

An Exploration of Recovery among Persons with Severe Mental Health Conditions in South Africa

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Abstract

Background

Severe mental health conditions have long-term impacts on multiple stakeholders, especially in low- and middle-income countries. Historically, public mental health services have focused on symptom reduction, emphasising clinical recovery. However, personal recovery, which considers mental health service users' lived experience, has received little attention. Since contextual factors influence outcomes, understanding and measuring recovery in low-resource settings is crucial. This study sought to explore personal recovery from severe mental health conditions in South Africa, where challenges, including poverty, stigma, and limited mental health resources intersect to shape the recovery process.

Aim and objectives

The overarching research question underpinning the thesis was: *What constitutes and facilitates recovery for persons living with severe mental health conditions in South Africa?* I aimed to answer this question and contribute to closing the research gap by pursuing four research objectives: (i) *To conduct a scoping review on how personal recovery is conceptualised for persons living with severe mental health conditions in low- and middle-income countries;* (ii) *To explore and describe service provider perspectives on what recovery is for persons with severe mental health conditions in South Africa;* (iii) *To explore and describe what recovery is for men with severe mental health conditions and their caregivers in South Africa;* and (iv) *To evaluate the psychometric properties of the Recovery Assessment Scale among persons with severe mental health conditions in South Africa.*

Methods

This mixed-methods study included both qualitative and quantitative components. Initially, a scoping review was undertaken to explore how recovery from severe mental health conditions is conceptualised and facilitated in low- and middle-income countries. Ten articles were included and thematically analysed. Next, semi-structured interviews and focus groups were conducted with 17 service providers in the Western Cape. This qualitative phase also included interviews with four male mental health service users and three of their caregivers. Visual participatory methods such as photovoice and life graphs were used to collect data. Finally, a quantitative evaluation was conducted to assess the psychometric properties of the Recovery Assessment Scale among 250 South African mental health service users.

Results

The scoping review revealed that recovery from severe mental health conditions is perceived as a continuous, non-linear process. While high-income countries focus on autonomy and independence, low- and middle-income countries emphasise social

connectedness and spirituality as key recovery elements. Service providers suggested that clinical recovery models dominate mental health care, but personal recovery requires an approach that addresses social, economic, and cultural inequalities. For mental health service users, long-term relational support was vital to recovery. Even though spirituality was crucial to recovery, stigma from faith-based communities sometimes hindered access to spiritual support. Finally, the psychometric evaluation of the Recovery Assessment Scale showed a five-factor structure, with “Empowerment and Inner Strength” emerging as a new factor. The adapted Recovery Assessment Scale demonstrated strong internal consistency and reliability, proving a suitable tool for measuring recovery in South Africa.

Discussion and conclusion

The findings were synthesised into the Recovery Mandala, which identifies seven interconnected elements central to recovery from severe mental health conditions in South Africa: Collaborative Co-creation, Person-Centeredness, Hope and Empowerment, Social Network Utilisation, Caregiver Involvement, Spirituality and Religion, and Employment. These elements reflect the relational and holistic nature of recovery.

Plagiarism declaration

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Dedication

This thesis is dedicated to my Palestinian brothers and sisters, whose steadfast reliance on Allah SWT's guidance and strength is a testament to the power of faith in the face of adversity.

Acknowledgements

In the name of Allah, the Beneficent, the Merciful

No PhD journey is a solo project.

I am grateful to my Creator Allah SWT for His protection, mercy, love, grace and guidance. May He be pleased with my efforts.

Alhamdulillah, there were many meaningful encounters in service of this project. This journey has embodied the spirit of “*Ubuntu: A person is a person through other people; I am because we are*”¹ Through this journey, I learnt that teamwork really makes the dream work.

I want to convey my heartfelt appreciation to the following people:

My parents, Ebrahim and Gadija, who instilled in me a love for lifelong learning. They believe in “seeking knowledge from the cradle to the grave”. May Allah SWT be pleased with them, Aameen. Dad, I wish you were here to see me tackle this, but I’m grateful that Mom has been here to cheer me on.

Professor Katherine Sorsdahl for taking a chance on me as a mature learner and introducing me to research in public mental health. Katt, your encouragement and commitment to guiding me through this research journey have left an indelible mark on me.

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The mental health service users and their caregivers who so willingly participated in the study. Thank you for sharing your stories with me. I feel blessed to have learned so

¹ Eze, M. (2016). *Intellectual history in contemporary South Africa*. Springer.

much from you, and I will continue to pursue an agenda that partners with service users as experts by experience.

The service providers who shared their views and graciously assisted me in connecting with participants. Thank you.

My husband, Moeneer, has been by my side since my undergraduate days. Shukran for supporting me while I pursue my various causes. I can't guarantee that this is the end of my activism; it is more like the beginning, but I look forward to some adventures in "preferment" with you.

My children, Tanzeel and Rania, for their love, sacrifice, humour, and understanding when I could not always be the mom they needed me to be. A special shout out to my favourite daughter, Rania, for her sassy, tech-savvy, and brave caregiving support, and to my favourite son, Tanzeel, for being a kind, curious and "lekker" human and inspiring me to be the same. Thank you both for teaching me to be a mom. I appreciate and love you!

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My brother, Taslim, for embracing his new responsibilities as part of the "sandwich generation" and for taking over school lifts and creating safe spaces for my children while I was distracted. I owe you big time.

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“So, surely, with hardship comes ease.

Surely with hardship comes more ease.”

(The Quran, 94:5-6)

The oath of a Muslim health professional²

In the name of Allah, Most Gracious, Most Merciful

Praise be to Allah, the Sustainer of His Creation, the All-Knowing.

Glory be to Him, the Eternal, the All-Pervading.

O Allah, though art the only Healer,

I serve none but Thee, and, as the instrument of Thy Will,

I commit myself to Thee.

I render this Oath in Thy Holy Name, and I undertake:

To be the instrument of Thy Will and Mercy, and, in all humbleness, to exercise justice, love and compassion for Thy Creation; To extend my hand of service to one and all, to rich and poor, to friend and foe alike, regardless of race, religion or colour; To hold human life as precious and sacred, and to protect and honour it at all times and under all circumstances in accordance with Thy Law; To do my utmost to alleviate pain and misery, and to comfort and counsel in sickness and anxiety; To respect the confidence and guard the secrets of all my patients; To maintain the dignity of the health profession, and to honour the teachers, students, and members of my profession; To strive in the pursuit of knowledge in Thy name for the benefit of mankind, and to uphold human honour and dignity; To admit my mistakes and forgive the wrongs of others; To be ever-conscious of my duty to Allah and His Messenger (SAWS), and to follow the precepts of Islam in private and in public.

O Allah, grant me the strength, patience and dedication to always adhere to this Oath.
Aameen.

² This oath is presented to all graduating students by the Islamic Medical Association (IMA) of South Africa. It is based on a version presented by Dr Hassan Hatout at the *First International Conference on Islamic Medicine* in Kuwait, January 1981. Al-Bar, M. A., & Chamsi-Pasha, H. (2015). *Regulation of Medical Profession and Medical Research* (pp. 85-103). Springer International Publishing. https://doi.org/10.1007/978-3-319-18428-9_5

Declaration on the inclusion of publications in the PhD thesis

The work described in this thesis was conducted between January 2018 and January 2024 under the supervision of Professors Katherine Sorsdahl, Roshan Galvaan and Bronwyn Myers. Several of the chapters in this thesis have content that is either published, undergoing peer review, or being prepared for publication. I confirm that I have been granted permission by the University of Cape Town's Doctoral Degrees Board (DDB) ([Appendix A](#)) to include the listed publications in my thesis. Where co-authorship is involved, my co-authors have agreed that I may include the publications:

I am the corresponding author of all papers in this thesis. My contributions to these papers include the following:

- Developing the research questions
- Drafting the thesis protocol
- Completing data collection and analysis
- Writing of manuscripts
- Preparation of manuscripts for submission
- Compiling the dissertation thesis

My supervisors were the co-authors who assisted with reviewing and preparing the manuscripts for publication. In addition, a research assistant helped me with the scoping review. It should be noted that some information may be repeated across the thesis due to necessity.

Student: **Fadia Gamieldien**

Signature: 

Date: **13 November 2024**

Publications included in this thesis

Gamieldien, F., Galvaan, R., Myers, B., Syed, Z., & Sorsdahl, K. (2021). Exploration of recovery of people living with severe mental illness (SMI) in low/middle-income countries (LMICs): A scoping review. *BMJ Open*, 11(3), e045005.

<https://doi.org/10.1136/bmjopen-2020-045005> (Appendix B)

Gamieldien, F., Galvaan, R., Myers, B., & Sorsdahl, K. (2021). Service providers' perspectives on personal recovery from severe mental illness in Cape Town, South Africa: A qualitative study. *Community Mental Health Journal*.

<https://doi.org/10.1007/s10597-021-00904-8> (Appendix C)

Gamieldien, F., Galvaan, R., Myers, B., & Sorsdahl, K. (2023). Mental health service users and their caregivers' perspectives on personal recovery from severe mental health conditions in Cape Town, South Africa: A qualitative study. *Journal of Psychosocial Rehabilitation and Mental Health*, 1-19.

<https://dx.doi.org/10.1007/s40737-023-00341-8> (Appendix D)

Publications that complement this thesis

Gamieldien, F., Galvaan, R., Myers, B., & Sorsdahl, K. (2020). Exploration of recovery of people living with severe mental illness (SMI) in low-income and middle-income countries (LMIC): A scoping review protocol. *BMJ Open*, 10(2), e032912.

<https://doi.org/10.1136/bmjopen-2019-032912> (Appendix E)

Publications being prepared for submission

Gamieldien, F., Galvaan, R., Myers, B., & Sorsdahl, K. The psychometric properties of the Recovery Assessment Scale (RAS) among persons with severe mental health conditions in South Africa. (Appendix F)

Summary of chapter contributions

Chapter One: Introduction

I conceived the scope and conducted the write-up of this chapter. This chapter contains no analysis and has not been published or prepared for publication.

Chapter Two: Literature and concept review

This chapter does not include any information submitted for publication. I reviewed the literature on the global disease burden related to mental, neurological and substance use disorders.

Chapter Three: An exploration of recovery of people living with severe mental illness in low- and middle-income countries: A scoping review

I conceived the study, developed the protocol, and registered the scoping review protocol with JBI Synthesis. I designed and tested the search terms in consultation with two subject librarians (MS and DB). I searched the literature, collated the results and eliminated the duplicates. I developed and revised the data extraction guidelines based on feedback from my supervisor, KS, and my research assistant, ZS. ZS and I were responsible for reviewing titles and abstracts for inclusion. We both reviewed all included full-text articles. Where we disagreed, we sought consensus with a third rater, KS. I extracted the data, and ZS checked for accuracy. I charted the data, conducted the analysis, wrote the review's first draft, and prepared the figures and tables. Findings were discussed with an Advisory Committee (AC). Co-authors RG, KS and BM commented on the manuscript and subsequent revisions.

Chapter Four: Service providers' perspectives on personal recovery from severe mental illness in Cape Town, South Africa: A qualitative study

I led all sections of this study, including conceiving the study idea, developing the protocol, and conducting the research. I thematically analysed the data; and, once themes were finalised with agreement from KS, they were presented to the advisory committee and stakeholders for member checking. I wrote the manuscript, and my co-authors commented on the manuscript and subsequent revisions.

Chapter Five: Mental health service users and their caregiver's perspectives on personal recovery from severe mental health conditions in Cape Town: A qualitative study

I led all sections of this study, including conceiving the study idea, developing the protocol, and conducting the research. I completed all service user and caregiver interviews and thematically analysed the data. Once themes were finalised with agreement from RG, they were presented to the AC and mental health service users for member checking. I wrote the manuscript, and my co-authors commented on the manuscript and subsequent revisions.

Chapter Six: The psychometric properties of the Recovery Assessment Scale (RAS) among persons with severe mental health conditions in South Africa

I led all sections of this study, including conceiving the study idea, developing the protocol, conducting the research, capturing the data, cleaning the data, conducting the analysis, and reporting the findings. KS and EG supported me in the data analysis. My research assistants and I completed interviews with 300 mental health service users (MHSUs). As part of this work, I had to revise the interview protocol to include a Standard Operating Procedure (SOP) to collect data once the lockdown during the COVID-19 pandemic was lifted and face-to-face research was permitted in 2020.

Chapter Seven: Bringing it together: Findings, recommendations and future directions

I conceived the scientific scope and conducted the write-up of the chapter. This chapter contains no analysis and has not been published or prepared for publication.

Overview of the chapters

The thesis is structured as follows:

Chapter One offers insights into the rationale for this study, highlighting the global burden of disease attributed to mental, neurological and substance use disorders. I then describe the public mental health services in South Africa, a low- and middle-income country (LMIC). The study's purpose, research question, aims and objectives, researcher positionality, study setting and preparations are presented.

Chapter Two reviews the literature relevant to each of the four study objectives. I report on developments in the public mental health field and efforts to decrease the treatment gap in low- and middle-income countries (LMICs). After that, I discuss the concept of recovery related to persons with lived experience (PWLE) of severe mental health conditions (SMHCs).

Chapter Three presents the research methods used and describes how the study was conducted in response to the first research question and objective one (i). The scoping review study exploring the recovery of persons with SMHCs in LMICs is described.

Chapter Four reports on the research methods used and describes the qualitative study exploring service providers' perspectives on personal recovery from SMHCs in Cape Town, South Africa. This fulfils objective two (ii) of the study.

Chapter Five reports on the research methods used and describes the qualitative study exploring MHSUs' and their caregivers' perspectives on personal recovery from SMHCs in Cape Town, South Africa. This fulfils objective three (iii) of the study.

Chapter Six presents the research methods used and describes the results of the quantitative study exploring the psychometric properties of the Recovery Assessment Scale (RAS) among persons with SMHCs in South Africa. This fulfils objective four (iv) of the study.

Chapter Seven concludes the thesis. This chapter draws on the accumulated evidence in Chapters Three, Four, Five, and Six. The findings are synthesised in an overall discussion. Chapter Seven concludes with study limitations, implications, and recommendations for using personal recovery as a lens for practice; there is also discussion of service provision, policy implementation, research, and training to address public mental health services in South Africa.

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Initials of people involved in the project

Initial	Name	Role
FG	Fadia Gamieldien	PhD Fellow/ Principal Investigator
KS	Katherine Sorsdahl	Principal Supervisor
RG	Roshan Galvaan	Supervisor
BM	Bronwyn Myers	Supervisor
ZS	Zarina Syed	Research Assistant
FC	Feroza Cassim	Research Assistant
AD	Ayesha Dollie	Research Assistant
AW	Aamena Waja	Research Assistant
MS	Mary Sheldon	Subject Librarian
DB	Dilshaad Brey	Subject Librarian

Style, key terms and abbreviations

A note on spelling:

South African spelling has been used throughout this thesis except for standard international terminology such as the World Health Organization.

