
Completion of primary school	46 (21.2)	31 (16.6)	77 (19.1)	
Completion of secondary school	39 (18.0)	25 (13.4)	64 (15.8)	
Completion high school and higher	19 (8.7)	12 (6.4)	31 (7.7)	
Receiving free antipsychotic treatment				
Yes	140 (64.5)	120 (64.2)	260 (64.4)	0.9
No	77 (35.5)	67 (35.8)	144 (35.6)	
Main caregiver				
Husband/wife	41 (18.9)	38 (20.3)	79 (19.6)	0.3
Family members	167 (77.0)	135 (72.2)	302 (74.8)	
Others	9 (4.1)	14 (7.5)	23 (5.6)	
Marriage				
Married	49 (22.6)	44 (23.5)	93 (23.0)	0.7
Divorce/widow	22 (10.1)	23 (12.3)	45 (11.1)	
Not married	146 (67.3)	120 (64.2)	266 (65.9)	
Prior employment status				
Never employed	125 (57.6)	**123 (65.8)**	**248 (61.4)**	**0.09**
Previously employed	92 (42.4)	64 (34.2)	156 (38.6)	
Having a comorbid chronic physical health problems				
Yes	46 (21.2)	54 (28.9)	100 (24.8)	0.07
No	171 (78.8)	133 (71.1)	304 (75.2)	
Having psychotic diagnosis				

After 2003	160 (73.7)	66 (35.3)	226 (55.9)	< 0.001
Before 2003	57 (26.3)	121 (64.7)	178 (44.1)	
Age (mean ± SD)	39.1 ± 15.9	43.2 ± 15.4	41.0 ± 15.8	0.008
Functioning status (mean ± SD)	82.9 ± 27.1	73.4 ± 23.0	78.5 ± 25.7	0.002
Annual financial burden (mean ± SD)	462.7 ± 369.9	469.0 ± 482.7	465.6 ± 425.3	0.9

The financial burden on families of care for people with SMI

The annual per capita income of people with SMI was about USD 260. The main income was from the government financial support (nearly USD 160 per year). Expenses of caring for them were more than USD 620 per year in which living costs and caregiving time contributed the most (approximately USD 500 per year). After deducting expenses from annual income, the financial burden on the families was more than USD 450 per year (Table 2).

Table 4: Univariate comparison of household factors and the delay to diagnosis

	Households having people with delay ≤ 1 year	Households having people with delay > 1 year	Total	P-value
Economic status				
Disadvantaged	32 (53.3)	36 (58.1)	68 (55.7)	0.6
Mid-level & advantaged	28 (46.7)	26 (41.9)	54 (44.3)	
Residence				
Urban	17 (28.3)	19 (30.7)	36 (29.5)	0.7
Rural	43 (71.7)	43 (69.3)	86 (70.5)	
Household size (Mean ± SD)	1.3 ± 0.5	1.3 ± 0.6	1.3 ± 0.5	0.6
Social capital (Mean ± SD)	11.1 ± 52.4	6.1 ± 17.9	8.6 ± 38.8	0.5

Factors associated with delay to diagnosis

In the univariate analyses, at individual level, participants who lived in the Northern province, had a diagnosis made before 2003, were younger, and had

lower functioning scores were more likely to have been diagnosed more than a year of onset of symptoms (Table 3). At household level, there was no statistically significant association between household factors and delay to diagnosis of more than one year (Table 4).

In the multi-level mixed-effects logistic regression, controlling for other factors (see Table 5), only living in Ben Tre province; younger age, and having psychotic diagnosis after 2003 made significant independent contributions.

Table 5: Adjusted coefficient odd ratios of socio-economic characteristics and the delay to diagnosis in Vietnam

Factors	Adjusted OR	95% CI	P-value
Province			
Thanh Hoa (northern Vietnam)	1.00		
Ben Tre (southern Vietnam)	0.51	0.27 –0.94	0.03
Residence			
Urban	1.00		
Rural	0.96	0.55 – 1.69	0.9
Age	1.04	1.02 – 1.07	< 0.001
Gender			
Male	1.00		
Female	1.1	0.67 - 1.78	0.7
Education			
Not completion primary school	1.00		
Completion of primary school	0.66	0.34 – 1.30	0.2
Completion of secondary school	0.74	(-8.02) – (-0.44)	0.4
Completion of high school and higher	0.53	(-10.58) – (-0.14)	0.2
Functioning status	0.99	0.98 – 1.00	0.06
Marriage status			
Married	1.00		
Divorced/widowed	0.89	0.19 – 4.22	0.8
Never married	1.18	0.28 - 4.91	0.8
Physical comorbidities			
No	1.00		
Yes	1.49	0.85 - 2.63	0.2
Prior employment status			
Never employed	1.00		
Previously employed	**0.57**	**0.30 –1.07**	**0.08**

Household economic status			
Disadvantaged	1.00		
Mid-level and advantaged	1.06	0.65 – 1.75	0.8
Household size	1.27	0.85 - 1.88	0.1
Receiving free antipsychotic treatment			
Yes	1.00		
No	1.03	0.63 – 1.70	0.9
Main caregiver			
Husband/wife	1.00		
Family members	1.34	0.31 – 5.83	0.6
Others	2.39	0.45 – 12.69	0.3
Social capital	1.00	0.99 - 1.01	0.9
Annual financial burden	1.00	0.99 – 1.00	0.7
Having psychotic diagnosis			
After 2003	1.00		
Before 2003	6.97	3.32 – 14.62	< 0.001

Discussion

The major finding of this study is that the data reveal the benefit of the national policies for community-based outreach care on reducing the delay to diagnosis among people with severe mental illness in the community. While the government's financial support contributed a major component to the income of people with SMI, which reduced the financial burden of informal care on their families, it but did not remove it.

The study had several strengths: (1) the use of multistage random sampling method from lists at national, provincial and commune levels to recruit a representative sample of caregivers of people with SMI. The recruitment fraction was high (97%), and data collection protocols were adhered to strictly by the local data collection teams. The interview schedule was carefully tested with local people prior to implementation to ensure that it was comprehensible.

However, we acknowledge some limitations. The main one being that people with SMI were not invited to contribute data about their own perspectives because when the project was designed expert advice was that they were likely

to be affected by chronic or acute symptoms of psychosis, to have cognitive impairments and to be unable to participate in an interview. Data about them were collected from their main caregivers. Second, the duration of the interval between recognition of symptoms and diagnosis was based on the main caregiver's recall and might have been imprecise. In addition, due to the limited mental health literacy of the population in Vietnam, the first experience of symptoms of mental illness may not have been recognised as requiring health care (29). Finally, although the modified and adapted Social Capital assessment tool was validated for use in Vietnam, the SLOF was translated but had not been formally validated against a gold standard or other local comparator. We believe nevertheless that the strengths outweigh the limitations and that the results can be generalised nationally with considerable confidence.

Delay from first symptoms of mental illness to diagnosis

In this study, the delay to diagnosis was nearly one year with a wide inter quartile range. This is higher than found by Patel et al in London (10), but lower than reported by Berk et al. in regional Australia (9). In addition to the difference in the definition of the delay period used and the sample recruitment method in these studies, the most important reason to explain the short delay is low mental health literacy among Vietnamese. It contributes to prevent family members from observation of first psychotic symptoms. The symptoms are noticed when they become mild/severe or dangerous to the family or the community (29).

Financial burden of people with SMI on their family

To date, there are limited studies calculating the financial burden on the family in low and middle income countries of having members with SMI. Informal care provided by family members, relatives and friends contributes substantially to the total cost in non-health-service studies (28). The costs are mostly attributable to productivity loss because of caregiving responsibilities

for people with SMI, which preclude income generating work. In the United Kingdom (UK) (2005), these costs accounted for nearly 50% of the total discounted costs of care for people newly diagnosed with schizophrenia. The study also reported costs of £421.2 million being born by families (30). However, due to limited information of cost estimation method, it is difficult to compare the annual expense in this study to the study in UK.

In Vietnam there is a lack of comprehensive care for people with SMI in the community such as no rehabilitation, mental health communication provided. The national community mental health program providing free medications is the only mental service in rural areas. The adherence to antipsychotic treatment of this program was reported to be low in the community (31). The findings of this study found that the government financial support accounted for more than 60% of the income sources. Although, this support was nearly $US160 annually, it contributed significant to reduce the financial insecurity of people with SMI due to the disadvantaged household economic status. According to the Law on persons with disabilities (2010), people who are diagnosed of having severe mental illness may receive financial support from the Ministry of Labour, Invalids and Social Affairs. The financial subsidy may vary because it depends on the state budget and the severity of the mental illness (32). The time that family members had to spend to take care of people with SMI which was mentioned as the productivity loss of informal care contributed a huge component of the expense. It is due to the low quality of treatment and the low treatment adherence of people with SMI. It led to difficult behaviours and severe disability among this group, hence their family members must spend more time of caring for them. Consequently, the average annual financial burden on the family was nearly a half of the average annual income per capita in the two provinces in 2013 (US $ 980 in Thanh Hoa and US$1300 in Ben Tre) (22, 23). It illustrates the necessity of a comprehensive mental health care for

people with SMI including rehabilitation, family education, occupational therapies, and integration activities into the community life. It would help to improve the quality of life of people with SMI and reduce the financial burden on the family.

Associated factors of the delayed duration of diagnosis

At the individual level, we found that there were several factors related to the delay to diagnosis. First, people having the diagnosis before 2003 were more likely to delay to seek diagnosis of more than one year, 2003 is the time that all study communes implemented the national community mental health program. Therefore, this result may due to the benefit of the program. The program provided examinations to all probable cases, hence people with psychotic symptoms were more likely to receive formal diagnosis. In addition, people with schizophrenia, or bipolar disorders were provided free medications from the commune health stations, and were reviewed to receive monthly financial support from the government (31). This encouraged caregivers to disclose and seek diagnosis for their members who had psychotic symptoms or abnormal behaviour. Therefore, the program contributed to reduce the delay to diagnosis of people with SMI in the community.

Second, participants living in the Sothern province was found to have more people with the delay to diagnosis of less than one year when comparing with those in the Northern province. This may due to the difference in economic status between the two provinces. The Northern province had 60% of participants with disadvantaged economic status, while this prevalence in the Southern province was less than 40% in this study. It is clear that poor families having members with SMI often could not afford the costs of traveling to the psychiatric hospitals and health service use. This finding is similar to the results of other studies among people with psychotic disorders that financial constraint is one of the key barriers that prevent people from seeking treatment (8, 13). In

addition, stigma and discrimination related to mental disorders, especially SMI are the common problems in low and middle income countries (33). In Vietnam, having mental illness is not a personal problem, it also affects the honour of the family (34, 35). Therefore, it prevents family members from seeking formal diagnosis. Southern people receive a better natural living standard and were under the long-term colonisation of American and French. Their common individual characteristics were more flexible, acceptable to a new concept. As a result, less stigma related to mental illness among Southern people when comparing with the North of Vietnam. People living in the South of Vietnam are more likely to disclose and seek diagnosis and treatment of SMI.

Finally, younger age was found to be associated positively with the group of people having the delay to diagnosis of less than one year. The result was not similar to the study in Australia among people with bipolar disorder. It found that the delayed duration decreased when the age of the study participants was increased (9). It may be explained that in our study context, caregivers may pay more attention to younger people, then it is more likely to identify the onset of psychotic symptoms. Hence, younger may be sought diagnosis and have shorter delay. Whereas, older people may have their first symptoms long time ago, family members and caregivers may be familiar with their abnormal behaviours. It may contribute to a longer delay to diagnosis among those people.

Overall, the associated factors suggest a significant need of a communication campaign to improve mental health literacy of the community and families having a member with SMI in terms of common early symptoms, and myths of SMI. It will contribute directly to reduce the delay to diagnosis.

Conclusion

The delay to diagnosis among people with SMI in Vietnam community was found to be associated strongly with the time receiving psychotic diagnosis. The findings suggested that the National Community Mental Health program had significant benefit in improving the delay to diagnosis of people with SMI. A need for strengthening the program to improve mental health literacy of the population is recommended.

List of abbreviations

SMI	Severe mental illness
SLaM	South London and Maudsley NHS Foundation Trust
RTCCD	Research and Training Centre for Community Development
UK	The United Kingdom

Declarations

Ethics approval and consent to participate

This survey was approved by an independent Ethics Committee in Vietnam (Decision No.25/12/QĐ-RTCCD) and the Monash University Human Research Ethics Committee (certificate number: 9515).

The study participants were given an oral or written plain language description of the study and were asked to sign a consent form. Those who could not write provided a thumbprint or verbal consent witnessed by an independent observer.

Consent to publish

Not applicable

Availability of data and materials

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

Authors' contributions

TT and HT designed the study and coordinated the data collection.TN analysed the data and drafted the manuscript. TT provided statistical support. JF provided detailed input to the reporting and interpretation of the data and revisions of the manuscript. All authors read and approved the final manuscript.

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Additional information

A paragraph was added in the first paragraph on page 200 of Chapter Six. It reads: "There is no evidence of difference between the North and the South in stigma and disclosure of mental illness in Vietnam. A research conducted by the University of Melbourne, and Institute for Social Development Studies in 2013 among 400 people with and without disabilities in Vietnam found that the stigma against people with disability is higher in North than in the South (University of Melbourne & Institute for Social Development Studies, 2013). "

The second paragraph was revised in the section Methods of Chapter Six on page 184. It reads: "Vietnam's national community mental health program has two main activities. First, psychiatrists of provincial mental health hospitals assess whether people identified by the commune health staff or caregivers have diagnosable conditions, including schizophrenia, bipolar disorders, and epilepsy. The commune health station staff who are specialized in mental health can change the prescription after consulting with psychiatrists at the provincial mental health hospital. Second, the program distributes free medications through community outreach to people meeting diagnostic criteria for one of these conditions. The medications are old generation antipsychotics which include Aminazin for people with schizophrenia, and Gardenal for people with epilepsy (Tuan et al., 2007). The program was initiated in 2000, to cover more than 7,000 communes in the 63 provinces in Vietnam. The program was scaled up in Thanh Hoa and Ben Tre provinces in the period 2000-2003 (Ng, Than, La, Than, & Dieu, 2011). "

CHAPTER 7 – DEVELOPMENT, PROOF OF CONCEPT OF PARTICIPANT INFORMED PSYCHO-EDUCATIONAL COMMUNITY-BASED INTERVENTION FOR PEOPLE WITH SEVERE MENTAL ILLNESS IN RURAL VIETNAM

Manuscript 5: Development, proof of concept, and cost analysis of participant informed psycho-educational community-based intervention for people with severe mental illness in rural Vietnam

The manuscript describes the development and proof of concept of a community-based intervention for people with severe mental illness in rural Vietnam. The intervention was delivered by Women's Union staff who are lay people in the community. The proof of concept consisted the results of three components: qualitative assessment, impact assessment, and cost analysis. This chapter was reported in manuscript five, which was submitted to Applied Health Economics and Health Policy.

Development, proof of concept and cost analysis of participant informed psycho-educational community-based intervention for people with severe mental illness in rural Vietnam

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Abstract

Background

There is a lack of an intervention model which empowers people with severe mental illness (SMI) and their families, and addresses the mental health gap in low and middle-income countries.

Objectives

To develop, in consultation with diverse stakeholders, an intervention delivered by informal community care providers for people with SMI, and to assess acceptability, feasibility, preliminary evidence of impact and potential cost savings.

Methods

Two stages were conducted in a rural commune in Vietnam: (1) formative research; and (2) proof of concept using a pre-post design with qualitative assessment, impact evaluation, and cost analysis.

Results

There is a significant gap in care for people with SMI in rural Vietnam due to the low quality of care in the formal mental health system and the lack of access to an evidence-informed informal approach to care. A mental health support group intervention facilitated by Women's Union staff using a positive deviance approach was conducted among 68 people with SMI. Qualitative evaluation showed that the approach was highly acceptable and feasible. There was a significant improvement in personal functioning, and a reduction in stigma and discrimination experienced by intervention participants. It cost USD 733.7 per participant per year to implement. The cost to support per frontline worker was US$3,837.9 per year. The intervention was found to reduce significantly the financial burden on the families having members with SMI.

Conclusions

The proof of concept of the mental health support group intervention delivered by informal community care providers for people with SMI provides promising evidence to address the mental health gap with high acceptability, feasibility and low-cost for low and middle income countries.

Introduction

People with a "severe mental illness" (SMI) are described as *a group of heterogeneous people who suffer from severe psychiatric disorders together with long-term mental disturbances, which entail a variable degree of disability and social dysfunction, and who must be cared for by means of different social and health resources of the psychiatric and social healthcare network* [1].

SMI not only impact the individuals who are experiencing the conditions, but also creates a burden on their families [2]. The burden on the caregivers is conceptualized in diverse ways as emotional distress [3, 4], financial difficulties [5, 6], lack of social and professional support [7], and physical health and functioning problems [8].

People with SMI in low and middle income countries (LMICs) generally have high needs for care, but only have access to mental health services that are under-resourced and weak in terms of financial resources, workforce, and infrastructure [9]. Consequently, around 90% of people with SMI in these countries did not use any mental health services in the previous 12 months [10].

In order to address the significant burden of SMI and the weak mental health services in LMICs, the World Health Organization recommends integrating mental health care into primary care [11]. This includes task-shifting from mental health professionals to less specialized workers. This approach is expected to address the shortage of human resource and the treatment gap in resource-constrained settings [12].

In Vietnam, there are two main types of mental health services provided by the government. Psychiatric hospitals provide inpatient treatment for people with SMI, the focus of which is pharmaceutical therapy. However, psychological therapy and social support are not provided in these facilities [13]. In addition, there have been serious human rights violations reported by caregivers of inpatient service users. The second type of service is the national community mental health program. People with a schizophrenic disorder or bipolar disorders are formally diagnosed by the psychiatric hospitals and receive antipsychotic treatment from the commune health station for free. The program covers more than 60% of communes in Vietnam. However, the program is not considered to be comprehensive due the lack of rehabilitation and mental health

education [14]. In addition, more than 90% of people with SMI are living in the community and are cared for by their family members and other community members on a voluntary basis. However, due to the low mental health literacy and severe stigma against SMI in the community, the quality of community and family care was found to be poor and does not uphold basic human rights [13]. Therefore, there is a need for a community-based mental health intervention for people with SMI to address the disadvantages of the national community mental health program and strengthen the quality of community and family care. This paper describes the development of a community-based mental health intervention, proof of concept, and cost analysis.

Method

Setting

The study including the development and the proof of concept was conducted in Tien Ngoai, a rural commune in Ha Nam province. Ha Nam is a typical Northern province which is located 60 kilometres far from Hanoi city. The intervention commune has an average economic status when comparing to other surrounding communes in Hanam province with the population of 5000 people (1391 households). Around 80% of the population were rice farmers.

In terms of the mental health care system, there are two main sectors involved in providing health services and social support to the people with SMI. The commune health station is in charge of providing mental health referral, and community mental health program. The Department of Labour, Invalids and Social Affairs at commune level is responsible for providing financial and social support to people with SMI who are economically disadvantaged (monthly income per person less than US$35) [15]. In addition, social organizations such as Women's Union, Youth Union, Farmers' Union also involve in poverty reduction (including households having a member with SMI) and promote community cohesion. All sectors are coordinated by the local authority (the Communal People's Committee) which has the responsibility to administer and manage national policies.

Multiple methods were employed in two stages: formative research and proof of concept of the intervention.

Stage 1 – Formative research
Step 1: Identifying the gap in care for people with SMI

Sample size: Qualitative methods were used to explore the treatment gap and the quality of care for people with SMI in Tien Ngoai commune. In-depth interviews were conducted with relevant stakeholders including commune health station; the local authority; communal department of Labour, Invalids, and Social Affairs; and social organizations. In addition, main caregivers of people with SMI were randomly selected from the list managed by the commune health station to undertake in-depth interviews.

Data collection tools: The guiding questions for in-depth interviews were based on a previous research study on mental health system Vietnam [13]. The questions included main activities to support people with SMI, challenges of these activities, and recommendations. The structured interview with the main caregivers consisted of the living standard, self-care, and family care of people with SMI.

Procedure: An official meeting was conducted with Hanam provincial Department of Health to get their approval to conduct the project activities in Tien Ngoai commune. A letter was sent by the Department to the local authority of Tien Ngoai commune to introduce the project. The research team had an official meeting with the Tien Ngoai authorities, including representatives of health, labour sectors and other social organizations to describe the project's aims and activities. The explanatory statement in plain language was given to the in-depth interviewees one week before the interview. All in-depth interviews were implemented in private rooms at the building of the local authority or commune health station.

Regarding the structured interview, a letter of invitation was sent by the local authority to the main caregivers of selected people with SMI to a meeting facilitated by the research team. Explanatory forms and any questions related to the project were provided to the participants in the meeting. At the day of the interview, consent forms were given to the main caregivers for obtaining their permissions to collection information of people with SMI.

Data management and analysis: All in-depth and structured interviews information were taken note. The notes were read carefully and transcribed by the researcher who conducted the interview. Deductive approach was used to analyse the qualitative data.

Information was allocated into main themes. Information of the structured interview was analysed in terms of living condition, self-care and family-care of people with SMI.

Step 2 – Developing intervention framework

The research team conducted a group discussion with four national experts in community mental health and community development in both the government and non-government sectors to explore common strategies used in community-based mental health projects.

In order to improve the quality of life of people with SMI in the community, their basic rights must be respected. However, there is no mental health law in Vietnam. The rights of people with mental disorders are mentioned separately in some related laws such as the law on health examination and treatment (2009), the law on the elderly, and the law on health insurance (2014). Therefore, after reviewing existing international human rights, the research team decided to use the Convention on the Rights of Persons with Disabilities developed by the United Nations to identify the key basic rights of people with SMI for the intervention. The convention was published by UN in 2006, and has been signed by 161 countries. It included of 50 articles which aimed to promote, protect and ensure the human rights and freedom of people with disabilities [16]. Among 50 articles, key human rights were selected using two criteria: Feasibility and necessity. Each research team member worked independently to select the key rights for the intervention. Then a discussion was organized to get the consensus among the team members.

Combination of the two steps helped the research team to develop the intervention. The gaps in care and results of the focus group discussions informed the implementation mechanism of the intervention. The key human rights suggested the key content of the intervention in the community.

Stage 2 – Proof of concept of the intervention

In order to provide the proof of concept of the intervention, three components was implemented: Qualitative assessment, impact evaluation (quantitative assessment), and cost analysis. A pre and post design was employed for the proof of concept stage.

Participants and recruitment

People with SMI such as schizophrenia, schizoaffective disorders, and bipolar disorder, were recruited for the intervention using two methods. First, the list of people with SMI managed by the community mental health program at the commune health station was used to recruit participants. Participants from this source had been diagnosed by the provincial psychiatric hospital staff and were receiving free medications from the program. Second, a meeting was organized with a mental health staff member of the commune health station to identify people whose behaviours suggested psychotic symptoms, but whose families could not afford to bring them to the mental health facility for diagnosis and treatment. The main caregivers of these people were encouraged to go to the provincial psychiatric hospital by commune health station staff and were given travel support by the research team. People who then received a formal diagnosis of SMI from the psychiatric hospital and became managed by the commune health station were invited to participate the intervention.

Qualitative assessment

This formative assessment aimed to identify the acceptability, feasibility and the alignment with the local context of the intervention.

Data sources: There were several methods used to gather information for the qualitative assessment. Group discussions with the Women's Union staff who were the facilitators of the intervention; intervention participants and their family members; and representatives of the community and other social organizations such as Farmer's Union, Youth's Union and Elderly Union were conducted to collect information of the acceptability and feasibility. In-depth interviews with local authority and critical analysis of mental health related strategies and polices were employed to assess the alignment with the strategic context.

Data collection tools: Deductive approach with the three themes (acceptability, feasibility, and alignment with local context) was employed to guide the collection of qualitative information [17]. Acceptability was defined as the agreement and perceptions of stakeholders on the concept, methods and content of the intervention [18]. The definition of the feasibility was the extent that the intervention could be conducted in rural Vietnam with limited resources, mental health capacity [18]. The last

component was employed to assess whether the intervention could be fit with the current local strategies [18].

Procedure: An invitation was sent to interviewees with a consent form by the research team. Completed consent forms will be collected before the interviews/discussions. The in-depth interviews and group discussions were conducted in private rooms and were recorded with permissions of the interviewees.

Data analysis: All information was transcribed by the research team and allocated into the three themes (acceptability, feasibility, and alignment with local context). Thematic method was used to analyse the qualitative data [19].

Impact assessment

Data collection tools: The effectiveness of the intervention was measured the changes in terms of functioning score, psychotic symptoms of participants, and stigma against these people and their families between the baseline and enline survey. The functioning score was measured using the adapted version of the Specific Level of Functioning Scale (SLOF). The original version consists of six sub-scales with 43 items. Each item uses the 5-point Likert scale which ranges from 1 (poorest function) to 5 (best function) [20]. The adapted version in this study included four out of six subscales (interpersonal relationship, social acceptability, activities, and work skills) to measure the functioning. This tool was translated to use in this study.

Psychotic symptoms in the previous month were assessed by using common psychotic symptoms which was advised by local psychiatrists. Six symptoms were included: seeing a vision that other people who were there could not see; hearing voice that other people could not hear; believing that some mysterious force was inserting many different strange thoughts; feeling that their mind was being taken over by strange forces that were making them do things they did not choose to do; believing that some strange force was trying to communicate directly with them by sending special signs or signals that they could understood but that no-one else could understand; and believing that there was an unjust plot going on to harm them or to have people follow them that your family and friends did not believe was true.

The stigma and/or discrimination that the families and/or their members with SMI experienced was measured. The information was obtained by asking whether the participants or family members have ever experienced the stigma or discrimination. Having at least one of these options was considered of having stigma and/or discrimination in this study.

Procedure: The project outcomes and other socio-economic characteristics were collected by face-to-face interviewing using paper-based questionnaires with the main caregivers in a private room. The data collection was conducted by an independent trained team in RTCCD who did not involve in the project activities. A consent form was given to the main caregivers to sign before the interviews.

Data management and analysis: The functioning score and psychotic symptoms were analysed using paired ttest because these primary outcomes were normal distribution. We employed McNermar's tests for paired binary variables of stigma.

Cost analysis

The cost analysis collected costs from the implementation of project activities and from the income and expense of participants. Therefore, the data was obtained from two corresponding sources: Research team and project officers; and main caregivers of participants.

Data collection tools: The project implementation costs consisted of three main components: start-up activities, ongoing central management activities, and ongoing program activities. The start-up phase included all costs related to designing the intervention, research activities, workshops and meetings to prepare for the intervention implementation. The ongoing central management activities were the salary of the project coordinator and project officers, and administration costs in the Hanoi office. The ongoing program activities comprised of the salary for the intervention facilitators, supportive supervision and in-service training provided by the research team, program resources (such as materitals for the club meetings or actitvites), and knowledge sharing (the participant's manual, DVD, and wall paintings) [21, 22]. All costs were measured on an annual basis.

The participants related costs was calculated by estimating the actual income and expenditure of people with SMI. The income consisted of monthly income from the job that the mentally ill people could generate, monthly financial support from the government, and annual income from other sources such as relatives or humanitarian organizations. The expenditure included the monthly living costs (for food, clothes, and other basic living costs), total hours per day that family members who were adults had to take caring of the mentally ill member, annual inpatient costs and monthly outpatient costs, and the annual costs that the family had to pay to find the mentally ill member when they wandering or to compensate for what the mentally ill member destroyed.

Procedure: The cost analysis was combined with the impact evaluation using face-to-face paper-based questionnaires. The data was collected by trained RTCCD data collectors.

Data management and analysis: The costs was collected and calculated in Vietnamese and then converted to annual cost in US dollars. The intervention was conducted in one year (2013), therefore, no adjustment to cost data was needed. The human capital approach was used to value the productivity costs of the informal care [23]. The local rate of farming labour was 160,000 Vietnam dong (US$ 7.67) for eight hours working day. Exchange rate was 20,858 Vietnam dongs for one US dollar (as of 6/2013). Wilcoxon matched paris signed-rank test was used to identify the difference between the non-normal distrubtion costs before and after the intervention.

Results

Stage 1 – Development of the intervention
Step 1: Identifying the gap in care
Theme 1 - Gap in treatment in the health and social systems

In the health sector, there was one commune health station staff member who was in charge of implementing the community mental health program. Her main mental health responsibility was to collect medications from the provincial psychiatric hospital, and to distribute them free of charge to people who had been diagnosed as having schizophrenia or bipolar disorders and were registered with the program. Thirty people were managed by the commune health station in this program. However, it was reported

by the mental health staff and caregivers of people with SMI that the medications were old generation, with adverse side effects and limited effectiveness. Adherence to pharmaceutical treatment was low. For those living in more economically advantaged households, it was common for out-pocket payments to have been made to purchase newer generation medications for people with SMI. *"I know that the medications provided by the program have side effects because they are cheap. In addition, the medications are distributed from the provincial psychiatric hospital, we are in charge of providing it to people with SMI in the community only"* (A mental health staff of the commune health station).

There was one social work staff in the commune who was responsible for providing monthly financial support and health insurance cards from the government to people with SMI. The financial support was around 270 thousand Vietnam dongs in 2013 (approximately US$13,5) per month. Due to the regulation of the Ministry of Labour, Invalids and Social Affairs, only people with SMI diagnosed at the public psychiatric hospitals could receive the social support. It was estimated that there were around 50% of people with SMI who were unable to receive this financial support due to lack of formal diagnosis of having SMI. The social work staff member was experiencing an overload of administrative work, and was not conducting any additional activities for people with SMI. *"I am so busy with administrative work to provide financial supports to disadvantage groups in the community, so that I cannot help families having members with SMI"* (Social work staff of the communal Department of Labour, Invalids, and Social Affairs).