Terminology:

During this study, the preferred terminology changed from severe mental illness (SMI) to severe mental health conditions (SMHCs) to reduce stigma (Thornicroft et al., 2022). I sought the advice of the Advisory Committee and mental health service users before changing terminology. The Lancet Commission highlighted the need to consider how language can be used to end stigma and discrimination in mental health. The most recent changes were adopted by some of the non-profit organisations included in the study and colleagues in the UCT Division of Disability Studies. I applied to change the title of my thesis to reflect this, and I have incorporated the terminology into the thesis, except for the publications included in Chapters Three and Four, which still reflect the terminology of severe mental illness (SMI).

The terms, mental health service users (MHSUs) and persons with lived experience (PWLE), refer to persons living with SMHCs who are experts by experience. The words ‘persons’ and ‘people’ are used interchangeably in the literature but the preferred term is ‘persons living with SMHCs’. In Chapters Three to Five, the publications included in this thesis, I refer to ‘people with SMI’ and ‘people with SMHCs’. Thereafter, I use ‘persons’ as it aligns with Anthony’s (2004) notion that personhood is the transcendent guiding principle from which all other recovery principles emanate. ‘Persons’ first language’ is also the preferred terminology adopted in the Convention on the Rights of Persons with Disabilities (United Nations, 2006).

Abbreviations

ASSIST	Alcohol, Smoking and Substance Involvement Screening Tool
CHC	Community Health Centre
DALY	Disability Adjusted Life Years
DOH	Department of Health
DSD	Department of Social Development
EIS	Empowerment and inner strength
FBO	Faith-Based Organisation
GBD	Global Burden of Disease
GSO	Goal and success orientation
HICs	High-Income Countries
LMICs	Low-and-Middle-Income Countries
MH-NGO	Mental Health Non-Government Organisation
MH-NPO	Mental Health Non-Profit Organisation
MHSUs	Mental Health Service Users
MNS	Mental, neurological and substance use
MSPSS	Multidimensional Scale of Perceived Social Support
NDS	No domination by symptoms
NGO	Non-Governmental Organisation
NPO	Non-Profit Organisation
OPD	Outpatients Department
PC	Personal confidence
PCC	Person-Centred Care
PCH	Personal confidence and hope
PHC	Primary Health Care
PRISMA	Preferred Reporting Items and Meta-Analyses
PSR	Psychosocial Rehabilitation/ Psychiatric Rehabilitation

PWLE	Person(s) With Lived Experience
RAS	Recovery Assessment Scale
ROO	Reliance on others
SMHCs	Severe Mental Health Conditions
SMI	Severe Mental Illness
SUD	Substance Use Disorder
WAH	Willingness to ask for help
WCP	Western Cape Province
WHO	World Health Organization
WHOQOL-BREF	World Health Organization Quality of Life-Abbreviated
YLD	Years Lived with Disability

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The Division of Occupational Therapy in the Department of Health and Rehabilitation Sciences, UCT. The content reflects the views of the author(s), not those of the division.

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Chapter One: Introduction

“This message is so simple, yet it gets forgotten.

The people living with the condition are the experts”

Michael J. Fox

Chapter One provides an orientation and background to the study, which is on the recovery of people with lived experience of severe mental health conditions (SMHCs) in South Africa.

1.1 Background to the study

Mental, neurological and substance use (MNS) disorders contribute significantly to the global disease burden (GBD 2019, Mental Disorders Collaborators, 2022; Jaeschke et al., 2021), and their increasing prevalence continues to be a concern (Vos et al., 2020). The MNS disorders category includes what is referred to as severe mental health conditions (SMHCs). SMHCs is a widely used umbrella term which refers to a range of diagnoses including schizophrenia spectrum disorders, bipolar affective disorders, major depressive disorder, substance-induced psychotic disorder or related psychotic disorders (Gonzales et al., 2022; Parabiaghi et al., 2006). SMHCs are also referred to in the literature as serious mental illness or severe mental illness (the abbreviation SMI is used for both), severe and persistent mental illness and serious mental disorders (Gonzales et al., 2022). As part of reducing stigma through language, the currently preferred term is SMHCs (Thornicroft et al., 2022).

SMHCs is neither an official diagnostic term nor defined in the two widely used classification systems for diagnosing mental health conditions (MHCs). Mental health professionals use the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) and the International Classification of Disease, (ICD-11) (World Health Organization, 2022a) as diagnostic systems. However, the two approaches differ in their diagnostic requirements (First et al., 2021). The DSM-5 and ICD-11 focus on mental conditions and not on the group of MHCs that could make up the SMHC category.

It is common for individuals with SMHCs to have co-morbid substance use disorder (SUDs), resulting in a dual diagnosis with concomitant functional implications for recovery. The relationship between SMHCs and SUDs is complex because it affects individuals in terms of severity, chronicity, disability and impairment in functioning, and it impacts families, communities and societies (Baranyi et al., 2019; Freeman, 2022; Mona et al., 2022; Weich & Pienaar, 2009; Yerriah et al., 2022). Persons with a dual

diagnosis might need extended treatment, suffer more frequent relapses, have more crises and move through treatment and recovery more slowly than those with a single disorder (Cleary et al., 2009; Mona et al., 2022).

Some debates suggest that severity should not refer to the diagnosis only but should include the duration of illness and a global assessment of functioning and disability (Gonzales et al., 2022; Parabiaghi et al., 2006; Ruggeri et al., 2000). The World Health Organization's International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) is a multipurpose classification system for measuring health and disability at the individual and population levels. The ICF aims to look beyond the diagnostic label and provide a common language for health and health-related states understood by different disciplines, sectors, countries, and cultures (World Health Organization, 2001).

There are different models and approaches to MHCs, but an urgent need is to improve classification approaches for public mental health (Stein et al., 2013; Stein et al., 2022). Therefore, in the absence of a universal definition for SMHCs and to avoid stigmatising language (Thornicroft et al., 2022), I use the term SMHCs throughout this thesis. The exception is in Chapters Three and Four where I use the term serious mental illnesses (SMI), as the studies in these chapters were published before terminology conventions shifted. The transformation of mental health services calls for a move from focusing on the MHC to a commitment to human rights, dignity and non-coercive practices.

Recovery was conceptualised as a process and an outcome in high-income countries (HICs), and the recovery movement has been promoted to transform clinical and rehabilitation practice. Personal recovery-oriented public mental health services acknowledge that, while MHSUs may live with the symptoms of SMHCs, they can reclaim their lives by developing a positive sense of self and taking up valued social roles. Mental health service transformation includes efforts to phase out extended-stay psychiatric care, build community-based mental health services and develop recovery-focused services within a human rights framework (Freeman, 2022; World Health Organization, 2022b). While there are many assertions that including persons with lived experience (PWLE) in planning, policy development, and interventions is critical for mental health service reform (Freeman, 2022; Thornicroft et al., 2022; Venkatesan, 2019), more information is needed about how PWLE of SMHCs view recovery in low- and middle-income countries (LMICs).

In Anthony's seminal work dating back 30 years, he defined recovery as:

a deeply personal, unique process of changing one's attitude, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness. (Anthony, 1993, p. 15)

As a person with lived experience herself, Deegan (1996) reminds us that recovery is rooted in the understanding that mental health service users (MHSUs) are human beings first and that recovery is an attitude and way of managing the challenges these users face as experts by experience. Slade (2009) distinguishes between clinical and personal recovery, where clinical recovery focuses on alleviating symptoms through preventative, promotive, curative, therapeutic and rehabilitative interventions; it is profession-led and invariant across MHSUs.

Clinical recovery is typical in mental health services that follow a custodial care model where the focus is on the medical management of the illness, and inadequate attention is given to the factors that might impact personal recovery (Slade, 2009; Slade et al., 2014). Personal recovery refers to a service user-based understanding of recovery that includes clinical recovery but looks beyond it to what constitutes a meaningful life (Slade, 2009). Personal recovery is a cyclical, non-linear, unique, lifelong and individually variant process that includes social, political and human rights aspects (Llewellyn-Beardsley et al., 2019; Sommer et al., 2021). In this thesis, I use the terms personal recovery and recovery interchangeably as these are the terms used in the recovery movement. Knowledge of recovery from SMHCs is scarce in LMICs including South Africa (Gamieldien, Galvaan, Myers, et al., 2021).

In LMICS, the male-to-female ratio of schizophrenia varies. In a study conducted in Ethiopia, the prevalence ratio of schizophrenia of males to females was 5:1 (Ghebrehiwet et al., 2020). This disparity may be due to a number of factors, including biological differences, sociocultural factors, the nature of help-seeking behaviour, caregiver involvement and community responses to SMHCs (Ghebrehiwet et al., 2020). This study included men and women living with SMHCs.

We know little about how people learn to live with SMHCs and reclaim their lives in South Africa. In the Western Cape, MHSUs with comorbid SMHCs and SUDs struggle to access treatment outside the psychiatric hospital. As a result of this treatment gap, many MHSUs relapse and have multiple admissions, resulting in them being referred to as high-frequency users or revolving door patients (Botha, Koen, Joska, Parker, et al., 2010; Gerber, 2018; Lund, Petersen et al., 2012). This study focuses on the PWLE of SMHCs and the public mental health services available to them in Cape Town, South Africa. The limited research available on MHSUs in the Western Cape tends to support variations in how men and women access mental health services. For example, there

was a 75% prevalence of dual diagnosis among men admitted to transitional care facilities in the Western Cape region (Botha et al., 2020; Gamielien, Galvaan, & Duncan, 2021). This was confirmed by research which reported that more men than women were using intermediate care services offered by specialist psychiatric hospital in the public mental health sector in Cape Town (Gamielien, Galvaan, & Duncan, 2021). The demographic profile of service users in transitional care facilities noted that 600 (82.2%) of the 730 service users admitted to an intermediate step-up-step-down care facility from 01 January 2011 to 31 December 2015 were male (Vava et al., 2022). The higher percentage of men admitted to psychiatric hospitals (Botha et al., 2020) could speak to the gendered nature of help-seeking behaviour in South Africa, contrasted with a higher prevalence of SMHCs, reported in Ethiopia (Ghebrehiwet et al., 2020). According to Vázquez-Reyes et al. (2021), women are more likely to seek help sooner and access help at primary levels of care without needing admission. On the other hand, men tend to wait longer and have more behavioural problems and family burdens, necessitating admission. A South African study, which drew on participants from the Western and Eastern Cape provinces, found that men had a higher community prevalence of co-occurring substance-use disorders – which, along with factors such as younger age, prior admissions, socio-economic problems and trauma, contributed to higher occurrence of comorbid substance-use disorders in men living with schizophrenia (Temmingh et al. 2021). While gender and development studies tend to exclude the exploration of men's gendered experiences or view men as obstacles to women's development, understanding men's perspectives can shed light on what impacts their mental health, their help-seeking behaviour, and their long-term recovery trajectory (Abdullah et al., 2022; Morrell, 2007; Sagar-Ouriaghli et al., 2019; Vázquez-Reyes et al., 2021).

1.2 The rationale for the study

While significant progress has been made in advancing mental health policies globally, the treatment gap in LMICs remains a concern. Mental health services have been critiqued for not being human rights-focused and for the use of coercive practices in service delivery (Adams et al., 2023; Lund, 2016; Stein et al., 2022). In South Africa, despite progressive policies which have been developed to support mental health reform, many MHSUs continue to experience mental health care that is coercive and institutionalised. Deinstitutionalisation was introduced in South Africa as part of the policy reforms associated with the end of apartheid and the beginning of democracy (Vava et al., 2022). The Mental Health Care Act (MHCA) No. 17 of 2002 (South Africa, 2002) was promulgated in South Africa in 2004. It is aligned with the Constitution of the Republic of South Africa (1996) in its orientation to human rights and access to humane care (Szabo & Kaliski, 2017).

The MHCA allows for voluntary, assisted or involuntary hospital admissions. Involuntary admissions occur when MHSUs are assessed as being in danger of harming themselves or others (National Department of Health, 2002). MHSUs are admitted to psychiatric hospitals after a 72-hour assessment in a designated district hospital. The MHCA affords MHSUs a maximum 72-hour assessment admission, whereafter they are admitted to a specialist hospital for further psychiatric care (Moosa & Jeenah, 2008). Many MHSUs are admitted to psychiatric hospitals in the Western Cape on an involuntary basis because they are acutely ill, might be aggressive, may need some form of sedation and restraint, and the police or emergency services might be involved in facilitating their admission (Madala-Witbooi & Adeniyi, 2019). The MHCA supports deinstitutionalisation by moving from custodial care to care that enables access to treatment and rehabilitation at all levels of care (Thomas et al., 2015). However, involuntary admissions, a lack of psychosocial support and limited community-based care options raise concerns regarding the lack of autonomy and the right to the least restrictive care for MHSUs. The principle of least restrictive care asserts that MHSUs should receive support in settings which respect their autonomy and enable their participation (Freeman, 2022).

The international deinstitutionalisation movement began in HICs with the aim of replacing long-term psychiatric hospital care with community-based services. The decrease in psychiatric beds was meant to coincide with the simultaneous scaling up and strengthening of community-based services so that people could access services close to where they live (Freeman, 2018; Pillay, 2017; Stein et al., 2022). There are several successful examples of deinstitutionalisation in HICs. For instance, in Italy, the 1978 Basaglia Law led to the closure of all psychiatric hospitals and a radical shift to community-based care (Mezzina, 2018). There was a shift towards community care in the UK, which reduced institutional care. Still, although this shift was grounded in human rights and social inclusion, the outcomes varied depending on the coordination between local resources (Thornicroft & Tansella, 2004).

Successful deinstitutionalisation requires strong community-based services, investment and planning. These conditions are often lacking in many LMICs, including South Africa (Pillay, 2017). The assumption was that community-based services would be more human rights-focused, therapeutic and cost-effective, but South Africa's implementation efforts were fragmented and shaped by post-apartheid reforms, poor planning, a lack of resources and gaps in mental health care (Lund et al., 2010; Vava et al., 2022). The deinstitutionalisation process drew attention to the needs of persons with SMHCs outside of psychiatric settings and the lack of service infrastructure, resources and trained healthcare providers to provide mental healthcare in the community (Thornicroft et al., 2016). The deinstitutionalisation strategy aimed to

decentralise institution-based care and transfer MHSUs from institutions to integrated community-based mental health services (Petersen & Lund, 2011).

However, the Life Esidemeni tragedy demonstrates the consequences of unsystematic planning where implementation was poorly managed, underfunded, and inadequately resourced. The tragedy occurred between October 2015 and June 2016 and resulted in the deaths of 144 mental health service users (MHSUs) with SMHCs or severe and profound intellectual disabilities. They were part of a group of 1711 MHSUs transferred from hospital facilities to non-governmental organisations (NGOs) and non-profit organisations (NPOs) in the Gauteng Province (Freeman, 2018). There is growing acknowledgement that deinstitutionalisation can only succeed with proper planning and sufficient resources to develop community-based services (Freeman, 2018; Pillay, 2017). While deinstitutionalisation efforts rely heavily on NGOs and NPOs, little is known about the mental health NPOs (MH-NPOs) providing community-based services for persons with SMHCs.