In general, there was no comprehensive care for people with SMI in the community such as rehabilitation, or reintegration into the community. There was severe stigma and discrimination against people with SMI due to limited mental health literacy and no public communications in mental health. *"In our commune, the community members do not understand much about severe mental illness. We all think they are crazy and dangerous. Therefore, families having people with SMI do not receive support from the community"* (Deputy Head of the local authority).

Theme 2 – Gap in community, family and self-care

Totally five main caregivers of people with SMI were selected for the structured interview. All of them were cared for by their families. The quality of the family care was low and did not respect to the human rights. Most of them did not have private and clean room. They were cared for with traditional experience in the community without scientific evidence. Two out of five selected people with SMI were wandering around the commune for food and slept in the rice field at the time of the interview. In order to prevent people with SMI from wandering, most of them were locked or confined in a room. They were not allowed to participate the festivals or common events in the village or commune.

All interviewed caregivers were female. They are wives, mothers, sisters or daughters of people with SMI. According to Vietnam tradition, the role of a woman in the family is to taking care of the whole family members. Therefore, if there is a mentally ill member, it will be the responsibility of the woman.

Theme 3 – Delayed duration of diagnosis and treatment

It was reported by both the mental health and social work staff that the government support could not reach all people with SMI. Due to limited mental health knowledge of caregivers of people with SMI, stigma of the community, and disadvantaged household economic status, families did not disclose if they observed psychotic symptoms of a member. Therefore, it is estimated by the mental health staff that there was at least 30% of people with SMI did not receive any formal diagnosis and treatment in the commune or had long delays to diagnosis.

Step 2 – Development of the intervention framework

A positive deviance approach was adopted by the research team after consultation with local experts. Positive deviance is defined that in a resource-constrained community facing a common health problem, there are several individuals or families initiating "uncommon" behaviours or practices that allow them to overcome the health problem to achieve a better health outcome when comparing to their neighbours [24]. It means that using the same resources and facing the same health problems, some people can find a "creative solution". This approach was used successfully in dealing with malnutrition among children in low and middle income countries, including Vietnam

[25, 26]. There are four main steps (four Ds) in the positive deviance design including: Define (problem or desired outcomes), determine (positive practice), discover (positive practice), and develop (implement the positive initiatives) [27].

After reviewing the rights of people with disability, the research team decided to select the following core themes to be addressed in the intervention: access to mental and physical health care and treatment; the right of having appropriate care in terms of sufficient food and access to hygiene; the right of being integrated into community activities; and the right to have rehabilitation. In addition, previous studies reported that the caring burden on caregivers affected their mental health seriously [28]. As a result, it would affect directly to the quality of family-care. A session of caregivers' stress was added into the intervention. Finally, eight topics were selected for the content of the intervention meetings: (1) personal hygiene; (2) nutrition; (3) other physical health care; (4) mental health care; (5) other rights and privileges of people with mental disorders; (6) rehabilitation; (7) returning to community life; and (8) decreasing stress for caregivers.

Women were the main caregivers of most people with SMI in Vietnam including in the intervention site. Therefore, the research team aimed to support those women by using the Women's Union as facilitators of the mental health support group. The Women's Union is a structured social organization and more than 90% of women in Vietnam are members. Its commitment to national interest is expressed in its aims to assist women both in "building prosperous, equal, progressive and happy families" and in income generation by increasing their "knowledge and capacities" [29]. In fact, Women's Union staff function as subsidiary social workers in the community when professional social work was newly introduced to Vietnam.

Mental health support group intervention is a structured program that combines eight topics, seven of which address the key human rights of people living with SMI (personal hygiene, nutrition, physical health care, mental health care, other rights and privileges of people with SMI, rehabilitation, and community integration) and one topic focuses on reducing stress of caregivers. Each topic was implemented using four steps (four Ds): (1) Define the topic and the context of implementation in the community; (2) determine the positive practice in the commune or village; (3) discover the positive practice by

introducing and sharing it in the mental health support group; (4) develop and implement the positive initiative among intervention participants.

The intervention meetings were facilitated by Women's Union staff trained in group facilitation, basic counselling skills and basic knowledge of mental health care. There was one mental health support group per village. The meetings were conducted every two weeks at the Women's Union staff's houses or participant's houses. Each meeting included people with SMI, and their caregivers. Each topic was delivered with two meetings and one home visit. The first meeting of the topic was to share the positive practice. It was followed by a 30 minute home visit conducted by the facilitator to reinforce the application of the positive practice. The second meeting focused on sharing any difficulties that participants may have encountered when implementing the initiative and discussing solutions with other participants. Each meeting took 60 to 90 minutes.

In addition to the group meeting, the Women's Union staff also conducted several activities to reduce the stigma against people with SMI in the community. These activities included: (1) a summer program for primary and secondary students to visit people with SMI in their village and help them with simple housework; (2) loudspeaker communication every week for 30 minutes to provide basic mental health knowledge and real stories of people living with SMI; and (3) a talent show with the performance of all intervention participants. Regarding the rehabilitation, each village had their own common garden for intervention participants to grow vegetables to support their daily nutritional needs. The seeds were provided by the Famer's Union.

As a whole, the intervention aimed to improve the psychotic symptoms and personal functioning of people with SMI and to support rehabilitation and reintegration into the community. The draft of the intervention framework was presented to the local authority, representatives of the community and social organizations in Tien Ngoai commune to collect feedback and permissions for implementation.

Figure 1: Theory of change

Resources

- Rights for people with disability
- Guidelines on integrating metal health into primary health care (WHO)
- Local experts' experience

Intervention delivery

Fortnight mental health support meetings and home visits

Personal hygiene	Nutrition
Mental health care	Physical health care
Rights and privileges	Rehabilitation
Community integration	Caregiving stress

Training for Women's Union staff
Community awareness

Intermediate outcomes

- Improved knowledge of families and people with severe mental illness
- Improved quality of care for people with severe mental illness
- Community and local authority awareness of mental disorders
- Improved skills of Women's Union staff

Long-term outcomes

- Reduced prevalence of stigma against people with severe mental illness and their families
- Decreased psychotic symptoms
- Increased functioning status

Impact

Improved quality of life of people with severe mental illness

Stage 2 – Proof of concept of the intervention in a rural setting in Vietnam

Participant recruitment

30 people with SMI were recruited in the list of the commune health station. There were 47 potential cases were identified by the health workers and the Women's Union staff. After conducting the screening with mhGAP-IG, 40 people with psychotic symptoms who were sent to the provincial psychiatric hospital for diagnosis, were invited to participate in the intervention. Totally, 70 people with SMI were invited to participate the intervention. However, two people refused to participate, due to moving to other districts. Therefore, 68 people with SMI and their caregivers actively involved in nine mental health support groups.

Operation of mental health support group

The intervention was undertaken with eight topics in 12 months. On average, one topic per month was implemented with two meetings and one home visit. The meetings were adjusted to the rice harvesting seasons and other local festivals. Other intervention activities were implemented with a high level of involvement and support of local students, the local authority, social organizations and community members. The talent show attracted 200 community members to attend the performance of people with SMI in a large community room provided by the local authority.

Based on the experiences of positive practices in each topic, a guideline package for people with SMI and their caregivers was developed including manuals with checklists, visual DVDs of positive practices and wall-paintings containing key messages. The materials were well designed with consultation with the mental health support group participants. For the guideline package, see https://www.globalinnovationexchange.org/innovation/women-with-positive-deviance-approach-in-mental-health-care.

Qualitative assessment

<u>Acceptability</u>

<u>Intervention content</u>: The content was informed by existing positive cases in the community, therefore, it was highly applicable, acceptable and comprehensible by the

participants. "*After applying the positive practice in the mental health support group, my daughters were not wandering, and helped me with simple household tasks*" (A 80-year – old women caring for two daughters with SMI in Doan village). The caregivers were more confident to prevent the crisis of mental disorders by observing some specific signs. "*Now I know the symptoms that he may begin to crisis, so that I encourage and supervise him to take medications*" (A wife having husband with schizophrenia in Yen Noi village). The mental health topic was guided using symptom-based approach which was more effective than the disease based approach. People did not understand the scientific name of SMI, however they knew well the symptoms. In addition, one topic focusing on providing stress reduction strategy for the caregivers was highly welcomed by the group participants. "*Taking the advice of the group, I sometimes, ask my husband to take care of my son, so I have time to visit my cousins in another province. I feel much better when I come back.*" (A mother having a son with SMI in Yen Bao village).

<u>Intervention format</u>: Each club meeting was organized independently in each village. There were around six to eight people with SMI in each club. Totally, approximately fifteen people attending the meetings. The first meeting was take place in the facilitator's house, then it was hosted by each club participant. "*I felt so happy to host of the next meeting in my house. I made me feel like I am a member in a big family.*" (A 50 – year –old woman having a younger brother with SMI in Lieu village). In addition, two meetings a month, and approximately 90 minutes each meeting were found to be appropriate for the facilitators and participants. The date and time of the meeting varied due to the agreement among club participants. It was adjusted due to the farming activities or local festivals.

Feasibility

All program stakeholders agreed that the intervention could be facilitated by the Women's Union in the rural area. "*Although mental health is a new concept to our Women's Union staff and our members, the project idea is practical. I am confident that our staff can implement the project activities*". (Chairwomen of Tien Ngoai communal Women's Union).

Participation rate: The participation rate of people with SMI and their caregivers was high (98%). There were several underlying reasons that contributed to the high adherence to the intervention activities. First, due to the typical symptoms of SMI, these people did not travel outside their living area. Hence, they could attend all meetings. Second, the time and date of each meeting were decided based on the discussion with all club participants. Finally, the meetings were taken place in the club participants' house, therefore, it increased to their commitment to the meetings. In addition, the adherence rate to antipsychotic treatment of people with SMI was more than 90% because of the close monitoring of their caregivers.

Facilitators' capacity: After the intervention, 100% of facilitators were confident with their basic mental health knowledge. "*Now I am confident to help the group participants and to guide them to seek for professional support if necessary.*" (A group facilitator of Thuong village). Nine out of 13 facilitators could provide short mental health talk in front of the community as well as on the loudspeaker. Before the intervention, only three facilitator had skills in terms of personal/group counselling and group meeting facilitation. After implementing the intervention, all of them have such skills which were benefit not only to the intervention, but also to other mandates. However, the facilitators had to admit the importance of mental health training courses and in-service supportive supervision from the research team. "*Mental health is a sensitive topic, we cannot facilitate the mental health meetings without the training courses and support from the research team during the project implementation*".

Information sharing: There was no need of special equipment in each meeting. The meeting were taken place in either the facilitator's or club participant's houses to build cohesion and trust among the group participants. Hence, the intervention could be employed in resource-constrained settings.

Alignment with the local context

The intervention was found to fit well the strategies of the Women's Union, local authorities, mental health and social sectors. "*Our key mandate is to support women in the community. This project would strengthen our activities and provide practical*

support to women with caring burden of people with SMI. Our staff also gained the respect from the community." (Chairwomen of Hanam provincial Women's Union).

From the local authority perspective, the program met the broad strategy of improving the living standard of all community members. *"We are happy that the social organizations such as the Women's Union involved in support people with severe mental illness in the community. It aligns well the Socialization of Public Service Supply policy of the National Assembly. This type of activities would help the authority to address the community needs"*. (Head of the People's Committee in Tien Ngoai commune).

The program received support from the health and social sectors. Due to the overloaded work of the commune health station and social work staff, the program could be the linkage between the formal services to the people with SMI. *"This approach is consistent to our vision. However, as you know, we have only one staff who is in charge of mental health activities, it is hard for her to conduct home visits to all people with severe mental illness. Therefore, the program helps to reduce the burden on our staff"*. (Head of Tien Ngoai commune health station).

Evidence of impact

A total of 68 people with SMI participated in the mental health support group and completed both quantitative baseline and end-line surveys. The group participants had a mean age of 45.38 years old (SD = 20.62), 63.24% were female, nearly 50% did not completed primary school, 90% living with families or partners, and nearly 40% families were poor or very poor, and 36.8% did not have enough money to buy food day-to-day.

There were noticeable changes among intervention participants between the two surveys. Although there was not a significant improvement in the six common psychotic symptoms (mean difference = -1.26 (95% CI: -2.78; 0.25)), the intervention had significant impact on the personal functioning of the study participants assessed by the adapted SLOF (mean difference = 5.91 (95% CI: 0.29; 11.53)). In addition, people with SMI and their families reported a significant lower prevalence of experiencing stigma

and discrimination in the community (proportion difference = -14.71% (95% CI: -29.23%; -0.17%)).

Qualitative results_showed that mental health literacy and understanding of mental disorders among community members and the local authority had been improved after the intervention. *"The touching stories from the loudspeakers every week made me understand that people with severe mental illness are not dangerous."* (A 42-year-old farmer in Noi village). *"We think that people with SMI just need medical treatment and it is the only responsibility of the health system. Now, we understand that our authority should be responsible to provide emotional, financial and practical support to this disadvantage group. It should be included as a criteria for the civil village competition."* (Deputy Head of the communal People's Committee).

It was reported by caregivers that people with SMI were changed due to the intervention. Most of them involved in family activities by helping them with simple household works such as sweeping the floor. They also were friendlier and open to their neighbours, especially nearly one-third of participants started to attend common meetings organized by the local authorities and other local festivals. Due to the adherence to medical treatment, there was no participant who wandered around the commune for food. Approximately one-fourth of participants secured a paid job to support their families.

Economic impact

The three main components of the program implementation costs contributed equally to the total budget. Under the ongoing program activities, the supportive supervision and in-service training accounted for around 14%, which was the highest percentage when comparing to other activities.

The salary paid to facilitators was nearly 6% of the total budget.

The intervention was conducted over one year with 13 facilitators of nine mental health support groups. When excluding the start-up phase, the cost (ongoing central management and program activities) per frontline worker per year was nearly US$3,800. The cost per intervention participant was more than US$700 per year (table 1).

Table 1: Costs of the mental health support group intervention (in US$ in 2013)

Cost category	Amount (%)
Start-up activities	29,685.2 (37.3)
Ongoing central management activities	22,278.7 (28.0)
Ongoing program activities	27,613.6 (34.7)
Personnel – frontline/direct delivery	4,686.93 (5.9)
Monitoring and in-service training	8,063.38 (14.1)
Program resources	10,992.15 (13.8)
Knowledge sharing	736.29 (0.9)
Total	**79,577.5 (100%)**
Cost (excluding the start-up phase) per month	**4,157.7**
Cost (excluding the start-up phase) per intervention participants per year	**733.7**
Cost per frontline worker per year	**3,837.9**

In terms of participant's income and expense, after the intervention, there was a significant increase in the annual income of the group participants from nearly US$80 to around US$120. In contrast, the annual financial burden on the family related to the group participants had a statistically significant reduction from around US$1500 to approximately US$1100 when comparing before and after the intervention. The income source of people with SMI mainly came from the governmental financial support. The expense source was most contributed by the informal care of their family members (table 2).