As part of its global mental health drive to close the treatment gap, especially in LMICs, the WHO recommends that countries scale up community-based mental health services focusing on psychosocial rehabilitation and recovery (World Health Organization, 2022b). In South Africa, the National Department of Health took its cue from WHO. It included developing psychosocial rehabilitation and recovery-focused services in its National Mental Health Policy Framework and Strategic Plan 2013–2020 (Dept of Health, 2014). This plan lapsed in 2020, and the revised Mental Health Policy Framework and Strategic Plan 2023–2030 was adopted in 2023 (National Department of Health, 2023). While the framework calls for psychosocial interventions and collaborative approaches to be implemented in the South African healthcare context, the gap between policy directives and implementation persists (Kramers-Olen, 2014). There is a lack of financial support to scale up community-based services, as evidenced by the overall mental health expenditure in South Africa where 45% of the total mental health budget is allocated to specialist psychiatric hospitals, 11.7% goes to district-level mental healthcare, and 8% goes to primary healthcare services (Sorsdahl et al., 2023).

Psychosocial rehabilitation (also known as psychiatric rehabilitation and PSR) refers to the tools and interventions that mental health practitioners use to assist MHSUs in their recovery (Farkas, 2007). Although psychosocial rehabilitation has been inconsistently defined in the literature, there is widespread agreement that it is a key service within the mental health system. It is aimed at supporting individuals with SMHCs through collaborative efforts. PSR focuses on helping these persons to develop skills and access the resources needed to succeed and find satisfaction in their chosen living, learning, working, and social environments (Farkas & Anthony, 2010). A limitation of PSR is its focus on functional outcomes, which may not reflect the personal recovery-

focused aspirations of people with lived experience of severe mental health conditions (Farkas & Anthony, 2010).

PSR promotes a vision of recovery (Farkas, 2007), with the overarching goal being social inclusion (Barbato, 2006). Barbato (2006) further asserts that we cannot only interpret PSR as focused on interventions for the individual but also need to reframe the PSR vision as a public health strategy and consider its implications in practice, research and policy. All stakeholders must remain mindful of key guiding principles within this frame of reference. For example, PSR is a humanistic approach that operates at the intersection of the individual's personal relationships and social environment. Its strategies should focus on addressing functional disabilities and psychosocial risk factors rather than long-term chronic conditions. Moreover, social and interpersonal outcome indicators must be developed along with clinical outcomes (Barbato, 2006).

Despite the significance of PSR, recovery as a construct to support the development of integrated recovery-focused mental health services for persons with SMHCs is underexplored in LMICs, including South Africa.

1.3 Problem statement

In 1948, the WHO defined health as “not merely the absence of disease or infirmity but a state of complete physical, mental and social wellbeing”. This definition is widely accepted, but has also been contested as being biomedical, focusing on disease and not whether service users feel ill or disabled (Misselbrook, 2014). Misselbrook (2014) suggests that health is a positive concept, and the goal of health care should be to support people to flourish and overcome illness or disability and not be impeded by it.

Although public mental health services are meant to adopt a biopsychosocial approach, the treatment of SMHCs tends to be biomedical and focused on clinical recovery (alleviation of symptoms and medication adherence), with limited attention to the psychosocial components of the approach. A personal recovery focus would include clinical recovery while also considering what has meaning and purpose for PWLE and what helps or hinders recovery in their living, learning, working and socialising environments. Similarly, the Social Model of Disability (Shakespeare, 2006) shifts the focus from individual deficits to social, economic, and attitudinal barriers that hinder participation. This framing aligns with recovery-focused mental health services and community development centred on equity, inclusion and the transformation of systems rather than individuals (Badu et al., 2020).

In South Africa, like other LMICs, the available mental health resources and services tend to be concentrated in specialist mental health services, although the WHO (World Health Organization, 2022b) and the South African National Mental Health Policy and

Strategic Plan (National Department of Health, 2023) recommend that community-based mental health services be recovery-focused and involve intersectoral collaboration. Recovery involves regaining an meaningful life, participating in community, living a dignified life and accessing work or learning opportunities. These outcomes depend on factors beyond the health sector and include access to housing, social support, education, labour and safety. Intersectoral commitment is a cornerstone of the National Mental Health Policy Framework and Strategic Plan 2023-2030 (National Department of Health, 2023) but the reality is that recovery-focused community-based services are limited. Intersectoral collaboration efforts offer MHSUs opportunities to recover in sustainable, just and equitable contexts as it shifts mental health care from a siloed medical model of care to a community-oriented, inclusive network of support (National Department of Health, 2023). Intersectoral collaborations require strengthening communication and written agreements across and between government and non-profit organisations (Brooke-Sumner et al., 2016; National Department of Health, 2023). There is a lack of continuity of care and limited collaboration between government mental health services and MH-NPOs, leaving MHSUs without timely access to necessary services (Thebus, 2022). Inadequate access to recovery-focused services impacts individuals with severe mental health conditions (SMHCs), service providers, and caregivers. MHSUs require services that offer sustained relational support to aid their recovery, but public mental health services fail to provide this. Instead, only a few mental health non-profit organisations (MH-NPOs) offer recovery-focused services that include long-term relational support (Comcare Trust, 2023; Davies et al., 2023).

Currently there is limited research exploring the personal recovery experiences of persons with SMHCs in South Africa. Most studies focus on clinical recovery, often overlooking the personal recovery journey – how individuals find meaning, purpose and fulfilment while living with mental health challenges. This gap in the research leaves a crucial aspect of mental health care underexplored, particularly in a context where recovery-focused services are scarce. This study aims to address this gap by investigating the personal recovery experiences of persons with SMHCs, shedding light on their needs and perspectives within the South African public mental health system.

1.4 Aim of the study

The aim of this study is to advance the understanding of personal recovery for individuals with severe mental health conditions (SMHCs) in South Africa, by exploring its conceptualisation and evaluating tools and perspectives relevant to recovery within this context. The knowledge generated on recovery from SMHCs in South Africa could guide public mental health researchers, policymakers, service planners and implementers interested in collaborating with PWLE as experts by experience.

1.5 Study objectives

The following four objectives supported the aim of the study:

- 1.5.1 To conduct a scoping review on how personal recovery is conceptualised for persons living with SMHCs in LMICs
- 1.5.2 To explore and describe what recovery is for persons with SMHCs in South Africa from service provider perspectives
- 1.5.3 To explore and describe what recovery is for men with SMHCs and their caregivers in South Africa
- 1.5.4 To evaluate the psychometric properties of the Recovery Assessment Scale (RAS) among persons with SMHCs in South Africa.

1.6 Study setting

This study was conducted in the City of Cape Town, one of six district municipalities in the Western Cape Province (WCP) of South Africa. The WCP has a population of over 7.4 million people, and it is the third most populous province in the country (Statistics South Africa, 2022). Most people living in the WCP reside in the City of Cape Town which has a population of approximately 4.8 million (Statistics South Africa, 2022). The circle in Figure 1.1 indicates the geographic location of the study setting.

Figure 1.1

Map of Western Cape Province (Insert: Cape Town)



Note: Copyright: City of Cape Town, 2018. Original source: Google Earth.

This study drew participants from the City of Cape Town. Key statistics for this district municipality drawn from the Census 2022 are reflected in Table 1.1.

Table 1.1

City of Cape Town Census Data and Statistics

Census Data	Key Statistics
Land size	2 461 km ²
Total population	4 772 846
Children (0-14)	1 069 118 (22.4%)
Working age (15-64)	3 383 948 (70.9%)
Elderly (65+)	319 781 (6.7%)
Males	2 306 058 (48.3%)
Females	2 464 255 (51.7%)
Access to basic services	1 240 088 (85.4%%)
Dependency ratio	42.2%
Unemployment rate	22.2%
Number of households	1 264 949
Formal dwellings	87.5%
Household income below the poverty line (1 227 per person)	35,7%

Note: From National Census 2022. Statistics South Africa, 2022.

The City of Cape Town metropolitan area is a diverse area that includes the poorly resourced Cape Flats, a vast region outside the city centre notorious for the high prevalence of poverty, gangsterism, and violence (Bowers Du Toit, 2014; Mncube & Madikizela-Madiya, 2014). During apartheid, people designated as Black were forcibly removed from their homes and relocated to the Cape Flats. Urban segregation between Coloured and Black people was legally sanctioned in Cape Town by removing people from the inner city to township areas on the fringes of urban areas. The discriminatory system of apartheid further restricted people in terms of property ownership, occupancy, and trade. Racial segregation resulted in adverse socio-economic repercussions for the people who were relocated. Low-cost, densely populated apartments and three-storey hostel-type housing were constructed with limited attention to creating recreational (sport, play), commercial and other social spaces.

In post-apartheid South Africa, residents across the Cape Flats continue to be marginalised as high crime levels, violence, gangsterism, substance abuse, poverty, and unemployment persist (Du Preez, 2013; Steinberg, 2011). In the WCP, the coloured³ (Erasmus, 2001) population forms the majority (47,5%), followed by black

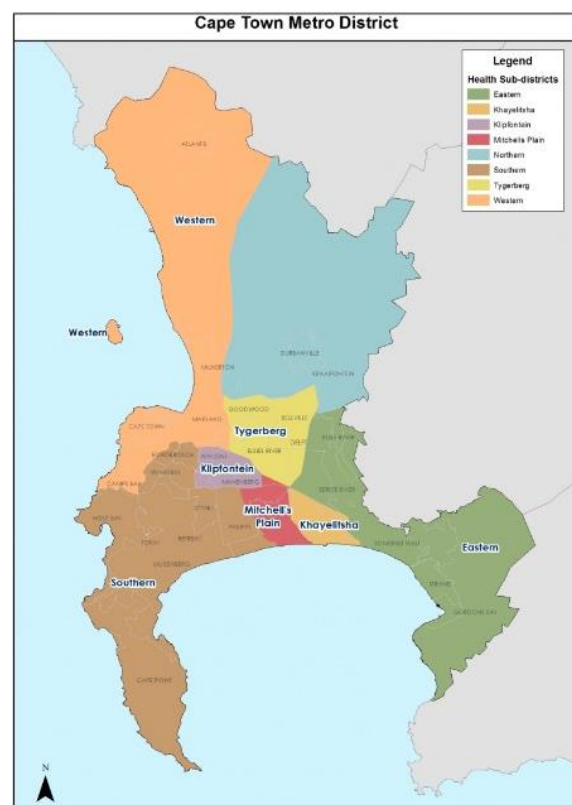
³ Coloured identity refers to people with mixed heritage and creolised identities shaped and re-shaped by historical practices in South Africa. See: Erasmus, Z. (2000). Recognition through pleasure, recognition through

Africans (35,7%), and 16,0% are white (Statistics South Africa, 2018). Although South Africa has twelve official languages (English, Afrikaans, sign language and nine ethnic languages), Afrikaans is the most commonly spoken language in the WCP (46,6%), followed by isiXhosa (31,1%) and English (19,6%) (Statistics South Africa, 2018).

The City of Cape Town comprises eight health sub-districts: Eastern, Western, Northern, Southern, Khayelitsha, Klipfontein, Tygerberg and Mitchells (See Figure 1.2)⁴.

Figure 1.2

City of Cape Town Metropolitan Municipality with Health Sub-districts



Note: Copyright: Western Cape Government, 2018.

Based on its geographic location and size, each sub-district is serviced by one of the three state-run psychiatric hospitals: Valkenberg, Lenteguur and Stikland. Due to the demand for psychiatric admissions, MHSUs residing on the Cape Flats need better access to the three psychiatric hospitals that provide specialist, inpatient services for SMHCs in the Western Cape (Docrat et al., 2019). Services at these hospitals, including

violence: Gendered coloured subjectivities in South Africa. *Current Sociology*, 48(3), 71-85.
[https://doi.org/https://doi.org/10.1177/0011392100048003006](https://doi.org/10.1177/0011392100048003006)

⁴ Rural municipalities were not part of this study owing to logistical and cost limitations.

their associated outpatient and outreach services, are occasionally augmented by mental health non-profit organisations (MH-NPOs), mental-health non-governmental organisations (MH-NGOs), faith-based organisations (FBOs), traditional healers and different mental health special interest groups (Kleintjes & Schneider, 2023).

MHSUs are admitted to psychiatric hospitals when assessed as being in danger of harming themselves or others (National Department of Health, 2002). MHSUs are referred from district hospitals after 72 hours when they need specialist mental health care (National Department of Health, 2002). Once deemed fit for discharge, MHSUs are discharged to the CHC closest to their home. MHSUs with first-episode psychosis or those with multiple relapses are sometimes referred to the OPD where they are followed up for three months post-discharge, whereafter they are devolved to the CHC at the primary health level (Hussey et al., 2023). Hospital admissions offer MHSUs and their caregivers respite; but the lack of community-based rehabilitation services at primary healthcare level limits MHSUs community integration (Gamielien, Galvaan, & Duncan, 2021). Once discharged from the hospital, MHSUs with SMHCs are sometimes referred to government-funded MH-NPOs (where available) for rehabilitation services and access to ongoing support (Brooke-Sumner et al., 2016).

1.7 Positioning the researcher

Much of my career has been as a clinician, manager, and policymaker in the public mental health sector. As a disability rights activist in public mental health, I have always been interested in the recovery goals of persons with SMHCs. My interest was piqued after supervising undergraduate students in various mental health care settings and noticing the services offered by different stakeholders.

My master's research explored the community integration needs of male MHSUs following their participation in intermediate care (Gamielien, 2015; Gamielien, Galvaan, & Duncan, 2021). The MHSUs who participated in this study, men with SMHCs, considered the intermediate care facility a respite space that fostered clinical recovery but that did not support personal recovery. As a coloured Muslim female occupational therapist who grew up on the Cape Flats, I am familiar with the areas and conditions in the communities to which MHSUs are discharged and the limited services promoting personal recovery as part of community-based services.

I recognised the need for mental health policies and practices to be aligned; and I understand that recovery-oriented services require service providers and policymakers to listen more carefully to MHSUs as PWLE (Kleintjes et al., 2010). Partnering with MHSUs as experts by experience helps stakeholders to ascertain what helps or hinders their recovery, prevent readmission, decrease relapse rates, and minimise the revolving door phenomenon. For this study, I used my experience as a mental health practitioner

as a resource to generate evidence that could be used to co-create knowledge on recovery from SMHCs from diverse stakeholder perspectives.

To deepen the transparency and reflexivity of my work, I am aware that my personal and professional identity has shaped the lens through which I view mental health, recovery and community-based care. While my positionality provided unique insights and access, it also introduced potential biases. These included: (i) that over-identification with MHSUs and practitioners meant I could have unintentionally privileged certain ways of knowing, especially if they were aligned to my own experiences; (ii) that my familiarity with the research context meant that, being a member of some of the communities where participants lived and having professional networks in the public sector, I could have been influenced in the questions I asked, how I interpreted responses, or the assumptions I made about systemic challenges; (iii) that my advocacy orientation predisposed me to interpret findings through a critical lens stemming from my commitment to human rights, recovery and deinstitutionalisation; (iv) that my expectation of system alignment meant that I was attuned to inconsistencies in the health system which made me aware of policy-practice gaps; and (v) that language and power dynamics made me cognisant of the need to step back to allow participants' voices to be foregrounded and to avoid imposing institutional interpretations or language. As part of reflexive practice, I hope my reflections showcase my efforts to be transparent, self-aware and critical of how my position could have influenced the research process.

1.8 Stakeholder research advisory committee

When initiating the study, I identified stakeholders, including PWLE, to form part of a stakeholder advisory committee (AC). The AC were consulted at multiple points in the research process, and they provided critical oversight and advice across the breadth of this study, which helped me make informed decisions to improve the research process. This committee allowed me to engage with diverse experts from different backgrounds and professions at every stage of the research process, keeping with the disability sector slogan: "Nothing about us without us" (Charlton, 1998). Before commencing fieldwork, I met with the AC to review the research protocol and the four research objectives. After that, I shared the scoping review protocol and the findings. Once I was ready to start data collection for objectives two to five, feedback from the committee helped me refine my data collection tools before implementing the research. Every aspect of data collection was trialled with a PWLE member of the AC, who offered feedback and insights into how to put the protocol into practice.

During the study, there were terminology changes which influenced how research on mental health reform was reported in the literature (Thornicroft et al., 2022). I changed

the title of my thesis twice, and all changes were discussed with stakeholders on the AC. The AC were a core part of the research process as they supported me in disrupting traditional hierarchies and creating spaces which fostered meaningful non-tokenistic participation and where lived experience and experiential knowledge were valued alongside professional and academic expertise (Bird et al., 2020; Dray et al., 2024). As a health professional and researcher, I consciously tried to step back, listen actively, and reflect on my positionality and potential biases. This involved holding meetings in accessible settings, using everyday language (not clinical jargon), and allowing PWLE to co-shape the research priorities. This collaborative process helped me build trust, negotiate power dynamics, and ensure that the research remained accountable to the stakeholders and the communities it served.

Study design

A mixed-methods approach was employed to achieve the four objectives of this study. My three supervisors vetted all research-related activities, but I was responsible for the execution thereof. This PhD was conducted independently and was not part of a larger study. As a result, I coordinated all the tasks related to securing site access, including liaising with facilities. I also trained research assistants for fieldwork and managed all communications and meetings with Department of Health officials and MH-NPO personnel. Prior to starting the study, I visited the outpatient departments (OPDs) and met with MH-NPO stakeholders.

Furthermore, I conducted all the qualitative interviews with the service providers, MHSUs and their caregivers. I was supported in the quantitative psychometric study by three research assistants who assisted me in conducting surveys with MHSUs. Finally, I guided all the research activities associated with generating, managing and analysing data and documentation for publication. A study overview is presented in Table 1.2.

Table 1.2

Chapter and Methodology Outline

Overarching research question What constitutes and facilitates recovery for persons with SMHCs in South Africa?						
Relevant chapter	Chapter Three	Chapter Four	Chapter Five		Chapter Six	Chapter Seven
Objectives	To conduct a scoping review on how personal recovery is conceptualised for persons living with SMHCs in LMICs	To explore and describe what recovery is for men with SMHCs in South Africa, from service providers, service users, and their caregivers' perspectives			To evaluate the psychometric properties of the Recovery Assessment Scale (RAS) among persons living with SMHCs in South Africa	To synthesise findings and offer recommendations to inform mental health systems reform for PWLE in the Western Cape
Fields of enquiry	Public Mental Health/Global Burden of Disease					
Conceptual framework	Personal Recovery					
Methodology	Mixed Methodology					
Study type	Scoping Review	Qualitative, descriptive			Quantitative, non-experimental, psychometric	Synthesis of findings
Data collection method	Charting evidence and synthesis	Individual interviews and focus groups with service providers	Individual time graph, community mapping and photo-elicitation interviews with MHSUs	Individual interviews with caregivers	Survey with 250 MHSUs to assess the psychometric properties of the RAS	
Analysis	Thematic analysis	Thematic analysis			Descriptive statistics	Implications for policy, research and practice

1.10 Structure of the thesis

This thesis is presented in chapters and published articles based on mixed methods research. Chapter One described the background and rationale for the study. In it I shared the problem, aim and objectives of the study and I provided an overview of the research design, research setting and my positionality as the researcher. In Chapter Two, I review the literature and concepts relevant to the thesis. The chapter commences with a description of the disease burden and prevalence of SMHCs in LMICs, followed by information regarding recovery from SMHCs. Due to the scarcity of literature on recovery from SMHCs in LMICs, data from high income countries (HICs) are included. I then contextualise recovery-oriented interventions by providing an overview of mental health care services in South Africa.

Subsequent chapters report the findings of studies linked to each of the four research objectives. Chapter Three describes the results of a scoping review of the recovery of persons living with SMHCs in LMICs. It builds on a publication that describes the development of the scoping review protocol. Chapter Four presents the findings of a qualitative, descriptive study on service providers' perspectives on personal recovery from SMHCs. Chapter Five, also based on qualitative methodology, describes male MHSUs and their caregivers' perspectives on personal recovery from SMHCs. Chapter Six is based on the quantitative, cross-sectional study I conducted to evaluate the psychometric properties of the Recovery Assessment Scale (RAS) among persons living with SMHCs in South Africa. Finally, the thesis concludes in Chapter Seven by presenting a synthesis of insights gained to address the aim of the study with due consideration of its limitations. In this chapter I also offer recommendations for mental health practice, service provision, policy implementation, training and future research and training.

1.11 Chapter summary

This chapter frames the thesis by providing an overview of recovery as it applies to SMHCs and as a rationale for strengthening public mental health services. Next, it outlines the research aim and objectives and describes the research setting, research process, researcher positionality, and thesis structure. The following chapter presents a review of the literature and relevant concepts to support the study rationale.

Chapter Two: Concepts and Literature Review

2.1 Chapter overview

This chapter presents critical concepts and a foundational literature review for this thesis. Due to the scarcity of literature on severe mental health conditions (SMHCs), recovery and co-morbid substance use disorders (SUDs) in LMICs, selected data from HICs and a few outdated references are included to provide context. The literature search in this chapter⁵ differs from the Scoping Review discussed in Chapter Three. Since Chapters Three, Four, Five and Six include publications of the sub-studies, some overlap exists between the literature and concepts presented in Chapter Two and the introduction sections of subsequent chapters, excluding Chapter Seven.

In Chapter Two, I present the prevalence and burden of SMHCs and co-morbid SUDs. After that, I discuss the disabling impacts of SMHCs on the individual and their caregivers. I then focus on the structure and function of public mental health services globally before honing in on public mental health services in the WCP of South Africa. Given that recent developments in the literature have led to a proliferation of studies on recovery, I present literature and exemplars supporting the recovery model as a philosophy for public mental health service reform, including LMICs. The chapter concludes with a section on the utility of recovery outcome measures in generating evidence for strengthening public mental health services.

2.2 The prevalence and burden of SMHCs and co-morbid SUDs

2.2.1 Prevalence: SMHCs and comorbid SUDs

Prevalence estimates of SMHCs in LMICs, including South Africa and the Western Cape Province, are scarce. While several South African studies have investigated the prevalence of common mental disorders (CMDs), such as depression and anxiety (Herman et al., 2009; Stein et al., 2008), the prevalence of SMHCs has not been similarly documented (Jacob & Coetzee, 2018). International estimates place the lifetime prevalence of SMHCs between 1% and 4% (Saha et al., 2005). However, the

⁵ I searched for published data for Chapter Two to identify literature on critical concepts and relevant literature related to my rationale for each of my research questions. A search strategy was developed with the help of a subject librarian. Databases were searched using MESH terms, and Boolean operators were included to increase the breadth of the search. I also included grey literature in my search. As far as possible, I included references not older than eight years, but this was not always possible due to the paucity of literature on specific topics. Seminal works have been included to illustrate their influence on later work.

literature suggests that hallucinations are also present in between 10% and 25% of the general population without these meeting the criteria for a diagnosis of SMHC (Johns & Van Os, 2001; Stip & Letourneau, 2009). Although the available nationally representative South African Stress and Health (SASH) study did not focus on SMHCs, one aspect of the study was to determine the prevalence of psychotic-like symptoms in the general population within South Africa (Temmingh et al., 2011). The prevalence of reported hallucinations was 12.7%, and this was associated with functional impairment, suicidal ideation, role interference and patterns of service utilisation (Temmingh et al., 2011). While the diagnosis of SMHCs requires functional impairment and the presence of psychotic symptoms, interest in viewing psychosis as a dimension of the human experience means that we cannot merely wait to treat psychotic symptoms; instead, we need to consider the socioeconomic, demographic and other risk factors that could contribute to psychosis in the general population (Stip & Letourneau, 2009).

In the South African context, dual diagnosis refers to the co-occurrence of mental health and substance use conditions in an individual. This is not surprising, given that the SASH study reports a high lifetime prevalence of SUDs, with alcohol being this group's most frequently abused substance (Herman et al., 2009). Alcohol has a controversial role in the history of South Africa. It has been used to manage labour since the arrival of the European settlers (Pasche & Myers, 2012). The South African Community Epidemiology Network on Drug Use (SACENDU) collects country-wide data from substance use treatment centres and reports on annual alcohol and other drug (AOD) use trends in South Africa (SACENDU, 2024).

SACENDU's most recent report includes data collected from specialist treatment centres and organisations providing harm reduction services across the nine provinces in South Africa. Each area reported different drug use patterns, but in the Western Cape, methamphetamine (32%), cannabis (24%), alcohol (18%) and heroin (15 %) were the most common primary substances of use among persons admitted to specialist treatment centres (SACENDU, 2024). Demographic information from the SACENDU report indicates that more males (73%) accessed treatment compared to females (27%); and more than half of the individuals were unemployed (55%) (SACENDU, 2024).

Globally, the occurrence of SUDs with SMHCs is underestimated, underdiagnosed and inadequately treated, despite the comorbidity contributing to the vulnerability of people with SMHCs (Fantuzzi & Mezzina, 2020). Literature, both internationally and in South Africa, suggests that a third of people with any mental health condition and 50% with SMHCs will also meet the criteria for substance abuse or dependence (Drake et al., 2007; Mona et al., 2022; RachBeisel et al., 1999; Temmingh et al., 2018; Weich & Pienaar, 2009). For example, a study in Tanzania (Hauli et al., 2011) found the prevalence of substance use amongst MHSUs to be 68.5%.

Research indicates a significant prevalence of comorbidity between SMHCs and SUDs among inpatients in psychiatric hospitals (Botha, Koen, Joska, Parker, et al., 2010; Weich & Pienaar, 2009). Two of the more recent studies found that 50% of MHSUs admitted to specialist psychiatric hospitals with an SMHC also have an SUD (Temmingh et al., 2021; Thungana et al., 2019). These studies show that comorbidity is regularly seen in specialist psychiatric hospitals, and the demographic profile of MHSUs has also been explored. A study in the KwaZulu-Natal province of South Africa reported that almost 50% of people admitted to a psychiatric hospital with schizophrenia and other psychotic disorders also had comorbid current and lifetime cannabis use (Mona et al., 2022).

The results of a multi-site study monitoring the prevalence of methamphetamine-related admissions at psychiatric hospitals in the Western Cape provide us with a demographic profile of MHSUs with comorbid substance use (Plüddemann et al., 2013). The majority of diagnoses were substance-induced psychotic disorder (41%), schizophrenia (31%), and bipolar mood disorder (12%); and most service users with methamphetamine-related admissions were male (69%) (Plüddemann et al., 2013). Further illustrating the magnitude of the problem of comorbidity, the most recent SACENDU report indicates that, of the people who were admitted to specialist treatment centres nationally, 59% reported a concurrent mental health condition (SACENDU, 2024).

2.2.2 Burden of disease: SMHCs and comorbid SUDs

The concept of burden of disease aims to quantify the impact of a condition impact on a population by going beyond prevalence and mortality figures. The main metric used to measure the global burden of disease (GBD) is the disability-adjusted life year (DALY). The DALY is calculated by summing the years having lived with a disability (YLDs) and years of life lost (YLLs) due to premature mortality (Charlson et al., 2018). DALYs tell us the number of healthy years of life lost due to a health condition. This combines the years of life lost as a result of earlier-than-expected death and years lived at less than 100% health due to living with a disability (GBD 2019, Mental Disorders Collaborators, 2022).

Given that mental health conditions do not frequently result in death, and the prevalence of SMHC is relatively low, the burden often lies in the disability-adjusted life years (DALYs). Mental, neurological and substance use (MNS) disorders contribute significantly to the global burden of disease. Whiteford et al. (2015) report that MNS disorders account for 10.4% of DALYs. Global burden of disease results analysed between 1990 and 2019 show an increased burden related to non-communicable diseases, which include MHCs (GBD 2019, Mental Disorders Collaborators, 2022; Patel et al., 2018). In 1990, MHCs accounted for 654.8 million estimated cases, which

increased by 48.1% to 970.1 million cases in 2019 (GBD 2019, Mental Disorders Collaborators, 2022). In 2019, MHCs accounted for 125.3 million of global DALYS (4.9%) and 125.3 million (14.6%) for YLDs (GBD 2019, Mental Disorders Collaborators, 2022). MHCs moved from where it was ranked as the 13th leading cause of DALYs in 1990 globally to seventh place in 2019. At the condition level, MHCs ranked among the top 25 leading causes of YLDs, with depressive disorders ranked second, anxiety disorders ranked eighth, and schizophrenia ranked twentieth across all ages (GBD 2019, Mental Disorders Collaborators, 2022).

However, it has been argued that the actual global burden of mental health problems may be underestimated by more than a third (Vigo et al., 2016). This underestimation, can be attributed to the following five factors: lack of consideration for the overlap between psychiatric and neurological disorders; exclusion of personality disorders from disease burden calculations; exclusion of self-harm and suicide from mental illness; and through combining chronic pain with musculoskeletal disorders (Vigo et al., 2016). These authors also argue that, since MHCs affect people across different life stages, diagnostic measurements must consider the clinical syndrome and the cause of the condition so that health systems can address the nature and scale of the challenges more appropriately. When accounting for these factors, estimations using published data show that the global burden of mental illness is at least 32.4% of years lived with disability (YLD) and 13% of disability-adjusted- life years (DALY) (Vigo et al., 2016).

2.2.3 Defining health

The WHO definition of health dates back to 1948 and states that health is not merely the absence of disease or infirmity but a complete state of mental, physical and social well-being. The 1986 Ottawa Charter describes health as a “resource for everyday life, not the object of living”. Over the years, there has been debate around the need to provide a more inclusive definition of health, which focuses on feeling healthy and living a healthy life, despite having a health condition (Fallon & Karlawish, 2019; Keyes, 2014; Oleribe et al., 2018; Saracci, 1997). These definitions illustrate that health is a relative concept that varies from person to person, and is influenced by individual circumstances, contexts and personal experiences. Managing multiple diseases across a lifespan, living well and participating in society means it is possible to be healthy and disabled.