Table 2: Expense and income of intervention participants (in US$ in 2013)

Variables	Before the intervention (Median ± SD)	After one year intervention (Median ± SD)	P-value
Annual income	**77.7 ± 372.5**	**120.8 ± 399.0**	**0.02**
Annual Expense*	**1488.6 ± 2352.1**	**1122.8 ± 1100.2**	**0.0004**
Living cost	191.8 ± 258.3	182.2 ± 348.9	
Informal care	1035.5 ± 2277.4	690.3 ± 977.8	
Medical cost	0 ± 399.0	0 ± 233.1	
Damages & wandering cost	0 ± 27.4	0 ± 17.8	

Discussion

This study describes the process of developing a mental health support group intervention to address the gap in care of people with SMI and provides proof of concept evidence for the effectiveness of the intervention in rural Vietnam.

The study has several strengths that should be considered. First, the study employed multiple methods to develop the intervention framework and proof of concept. Qualitative and quantitative methods were used in two stages. The proof of concept provided evidence for the qualitative assessment, the impact assessment and the cost analysis which contributed to depicting a comprehensive picture of the impact of the intervention. Second, all study activities were conducted in consultation with relevant stakeholders such as national and local experts and intervention participants.

Nevertheless, the main limitation that should be acknowledged is that the proof of concept used pre and post intervention design with a small sample size (68 people with SMI) and without a control group. Although it is acceptable for a proof of concept, generalization is limited to people with SMI in resource-constrained settings.

The most considerable strength of the intervention is the participant-informed. This approach is a strength-based approach which is appropriate to use in mental health field. The "traditional" approach is that the intervention content is designed by mental health professionals such as psychiatrists or psychologists. It may be difficult to adopt or may not culturally sensitive because mental health is a sensitive topic which heavily depends on the culture, customs, and common belief. Therefore, a model developed by the "outsiders" may not work in a highly stigmatized and limited mental health knowledge community, such as in rural Vietnam. The positive deviance approach can be considered as appropriate solution to address the disadvantages of the "traditional" approach. It empowered people with SMI by promoting the existing positive practices in the community. The role of mental health experts – "outsiders" was just to enable and reinforce the application of this practice. Therefore, the model can be applied in diverse community settings with high acceptability and feasibility.

Another advantage of the intervention is the frontline personnel – Women's Union staff. In fact, like other LMICs, the primary mental health care in Vietnam is weak and

incomprehensive to address the community needs [9]. In addition, most people with SMI are cared for by the community and their families due to the community attachment culture and multi-generation family. In LMICs, especially Vietnam, women are responsible for caring for both physical and mental health of the family members. Therefore, using Women's Union staff as the facilitator of the intervention was found to be appropriate and effective in delivering the intervention.

A noteworthy strength of the model is the multi-disciplinary approach. This model aimed to improve the comprehensive quality of life of people with SMI based on their key human rights, while the community mental health program focused heavily on the antipsychotic treatment. Women Union staff – the facilitator of the intervention were performed as community connectors to utilize resources from the formal system (health and social sectors, local authority and primary school), and informal system (social organizations, family members, community members) to support people with SMI. It promoted the re-integration of people with SMI into the community sustainably.

In terms of main outcomes, there is a small set of trials of interventions which were implemented around the same time using the task-shifting approach to support people with SMI in LMICs [30-33]. These community-based interventions were delivered by lay health workers [30]and paraprofessional health workers [31-33]. The interventions included medical treatment [32, 33], traditional healing [34], rehabilitation programs [32, 33] and self-help groups [31, 35]. The results of this study are consistent with those of previous papers, which show that the intervention has promising positive impacts on the clinical (personal functioning), social and economic well-being (stigma/discrimination) of people with SMI and their caregivers. However, due to the difference of measurement methods used among studies, it is hard compare the results.

In terms of the cost of implementing the ongoing program activities, the cost spent for monitoring and in-service training for the Women's Union staff was double their regular salary. This finding is similar to that in a community-based mental health intervention for people with schizophrenia delivered by lay people in India in 2014. The authors reported that the total implementation costs was mainly comprised of the staff supervision costs [33]. This is a common problem of interventions using lay people due

to their limited background in mental health. On the other hand, the facilitators of this intervention required approximately US$30 per person per month for salary to conduct the activities. Meanwhile, the average salary of a commune health staff in rural areas was around US$340 per person per month, which is ten times higher than that of frontline workers. Therefore, this study suggests that the approach of using lay people (Women's Union staff) is economically feasible in rural areas. However, due to the lack of established cost of the community mental health program per person with SMI in Vietnam, it is difficult to compare the economic feasibility. However, the study is supported by WHO's statement that primary mental health care in rural areas is cost effective due to the distant location, low investment and its sustainability [11].

In terms of addressing the financial burden of people with SMI on their families, the study found a significant increase in the annual income and decrease in the annual expense of people with SMI after the intervention. Lund et al. also mentioned in their mental health intervention in rural Kenya among 203 people with SMI in 2012 that intervention participants and their family had higher income generation [31]. Hence, the intervention contributes to reducing the financial insecurity of people with SMI and their families.

Conclusion

The proof of concept of the mental health support group intervention delivered by the Women's Union staff using positive deviance approach suggests that this model had positive impacts on the clinical, social and economic well-being of people with SMI and their caregivers in LMICs.

Declarations

Ethics approval and consent to participate

This survey was approved by an independent Ethics Committee in Vietnam (Decision No.25/12/QĐ-RTCCD) and the Monash University Human Research Ethics Committee (certificate number: 9515).

The study participants were given an oral or written plain language description of the study and were asked to sign a consent form. Those who could not write provided a thumbprint or verbal consent witnessed by an independent observer.

Consent to publish

The approval is sought from the Grand Challenges Canada prior to publication

Availability of data and materials

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

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

TT and TN designed the study and coordinated the study implementation.TN analysed the data and drafted the manuscript. TT provided statistical support. JF provided detailed input to the reporting and interpretation of the data and revisions of the manuscript. All authors read and approved the final manuscript.

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Additional information

The third paragraph in section Results of Chapter Seven, page 225 was revised. It reads: "A total of 68 people with SMI participated in the mental health support group and completed both quantitative baseline and end-line surveys. The group participants had a mean age of 45.38 years old (SD = 20.62), 63.24% were female, nearly 50% did not completed primary school, 52.9% had been given a formal diagnosis of schizophrenia, and around 50% caregivers did not remember or had not been told the psychiatric diagnosis, 90% were living with families or partners, and nearly 40% families were poor or very poor, and 36.8% did not have enough money to buy food day-to-day."

CHAPTER 8 – DISCUSSION AND CONCLUSIONS

The overall goal of the research program reported in this thesis was to delineate mental health policy gaps in Vietnam, and to generate evidence to address these gaps. This research has contributed the following components to address the policy gaps: established the burden of common mental disorders (CMDs) and severe mental disorders (SMDs) among adults in the community, the powerful impact of a policy initiative on reducing the delay to diagnosis and access to treatment for people with severe mental illness (SMI), and a promising cost-effective community-based intervention to strengthen informal mental health care in Vietnam.

8.1 Strengths and limitations of the thesis

8.1.1 Strengths

This thesis has notable strengths. All evidence was from population-based surveys or preliminary testing, with high participation rates (more than 95% in all three studies). The recruitment rates were high even in comparison to other studies in Vietnam (Amstadter et al., 2009; Richardson et al., 2010). This was achieved through strict compliance with pre-established protocols for data collection or intervention implementation. The research team obtained approval from the government at provincial, district and commune levels, followed by formal meetings with potential research participants. Detailed information about the survey/intervention was provided to participants with opportunities for them to seek further clarification if there were any concerns. All data collectors were trained not only in questionnaire administration, but also how to deal with unexpected situations such as concerns about confidentiality, local communication styles, and emotional distress during the interview. Therefore, although mental health is a sensitive topic, the three studies were able to recruit samples with low refusal rates which allowed adequate power for statistical analyses.

In Study 1, 611 households in the general population, and in Study 2, 370 households with a member with SMI were randomly selected from two randomly selected provinces, and recruited. The samples of the two studies are accurately representative of the North and the South of Vietnam. It addressed the limitation of previous studies which were conducted in only either the North or the South of Vietnam (Amstadter et al., 2009; Richardson et al., 2010).

Study 1 used a validated screening tool (WHO SRQ) which was developed by the World Health Organization. It allows the results to be compared with data from other countries and other studies in Vietnam (World Health Organization, 1994). In addition, the study also investigated both common mental disorders (CMDs) and severe mental disorders (SMDs). Previous studies have only examined either CMDs or SMDs (Amstadter et al., 2009; Giang, Dzung, Kullgren, & Allebeck, 2010; Richardson et al., 2010). The prevalence of CMDs and SMDs were estimated using weighting for sex and age groups to improve precision. Together these enable a more accurate estimation of the burden of CMDs or SMDs in the Vietnamese population to be provided than was available prior to these studies.

Study 2 provides the first ever population-based estimate of the financial burden for families in Vietnam of having a member with SMI. The estimate was calculated not only on the basis of the income of people with SMI, and their expenses, but also measured the productivity loss due to the time that their family members incurred through having to provide care and supervision and being unable to generate income. Few studies worldwide have been able to estimate this type of cost due to the difficulties in collecting these data (Gray et al., 2011).

Finally, the most significant strength of the Study 3 is the combination of data collected by both qualitative and quantitative methods. The qualitative method was mainly used to identify the gap in care, to inform the intervention framework and to measure the acceptability, feasibility, and the alignment with the local context of the

intervention. Meanwhile, a quantitative method was used to build evidence about the change in participants' outcomes and the cost-savings associated with the intervention. The combination of the two methods was to overcome the limitation of each method and to provide comprehensive evidence for the impact of the intervention. In addition, Study 3 (a community-based intervention) used a participatory approach during the two stages of building the intervention framework and establishing proof of concept. This approach is a well-known method for working within the community. The approach requires the active involvement of the community in decision making, implementation, and evaluation of the a health program or intervention (Rifkin, Lewando-Hundt, & Draper, 2000). Therefore, each step of Study 3 was implemented with careful consultation with stakeholders and the intervention.

8.1.2 Limitations

Nevertheless, there are also some limitations to this research. For all three studies, individual information about people with SMI was obtained by interviewing the heads of the households in which they lived, or their main caregivers. For Study 1, it is culturally normative to collect information about family members from their household heads because in Vietnam these are the people who know about and represent other family members. This approach is also commonly used by local authorities to collect administrative information or in national surveys in Vietnam. For Study 2 and Study 3, the research team was advised by local mental health experts that people with SMI would have limited cognitive capacity and therefore that their main caregivers should give consent on their behalf and provide information about them. Although it may not align with international ethical requirements, this method was acceptable and approved by the ethical committee in Vietnam, study participants and the main caregivers.

Study 2 is the first investigation of delays to diagnosis among people with SMI in the community in Vietnam. However, I acknowledge that the method of estimating the interval between the first recognition of psychotic symptoms and the time of psychotic diagnosis relied on memory and therefore might have been influenced by recall bias. It is possible that the delay to diagnosis among people with SMI has been underestimated.

Finally, Study 3 involved a pre- and post-design, and there was no control group, the sample size of 68 people was relatively small and the outcomes were measured using study-specific but as yet non-validated tools. These limitations mean that it is difficult to compare the findings of this study with those of other studies internationally. However, the quantitative impact assessment was only one of three methods used to provide evidence of the proof of concept. The qualitative assessment and cost analysis also contributed to the provision of a comprehensive outcome.

Despite these limitations, I believe the results of this research are robust enough to provide promising evidence to address policy gaps about appropriate mental health care for people with SMI in Vietnam.

8.2 Empirical evidence about the prevalence, associated factors of common and severe mental disorders among adults in Vietnam

Study 1 consists of evidence of the prevalence of CMDs and SMDs, and the factors associated with each at individual and household levels.

8.2.1 Common mental disorders and associated factors

This study addresses the knowledge gap of the burden of common mental disorders in a sample which is representative of the general populations in the North and the South of Vietnam. It addressed the limitations of previous studies in Vietnam which had been conducted in one area (North or South of Vietnam) (Amstadter et al., 2009; Giang et al., 2010; Steel et al., 2009). The study provided point-prevalence estimates

of CMDs among adults in a population-based survey that around one in five adults were experiencing CMDs before weighting for age and sex. This raw prevalence is similar to the results of previous studies in Vietnam using the same screening tool of SRQ 20 items (Amstadter et al., 2009; Richardson et al., 2010). However, after weighting for age and sex, the point-prevalence reduced to around 14%. Meanwhile, the reference studies did not weight their population-based prevalences. Hence, this is one of the strength of this study when comparing to previous studies. This estimate is higher than those of the Vietnam Ministry of Health (MOH) and Steel et al.'s study. The difference is probably attributable to the use of a diagnostic rather than a screening tool in these reference studies. In Steel et al's study, the Composite International Diagnostic Interview (CIDI) was used to estimate the burden of depression and anxiety (Steel et al., 2009). Regarding the MOH results, the finding was estimated from routine reports of psychiatric hospitals. Therefore, it is assumed that it was assessed by psychiatrists using diagnostic tools (Vuong, Ginneken, Morris, Ha, & Busse, 2011). The prevalence was lower than that in LMICs reported in a systematic review (Steel et al., 2014). It was explained by the different tools used to estimate the prevalence, cultural adaptation of data collection tools, and low mental health literacy in Vietnam. Nevertheless, the evidence is that CMDs are prevalent, poorly recognised and constitute a significant burden for the mental health service system in Vietnam.

This research found that CMDs were associated mainly with family factors. It has been concluded in previous studies that there is a strong relationship between social determinants and CMDs (Goldberg, Bridges, Cook, Evans, & Grayson, 1990). In high income countries, it is been common to explore the link of CMDs among adults and individual risk factors such as personality (Khan, Jacobson, Gardner, Prescott, & Kendler, 2005), physical illness (Kivimäki et al., 2009), and socioeconomic position (Weich & Lewis, 1998). This might be because the cultural tradition in these settings

emphasizes individuality and independence. Adults often live by themselves and not with their families. They are more likely to be financially and emotionally independent, and might be less likely to be affected by their parents. In contrast, this situation is totally different in LMICs. The family environment plays a crucial role in developing CMDs among adults. In resource-constrained settings, the culture of family attachment and multiple generations living in the same house is common. Therefore, family factors affect directly to mental health status of the family members who are adults. From the negative side, factors such as domestic violence (Fisher et al., 2013), and alcohol abuse by a family member (Burns, Teesson, & Lynskey, 2001) are associated strongly with CMDs. From the positive side, families protect adults from CMDs by providing emotional, financial and instrumental support to individuals. The positive impact of family was consistent a review of mental health care service provision in LMICs conducted by Rathod et al. that family is the key factor that affects mental health status and health service seeking of the family members (Shanaya et al., 2017).

8.2.2 Severe mental illness and associated factors

A noteworthy finding of this research is its estimation of the prevalence of SMDs in the general population in Vietnam. The finding of nearly 8% of the population having clinically significant symptoms of SMDs. After weighting for age and sex, the prevalence is higher than that reported by MOH which is due to the different data collection method and data collection tools. The MOH result may have been estimated by psychiatrists on the basis of numbers of admissions to the psychiatric hospitals as a proportion of the local population (Vuong et al., 2011). However, this method would not include people who were experiencing an SMI but were cared for at home and not taken to hospital, which this research establishes is a common practice. Due to the lack of access to the full report, it is difficult to understand the methodological differences which might explain this disparity. The prevalence

estimated in this research is higher than the proportion of SMDs in LMICs reported by a WHO Multi-Country survey using the CIDI. However, there are wide ranges of prevalence estimates of SMDs among LMICs, despite using the similar methods in each country (Nuevo et al., 2012). It can be explained by the sampling method, the difference in economic status, the variation of risk and protective factors, and the significant cultural difference among these countries.