The WHO definition of health has been critiqued due to a perceived bias towards the West and its orientation to the biomedical model (Misselbrook, 2014). The biomedical model does not address cultural diversity, structural inequalities, stigma and discrimination, and resource constraints. WHO is cognisant of this, and work is being done to consider different cultural perspectives of health, personal experience, social

determinants and empowerment of PWLE as experts by experience (World Health Organization, 2022b). Stigma from self and others remains a significant barrier to recovery for MHSUs in LMICs, contributing to social isolation, reduced help-seeking, and limited access to support networks and relationships (Hailemariam et al., 2019; Javed et al., 2021; Jenkins et al., 2023; Thornicroft et al., 2022). While most stigma perspectives are adapted from HICs, LMIC perspectives remain underexplored (Thornicroft et al., 2022). Self-stigma has been seen to undermine recovery as it affects identity and hope (Makanjuola et al., 2016). Social determinants, such as poverty, inequality, social exclusion, violence, education level, employment, working conditions, and available social support networks that support recovery, play a role in health, especially in LMICs (World Health Organization, 2022b). However, these social and environmental factors contribute to the mental health treatment gap. Including a recovery orientation in the WHO definition of health favours a salutogenic approach, drawing attention away from an emphasis on disease to factors that support health and well-being (Keyes, 2014; World Health Organization, 2022b).

Dominant mental health discourse has been shaped by a biomedical model which frames SMHCs primarily as a condition to be treated with medication, with the goal being the alleviation of symptoms and the improvement of individual functioning (Slade, 2009). However, the Social Model of Disability (Shakespeare, 2006) views functioning as an attribute influenced by contextual, social and cultural factors. Disability is not understood only as an impairment but the outcome of systemic barriers, including stigma, poverty and lack of access to resources that restrict full participation of MHSUs in their environments of choice (Lund et al., 2018). Reframing recovery through this lens positions it as a socially constructed, collective, rights-based and meaningful process rather than an isolated return to normal functioning (Llewellyn-Beardsley et al., 2019; Sommer et al., 2021). A recovery orientation considers the importance of social inclusion, self-determination, quality of life, engagement in purposeful activities and access to support systems that promote the rights of PWLE on their journey to a meaningful life.

2.3 The disabling impacts of SMHCs

Disability associated with SMHCs stems from the dynamic interaction between the individual's mental state impairments, activity limitations and participation restrictions, with due consideration of their personal factors and lived environments (Bickenbach, 2019; Gorostiaga et al., 2017; Sánchez, 2022; World Health Organization, 2001). SMHCs have long-term impacts on MHSUs, and interventions must be considered beyond acute hospital-based treatment. As described in Chapter One, the DSM-5 notes disability as a significant indicator of functioning in daily life and overall quality of life. The ICF provides a classification system which can be used to study morbidity

associated with MHCs (World Health Organization, 2001). Investigating personal recovery contributes to a deeper understanding of the disabling functional impacts of SMHCs.

2.3.1 Impacts on the person: Functioning in daily life

The onset of SMHC is often in young adulthood, and its persistent and fluctuating symptoms result in several functional implications at the individual level. SMHCs impact MHSUs' role functioning, workability, and relationships with others (Håkansson Eklund et al., 2019; Sánchez, 2022). Added to this, the high relapse rate for SMHCs and SUDs often causes disruptions in the person's life that impact their access to education, employment and finances and could lead to involvement in criminal activities (Baranyi et al., 2019). Furthermore, people living with SMHCs face barriers related to decreased educational achievement, marital instability, lower occupational levels, decreased financial status, stigma, discrimination, unemployment, loss of income and decreased productivity (Achoki et al., 2022; Javed et al., 2021; Kessler et al., 2009; Lund et al., 2013).

Facing stigma and discrimination from family and their community is another factor that people with SMHCs have to contend with. Several studies have highlighted how these negative perceptions can hinder an individual's willingness to seek help, exacerbate feelings of isolation, and adversely impact their recovery journey (Fekadu et al., 2019; Javed et al., 2021; Mascayano et al., 2015). MHSUs may also face stigma related to their repeated relapses and hospital admissions (Iseselo & Ambikile, 2017; Ogunnubi et al., 2017). In the field of mental health, stigma and discrimination are human rights violations; hence the Lancet Commission on ending stigma and discrimination has involved PWLE to synthesise evidence and experiences of stigma, along with co-creating stigma reduction interventions (Thorncroft et al., 2022).

2.3.2 Impacts on the caregivers

When someone in the family is diagnosed with an SMHC, the burden of care in physical, emotional, financial and social duties becomes the responsibility of their caregivers. Caregivers include, but are not limited to, blood relations and can include family, friends and other supporters (Wyder & Bland, 2014). The diagnosis has economic and societal impacts on the individual and their caregivers (Cham et al., 2022; Fekadu et al., 2019; Olagundoye et al., 2017; Silaule, Casteleijn, et al., 2024; Vera San Juan et al., 2021). A systematic review conducted in Turkey to determine the burden on caregivers of people with SMHCs highlighted that schizophrenia places the highest load on caregivers compared to other MHCs because of its early onset, chronic nature and effect on behaviour and emotions (Yildirim et al., 2017).

Caregivers often constitute an ‘invisible healthcare system’, bearing the bulk of responsibility for the long-term care of persons with SMHCs in resource-constrained settings (Yerriah et al., 2022). Unlike in HICs, where formal supports such as respite care, in-home services, and financial support for caregivers are more readily available, caregivers in LMICs frequently operate with minimal institutional support (Silaule, Casteleijn, et al., 2024). In LMIC contexts, caregiving is shaped by collectivist norms where the emphasis is not solely on individual recovery outcomes but also the preservation of family and social ties (Silaule, Casteleijn, et al., 2024). Additionally, help-seeking behaviour beyond the family unit is typically a last resort, with cultural and social expectations that the family will be the primary caregivers of people with SMHCs (Yerriah et al., 2022).

Caregiver identity transforms through the experience of SMHCs. The MHSUs become the new reference point as relationships, roles and expectations change and are reconfigured in the process of loss and finding new meaning for the family and the MHSU (Acero et al., 2017; Silaule, Adams, et al., 2024; Silaule et al., 2023). In many cases, caregivers can either motivate MHSUs to recover by providing moral and practical support, or potentially they hinder recovery when they contribute to the stress of MHSUs through stigmatising attitudes and forced hospitalisation (Aldersey et al., 2017). The understanding of SMHCs amongst caregivers is embedded in cultural beliefs, which can change over time and influence the attitudes and help-seeking behaviour of the MHSU and their caregivers (Kpanake, 2018; Subandi et al., 2021; Whitley, 2016).

2.4 Public mental health services: Structure and function

Despite the burden of mental health conditions, the global challenge is that most people with MHCs will not access the treatment they need when they need it, resulting in a treatment gap (Keynejad et al., 2021). The treatment gap is the difference between the actual prevalence rate and the proportion of people who access treatment. Besides MHSUs not accessing necessary treatment, the treatment gap also has other consequences, including abuse, discrimination, stigma, social exclusion, decreased quality of life, poor physical health and premature mortality (Patel et al., 2023). The SASH study (Herman et al., 2009) found a 75% treatment gap for common mental health conditions. When people with SMHCs are included, this estimate increases to 90% (Docrat et al., 2019).

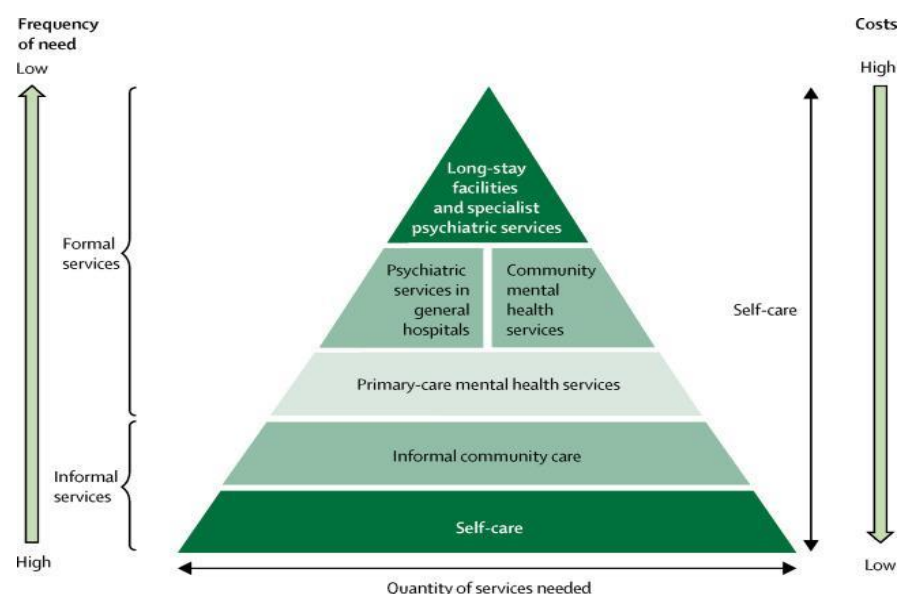
2.4.1 WHO recommendations to decrease the mental health treatment gap

To address the treatment gap, the WHO has made several recommendations regarding the best mix of services for providing high-quality public mental health care in LMICs. For example, the WHO has developed an optimal mix of services pyramid as a guiding

framework for developing mental health services across the levels of care (Figure 2.1) (World Health Organization, 2003) and a network model for community-based mental health services (World Health Organization, 2022b). Through its optimal service mix pyramid model, the WHO recommends that LMICs do the following: limit the number of specialist psychiatric hospitals; develop community mental health services; develop mental health services in general hospitals; integrate mental health services into primary health care; develop informal community mental health services (including support from religious and traditional healers); and promote self-care (World Health Organization, 2003).

Figure 2.1

WHO Pyramid for an Optimal Mix of Services for Mental Health



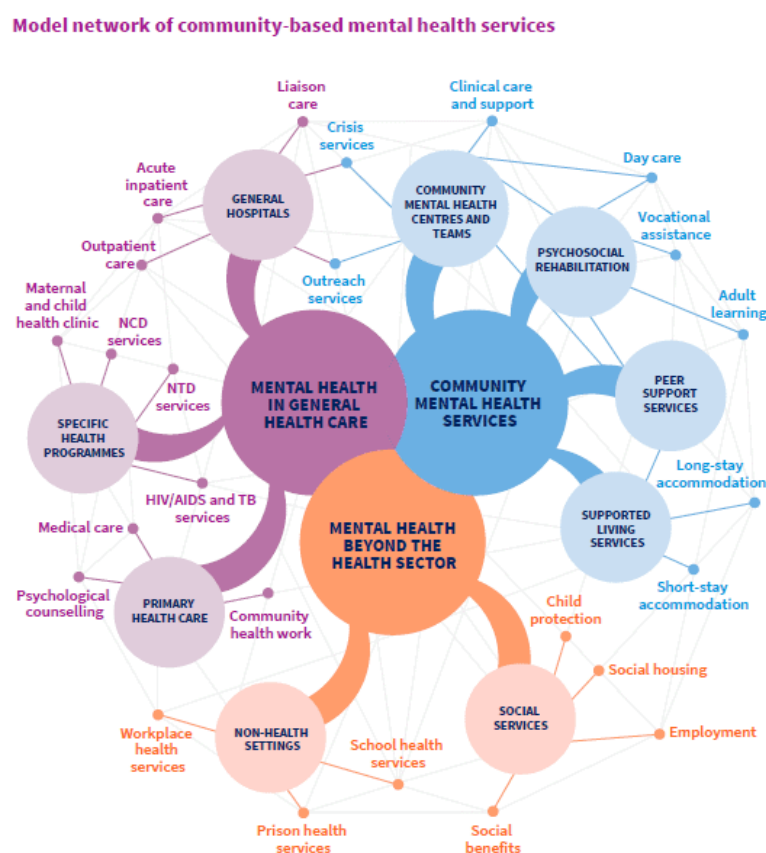
Note: Copyright: World Health Organization, 2003.

As illustrated in Figure 2.1, the least frequently needed but most costly specialised services are at the top of the pyramid, and the more widely community-based services, available at low cost, are at the bottom (Bhugra et al., 2017; World Health Organization, 2003). The bottom of the pyramid reflects mental health care that can be self-managed. In contrast, the move towards the pyramid's apex shows the network of formalised health services becoming more specialised as the severity of the MHC becomes more complex. This upward specialisation starts with integrating mental health into primary health care, developing community mental health services, providing psychiatric services at the district, regional, and general hospital levels, and finally, offering specialised mental health services (World Health Organization, 2003).

To offer direction and support for developing community-based mental health services to achieve universal mental health coverage, the WHO has taken the lead globally in transforming public health systems (World Health Organization, 2022b). WHO acknowledges that there is no single way of organising services, and countries will scale up mental health care depending on their contexts and resources. Figure 2.2 presents the WHO Model network of community-based mental health services, which offers a mix of interconnected formal services and support in recognition of the varied mental health care needs of people.

Figure 2.2

WHO Model Network of Community-Based Mental Health Services



Note: Copyright: World Health Organization (2022b).

As illustrated in Figure 2.2, the community-based mental health system has three core components: (i) mental health services that are integrated into general health care; (ii) community mental health services, and (iii) services beyond the health sector (World Health Organization, 2022b). MHUs need different types of services at various points in their recovery journeys, including critical services extending beyond the health sector, such as housing, education, employment and social development. While Figure 2.2 reflects formal services, there are also social and informal community support systems

that MHSUs access. These supportive environments include community providers such as family members, friends, volunteers, educators, faith-based leaders, PWLE supporting each other, social clubs and traditional and complementary practitioners (World Health Organization, 2022b). WHO recommends that, as formal services are being developed, governments should simultaneously invest in community-based initiatives to develop informal support systems for persons with MHCs (World Health Organization, 2022b).

Although mental health policies exist, access to treatment continues to lag globally. In 2008, the WHO launched the Mental Health Gap Action Plan (mhGAP) to address the gap between health needs and access to services, especially in LMICs (World Health Organization, 2023). The mhGAP programme targets non-specialist health care providers and primary and community health facilities aiming to scale up services for MNS disorders through its five key objectives: advocating for mental health as part of global public health; enhancing health service providers' capacity; integrating mental health into primary health care; promoting human rights of persons with MHCs; and monitoring and evaluating the impact of interventions (World Health Organization, 2023).

While the WHO's optimal service mix and the mhGAP framework provide important guidance on strengthening mental health systems, their direct applicability to people with SMHCs is limited (Keynejad et al., 2021). Much of mhGAP's focus is on clinical management, with little emphasis on long-term psychosocial rehabilitation and recovery needs. This gap highlights the misalignment between global policy frameworks and the complex recovery needs of MHSUs with SMHCs in low-resource settings where context-specific service models are needed to address the social determinants of health, promote social inclusion and involve MHSUs in their own care planning (Keynejad et al., 2021; World Health Organization, 2023).

More needs to be learnt about how non-specialist primary care workers provide mental health care. A systematic review conducted by Keynejad et al. (2018) synthesised data on how the mhGAP and the mhGAP-Intervention Guide (mhGAP-IG) are used by health ministries, NPOs, and academics to support mental health scale-up and clinical decision-making in 90 LMICs. This review included 33 peer-reviewed studies (Keynejad et al., 2018) and was later updated to include another 162 studies (Keynejad et al., 2021). They concluded that stakeholders have taken up the mhGAP; however, the implementation is either not evaluated, or it is not being disseminated so that others can benefit from the emerging lessons (Keynejad et al., 2021).

Research on integrated care packages is still developing, although community-based rehabilitation is recommended as a practical approach for LMIC settings (Patel et al., 2016). While policies exist to promote the scaling up of services, generating evidence to

support the scaling up of integrated care packages is needed (Lund et al., 2012; Petersen et al., 2019; Rathod et al., 2017). The Programme for Improving Mental Health Care (PRIME) aimed to generate evidence on the implementation and scaling up of integrated care packages for four priority MNS disorders (depression, alcohol use disorder, psychosis and epilepsy) in one district per LMIC country (Ethiopia, India, Nepal, South Africa and Uganda) (Baron et al., 2018; Lund, Tomlinson et al., 2012). These PRIME studies aimed to assess the impact of implementing district-level mental health care plans on the severity of symptoms and disability in adults diagnosed with one of the priority MNS disorders and assess productivity, stigma, health equity, health outcomes per gender, and socioeconomic status (Baron et al., 2018).

The PRIME South Africa study (Petersen et al., 2016) demonstrated that psychosocial rehabilitation was integral to the collaborative care plans for common and severe mental health conditions at district levels of care. While PRIME focused on the integration of services with measurable clinical outcomes, this South African study extended the work, exploring psychosocial rehabilitation as a context-specific process shaped by structural and relational factors (Petersen et al., 2016).

Countries participating in PRIME were included in the updated review by Keynejad et al. (2021). In Nepal, recovery narratives have been adopted to support PRIME by amplifying lived experience and creating opportunities for interaction between MHSUs and stakeholders to reduce stigma among service providers (Kaiser et al., 2019).

For the WHO service mix to be implemented in South Africa, the model requires the involvement of different stakeholders to co-create knowledge on service offerings and implementation strategies. Despite South African legislation and policies, such as the MHCA, the National Rehabilitation Policy, and the National Mental Health Policy and Strategic Framework, inequality and inadequate policy implementation persist (Botha, Koen, Joska, Parker, et al., 2010; Lund, Kleintjes, et al., 2010; Lund, Oosthuizen, et al., 2010). While legislation exists to protect the human rights of MHSUs, this needs to translate into implementation, as was highlighted in the Life Esidimeni tragedy (Freeman, 2018).

2.4.2 The South African public mental health system

South Africa's socio-political history shaped the health system, resulting in disparities in accessing health care (Kleintjes & Schneider, 2023). While there are public and private models of health care, 80% of the population depends on public health services (Statistics South Africa, 2022). The WHO's optimal service mix pyramid offers a useful framework for considering mental health care and addressing the treatment gap in the country (Sorsdahl et al., 2023). In South Africa, most resources and finances are allocated to specialist tertiary and secondary hospitals concentrated at the top of the pyramid, with fewer resources at the base (Sorsdahl et al., 2023). A national survey

conducted in 2017 reported that 86% of the mental health expenditure was allocated to inpatient services, while the remaining budget was allocated to outpatient services (Docrat et al., 2019).

2.4.2.1 Specialist mental health services

In the current system, MHSUs with SMHCs access psychiatric hospitals as revolving door, high-frequency users who use the inpatient and out-patient services (Eaton et al., 2011; Gerber, 2018). While specialist hospitals are often stigmatised and geographically inaccessible to many South Africans, 45% of the total mental health is spent at this level of care (Docrat et al., 2019).

Mental health acute admissions in specialist hospitals are short, with an average length of stay of 46 days (Western Cape Government Health, 2023); and these are focused on clinical recovery through psychotropic medication and alleviating acute symptoms. The Western Cape has four specialist mental health hospitals: Valkenberg, Lentegeur, Stikland and Alexandra. Alexandra Hospital services persons with intellectual disabilities, while Stikland, Lentegeur and Valkenberg serve persons with MHCs. Lentegeur and Valkenberg hospitals also render forensic services. Stikland Hospital has 423 beds, Lentegeur Hospital has 690 beds, and Valkenberg Hospital has 391 beds (Western Cape Government Health, 2023).

A summary of diagnostic trends across these three psychiatric hospitals from January 2015 to April 2023 reports that males accounted for 63.8% of hospital admissions. Table 2.1 provides a breakdown of diagnostic categories of hospital admissions across the three hospitals.

Table 2.1

Diagnostic Trends across the Three Psychiatric Hospitals in The Western Cape

Diagnosis	Male N (%)	Female N (%)
Schizophrenia	5178 (57.5)	2307 (41.5)
Substance-related	2021 (22.5)	754 (13.6)
Mood disorders	1359 (15.1)	1838 (33.1)
Other	446 (5.0)	657 (11.8)

Note: Copyright: Western Cape Government Health, 2023.

The Western Cape continues to experience a demand for acute mental health hospital admissions and human resources to cope with the need for admissions. Consequently, the pressure for acute admissions negatively affects the availability of more prolonged admissions for therapeutic care (Jeranji, 2021; Thebus, 2022). The structure of hospital-based services is focused on providing services to the individual in the hospital, not the

context or society they come from or return to, and current community-based services do not meet the 2.5 needs of MHSUs.

In the Western Cape, the increase in substance-induced psychosis has increased the demand for admissions at the designated psychiatric hospitals in the province (Jeranji, 2021; Thebus, 2022). While other regions report cannabis as its predominant substance of use, it consistently comes second in the Western Cape where methamphetamine is the highest driver of psychiatric and substance use treatment demand (Pasche & Myers, 2012; SACENDU, 2024). Despite the high prevalence of substance use amongst persons with SMHCs, across the provinces, there is a scarcity of treatment programmes that service users can access to treat their dual diagnosis (Drake et al., 2007; Schulte et al., 2011), including in the Western Cape (Weich & Pienaar, 2009).

2.4.2.2 Transitional care facilities in specialist mental health services

To mitigate readmissions precipitated by MHSUs being discharged prematurely and to reduce pressure on psychiatric inpatient units, transitional care facilities were launched in the WCP by the National Department of Health in 2008 (Botha et al., 2020). These transitional care facilities based at the tertiary hospitals are used as step-down (transfer from inpatient unit) or step-up (admission from primary health care) facilities (Vava et al., 2022). The transitional care unit offers MHSUs opportunities to participate voluntarily in a structured PSR programme running over eight weeks, while giving them time to recover in a hospital setting (Vava et al., 2022). The programme includes exercise groups, daily chores to foster independent living, life skills groups, creative craft projects, and psychoeducation on mental health conditions, medication use, and substance abuse (Botha et al., 2020). Transitional care units offer MHSUs and their caregivers some respite while focusing mainly on promoting a stable mental state, but it does not adequately prepare MHSUs to be reintegrated back into their communities (Gamieldien, Galvaan, & Duncan, 2021).

2.4.2.3 Hospital-based intervention initiatives

There is growing interest in the challenges faced in implementing PSR interventions in historically biomedical hospital-based services (Lorien et al., 2020). At Valkenberg Psychiatric Hospital in Cape Town, a multidisciplinary team with a recovery vision was started in 2009. It is called the Early Intervention, Support and Help (EISH) Team (Rodwell, 2018). This team considers recovery in terms of relationships, developing a sense of meaning, and involving the MHSU, their family, friends, community and occupational systems. The EISH team receives referrals from the acute admissions teams or district hospitals, and they focus on the individual and family of newly diagnosed MHSUs with a psychotic disorder in the age group 18–35 years. The service offers transport for MHSUs and their family members to attend the psychiatric hospital

out-patients department once a week. The EISH programme includes psychoeducation and support to the family, occupational therapy groups for MHSUs, social work interviews, medication review and medication collection (Rodwell, 2018). To date, the EISH service has not been formally evaluated.

The Spring Foundation (SF) is a recovery-focused approach to institution-based public mental health services in South Africa. The SF offers MHSUs initiatives to support their recovery. The project was founded at Lentegeur Hospital in 2012 by a psychiatrist (De Wet et al., 2019). One of the projects is a market garden where MHSUs learn gardening and work skills by providing organic vegetables for sale to the community. Another project is the identity document drive, where MHSUs are assisted in getting an identity document. Identity documents are needed for social grant applications. The SF has also embarked on an anti-stigma T-shirt project where thought-provoking slogans connected to living with SMHCs are sold to the public as part of the SF's fundraising campaign. While there are plans to expand the SF's work with additional projects, it has yet to be determined if the current projects contribute to the recovery of MHSUs.

2.4.2.4 Hospital-initiated assertive community outreach

While district mental teams are still being developed, there has been a focus on extending psychiatric hospital outreach and support to MHSUs at risk of relapse. According to Botha, Koen, Joska, Hering, et al. (2010), there has been a worldwide focus on using assertive community-based interventions to counter the effects of deinstitutionalisation and decrease the revolving door phenomenon. However, the evidence for the efficacy of this model needs to be more consistent (Botha et al., 2014; Dixon et al., 2010; Kerlinger et al., 2021; Salyers et al., 2010). The Assertive Community Treatment (ACT) teams based at Western Cape psychiatric hospitals provide a specialist outreach service to MHSUs considered to be high-frequency service users (Botha, Koen, Joska, Hering, et al., 2010; Lund, Oosthuizen, et al., 2010). Through home visits, ACT teams support MHSUs in the community to decrease relapse and readmission rates. ACT teams mainly focus on medication adherence, as poor adherence has been found to precipitate relapse (Lund, Oosthuizen, et al., 2010). The multidisciplinary team comprises a psychiatrist, social worker, medical officer, psychiatric nurse, and sometimes an occupational therapist. A randomised control trial on assertive interventions in South Africa suggests that ACT teams decrease readmission rates due to its location as an additional resource in community mental health services and through the adherence support offered by the team through home visits (Botha et al., 2014). Although resource-intensive and unsuitable for all MHSUs, it may be the best option for MHSUs living in communities that are at high risk of relapse (Petersen, Lund, et al., 2011). The team is, however, seen as a psychiatric hospital outreach and offers no support to district or primary levels of care.

2.4.2.5 District and community mental health services

MHSUs are referred to tertiary hospitals from district hospitals when they cannot be managed at the district or primary health care level, often due to the severity of the mental illness and the need for more specialised care, treatment and rehabilitation. As legislated by the MHCA 17 of 2002 (National Department of Health, 2002), district hospitals provide 72-hour admission and observation of mental healthcare users. They are often the first contact for MHSUs accessing hospital services. The district hospital receives 11.7% of the mental health care budget (Docrat et al., 2019). There are few mental health rehabilitation professionals on district health teams as these health care workers are still based at tertiary hospitals, thus the staff composition of district mental health teams does not reflect the comprehensive health perspective. National Treasury is trying to address this through a grant for provinces to contract mental health practitioners to complement current staff rendering mental health services at the primary healthcare level (National Department of Health, 2023). However, this is being implemented at different paces.

While the Western Cape is well-resourced in terms of hospital infrastructure, community-based service packages still need to be developed (Lund, Oosthuizen, et al., 2010; National Department of Health, 2023; Sorsdahl et al., 2023). MHSUs have limited access to rehabilitation services while in hospital; and, once discharged, there are no personnel to offer community integration support. One of the mechanisms to strengthen the district mental health system is introducing specialist mental health teams to support non-specialist staff in the primary care sector (National Department of Health, 2023). Including rehabilitation therapists like occupational therapists on these teams is not prescribed in South Africa, despite the disability issues resulting from the country's quadruple disease burden (Ned et al., 2020).

The health sector plays a vital role in addressing human rights issues and social injustice and, as such, must be adequately staffed with a competent workforce committed to achieving equitable health outcomes (Ned et al., 2020). In addition, the National Mental Health Policy and Strategic Framework (National Department of Health, 2023) takes its lead from the WHO Mental Health Report (World Health Organization, 2022b) and recommends that medication monitoring and access to psychosocial rehabilitation occur within a recovery framework for SMHCs. However, the policy must outline the human resources necessary to render this service or indicate what the service should offer and at which level of care. Kelly et al. (2010) state that occupational therapists can be valuable contributors in assisting mental health services at the PHC level to reorganise the content of their programmes so that the links between recovery, mental health and occupations can be developed. Thus, the

omission of occupational therapists as part of district mental health teams could slow the development of community-based rehabilitation services for mental health.

The National Mental Health Policy and Strategic Framework recommend strengthening the district mental health teams by adopting a task-shifting approach that would allow trained non-specialist workers to deliver psychosocial interventions to persons with MHCs (National Department of Health, 2023). Task shifting involves delivering mental health care by community workers or non-specialist health workers trained and supervised by specialist mental health care providers who train and supervise the management of less complex cases of MHCs (Galvin & Byansi, 2020; National Department of Health, 2023; Petersen, Lund, et al., 2011; Spedding et al., 2014; Stein et al., 2022). Task shifting addresses the shortage of specialist health professionals by improving access to health services for a more significant part of the population through midlevel workers. Mid-level workers are not currently part of the district health teams.

The limited resources and staff capacity to render mental health services at primary levels of care, coupled with inadequate screening and detection of mental disorders, means high-frequency service users with SMHCs and comorbid SUDs access specialist mental health services by bypassing lower levels of health care (Lund, Oosthuizen, et al., 2010). One of the ways to optimise access to community-based rehabilitation is by implementing stepped packages of care for those MHSUs that non-specialists can manage. This will require task shifting and frameworks that embrace social inclusion and community collaboration across sectors (Petersen, Lund, et al., 2011; Van Rensburg & Brooke-Sumner, 2023). Service providers who understand their role as facilitators of recovery and community integration can be included as recovery guides in the mid-level category of workers (Davidson et al., 2008).

2.4.2.6 Primary level of healthcare

The primary level of health includes primary healthcare (PHC) and community-based services. At the PHC service level, the focus is on the detection, diagnosis and treatment of CMHCs, with complicated cases being referred to more appropriate levels of care. CMHCs can be managed through self-care, informal community care or primary care. For SMHCs, PHC services are focused on the availability of psychotropic medication and medication adherence, and services do not extend to community-based support beyond the biomedical model for persons with SMHCs.

While PHC is a means to provide care to the scale of need, stigma and staff attitudes are barriers to integration. MHSUs report that, due to the lack of psychosocial support, they find the PHC clinic impersonal, unfamiliar, unstable and devoid of the long-term relational support they receive at the OPD clinic attached to the specialist hospitals or

via a dedicated mental health nurse (Gamieldien, 2015; Gamieldien, Galvaan, & Duncan, 2021). Despite the WHO pyramid advocating for the integration of mental health into primary levels of care, the under-resourced mental health care systems in LMICs negatively impact pathways to care, treatment delays and service utilisation patterns (Lund, Oosthuizen, et al., 2010; Sorsdahl et al., 2023). Current community-based services in South Africa fall short of meeting the psychosocial rehabilitation and recovery needs of MHSUs (Petersen et al., 2016; National Department of Health, 2023). Despite national policy commitments to embed psychosocial rehabilitation into community-based services (National Department of Health, 2023), the disconnect between policy intention and implementation contributes to the unmet recovery needs of MHSUs in South Africa (Kleintjes et al., 2023).

At the primary health care level, MHSUs do not access the most appropriate services or expertise due to the inadequate human and financial resources allocated to this level of care, despite legislation through the MHCA mandating the availability and accessibility of community-based mental health services (Lund, Oosthuizen, et al., 2010; National Department of Health, 2023). MHSUs' views contradict the drive to integrate mental health into general health care. They highlight the need for scaling up services that include resources for recovery-oriented care in LMICs.