The finding of this research indicates a strong relationship between SMDs and the family environment. It is the first study in Vietnam to investigate the family role in relation to SMDs. It is different from CMDs, social determinants may not contribute significantly to the developing of SMDs such as schizophrenia and bipolar disorders, because these are argued to be predominantly biologically determined (Radua et al., 2018). However, studies have been conducted to investigate the social factors because of its impact on the quality of life of people with SMI, especially who are living in the community. In high income countries, people with SMI can live by themselves with social support from a multi-disciplinary team available in the community. On the other hand, LMICs have a shortage of mental health human resources, and lack comprehensive mental health services in the community which lead to a huge treatment gap. Hence, people with SMDs are mainly cared for by their families in the community. It explains the crucial role of household factors in influencing the course of SMDs in LMICs. This finding is supported by a study conducted in India which found that more than 90% of people with SMDs are living with their families (Thara et al., 1994)

Overall, the study furthers our understanding about the prevalence of CMDs and SMDs, and the significant association of the family hazards (e.g family violence, alcohol abuse, and lack of instrumental support) to CMDs or SMDs. The results suggest that instead of focusing on the individual factors, there is a need to alleviate

the household risk factors to people with CMDs or SMDs. Psychosocial or family interventions is needed to address this problem in rural Vietnam.

8.3 Empirical evidence about the delay to diagnosis and costs for people with severe mental illness in rural Vietnam

Another noteworthy contribution of this research is the findings about the delay to diagnosis and costs for people with SMI in rural Vietnam. Up to date, there have been no published investigation in peer-review journals on the delay to diagnosis among people with SMI in Vietnam. The negative impact of prolonged delay to diagnosis to treatment outcomes and likelihood of long-term recovery has been established in substantial studies (Lieberman & Fenton, 2000). Early detection of SMI is crucial to achieve optimal treatment outcomes (Díaz-Caneja et al., 2015; Drancourt N et al., 2013; Lieberman & Fenton, 2000). Due to the impact of early detection of SMI mentioned above, it is important to provide evidence of the delays to diagnosis among people with SMI in Vietnam. The delay to diagnosis is higher than a study conducted by Patel et al. in the UK (Patel et al., 2015), but lower than reported by Beck et al.'s in regional Australia (Berk et al., 2007). It is due to the difference in the definition of delays to diagnosis, sample recruitment method, and metal health literacy among participants of these studies. Further, this study was conducted among people who were formally diagnosed with SMI already by a mental health professional of the community mental health program. It means that people who had psychotic symptoms living in the community and did not receive a formal diagnosis were not identified to be part of this study. It was estimated by local mental health experts that at least 30% of this population has not been formally diagnosed. Therefore, the finding of this study may underestimate the real delay to diagnosis in the community.

In addition to the delay to diagnosis, the study also estimated for the first time the financial burden on families having a member with an SMI in Vietnam. This topic

has rarely been reported in international publications (Gray et al., 2011). Commonly, the cost born by the health system or the social system is reported on the basis of routine data collection systems. Costs born by the family are hard to estimate because of the difficulty in data collection, valuing the cost and recall bias, especially in LMICs. There are two main types of costs which are carried by the family. The first type is the direct cost which is the out-of-pocket money that the family pays for using services such as inpatient or outpatient services, food, and bills for people with SMI. The second type is the indirect cost which is due to productivity loss. It consists of waiting time while using health services, time that family members care for people with SMI so that they have to give up their time for income generation. In this study, the cost born by family was fully examined with two main types of cost. The financial burden of people with SMI on their family of this study was calculated using both the income and expense of people with SMI. The income was limited due to the lack of capacity to secure a job of people with SMI. It found that the main source of income was financial support from the government for people with SMI. However, due to limited studies which investigate the income of people with SMI, it is hard to compare to. The annual income of people with SMI was around US$260 which was nearly one-fourth of the average income per capita per year of the general population living in the same settings (Ben Tre Portal, 2017; Thanh Hoa Portal, 2017). In terms of the expense, the productivity loss due to caring for people with SMI accounted for more than half of the expense. This finding is consistent to the results in previous studies. Magliano et al. found that caregivers of people with schizophrenia spent from 6 to 9 hours per day in caregiving (Magliano et al., 1998). It was reported by Weisbrod et al that the lost earnings of families having people with SMI was US$120 per year in the community (Weisbrod, 1983). Although it is hard to compare the results among studies due to the different cost valuing method, time that the survey was conducted, the productivity loss is a significant economic burden on the families

having a member with SMI in the community. The annual financial burden of people with SMI on the family in Vietnam is equivalent to nearly half of the average income per capita per year of people living in these settings (Ben Tre Portal, 2017; Thanh Hoa Portal, 2017). This is a huge burden on the families that indicates an urgent need of an intervention to address.

The most important finding of Study 2 is the significant impact of the national policies on both delays to diagnosis and the financial burden of people with SMI. The study reported the significant impact of the implementation of the policy for having a community mental health program in reducing the delay to diagnosis. The program is not comprehensive due as its sole aim is to provide antipsychotic medication. Nevertheless, its impact demonstrates the huge contribution of national policies to improving access to health services for treatment of people with SMI in the community, because people with formal diagnoses of SMI are eligible to receive free pharmaceutical treatment. It addresses one key principle of "access to essential psychotropic medications in primary care" which is recommended by WHO (World Health Organization & World Organization of Family Doctors, 2008). In addition, having a diagnosis of SMI is a key criterion, together with living in a household of disadvantaged economic status to get the monthly financial support from the government. Although this financial support is limited (around US$14 per month in 2013) (Vietnam Prime Minister, 2013), the subsidy was found to be the main income source for people with SMI and to contribute significantly to reducing the financial burden of people with SMI on their families.

8.4 Empirical evidence of mental health support group for people with severe mental illness in rural Vietnam

In addition to the significant impact of the policy (formal services) on reducing the delays to diagnosis and financial burden of people with SMI in the community, Study 3 provides promising evidence of a participant-informed mental health

intervention delivered by Women's Union staff on improving health outcomes, and the financial burden of these people in the community. The intervention was found to be feasible to duplicate in other rural areas in Vietnam, and in LMICs.

The research depicts the context of mental health care in Vietnam. Regarding to the formal services, although people with SMI were provided free diagnosis, antipsychotic treatment, and monthly financial subsidy in the community, however, the services have been shown to be insufficiently comprehensive due to the lack of any form of rehabilitation, or collaboration among relevant sectors. In terms of the informal services, most people with SMI were cared for by their families, however the quality of care was low and did not respect their human rights. Therefore, the intervention was designed to address these gaps in both formal and informal services.

First, the intervention empowered the informal community care providers such as the community-based social organizations, and family members which contributed to reduce the burden on the formal services and provided a supplemental service to people with SMI and their families in the community. This task-shifting method aligns well with the WHO recommendations to integrate mental health into primary care. It is identified in the WHO service organization pyramid for an optimal mix of services for mental health, that informal services are the foundation which serves large population needs at low cost when compared to formal services (World Health Organization & World Organization of Family Doctors, 2008). The intervention method is also supported by Shanaya et al. in their review of mental health service provision in LMICs that the role of this informal workforce was considered to be the strength of mental health services in LMICs (Shanaya et al., 2017). However, one essential condition to use this method is the training of informal community care providers followed by ongoing in-service support (World Health Organization & World Organization of Family Doctors, 2008). In this intervention, informal

community care providers are Women Union staff who are lay people with low mental health literacy, and lack of basic skills on counselling, and group facilitation. Hence, training and supportive supervision were provided to equip them with basic mental health knowledge and skills to deliver the intervention activities effectively to people with SMI and their families in the community.

Second, the mental health support group intervention which was a structured program with eight topics was designed by mental health researchers, however, the content of each session was contributed to by people with SMI and their caregivers. Hence, the intervention was found to be feasible for informal community care providers to facilitate the mental health support group and be acceptable to the intervention participants. A positive deviance approach was employed in this intervention. This approach was used successfully in alleviating child malnutrition in LMICs including Vietnam (Lapping et al., 2002; Marsh & Schroeder, 2002). This is a "creative idea" by identifying and sharing existing positive practices in the community to overcome the problems. It was appropriate to use in mental health area, especially rural Vietnam, due to the cultural sensitivity of the mental health topic and low mental health literacy of the community. The positive deviance approach was found to be better than the "traditional approach" in which the intervention content is designed by mental health professionals who are "outsiders" to the community. The traditional approach may not be suitable when applied in resource constrained settings due to the need for highly trained frontline workers such as physicians and primary care mental health workers. Hence, the task is not feasible for informal community care providers.

Third, using members of the Women's Union to facilitate the mental health support group is a unique idea. In Vietnam, the Women's Union is a highly structured social organization which more than 90% of Vietnamese women are members of. The union's mandate is to assist women in "building prosperous, equal, progressive and

happy families". In addition, in the family, women are the key people who take care of all family members in terms of both physical and mental health. Most people with SMI are cared for by their female caregivers. Due to these reasons, Women's Union staff were chosen to deliver and reinforce the best practices for caring for people with SMI in the community.

Fourth, the content of the intervention was based on key human rights with the aim to improve the quality of life of people with SMI comprehensively. It is different from previous studies using informal community care providers with mainly focus on reducing psychotic symptoms (Chatterjee et al., 2014; Chatterjee, Pillai, Jain, Cohen, & Patel, 2009; Lund et al., 2013). The ultimate goal of the intervention in this research was to re-integrate people with SMI into the community sustainably. Hence the intervention addressed a variety of aspects of life for people with SMI and their caregivers including physical and mental health, rehabilitation, the basic rights of people with SMI, re-integration into the community and the impact of stress on caregivers. The intervention also encouraged people with SMI to participate in local activities such as local meetings, festivals or becoming a member of the Farmer's Union which is the most influential organization in the community.

Another noteworthy feature of the intervention is its multi-disciplinary approach. Women's Union staff became community connectors to mobilize the health and social sectors, social organizations, and the local authorities in supporting the people with SMI. In high income countries, people with SMI in the community are cared for by a multi-disciplinary team of professional people as a usual standard of care. However, in Vietnam, there is a lack of collaboration among health, social, and labour sectors. Hence, the intervention used Women's Union staff to enable this collaboration at grassroots level under the coordination of the local commune authority.

In term of cost savings, the intervention was reported to reduce the financial burden of people with SMI on their families by reducing the productivity loss and increasing their income from paid jobs. The improvement in psychotic symptoms due to the high adherence to antipsychotic treatment of people with SMI led to less time that caregivers spent on supervisory informal care. Productivity loss due to informal care was the main expense incurred by having a family member with an SMI. Hence, the intervention contributed significantly to reduce this productivity loss, so that it reduced expense of these people. In addition, it was reported that at the end of the intervention one-third of participants had a paid job, a program that was introduced by the Farmer's Union and the local authority. Some of them grew vegetables in the common village garden with free seed provided by the commune leaders to cover their daily consumptions. As a consequence, the study has shown its effectiveness in reducing the financial insecurity, which directly contributed to break the association between the poverty and SMI.

8.5 Implications for the policy gap and practice

The most important implication of this thesis is to address the policy gaps in Vietnam. This research provides evidence of a feasible, acceptable, cost-effective method to address the challenge of the lack of evidence-based intervention for integrating mental health into primary care. The intervention can contribute to the implementation of Decision 1215 which aims to improve quality of life of people with SMI in the community (Research and Training Center for Community Development, 2014). Policy for Program 1215 requires multi-disciplinary collaborations to develop community-based services to address the burden of mental disorders. However, the Ministry of Labour, Invalids, and Social Affairs (MOLISA) who coordinates Program 1215 are struggling to find an appropriate and evidence-informed model for people with SMI in the community. In addition, due to the different visions of the two main

mental health service providers (MOH and MOLISA), there is a lack of collaboration between these sectors. The evidence of this thesis suggests that a solution to this lack of collaboration is by using informal community care providers at grass root level as the connectors of the health sector and social sectors under the overall coordination of the local authorities. The approach of providing community –based mental health services for common mental disorders such as depression was also found to be feasible and to support Program 1215 in the Vietnam context (Murphy et al., 2018).

In terms of human shortage, it may take decades to train mental health professionals to meet the needs of a comprehensive mental health service. The proportion of psychiatrists per 100,000 population of Vietnam is lower than other Asian LMICs such as Thailand and the Philippines (Vuong et al., 2011). Psychiatric nurses and psychologist are rare in Vietnam. The social work profession was introduced to Vietnam recently, regulated by Program 32 in 2010 (Vietnam Prime Minister, 2010), but the number of social workers remains limited. Further, most mental health professionals work in the big cities or psychiatric hospitals, therefore, the shortage of mental health workforce in the rural areas is more severe. In addition to the shortage of mental health workforce, the quality of this workforce is also a considerable concern. Psychiatric graduates are trained with the focus on pharmaceutical therapy, they lack access to up to date professional materials, and lack clinical training and clinical experience (Nemi, Thanh, Tuan, & Falkenberg, 2010; Research and Training Center for Community Development, 2011). In order to address this shortage in both quantity and quality of mental health workforce, it is recommended by WHO to strengthen the capacity of informal community care providers to meet the basic needs of people with SMI in the community in parallel with the training of mental health professionals for formal services (World Health Organization & World Organization of Family Doctors, 2008). The evidence of this thesis suggests that social organizations such as the Women's Union can be considered as para-social workers

and that they can work effectively to support people with SMI in the community with short training courses and ongoing in-service supportive supervision. This approach is likely to reduce the burden on the formal mental health services and improve the quality of care for people with SMI in the community in a sustainable manner.

In terms of mental health service delivery, using informal community care providers can supplement the lack of a comprehensive community mental health program and social work support at commune level. It fits Program 1215 well, and requires only modest investment from the government by utilizing resources of the community, family members, and social organizations. Informal community care providers can be trained and provided with in-service supportive supervision from the mental health and social work staff at commune level. The role of this informal workforce is broad as they provide a comprehensive care package by combining both social and medical supports to people with SMI and their caregivers. It will help to improve the access to health and social support services which is a highly recommended principle by WHO to integrate mental health into primary care (World Health Organization & World Organization of Family Doctors, 2008).

The policy on Socialization of Public Services Supply of the Vietnam National Assembly (Center for Information and Documentation, 2006) which encourages the involvement of private sector and social organizations in providing health care services to address the needs of the community. The policy has been a significant reform on public supply in Vietnam since 2006. The policy has had a positive impact on the society including resource mobilization, and increased social awareness and responsibility in providing public services. In addition, the socialization policy has contributed to social equality by reducing the gap between the rich and the poor in access to health care service (Center for Information and Documentation, 2006). The evidence of this thesis suggests a practical method to attract and utilize resources

from private sector, social organizations and the community to address the needs of one of the most vulnerable and disadvantaged groups - people with SMI. The evidence indicates a cost-effective investment for mental health care for the government and more respect for the human rights of people with mental disorders. Finally, from international perspective, although it is suggested by WHO that integrating mental health into primary health care approach is promising to address the large treatment gap of SMI in LMICs, however further evidence of the implementation process to assess the acceptability and feasibility of this approach is needed (World Health Organization & World Organization of Family Doctors, 2008). This statement was supported by the Cochrane review of the effectiveness of interventions delivered by non-specialist health workers for mental, neurological, and substance abuse in LMICs in 2011. The review reported that the task-shifting from mental health professionals to non-specialist health workers was effective to address some CMDs such as general and perinatal depression. There was limited evidence of the role of informal community care providers which is a sub-group of non-specialist health workers in providing mental health support to people with SMI in the review (Ginneken et al., 2013). In 2013, Padmanathan and Silva conducted a systematic review to investigate the acceptability and feasibility of the task-shifting approach in LMICs. The authors also indicated the lack of evidence to support this approach. Hence, the results of this PhD research contribute evidence to address the need recommended the WHO guidelines and the two systematic reviews by providing a comprehensive evidence of the acceptability, feasibility, alignment with local context, effectiveness in improving mental health outcomes, and the cost-saving of the community-based intervention.

8.6 Conclusions

To address the challenges of integrating mental health into primary health care in Vietnam, this thesis contributes by providing evidence about the burden of common

and severe mental disorders among adults, the delays to diagnosis among people with SMI, and a proof of concept of a community-based intervention which was delivered by informal community care providers for people with SMI. In the general population, the burden of CMDs and SMDs in Vietnam is significant, especially the SMDs. There were strong associations between CMDs and SMDs and household characteristics such as disadvantaged household economic status, family violence or alcohol abuse. Among people with SMI in the community, there was a significant impact of the policy on reducing the delays to diagnosis and financial burden on their families. However, there is still a lack of comprehensive mental health services in the community for people with SMI, hence, a community-based intervention was developed and tested for a proof of concept. The intervention was found to be acceptable by people with SMI and their caregivers; feasible for facilitators to implement; effective in terms of increasing functioning of people with SMI and reducing stigma against people with SMI and their families; and cost saving.

Integrating mental health into primary health care with the promotion of the role of informal community care providers is recommended for low and middle income countries (World Health Organization & World Organization of Family Doctors, 2008). This thesis contributes by providing promising evidence of this approach in Vietnam. For a stronger recommendation, a well-designed community-based intervention delivered by informal community care providers for people with SMI in the community should be implemented.

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APPENDIX 1: ETHICS APPROVAL

VIETNAM UNION OF SCIENCE AND
TECHNOLOGY ASSOCIATIONS
RESEARCH AND TRAINING CENTER FOR
COMMUNITY DEVELOPMENT - RTCCD

No.: 25/12/QĐ-RTCCD
Re: Ethics and scientific approval for the research
protocol of "Effectiveness of informal mental health
intervention for people with severe mental illness in
Vietnam"

SOCIALIST REPUBLIC OF VIETNAM
Freedom – Independence - Happiness

Hanoi, 10ᵗʰ October 2012

THE DIRECTOR OF RESEARCH AND TRAIING CENTER
FOR COMMUNITY DEVELOPMENT

- Based on the Decree No. 13/2004/QD-BKHCN for the regulations and procedure of ethical approval of scientific research studies approved by Ministry of Science and Technology, issued on 25ᵗʰ May 2004.
- Based on the guidance and procedure of ethics approval approved by the Ministry of Health.
- Based on the Decision No.23/12/QĐ-RTCCD for forming the Ethics Committee approved by the Director of RTCCD, issued on 23ʳᵈ September 2012.
- Based on the meeting minute recorded in the discussion of the Ethics and Scientific Committee on the ethics and research protocol issues.
- Considering the suggestion for research protocol approval submitted by the Chairman of the Ethics and Scientific Committee.

DECIDE THAT

Article 1: Approve the ethical and scientific aspects and the budget for the research project: "*Effectiveness of informal mental health intervention for people with severe mental illness in Vietnam*". Principally investigated by the Research and Training Centre for Community Development (*hereinafter referred to as RTCCD*), which stands under the Vietnam Union of Scientific and Technology Associations.

1. *Overall research objective:* To develop and collec evidence of effectiveness of a pilot informal mental health intervention for people with severe mental illness in rural Vietnam".

2. *Research content:*

   Phase 1 (Epidemiological survey):
   - Identify the burden of common mental disorders among adults;
   - Describe the treatment gap of people having severe mental illness

<u>**Phase 2 (Community intervention)**</u>

- Determine the effectiveness of a pilot informal mental health intervention for people with severe mental illness in a rural commune in Hanam province

3. *Outputs:*
    - Technical reports;
    - Peer-reviewed journal publications;
    - Provide a good model for community-based mental health care for people with severe mental illness for Program 1215 "*Support for community-based social protection and rehabilitation for people with mental disorders in Vietnam*" approved by the Prime Minister dated 22/07/2011.

4. *Implementation duration:* 3 years (June 2012 to June 2015)

Article 2: RTCCD and the principal investigator are to collaborate with related organizations to conduct the study following approved research protocols.

Article 3: The Office Manager of the RTCCD, the principal investigator and related stakeholders are the personal who conduct and follow-up the project activities.

Recipients: **DIRECTOR OF RTCCD**

- As referred at the Article 2
- Archive: RTCCD office, project files

Tuan Tran MD, PhD

Monash University Human Research Ethics Committee

Approval Certificate

This is to certify that the project below was considered by the Monash University Human Research Ethics Committee. The Committee was satisfied that the proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research* and has granted approval.

Project Number: 9515
Project Title: Burden of common and severe mental health problems in Vietnam and effectiveness of informal mental health interventions
Chief Investigator: Professor Jane Fisher
Expiry Date: 18/01/2023

Terms of approval - failure to comply with the terms below is in breach of your approval and the *Australian Code for the Responsible Conduct of Research*.

1. The Chief Investigator is responsible for ensuring that permission letters are obtained, if relevant, before any data collection can occur at the specified organisation.
2. Approval is only valid whilst you hold a position at Monash University.
3. It is responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash letterhead and the Monash University complaints clause must include your project number.
6. Amendments to approved projects including changes to personnel must not commence without written approval from MHUREC.
7. Annual Report - continued approval of this project is dependent on the submission of an Annual Report.
8. Final Report - should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected completion date.
9. Monitoring - project may be subject to an audit or any other form of monitoring by MUHREC at any time.
10. Retention and storage of data - The Chief Investigator is responsible for the storage and retention of the original data pertaining to the project for a minimum period of five years.

Thank you for your assistance.

Professor Nip Thomson

Chair, MUHREC

CC: Ms Trang Nguyen

List of approved documents:

Document Type	File Name	Date	Version
Supporting Documentation	Ethical_approval_Vietnam	10/10/2012	1
Consent Form	consent-form-Epidemiological_surveys	22/11/2017	1
Consent Form	consent-form-MH_support_group	22/11/2017	1
Supporting Documentation	explanatory-statement-commonMH_problems_survey	22/11/2017	1
Supporting Documentation	explanatory-statement-severeMH_problem_survey	22/11/2017	1
Supporting Documentation	explanatory-statement-MHsupport_group	22/11/2017	1
Supporting Documentation	TrangNguyen_Protocol	23/11/2017	1
List of data variables	List_variables	18/01/2018	1
Consent Form	consent-form-Epidemiological_surveys	18/01/2018	1
Consent Form	consent-form-MH_support_group	18/01/2018	1

EXPLANATORY STATEMENT

(Epidemiological survey of common mental health problems)

Project Title: Burden of common and severe mental health problems in Vietnam and effectiveness of informal mental health interventions.

Principal Investigator: Dr Tuan Tran
Research and Training Centre for Community Development, Vietnam (RTCCD)
Phone: + 84 4 36280350
Email: trantuanrtccd@gmail.com

You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone numbers or email addresses listed above.

What does the research involve?
The aim of this project is to assess the burden of common and severe mental health problems in Vietnam and effectiveness of informal mental health interventions. Participants will be invited to complete an interview. The interview will last about 30 – 45 minutes. The interview will include questions about your socio-economic status, your general health and your emotional health, and any complex circumstances you or your family are experiencing.

Why were you chosen for this research?
Thirty communes in Thanh Hoa or Ben Tre province were randomly selected, which means by chance like the toss of a coin. A list of households was made by the commune administrators and 15 households were selected randomly from it to participate in this study. You were told about the study by the village head and he has told us that you are eligible to participate because you meet these criteria.

Consenting to participate in the project and withdrawing from the research
Participation in this research project is entirely voluntary. If you do not wish to take part you do not have to and you do not need to explain why you do not wish to take part. If you decide you want to participate in the research project, we will ask you first to read this statement or to ask someone to read it to you and then to sign a Consent Form or tell us in front of a village head that you want to participate, or mark the form with your thumb print on the recruitment day in your commune.

If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect the care you receive from the commune health centre or other public health providers in Thanh Hoa or Ben Tre Province.

Possible benefits and risks to participants
We do not believe that there are any risks to participating in this research. However it is possible that discussion of personal experiences can be distressing or a little embarrassing. We take your privacy and your wellbeing very seriously.

Services on offer if adversely affected

If you become upset or distressed as a result of your participation in the research, or if you have problems about your own circumstances, the researcher is able to arrange for counselling or other appropriate support or you can also contact the special clinic in Thanh Hoa or Ben Tre province who will be able to assist you.

Payment

You will be not be paid for your participation in this study. However, because we recognise that you have to be away from your work in order to complete the interviews we would like to give you a small gift in recognition of this inconvenience.

Confidentiality

Your privacy will be protected in a number of ways. First we will not use your name, but only a special code number on all forms and computer files. Second the interviews will be in separate private rooms where you cannot be overheard. Third all forms and computer files will be stored securely and finally only summary data from which no individual could ever be identified will be released.

Storage of data

We will store all information you give us very securely. When you have completed the interview, the paper forms will be stored in a secure locked box at the commune health centre and then they will be taken to the Research and Training Centre for Community Development in Hanoi and locked in a filing cabinet in the secure data store there. Your information will be entered into a computer database using your code number and not your name. Information in electronic form will be stored on a password protected folder in the secured server of Research and Training Centre for Community Development. Only approved research staff will have access to the information.

Results

A summary of findings will be prepared in the form of a poster and sent to your commune health centre so that it can be posted on the notice board for members of the commune to read it. An announcement about the availability of the poster will be made on the village loudspeaker system. All results will be available 3 months after data collection complete. If you want to know more about the results, you are welcome to contact us by telephone.

Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Vietnamese Chief Investigator, RTCCD:

Dr Tuan Tran

Research and Training Center for Community Development (RTCCD)
39/255 Vong street, Hanoi, Vietnam
Tel: + 84 4 36280350   Email: trantuanrtccd@gmail.com   Fax: +84 4 3628 0200

Thank you,

Dr Tuan Tran

CONSENT FORM

(Epidemiological surveys)

Project: Burden of common and severe mental health problems in Vietnam and effectiveness of informal mental health interventions.

Chief Investigator: Dr Tuan Tran
Director of Research and Training Centre for Community Development (RTCCD)
39/255 Vong Street, Hanoi, Vietnam
Phone: + 84 4 3628 0350
Email: trantuanrtccd@gmail.com

I have been asked to take part in the research project specified above. I have read and understood the Explanatory Statement or have had it read to me and I hereby consent to participate in this project.

I consent to the following:	Yes	No
Participate the survey	☐	☐

Name of Participant _____

Participant Signature _____ Date _____

EXPLANATORY STATEMENT

(Mental health support group participants)

Project Title: Women with positive deviance approach in mental health.

Vietnamese Principal Investigator: Dr Tuan Tran
Research and Training Centre for Community Development, Vietnam (RTCCD)
Phone: + 84 4 36280350
Email: trantuanrtccd@gmail.com

You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone numbers or email addresses listed above.

What does the research involve?

The aim of this project is to learn whether the "mental health support group" is helpful to people with severe mental health problems in rural Vietnam. It has two parts:

1. Participants and their main caregivers will be invited to participate in 16 one- to two-hour group meetings in their local villages facilitated by trained local Women's Union members to learn about and discuss how to achieve good health for people with severe mental health problems.
2. Participants or their main caregivers will also be asked to complete two interviews, one at this time and one after one year operating the mental health support group. Each interview will last about 30 – 45 minutes. The interview will include questions about your household resources, your general health and your emotional health, any complex circumstances you or your family are experiencing.

Why were you chosen for this research?

One commune in Ha Nam province have been chosen randomly, which means by chance like the toss of a coin, from the list of communes. All people with severe mental health problems who are living in this commune are eligible to participate in this study. You were told about the study by a member of the Women's Union and she has told us that you are eligible to participate because you meet these criteria.

Consenting to participate in the project and withdrawing from the research

Participation in this research project is entirely voluntary. If you do not wish to take part you do not have to and you do not need to explain why you do not wish to take part. If you decide you want to participate in the research project, we will ask you first to read this statement or to ask someone to read it to you and then to sign a Consent Form or tell us in front of a staff member that you want to participate, or mark the form with your thumb print on the recruitment day in your commune.

If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect the care you receive from the commune health centre or other public health providers in Ha Nam Province.

Possible benefits and risks to participants

We do not believe that there are serious risks to participating in this research. However it is possible that discussion of personal experiences can be distressing or a little embarrassing. We take your privacy and your wellbeing very seriously.

Services on offer if adversely affected
If you become upset or distressed as a result of your participation in the research, or if you have problems about your own circumstances, the researcher is able to arrange for counselling or other appropriate support or you can also contact the special clinic in Hanoi who will be able to assist you.

Green Pine Clinic
No 39, lane 255, Vong Street, Hai Ba Trung, Hanoi, Vietnam
Tel: +84 3 628 5656   Email : lienhe@phongkhamcaythongxanh.org.vn

Payment
You will be not be paid for your participation in this study. However, because we recognise that you have to be away from your work in order to complete the interviews we would like to give you a small gift in recognition of this inconvenience.

Confidentiality
Your privacy will be protected in a number of ways. First we will not use your name, but only a special code number on all forms and computer files. Second the interviews will be in separate private rooms where you cannot be overheard. Third all forms and computer files will be stored securely and finally only summary data from which no individual could ever be identified will be released.

Storage of data
We will store all information you give us very securely. When you have completed the interview, the paper forms will be stored in a secure locked box at the commune health centre and then they will be taken to the Research and Training Centre for Community Development in Hanoi and locked in a filing cabinet in the secure data store there. Your information will be entered into a computer database using your code number and not your name. Information in electronic form will be stored on a password protected folder in the secured server of Research and Training Centre for Community Development. Only approved research staff will have access to the information.

Results
A summary of findings will be prepared in the form of a poster and sent to your commune health centre so that it can be posted on the notice board for members of the commune to read it. An announcement about the availability of the poster will be made on the village loudspeaker system. All results will be available 3 months after data collection complete. If you want to know more about the results, you are welcome to contact us by telephone.