2.4.2.7 MH-NPOs in the Western Cape

MH-NPOs have a long history in South Africa. Many MH-NPOs started out being resourced by families who had children with intellectual disabilities and SMHCs who could not live in an institution or the family home (Open Circle, 2024). This is how many group homes, supported housing projects, and MH-NPOs started. Cape Mental Health (CMH) and Comcare Trust are two MH-NPOs that provide services, including supported housing, for persons with psychosocial disabilities in the Western Cape. These MH-NPOs are funded by the Departments of Health and Social Development and their referrals come primarily from psychiatric hospitals. Currently, the number of MH-NPO services does not meet these needs (Cape Mental Health, 2023; Kleintjes et al., 2013; Lund et al., 2010).

CMH was founded in 1913 and is the oldest mental health organisation in South Africa (Cape Mental Health, 2023). CMH provides counselling, support, rehabilitation, and reintegration services to MHSUs with SMHCs. CMH has a community-based rehabilitation centre called Fountain House (FH), where MHSUs can benefit from a work-ordered day programme in the suburbs of Observatory and Mitchells Plain. The FH programme is an international clubhouse model that has existed for approximately seventy years (McKay et al., 2018; Raeburn et al., 2013). FH aims to give MHSUs reintegration opportunities to begin their recovery journeys, find meaning in their lives, and contribute to their and their family's social and economic well-being (Cape Mental

Health, 2023). CMH also has 26 psychosocial support groups for MHSUs across greater Cape Town. Groups meet weekly in community facilities such as libraries, halls and clinics, and their activities are focused on developing life skills in the areas of living, learning, working and socialising. The groups also provide psychoeducation and support to MHSUs and their families. Kimber House (KH) is the supported accommodation programme offered by CMH. KH offers affordable, safe, and supportive shared accommodation to eleven MHSUs. The programme provides support and individual case management for each member to set goals, develop life skills and access vocational training opportunities (Cape Mental Health, 2023).

Another Western Cape-based MH-NPO to which MHSUs are referred at different stages of their recovery journeys is Comcare Trust which has provided stable and affordable supported accommodation for MHSUs in suburbs across Cape Town for over fifteen years (Comcare Trust, 2023). Comcare accommodates 60 adults with SMHCs in seven group homes and one block of flats. Residents are aided by residential care workers who visit the house daily and, if needed, help in home management and conflict resolution. In addition, residents are encouraged to leave their homes during the day to attend FH or another Comcare project called The Welcome Club. The Welcome Club is located on the premises of Valkenberg Hospital, and it operates on weekday mornings. The Welcome Club offers members a space to give and receive support and engage in creative activities (Ramafikeng et al., 2020). The Welcome Club is open to Comcare residents, non-residents, and MHSUs attending Valkenberg Hospital as inpatients and outpatients (Comcare Trust, 2023).

These MH-NPOs promote recovery and follow a PSR approach. However, PSR has been critiqued as focusing on rehabilitation from service provider perspectives and not driven by PWLE. Further, the MH-NPO interventions are individual-based and not population-based. The contextual barriers which limit the amount of choice MHSUs have when they want to reintegrate into their communities of choice, especially in a country such as South Africa, are not reflected in current mental health services.

2.5 Recovery: A philosophy for public mental health services

2.5.1 Defining recovery: The essential elements

The recovery model was introduced in the USA and UK in the 1990s, but it had a shaky start due to debates on whether or not health professionals should be involved (Chamberlin, 2007). Since Anthony's seminal work in 1993, there have been different definitions of recovery, all aimed at understanding recovery from SMHCs beyond the medical model. The recovery model started with the mental health consumer and survivor movement when mental illness was highly stigmatised (Deegan, 1988). The idea that persons with SMHCs cannot recover was challenged by persons with

schizophrenia who were leading meaningful lives in their communities after deinstitutionalisation, highlighting that recovery was not dependent on long-term medical and inpatient treatment (Farkas, 2007; Webb, 2012).

However, the debate continued amongst MHSUs, service providers and stakeholders on the concept of recovery from SMHCs. While the medical definition of recovery considers symptom remission as the primary marker of recovery, personal recovery includes the person with an SMHC developing new meaning and purpose in their life over the longitudinal course of their illness (Slade, 2009; Tew et al., 2012). Slade (2009) differentiates between clinical and personal recovery. While clinical recovery focuses on alleviating symptoms, personal recovery is a cyclical, non-linear, unique, lifelong process. Clinical recovery is viewed as a subset of personal recovery, which is profession-led and invariant across service users. On the other hand, personal recovery refers to a service user-based understanding of recovery that looks beyond clinical recovery to what constitutes building a meaningful life (Slade, 2009). This view acknowledges that, while MHSUs may live with distressing symptoms, they can reclaim their lives by developing a positive sense of self and taking up valued social roles.

Recovery is viewed as personal change and social engagement, which can be promoted through the collaborative efforts of individuals, their caregivers, service providers, and society. Re-engagement with life in a personally meaningful way is a cyclical, ongoing, idiosyncratic journey for MHSUs, which includes dimensions of hope, knowledge, empowerment and life satisfaction (Bird et al., 2014; Farkas, 2007; Slade & Longden, 2015). Davidson et al. (2010) propose that we delink recovery as a process from recovery as an optimal clinical outcome. They reflect that the only outcome for humans is eventual death; therefore, being in recovery means being in active pursuit of a meaningful life while coping with the vicissitudes of everyday life (Davidson et al., 2010). In a systematic review conducted by Tew et al. (2012), the social factors that promote or impede recovery include overcoming stigma and discrimination and developing connections through social inclusion, social capital, responsibility, friendships, coping skills and autonomy. According to Farkas (2007), recovery-oriented services aim to keep persons with SMHCs out of the hospital and support them in living socially connected, meaningful and productive lives in their communities of choice.

Recovery is influenced by the individual's experience relative to social, cultural and relational aspects, including connectedness with friends, family, service providers and others (Leamy et al., 2011). Recovery-focused interventions that build social networks, such as supported employment, supported housing, family support and psychoeducation, often have a family component (Aldersey & Whitley, 2015). In an empirical review of mental health and recovery evidence, Slade and Longden (2015) challenge the discourses on mental health research and practice. They contest the discourses on the disabling limitations of having an SMHC, and they advocate for a view

focused on living well, despite mental health problems. To achieve this, they recommend increasing evidence from the subjective experiences of MHSUs, their families, informal supporters and mental health workers (Slade & Longden, 2015; Whitley, 2014).

Much discussion in the literature relates to finding a structure to describe the complexity of the recovery process, illustrating the systemic and personal features of recovery. In the conceptualisation of recovery in HICs, Farkas (2007) suggested recovery subscribes to four fundamental values: person orientation; involvement; choice or self-determination; and hope or growth potential. Slade (2009) refers to four critical domains of recovery: hope, identity, meaning, and personal responsibility. Little is known about whether these values and domains apply to PWLE from LMICs. However, service providers, caregivers and MHSUs in HICs and, more recently, LMICs, have shown interest in understanding the recovery process.

2.5.2 Framing recovery

Psychiatric rehabilitation has highlighted the need to move beyond treating symptoms of the illness to treating its functional and disabling consequences (Anthony, 1993). In Anthony's definition, recovery is focused on the individual affected by the mental illness and does not include the caregivers or context that makes this ideal possible. As a mental health professional with schizophrenia, Deegan says that MHSUs do not "get rehabilitated" by others. Instead, they actively participate in their journey to recover new and valued personal meaning and purpose (1988, p. 1). Recovery then is multidimensional and connected to MHSUs' circumstances and experience of their mental health.

While Anthony is widely credited with formalising the concept of personal recovery in the 1990s, several frameworks have been developed to describe personal recovery for persons living with SMHCs. These frameworks emphasise recovery as a personalised, strengths-based process rather than merely the absence of symptoms. For example, for Anthony (2004), personhood is the overarching guiding principle from which all other recovery principles emanate. Anthony's recovery model emphasises the individuals' strengths as they take control of their non-linear journey (Anthony, 1993, 2004). The Tidal model, on the other hand, focuses on the fluid nature of recovery and the importance of peer support and relational networks to empower MHSUs to take charge of their own lives (Barker, 2001). The Substance Abuse and Mental Health Services Administration (SAMHSA) also offers a foundational framework which reflects ten widely endorsed components of recovery: (i) self-direction; (ii) individualised and person-centred services; (iii) empowerment; (iv) holistic; (v) non-linear; (vi) strength-based; (vii) peer support; (viii) respect; (ix) responsibility; and (x) hope (2006). Slade is known for advocating for a personal recovery approach distinguishing between clinical

and personal recovery (Slade, 2009). The REFOCUS model (Slade et al., 2015) builds on staff training and collaboration with MHSUs to promote recovery-oriented practices that emphasise hope and personal responsibility. Clinical and personal recovery goals are blended in the Integrated Recovery-oriented Model to address symptom management and personal growth (Frost et al., 2017). A summary of some of the Recovery Models featured in the literature is provided in Table 2.2.

Table 2.2

Recovery Frameworks

Model/ Framework	Anthony's Recovery Model (1993)	Tidal Model (2001)	SAMHSA's Ten Components (2006)	Slade's Personal Recovery Framework (2009)	CHIME Framework (2011)	REFOCUS Model (2015)	Integrated Recovery Model (2017)
Focus	Person-centred holistic recovery	Lived, experienced, fluidity, empowerment	Empowerment, hope, peer support	Subjective, individualised recovery goals	Social and personal processes influencing recovery	Recovery-oriented collaborative practice	Combines clinical and personal recovery
Core components	Hope, self-direction, individualised	Fluid experience of illness, empowerment, peer support	Self-direction, person-centred, holistic, strength-based	Hope, identity, meaning, personal responsibility	Connectedness, hope, identity, meaning, empowerment	Hope, self-management, personal responsibility	Self-agency, advocacy
Approach	Strength-based, non-linear, person-centred	Focus on life stories and personal narrative	Ten structured components that define recovery-oriented practice	Emphasis on personal definitions of recovery	Narrative-driven focus on recovery process	Structured practice framework for staff	Balances clinical care with personal recovery goals
Measurement	Qualitative, based on lived experience	Qualitative, based on narratives	No specific measurement tool, but provides guiding principles	Subjective, no specific measurement	Qualitative, based on lived experience	Process-oriented, no specific measurement	Balances clinical and personal outcomes
Key principles	Self-directed, recovery is possible for everyone	Empowering individuals through lived experience	Person-centred, empowerment, respect and hope	Personal recovery distinct from clinical recovery	Connectedness and identity central to recovery	Staff collaboration with service users in recovery	Balancing personal growth with clinical support

Each of the frameworks reflected in Table 2.2 tries to bring a distinct contribution to understanding recovery but overlap exists. Leamy and colleagues developed the widely endorsed CHIME framework. CHIME resulted from a systematic review and narrative synthesis of the concept of recovery from mental illness in 13 HICs (Leamy et al., 2011). Ninety-seven papers were included in the review. The CHIME model consists of five domains which organise the dimensions of recovery. These domains are Connectedness, Hope and optimism about the future, Identity, Meaning in life and Empowerment (Leamy et al., 2011).

While the five CHIME domains encapsulate the recovery experience, it has been critiqued for focusing more on personal success and positive aspects of recovery in the individual and not representing the difficulties and struggles involved in recovery (Onken et al., 2007; Stuart et al., 2017). Leamy et al. (2011) acknowledge the limitations of recovery models conceptualised in HICs and their applicability in settings with varied populations, where recovery is socially mediated and influenced by context. More research with culturally diverse groups is needed because culture-specific factors and collectivist (family and community) notions of recovery help and hinder recovery. Additionally, family and community involvement, spirituality, and stigma all influence recovery differently in diverse contexts (Brijnath, 2015; Leamy et al., 2011; Van Weeghel et al., 2019). There is a need to understand better how contextual barriers and resource access influence recovery and disability in LMICs (Leamy et al., 2011; Slade, 2021; Vogel et al., 2020; Shakespeare, 2006).

2.6 Measuring recovery to generate evidence for strengthening mental health services

2.6.1 How is recovery measured?

Finding ways to measure recovery outcomes, given the different dimensions and definitions of recovery, has proven to be a global challenge. Although recovery-oriented services are recognised as necessary for strengthening mental health services, how services outcomes are measured is still developing (Anthony, 1993; Davidson et al., 2021; Slade, 2002; Slade et al., 2021). Despite the growing interest in understanding recovery outcomes, measuring an inconsistently defined concept is problematic. There are no universally accepted guidelines to operationalise the concept of recovery and no gold standard measure of recovery (Burgess et al., 2011; Corrigan et al., 2004; Shanks et al., 2013).

To ensure the uptake of a measure, it should be feasible in terms of brevity, simplicity, relevance, availability, acceptability and value (Slade, 2009). There has been a reluctance to reduce recovery to an outcome because it is a non-linear, unique,

personal journey (Davidson et al., 2010; Shanks et al., 2013). There are suggestions that, for recovery processes to be understood, it is necessary to use frameworks that can guide conceptual clarity, while also evaluating the psychometric properties of available recovery measures (Shanks et al., 2013). Given that recovery occurs across the lifespan, PWLE critique conventional clinical measures for being too impairment-focused through their emphasis on clinical recovery (symptom reduction, medication adherence and hospital admissions). MHSUs indicate that there is not enough focus on choice and autonomy in leading a meaningful life despite ongoing symptoms (Slade, 2009; Slade & Longden, 2015). To validate a recovery measure, it should reflect the personal goals of the PWLE while also being compared to objective measures such as peer support, participation, community integration, employment, and functional capacity (Andresen et al., 2010).

Over the years, interest in developing instruments to measure recovery has grown. A compendium of recovery measures was compiled by Campbell-Orde et al. (2005); and several recovery measures have been included in several reviews (Burgess et al., 2010; Cavelti et al., 2012; Scheyett et al., 2013; Shanks et al., 2013; Shillington et al., 2014; Sklar et al., 2013; Williams et al., 2012). These reviews sought to identify the instruments which assess recovery dimensions, including hope and optimism, self-determination, resilience, positive identity, meaning and finding life purpose. Some of the recovery measures featured in the reviews are included in Table 2.3. These measures assess personal recovery from MHSUs' perspectives and do not measure the recovery orientation of the mental health services. Although such measures exist, they were not the focus of this study.