Complaints
Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Vietnamese Chief Investigator, RTCCD:

Dr Tuan Tran
Research and Training Center for Community Development (RTCCD)
39/255 Vong street, Hanoi, Vietnam
Tel: + 84 4 36280350   Email: trantuanrtccd@gmail.com   Fax: +84 4 3628 0200

Thank you,

Dr Tuan Tran

CONSENT FORM

(Mental Health Support Group participants)

Project: Burden of common and severe mental health problems in Vietnam and effectiveness of informal mental health interventions.

Chief Investigator: Dr Tuan Tran
Director of Research and Training Centre for Community Development
39/255 Vong Street, Hanoi, Vietnam
Phone: + 84 4 3628 0350
Email: trantuanrtccd@gmail.com

I have been asked to take part in the research project specified above. I have read and understood the Explanatory Statement or have had it read to me and I hereby consent to participate in this project.

I consent to the following:	Yes	No
Participate the baseline surveys	☐	☐
Participate in Mental Health Support Group meetings	☐	☐
Participate in the end-line survey	☐	☐

Name of Participant _____

Participant Signature _____ Date _____

APPENDIX 2: THE QUESTIONNAIRE

MẪU H0

ĐÁNH GIÁ THỰC TRẠNG HỆ THỐNG CHĂM SÓC NGƯỜI BỆNH TÂM THẦN

H0: MẪU ĐIỀU TRA HỘ GIA ĐÌNH
Dành cho phỏng vấn chủ hộ

Tên tỉnh:_____	Mã tỉnh: __
Tên huyện: _____	Mã huyện: __
Tên xã: _____	Mã xã: __ __
Tên thôn: _____	Số thứ tự HGĐ: __ __
Họ tên chủ hộ: _____	Điện thoại: _____

QUẢN TRỊ SỐ LIỆU	
Điều tra viên: _____	Ngày __ /__ __ /2013
Giám sát viên: _____	Ngày __ /__ __ /2013
Nhập tin viên: _____	Ngày __ /__ __ /2013

1. **Hộ gia đình anh/chị có mấy người** (*gồm những người ăn chung ở chung trong 6 tháng gần đây*): __ __ người

PHẦN 1 - ĐẶC ĐIỂM KINH TẾ XÃ HỘI

1. Theo phân loại của chính quyền xã/phường, kinh tế của gia đình anh/chị thuộc loại nào?
   - ☐ 0. Không biết
   - ☐ 3. Trung bình
   - ☐ 1. Nghèo
   - ☐ 4. Khá
   - ☐ 2. Cận nghèo
   - ☐ 5. Giàu

2. Theo đánh giá của anh/chị, kinh tế gia đình mình ở mức nào so với mặt bằng kinh tế chung của xã?
   - ☐ 1. Rất nghèo
   - ☐ 3. Trung bình
   - ☐ 2. Nghèo
   - ☐ 4. Khá   ☐ 5. Giàu

PHẦN 2 - LẠM DỤNG CHẤT

3. Trong gia đình anh/chị, có ai gặp các vấn đề sau đây không? *Gia đình gồm:* + Bố mẹ của anh/chị và của vợ/chồng + Anh/chị/em ruột + anh/chị em của vợ/chồng + Con của anh/chị	*Có =1; Không có = 0; Không biết = 99*	Có, mấy người
Nghiện hút		__ __
Uống đồ uống có cồn (rượu, bia...) mức độ ≥ 1 lần say xỉn/tuần		__ __
Bị pháp luật giam giữ		__ __

PHẦN 3 - BẠO LỰC GIA ĐÌNH

4. Sau đây tôi xin hỏi về cách cư xử của các thành viên gia đình với nhau trong năm qua (nội bộ gia đình)?

Trong năm qua, gia đình....	Không bao giờ	Hiếm khi (< 1 lần/năm)	Thỉnh thoảng (< 6 lần/năm)	Khá thường xuyên (< 12 lần/năm)	Rất thường xuyên (≥12 lần/năm)
a. Có ai đánh nhau hoặc gây thương tích cho người trong nhà không?	☐0	☐1	☐2	☐3	☐4
b. Có ai xúc phạm hoặc hạ nhục thành viên trong gia đình không?	☐0	☐1	☐2	☐3	☐4
c. Có ai đe dọa/ hăm hại thành viên trong gia đình không?	☐0	☐1	☐2	☐3	☐4
d. Có ai quát mắng, chửi bới hoặc nguyền rủa thành viên trong gia đình không?	☐0	☐1	☐2	☐3	☐4

PHẦN 4 - VỐN XÃ HỘI

5. Hiện nay anh/chị tham gia những hội/đoàn nào? (Ghi rõ tên hội/đoàn tham gia)	a. Có là thành viên tích cực của hội/đoàn này không? (Tham gia tích cực là tham gia nhiều hơn so với số đông thành viên khác) 0 = Không 1 = Có	b. Trong 12 tháng qua, hội đoàn anh/chị tham gia có hỗ trợ gì cho gia đình/bản thân anh/chị không? 0 = Không hỗ trợ gì 1= Vật chất:Tiền, quà, ngày công, thuốc men... 2= Tinh thần: Tư vấn, chia sẻ, giải quyết mâu thuẫn... 3 = Cả vật chất và tinh thần
	_____	_____
	_____	_____
	_____	_____
	_____	_____

6. Trong 12 tháng qua, anh/chị và gia đình có nhận được sự hỗ trợ giúp đỡ của ai trong những người sau không? Kể cả người nước ngoài (Giúp đỡ về tinh thần hoặc vật chất)	Vật chất, tiền 1 = Có 0 = Không	Tinh thần 1 = Có 0 = Không
Gia đình, họ hàng	__	__
Hàng xóm	__	__
Bạn bè (không phải hàng xóm)	__	__
Lãnh đạo xã, thôn	__	__
Những người đứng đầu về tôn giáo (cha đạo, nhà sư..)	__	__
Tổ chức từ thiện, các tổ chức phi chính phủ	__	__
Khác (ghi rõ): _____	__	__

	Không	Có

7.	Trong 12 tháng qua, anh/chị có họp với các gia đình khác trong cộng đồng (thôn/xã/huyện/tỉnh) để nêu ra những vấn đề chung cần giải quyết không?	☐ 0	☐ 1
8.	Trong 12 tháng qua, anh/chị có nói chuyện với cán bộ xã (bất kể cấp nào) về các vấn đề xảy ra trong xã không? Nếu có, cấp nào (ghi rõ: _____)	☐ 0	☐ 1
9.	Anh/chị có cho rằng phần lớn dân cư trong cộng đồng có thể tin tưởng được không? (Ví dụ: Đi vắng có thể nhờ giữ nhà giùm....)	☐ 0	☐ 1
10.	Anh/chị có nghĩ rằng phần lớn dân cư trong cộng đồng có mối quan hệ tốt với nhau không?	☐ 0	☐ 1
11.	Anh/chị có nghĩ rằng mình thực sự là một phần của cộng đồng/xóm làng không?	☐ 0	☐ 1
12.	Anh/chị có nghĩ rằng phần lớn những người trong xã sẽ lợi dụng anh/chị khi có điều kiện không?	☐ 0	☐ 1

13. Trong 3 năm qua, gia đình chị có ai bị mất trộm, tài sản bị thu giữ…: (NHIỀU LỰA CHỌN)

☐ 0. Chưa bao giờ → *Chuyển câu 17*

☐ 1. Mất trộm/cướp

☐ 2. Bị đe dọa mất quyền thừa kế

☐ 3. Bị đe dọa mất quyền sử dụng đất và nhà ở

14. Khi những sự việc trên xảy ra, chị hoặc bất kỳ ai trong gia đình có: (NHIỀU LỰA CHỌN)

☐ 0. Không làm gì

☐ 1. Báo công an

☐ 2. Báo cho những người có vị trí cao trong thôn/xã, trưởng họ không

☐ 3. Có đơn kiện gửi các nơi liên quan hoặc tòa án

MẪU H1: PHIẾU SÀNG LỌC SỨC KHỎE TÂM TRÍ NGƯỜI LỚN (≥ 17 TUỔI)

Điều tra viên **phỏng vấn** trực tiếp đối tượng

Mã HGĐ __ . __ __ . __ __   Mã TV __ __ (STT trong bảng thành viên hộ - mẫu H0)

1.1	Năm sinh?	__ __ __ __
1.2	Giới tính	
	+ Nam	[ ] 1
	+ Nữ	[ ] 2
1.3	Cấp học cao nhất?	
	+ Không đi học	[ ] 1
	+ Chưa tốt nghiệp cấp 1	[ ] 2
	+ Đã tốt nghiệp cấp 1	[ ] 3
	+ Đã tốt nghiệp cấp 2	[ ] 4
	+ Đã tốt nghiệp cấp 3	[ ] 5
	+ Trường dạy nghề, trung cấp	[ ] 6
	+ Cao đẳng	[ ] 7
	+ Đại học và sau đại học	[ ] 8

*Những câu hỏi dưới đây liên quan đến một số loại đau và những vấn đề gây cho anh/chị khó chịu **trong 30 ngày qua**. Nếu anh/chị có bị vấn đề như tôi nêu với anh/chị, xin hãy trả lời là ĐÚNG. Nếu anh/chị không có vấn đề đó **trong 30 ngày qua**, xin hãy trả lời là KHÔNG. Nếu anh/chị không chắc chắn về việc trả lời câu hỏi nêu ra như thế nào, xin hãy đưa ra câu trả lời theo khả năng anh/chị nghĩ là gần đúng nhất có thể được.*

STT	TRONG 30 NGÀY QUA	Đúng/ Có	Không đúng/ không có
1	Anh/Chị có hay bị đau đầu không?	☐ 1	☐ 0
2	Anh/Chị có cảm thấy ăn kém ngon miệng không?	☐ 1	☐ 0
3	Anh/Chị ngủ không ngon?	☐ 1	☐ 0
4	Anh/Chị có dễ bị sợ hãi không?	☐ 1	☐ 0
5	Tay anh/chị có bị run không?	☐ 1	☐ 0
6	Anh/chị có cảm thấy hồi hộp, căng thẳng hoặc lo lắng không?	☐ 1	☐ 0
7	Tiêu hoá của anh/chị có kém không? (có hay bị rối loạn tiêu hoá không?)	☐ 1	☐ 0
8	Anh/Chị có cảm thấy khó suy nghĩ rõ ràng không?	☐ 1	☐ 0
9	Anh/Chị có cảm thấy không được vui không?	☐ 1	☐ 0
10	Anh/Chị có khóc nhiều hơn bình thường không?	☐ 1	☐ 0
11	Anh/Chị có cảm thấy khó hứng thú với các hoạt động hàng ngày không?	☐ 1	☐ 0
12	Anh/Chị có thấy khó khi đưa ra quyết định không?	☐ 1	☐ 0

STT	TRONG 30 NGÀY QUA	Đúng/ Có	Không đúng/ không có
13	Anh/chị có cảm thấy miễn cưỡng khi làm các công việc hàng ngày không?	☐ 1	☐ 0
14	Anh/chị không có vai trò gì trong cuộc sống phải không?	☐ 1	☐ 0
15	Anh/Chị có mất hứng thú trong cuộc sống không?	☐ 1	☐ 0
16	Anh/Chị có cảm thấy mình là người không có giá trị không?	☐ 1	☐ 0
17	Mọi thứ có tồi tệ đến mức anh/chị cảm thấy là anh/chị không thể nào vượt qua được không?	☐ 1	☐ 0
18	Anh/Chị có cảm thấy lúc nào cũng mệt mỏi không?	☐ 1	☐ 0
19	Anh/Chị có những cảm giác khó chịu ở dạ dày không?	☐ 1	☐ 0
20	Anh/Chị có dễ bị mệt mỏi không?	☐ 1	☐ 0

STT	TRONG 30 NGÀY QUA	Đúng/ Có	Không đúng/ không có
Anh/chị có các vấn đề mà tôi nêu dưới đây không:			
21	Có bao giờ, Anh/chị cảm thấy ai đó đang cố ý hãm hại/theo dõi Anh/Chị bằng cách nào đấy mà gia đình và bạn bè không tin đó là sự thật không?	☐ 1	☐ 0
22	Có phải Anh/Chị là người tài giỏi, quan trọng hơn nhiều so với những gì mà người khác nghĩ về Anh/Chị?	☐ 1	☐ 0
23	Có bao giờ Anh/chị để ý thấy những ý nghĩ rất khác lạ/bị áp đặt/đánh cắp/bị điều khiển khiến anh/chị phải làm những việc mình không muốn không?	☐ 1	☐ 0
24	Có bao giờ, Anh/chị nghe thấy tiếng nói trong đầu không rõ từ đâu vọng tới mà người khác không nghe thấy không?	☐ 1	☐ 0
25	Có bao giờ anh/chị nhìn thấy hình ảnh mà người khác cũng ở đấy không thể nhìn thấy không?	☐ 1	☐ 0
Cảm ơn anh/chị đã trả lời!			

MẪU H5

ĐÁNH GIÁ THỰC TRẠNG HỆ THỐNG CHĂM SÓC NGƯỜI BỆNH TÂM THẦN

MẪU H5: ĐIỀU TRA TÌNH TRẠNG SỨC KHỎE VÀ CHĂM SÓC NGƯỜI BỆNH TÂM THẦN
Phỏng vấn người chăm sóc chính

Mã HGĐ __ .__ .__ __ .__ __

Tên người bệnh: ………………………………………….   STT trong bảng HGĐ (mẫu H0) __ __

PHẦN 1 – THÔNG TIN CHUNG VỀ HỖ TRỢ TỪ CHÍNH SÁCH NHÀ NƯỚC

1. [Tên BN] hiện mắc loại bệnh tâm thần gì? (NHIỀU LỰA CHỌN)

   ☐ 1. Tâm thần phân liệt   ☐ 2. Động kinh

   ☐ 3. Trầm cảm   ☐ 4. Khác (ghi rõ): _____

2. [Tên BN] được chẩn đoán mắc bệnh tâm thần từ bao giờ?   __ __ / __ __ / __ __ __ __

3. Hiện nay [Tên BN] nhận được hỗ trợ gì từ chế độ nhà nước?

	Có hay không? *1 = có; 0 = Không*	Từ bao giờ? *(tháng/năm)*	Mô tả sự nhận được và mức độ thường xuyên
Thuốc	___		
Bảo hiểm y tế			
Tiền trợ cấp			
Khác (ghi rõ):_____			

4. Hiện nay, ai là người chăm sóc <u>chính</u> của [Tên BN] (quan hệ với BN)?(MỘT LỰA CHỌN)

   ☐ 1. Chồng/Vợ   ☐ 5. Họ hàng

   ☐ 2. Con   ☐ 6. Tự bản thân

   ☐ 3. Bố mẹ   ☐ 7. Người khác

   ☐ 4. Anh/chị em

5. Tình trạng hôn nhân của [Tên BN] hiện nay? (MỘT LỰA CHỌN)

   ☐ 1. Sống cùng chồng/vợ   ☐ 4. Góa

   ☐ 2. Ly thân/ly hôn   ☐ 5. Còn nhỏ

   ☐ 3. Chưa kết hôn   ☐ 6. Khác (*ghi rõ*):..............................

6. Cấp học cao nhất của [Tên BN] là gì? (MỘT LỰA CHỌN)

   ☐ 1. Chưa bao giờ đi học   ☐ 5. Tốt nghiệp cấp 3

   ☐ 2. Chưa tốt nghiệp cấp 1   ☐ 6. Trung cấp, cao đẳng

   ☐ 3. Tốt nghiệp cấp 1   ☐ 7. Đại học hoặc sau đại học

   ☐ 4. Tốt nghiệp cấp 2   ☐ 8. Còn nhỏ (dành cho trẻ dưới 6 tuổi)

7. Trước đây, [Tên BN] đã từng đi làm chưa?

☐ Chưa bao giờ đi làm

☐ Đã từng đi làm đi làm

8. Hiện tại [Tên BN] mắc các bệnh gì khác ngoài bệnh tâm thần?

☐ 1. Không → *chuyển câu phần 2*   ☐ 1. Có

ĐÁNH GIÁ TÌNH TRẠNG SỨC KHỎE VÀ CHẤT LƯỢNG CHĂM SÓC

Phần 2: Đánh giá các triệu chứng tâm thần, động kinh

Xin mô tả mức độ thường xuyên các triệu chứng của BN trong **1 tháng vừa qua**

Triệu chứng	Không bao giờ	Hiếm khi	Thỉnh thoảng	Khá thường xuyên	Rất thường xuyên
1. Nhìn thấy hình ảnh mà người khác không thể nhìn thấy.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. Nghe thấy tiếng nói mà người khác không nghe thấy	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. Ý nghĩ bị áp đặt hoặc bị đánh cắp bởi một thế lực kỳ bí	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. Trí óc bị thế lực huyền bí điều khiển khiến BN phải làm những việc mà BN không muốn làm	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. Niềm tin rằng có một vài thế lực huyền bí nào đó đã cố gắng liên lạc với bạn bằng cách gởi những ký hiệu hay những tín hiệu mà chỉ có BN có thể hiểu được còn người khác thì không thể.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. Tin rằng có một âm mưu đang chuẩn bị ám hại bệnh nhân hoặc có người nào đó đang theo dõi mà nói ra gia đình và bạn bè không tin đó là sự thật.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7. Bị bất tỉnh, chân tay co giật hoặc bị ngã xuống đất, cắn vào lưỡi hoặc mất ý thức	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Phần 3: Các chức năng của người bệnh và chất lượng chăm sóc

Hướng dẫn: Tại thời điểm hiện tại, với mỗi hành vi dưới đây, khoanh tròn 1 lựa chọn phù hợp nhất với người bệnh tâm thần theo từng dòng. Kiểm tra để đảm bảo tất cả các dòng đã được đánh dấu

A. Các chức năng xã hội

1. Mối quan hệ với người khác

Tên mục	Đánh giá				
NGƯỜI BỆNH	*Xảy ra rất thường xuyên*	*Xảy ra thường xuyên*	*Thỉnh thoảng xảy ra*	*Hiếm khi xảy ra*	*Chưa bao giờ xảy ra*
1. Chấp nhận tiếp xúc với người khác (Không rút lui hoặc quay đi)	5	4	3	2	1
2. Bắt chuyện làm quen với những người khác	5	4	3	2	1
3. Giao tiếp hiệu quả (lời nói và cử chỉ dễ hiểu và đi thẳng vào vấn đề)	5	4	3	2	1
4. Tham gia vào các hoạt động sinh hoạt hàng ngày mà không cần nhắc nhở	5	4	3	2	1
5. Tham gia vào các nhóm tại cộng đồng	5	4	3	2	1
6. Tạo và duy trì các mối quan hệ bạn bè	5	4	3	2	1
7. Nhờ giúp đỡ khi cần thiết	5	4	3	2	1

2. Tính chấp nhận xã hội

Tên mục	Đánh giá				
	Chưa bao giờ	*Hiếm khi*	*Thỉnh thoảng*	*Thường xuyên*	*Luôn luôn*
8. Thường cãi nhau với những người khác	5	4	3	2	1
9. Đánh nhau với những người khác	5	4	3	2	1
10. Đập phá tài sản	5	4	3	2	1
11. Tự gây tổn thương	5	4	3	2	1
12. Sợ hãi, khóc lóc, đeo bám người khác	5	4	3	2	1
13. Lấy tài sản của người khác mà không xin phép	5	4	3	2	1

B. Các kỹ năng sống trong cộng đồng

3. Các hoạt động

Người bệnh có làm được các việc sau không? Và làm được ở mức độ nào?	Làm được				Không làm được, hoàn toàn phụ thuộc vào người khác
	Hoàn toàn có khả năng tự làm tốt	Cần hướng dẫn	Cần hỗ trợ	Cần trợ giúp liên tục	
14. Công việc nhà (lau nhà, nấu ăn, giặt quần áo)	5	4	3	2	1
15. Mua sắm (lựa chọn hàng hóa, lựa chọn cửa hàng, trả tiền tại quầy thu ngân)	5	4	3	2	1
16. Tự quản lý tài chính cá nhân (quản lý tiền bạc, chi trả các hóa đơn)	5	4	3	2	1
17. Sử dụng điện thoại (lấy số điện thoại, quay số, nói chuyện và nghe điện thoại)	5	4	3	2	1
18. Di chuyển khỏi nơi cư trú mà không bị lạc	5	4	3	2	1
19. Sử dụng phương tiện vận chuyển công cộng (lựa chọn hành trình, sử dụng lịch trình, trả tiền lộ phí, chuyển tuyến/phương tiện)	5	4	3	2	1
20. Sử dụng thời gian rảnh rỗi (đọc sách báo, thăm bạn bè, nghe nhạc)	5	4	3	2	1
21. Nhận biết và phòng tránh các mối nguy hiểm thông thường (an toàn giao thông, an toàn hỏa hoạn)	5	4	3	2	1
22. Tự dùng thuốc (hiểu mục đích, sử dụng đúng theo đơn, phát hiện các tác dụng phụ)	5	4	3	2	1
23. Sử dụng dịch vụ y tế và các dịch vụ cộng cộng khác (biết những người cần liên lạc, bằng cách nào và khi nào cần sử dụng các dịch vụ đó)	5	4	3	2	1
24. Đọc, viết và tính toán cơ bản (đủ cho nhu cầu sử dụng hàng ngày)	5	4	3	2	1

4. Khả năng làm việc

NGƯỜI BỆNH	Đánh giá				
	Xảy ra rất thường xuyên	*Xảy ra thường xuyên*	*Thỉnh thoảng xảy ra*	*Hiếm khi xảy ra*	*Chưa bao giờ xảy ra*
25. Làm tốt các việc được giao (chăn bò, làm việc kiếm tiền)	5	4	3	2	1
26. Làm được nhưng phải có giám sát (thỉnh thoảng để mắt tới)	5	4	3	2	1
27. Có thể tập trung hoàn thành công việc (không dễ mất tập trung, có thể làm việc dưới áp lực)	5	4	3	2	1
28. Biết đến đúng hẹn/ đúng giờ để làm việc	5	4	3	2	1
29. Làm theo các hướng dẫn bằng lời một cách chính xác	5	4	3	2	1
30. Hoàn thành các nhiệm vụ được được phân công	5	4	3	2	1

PHẦN 4 – QUÁ TRÌNH PHÁT HIỆN BỆNH VÀ KHÁM CHỮA BỆNH

1. Dấu hiệu khởi phát bệnh bắt đầu từ năm nào?   Tháng __ __ /năm __ __ __ __

2. Bệnh được chẩn đoán xác định năm nào?   Tháng __ __ /năm __ __ __ __

PHẦN 5 -- CHI PHÍ TRONG MỘT THÁNG HOẶC MỘT NĂM GẦN ĐÂY

Nguồn thu

1. Trung bình 1 tháng [Tên BN] kiếm được bao nhiêu tiền? *(tính cả tiền kiếm được từ công việc chính + công việc phụ (nếu có)?*   _____VNĐ/tháng

2. Trung bình 1 tháng [Tên BN] được nhận bao nhiêu tiền Trợ cấp từ phòng LĐTBXH xã? (từ nhà nước)   _____VNĐ/tháng

3. Trung bình một tháng [Tên BN] được cho/biếu bao nhiêu tiền? (từ người thân, các cơ quan đoàn thể…Tính trung bình trong 6 tháng gần đây)   _____VNĐ/tháng

4. Ngoài ra, [Tên BN] có thường xuyên được cho biếu các loại quà tặng, vật phẩm khác không? Ghi rõ (nếu có)   ....

5. Anh/chị ước tính trung bình một ngày [Tên BN] làm việc nhà mấy tiếng?   __ __ tiếng/ngày

Khoản chi

6. Trung bình 1 tháng gia đình anh/chị chi bao nhiêu tiền cho việc ăn uống và các sinh hoạt cá nhân hàng ngày? (gạo, mắm, muối, xà phòng, bột giặt….-Tính chung cả gia đình)

_____VNĐ

7. Anh/chị hoặc người lớn (> 15 tuổi) trong gia đình DÀNH BAO NHIÊU TIẾNG/1 NGÀY để chăm sóc [Tên BN]?(Nếu có nhiều người chăm sóc thì tính ra số giờ của từng người rồi cộng tổng vào)

___ ___ tiếng/ngày

8. Trung bình 1 năm anh/chị mua sắm quần áo, vật dụng cho [Tên BN] hết bao nhiêu tiền?

_____VNĐ/năm

9. Trong 1 năm qua, [Tên BN] có hay đập phá đồ đạc (trong gia đình, hay của nhà khác) không?

Nếu có, mỗi lần gia đình anh/chị phải đền/hoặc mua đồ thay thế hết bao nhiêu tiền?

☐ 0. Không lần nào

☐ 1. Lần 1   _____VNĐ/lần

☐ 2. Lần 2   _____VNĐ/lần

☐ 3. Lần 3   _____VNĐ/lần

☐ 4. Lần 4   _____VNĐ/lần

10. Trong một năm qua, [Tên BN] bỏ nhà đi lang thang mấy lần?

Mỗi lần [Tên BN] bỏ đi, anh/chị chi bao nhiêu tiền để tìm BN về? (tiền đi lại, tiền liên lạc, tiền thuê người tìm giúp...)

Mỗi lần [Tên BN] bỏ đi gia đình anh/chị mất bao nhiêu thời gian đi tìm [Tên BN] về? (Nếu có nhiều người đi tìm thì cộng tổng thời gian của tất cả mọi người)

☐ 0. Không lần nào

☐ 1. Lần 1   _____VNĐ/lần   ___ ___ tiếng/ lần

☐ 2. Lần 2   _____VNĐ/lần   ___ ___ tiếng/ lần

☐ 3. Lần 3   _____VNĐ/lần   ___ ___ tiếng/ lần

☐ 4. Lần 4   _____VNĐ/lần   ___ ___ tiếng/ lần

Chi phí điều trị ngoại trú (KHÔNG QUA ĐÊM) trong 1 tháng qua *(Lưu ý: tính cả những lần đi khám/chữa bệnh bằng cúng bái, lên đồng...)*

11. Trong 1 tháng qua, bệnh nhân có điều trị ngoại trú không? ☐ 0. Không → chuyển câu 12   ☐ 1. Có   Nếu có, số lần __ __   → *Hỏi chi tiết theo bảng dưới đây.*

SỐ LẦN KHÁM ĐIỀU TRỊ	11.1 Cơ sở đến khám (ghi rõ tên cơ sở); Lưu ý đánh dấu : * cho nơi khám chữa đông y, **khám chữa thuốc nam; *** cúng bái, lên đồng...	11.2 Đợt khám/ điều trị này, có bao nhiêu người trên 15 tuổi đi theo chăm sóc	11.3 Tổng số ngày của người đi theo chăm sóc cho BN trong đợt này là bao nhiêu ngày?	11.4 Tổng chi phí thanh toán **từ tiền túi** cho cơ sở y tế/nơi cúng bái (tiền khám chữa bệnh, thuốc, xét nghiệm, giường bệnh,...)	11.5 Chi phí bồi dưỡng, quà cáp cho nhân viên y tế/thầy cúng.	11.6 Chi phí đi lại (của người bệnh và người đi theo chăm sóc)	11.7 Chi phí khác (ăn ở của bệnh nhân, người chăm sóc, mua vật dụng,...)	11.8 Ước tính tổng chi phí cho đợt điều trị này *(Chỉ ghi cột này nếu 11.4 – 11.7 không có thông tin)*
		Người	Số ngày	Ngàn Đồng	Ngàn Đồng	Ngàn Đồng	Ngàn Đồng	Ngàn Đồng
1								
2								
3								
4								
5								
6								
7								

Chi phí điều trị nội trú (NẰM QUA ĐÊM) trong 1 năm qua? *(Lưu ý: tính cả những lần đi khám/chữa bệnh bằng cúng bái, lên đồng…)*

12. Trong 1 năm, bệnh nhân có điều trị nội trú không? ☐ 0. Không → Kết thúc ☐ 1. Có Nếu có, số lần __ __ → *Hỏi chi tiết theo bảng dưới đây.*

SỐ LẦN ĐIỀU TRỊ NỘI TRÚ	12.1 Cơ sở đến khám (ghi rõ tên cơ sở); Lưu ý đánh dấu : * cho nơi khám chữa đông y, ** khám chữa thuốc nam; *** cúng bái, lên đồng…)	12.2 Số ngày [TÊN] nằm điều trị trong đợt là bao nhiêu ngày?	12.3 Đợt khám/ điều trị này, có bao nhiêu người trên 15 tuổi đi theo chăm sóc	12.4 Tổng số ngày của người đi theo chăm sóc cho BN trong đợt này là bao nhiêu ngày?	12.5 Tổng chi phí từ tiền túi thanh toán cho cơ sở y tế/nơi cúng bái (tiền khám chữa bệnh, thuốc, xét nghiệm, giường bệnh,…)	12.6 Chi phí bồi dưỡng, quà cáp cho nhân viên y tế/thầy cúng.	12.7 Chi phí đi lại (của người bệnh và người đi theo chăm sóc)	12.8 Chi phí khác (ăn ở của bệnh nhân, người chăm sóc, mua vật dụng,…)	12.9 Ước tính tổng chi phí cho đợt điều trị này **(Chỉ ghi cột này nếu 12.5 – 12.8 không có thông tin)**
		Người	Số ngày	Ngàn Đồng	Ngàn Đồng	Ngàn Đồng	Ngàn Đồng	Ngàn Đồng	Ngàn Đồng

APPENDIX 3: THE GUIDING QUESTIONS FOR IN-DEPTH INTERVIEWS

Name: _____

Position: _____

Date: __ __ / __ __ / __ __ __ __

1. What is your main responsibilities to support people with severe mental illness in your commune?

2. What are challenges that you experience when implementing these responsibilities?

3. What are recommendations to improve the quality care of these responsibilities that you provided?