Table 2.3

Recovery Measures

Instrument	Citation	Country developed	Description
Illness Management and Recovery Scales (IMR)	Mueser et al. (2006)	United States	15 items covering personal goals, mental illness knowledge, involvement of significant others, functional impairment, medication and use of substances
Mental Health Recovery Measure (MHRM)	Young and Bullock (2003)	United States	30 items covering domains related to empowerment, strengths, responsibility and hope
Mental Health Recovery Star (MHRS)	MacKeith et al. (2010)	United Kingdom	10 items covering mental and general health management, self-care, living skills, addictive behaviour, and social networks
Psychosis Recovery Inventory	Chen et al. (2005)	Hong Kong	25 items covering attitude to illness and treatment; and perceptions of recovery and relapse
Recovery Assessment Scale	Corrigan et al. (2004); Giffort et al. (1995)	United States	41-items (reduced to 24 after factor analysis) covering personal confidence, willingness to ask for help, goal and success orientation, reliance on others, and not dominated by symptoms
Recovery Process Inventory (RPI)	Jerrell et al. (2006)	United States	22 items covering factors related to anguish, connectedness, confidence and purpose, and care for self
Stages of Recovery Instrument (STORI)	Andresen et al. (2006)	Australia	50 item scale related to the five stages of recovery
Self-Identified Stages of Recovery	Andresen (2007)	Australia	Two subscales measuring recovery stages and recovery processes

In Sklar et al.'s (2013) review of 13 scales and inventories to measure recovery, the 41-item RAS was considered the most psychometrically robust instrument, but it took the longest to complete. Corrigan et al. (2004) examined the factor structure of the RAS and found it to have sound psychometric and conceptual features, with a 24-item RAS being sufficient to assess recovery. An instrument to measure the recovery of MHSUs in the South African context has been identified as a gap, however, so ongoing research in this area is needed (De Wet et al., 2019).

2.6.2 The Recovery Assessment Scale (RAS)

Without a gold standard, the Recovery Assessment Scale (RAS) is cited as the most frequently used, widely published and psychometrically tested measure across several studies (Salzer & Brusilovskiy, 2014). The RAS was developed in 1995 by Giffort and colleagues (Corrigan et al., 1999; Giffort et al., 1995) and is still the most frequently used outcome measure for consumer-rated recovery evaluations. The RAS is a 41-item 5-point Likert scale instrument, later shortened to 24 items after factor analysis (Corrigan et al., 2004). The RAS covers five domains: Personal confidence and hope (PCH), Willingness to ask for help (WAH), Goal and success orientation (GSO), Reliance on others (ROO), and No domination of symptoms (NDO). Although the RAS was developed in the United States, it was tested with adults from diverse ethnic and racial backgrounds (Campbell-Orde et al., 2005). Different iterations of the RAS have been used in other countries since its emergence in the 1990s.

Given the critique that the 41-item RAS was time-consuming to administer, research has gone into developing shortened versions of the RAS while still maintaining the psychometric properties of the original. In a study to examine the factor structure of the RAS, Corrigan et al. (2004) found that the five factors correspond to many recovery processes, such as empowerment, confidence, self-determination, self-management and reaching out for help. In their study, the exploratory factor analysis (EFA) and the confirmatory factor analysis (CFA) yielded items that incorporated 24 of the 41 RAS items, suggesting that there might be additional factors involved in the process of recovery that were not found in this study; conversely, the results could mean that the 24-item RAS is sufficient to assess recovery (Corrigan et al., 2004). From the literature, it is reported that the RAS consistently upheld its psychometric properties, and the shortened versions were simultaneously time and cost-effective (Salzer & Brusilovskiy, 2014).

The literature review on the psychometric properties of the RAS conducted by Salzer and Brusilovskiy (2014) included 77 studies from 11 countries: United States, Australia, United Kingdom, Japan, Canada, Portugal, Spain, Israel, Sweden, Switzerland, and Taiwan. No LMICs were included in their review. In the included countries, use of the RAS was found to be feasible because of its brevity, simplicity, relevance, availability,

acceptability and value. The RAS was found to have test-retest reliability, inter-rater reliability, and internal consistency. Regarding concurrent validity, the RAS was inversely associated with psychiatric symptoms and positively associated with constructs such as quality of life and empowerment (Corrigan et al., 2004; Salzer & Brusilovskiy, 2014). Salzer and Brusilovskiy (2014) conclude that there is evidence to support the construct validity of the RAS. The RAS is sensitive to change in intervention research over time, and the shorter versions of the RAS (RAS-20 and RAS-24) demonstrate solid and consistent psychometric properties. In addition, the RAS has also been used to measure recovery with youth abusing substances, and it had good psychometric properties in this population as well (Douglas et al., 2015).

The psychometric properties of the RAS have been studied in other countries. Table 2.4 presents the fit indices for adaptations of the 24-item RAS in seven countries: Spain (Saavedra Macías et al., 2021), Norway (Biringer & Tjøflåt, 2018), Argentina (Zalazar et al., 2017), Germany (Cavelti et al., 2017), Portugal, Japan (Chiba et al., 2010), and Australia (McNaught et al., 2007).

Table 2.4

Fit Indices of Validation Studies of the RAS

	Saavedra Macias et al., 2021 Spain	Biringer and Tjøflåt, 2018 Norway	Cavelti et al., 2017 Germany	Zalazar et al., 2017 Argentina	Jorge- Monteiro et al., 2015 Portugal	Chiba et al., 2010 Japan	McNaught et al., 2007 Australia	Corrigan, 2004
<i>N</i>	305	231	156	337	213	209	168	1824
Items	24		14	21	22	24	24	24
Number of factors	5	5	5	5	4		5	5
Cronbach's Alpha	F1 .85	.83	.79	.75	.88		>.70	.87
	F2 .87	.85	.65	.82	.77			.84
	F3 .82	.77	.88	.88	.75			.82
	F4 .67	.65	.60	.66	.78			.74
	F5 .74	.76	.60	.76				.74
Total	Total .93	.90		.88	.90	.89		

According to Cavelti et al. (2017), there is a slight variation in recovery conceptualisations and factor structures between countries. However, given that the RAS is the most widely cited and psychometrically tested measure of recovery globally, it may be valuable for an LMIC like South Africa if its psychometric properties are evaluated.

2.7 Chapter summary

The purpose of this chapter was to review the relevant concepts and literature relating to the research objectives derived in Chapter One. I have assembled available evidence to illustrate how different scholars have viewed key topics and gaps to support the study rationale. While this chapter has discussed the challenges that persons with SMHCs face in LMICs, including South Africa, it has also uncovered the need to look beyond the knowledge of recovery from HIC perspectives. Chapter Three will address Objective One and report on the scoping review exploring how personal recovery is conceptualised for persons living with SMHCs in LMICs.

Chapter Three: Exploration of Recovery of People Living with Severe Mental Illness (SMI)⁶ in Low- and Middle-income countries (LMICs): A Scoping Review⁷

3.1 Chapter outline

In Chapter Two, the academic literature was reviewed as a background to subsequent chapters. Chapter Two revealed a high burden of disease attributed to SMHCs and SUDs globally. As pointed out in previous chapters, the treatment gap in LMICs has disabling impacts on the person living with an SMHC and their family. The recovery model was conceptualised in HICs, and the literature on recovery from SMHCs primarily reflects HIC perspectives. No scoping review has examined the theoretical underpinnings of recovery from SMHCs as a construct in LMICs. The scoping review discussed in this chapter, as well as Objective One of this thesis, addresses this gap by offering conceptualisations of recovery for people living with SMHCs from LMIC perspectives. The objective of this chapter was: (i) to examine the literature on how the recovery of people with SMHCs is conceptualised in LMICs; and (ii) to examine the factors which facilitate recovery in LMICs. A background is provided per the published peer-reviewed scoping review, and a comprehensive literature overview is supplied in Chapter Two.

3.2 Abstract

Objective: To examine the literature on how the recovery of people with SMI is conceptualised in low/ middle-income countries (LMICs) and, in particular, what factors are thought to facilitate recovery.

⁶ The term severe mental illness (SMI) was used in this publication. Since the publication is presented verbatim, it has been retained here. The preferred terminology changed during the finalisation of this thesis from SMI to severe mental health conditions (SMHCs).

⁷ As per the DDB recommendations for including publications in the dissertation, this chapter includes the following publication, verbatim: **Gamielien, F.**, Galvaan, R., Myers, B., Syed, Z., & Sorsdahl, K. (2021). Exploration of recovery of people living with severe mental illness (SMI) in low/middle-income countries (LMICs): A scoping review. *BMJ Open*, 11(3), e045005. <https://doi.org/10.1136/bmjopen-2020-045005>

Design: Scoping review

Data sources and eligibility: We searched 14 electronic databases, hand-searched citations, and consulted with experts during the period May to December 2019. Eligible studies were independently screened for inclusion and exclusion by two reviewers. Unresolved discrepancies were referred to a third reviewer.

Data extraction and synthesis: All bibliographic data and study characteristics were extracted using a data charting form. Selected studies were analysed through a thematic analysis emerging from extracted data.

Results: The flow diagram for the Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Scoping Reviews offers a summary of the results: 4201 titles, 1530 abstracts and 109 full-text articles were screened. Ten articles were selected for inclusion: two from Turkey, two from India, and one each from China, Swaziland, Indonesia, Egypt, South Africa and Vietnam. Although most studies used qualitative methods, data collection and sampling methods were heterogeneous. One study reported on service provider perspectives, while the rest provided perspectives from a combination of service users and caregivers. Three themes emerged from the data analysis. First, studies frame recovery as a personal journey occurring along a continuum. Second, there was an emphasis on social relationships as a facilitator of recovery. Third, spirituality emerged as both a facilitator and an indicator of recovery. These themes were not mutually exclusive, and some overlap exists.

Conclusion: Although there were commonalities with how high-income countries describe recovery, we also found differences in conceptualisation. These differences in how recovery was understood reflect the importance of framing the personal recovery concept in relation to local needs and contextual issues found in LMICs. This review highlighted the current sparse evidence base and the need to better understand recovery from SMI in LMICs.

3.3 Introduction

Mental, neurological and substance use (MNS) disorders are significant contributors to the global burden of disease, including severe mental illness (SMI). The lifetime prevalence of SMIs ranges between 1% and 4% (Kessler et al., 2001). Although this is relatively low in comparison to the prevalence of common mental disorders, people with SMIs require complex, long-term interventions (Vigo et al., 2016). Historically, most resources to respond to MNS were allocated to specialised psychiatric hospitals, with limited provision of mental health services at primary levels of care (Eaton et al., 2011).

Deinstitutionalisation initiatives in high-income countries (HICs) shifted people out of institutions to community living. The goal of deinstitutionalisation was to promote social inclusion for people with MNS disorders, a goal which remains in progress in low/middle-income countries (LMICs). The drive to de-centralise services has led to an increase in premature discharge rates, shorter hospital stays, and repeated relapses (Petersen, Lund, et al., 2011; Sfetcu et al., 2017; Slade, 2009). This is exacerbated by a scarcity of community-based resources (Razzouk, 2019) to address the psychosocial needs of service users (Eaton et al., 2011; Lund, Oosthuizen, et al., 2010; Petersen, Lund, et al., 2011).

Personal recovery for people with SMI is conceptually distinct from clinical recovery, which places more value on medication adherence and symptom remission (Myers, 2010; Slade, 2009, 2010). At a time when having a diagnosis of SMI was highly stigmatised, and the clinical prognosis was poor, the recovery model was initiated by the mental health consumer and survivor movement in HICs (Deegan, 1988). The notion that recovery was impossible for people with SMI was challenged by people living with schizophrenia, some of whom went on to lead meaningful lives post-deinstitutionalisation (Farkas, 2007; Webb, 2012).

Psychiatric rehabilitation has highlighted the need to manage the functional and disabling consequences of SMI. However, Deegan (a mental health professional and person living with schizophrenia) says that people do not “get rehabilitated” (1988, p. 1) by others; instead, they are active participants in their journey to recover new and valued personal meaning and purpose. Personal recovery thus requires a shift beyond treating symptoms to the development of meaning and purpose across the lifespan (Anthony, 1993; Slade, 2009; Tew et al., 2012).

Recovery means different things to different people. Consequently, there are multiple interpretations and definitions of recovery. For instance, 17 studies included in a review on the meaning of recovery amongst people living with schizophrenia (Mathew et al., 2018) described recovery as both a process and an outcome with multidimensional indicators. Recovery depended on perceptions related to social support, absence of symptoms, minimal to no relapse, regaining regular functioning and resuming responsibilities. This review found that the recovery process was influenced by acceptance of illness, developing meaning in life, gaining coping mechanisms and regaining functional abilities (Cabassa et al., 2013; Kelly et al., 2010; Mathew et al., 2018). The complexity embedded in viewing recovery as a process and an outcome with multidimensional indicators has been acknowledged elsewhere (Aldersey et al., 2017; Frost et al., 2017; Lysaker et al., 2018). Although recovery cannot be defined in a single way, cognisance must be taken that various elements of recovery identified might be common to people’s understandings of the experience. Further to this, scholars recommended that clinicians, caregivers and researchers conduct more qualitative

research to explore personal narratives of recovery, develop tools needed to measure recovery and design community-based recovery-oriented services (Mathew et al., 2018).

Most of the research on personal recovery has emerged from a HIC perspective, with little attention given to describing personal recovery from LMIC perspectives. Of the 17 studies in the aforementioned review (Mathew et al., 2018), the majority were from HICs ($n = 13$). Similarly, all 97 papers included in a systematic review and narrative synthesis of models of personal recovery (Leamy et al., 2011) originated from just 13 HICs. However, some studies did include ethnic minorities. The value of including perspectives from LMICs and from diverse cultural settings is reflected in the richness and additional themes that emerged from the studies that included ethnic minorities. These additional themes included stigma, spirituality, culture and the collectivist aspects of recovery (Leamy et al., 2011).

Given that recovery is influenced by social, cultural, political, and economic factors and respect for human rights, recovery in LMICs is likely to be influenced by sociocultural context (Llewellyn-Beardsley et al., 2019). Consequently, a synthesis of the current body of evidence regarding recovery from SMI of people living in LMICs is warranted so as to offer an alternate perspective to the literature predominantly emanating from HICs; this may allow for more diverse perspectives to emerge (Arksey & O'Malley, 2005; Cabassa et al., 2013; Peters et al., 2015; Slade & Longden, 2015). This scoping review thus set out to explore and report on how recovery is described and the factors that influence the personal recovery of people with SMI in LMICs.

3.4 Methods

The protocol for this review⁸ (Gamielidien et al., 2020) ([Appendix E](#)) provides full details on the methods followed, and the protocol title was registered with the Joanna Briggs Institute. Following Arksey and O'Malley's (2005) methodological framework, this scoping review comprised six iterative stages, namely: (1) identification of the review question; (2) identification of relevant studies; (3) selection of studies; (4) charting the data; (5) collating, summarising and reporting of results; and (6) consultation with stakeholders. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Scoping Reviews checklist was used as a reporting standard for documenting the process and results (Arksey & O'Malley, 2005; Tricco et al., 2018).

⁸ The protocol for this scoping review was published in *BMJ Open*: **Gamielidien, F., Galvaan, R., Myers, B., & Sorsdahl, K. (2020). Exploration of recovery of people living with severe mental illness (SMI) in low-income and middle-income countries (LMIC): A scoping review protocol. *BMJ Open*, 10(2), e032912. <https://doi.org/10.1136/bmjopen-2019-032912>**

Stage 3.4.1 Identify the research question

We developed a broad research question for our literature search, namely, ‘What is known about recovery from SMI in LMICs?’

Stage 3.4.2 Identify the relevant studies

A detailed description of the inclusion and exclusion criteria for study selection has been published (Gamieldien et al., 2020) ([Appendix E](#)). Only studies published between 1 January 1993 and December 2019 were included. This covers the roughly 25 years of scholarship since Anthony’s seminal work on defining personal recovery from mental illness (Anthony, 1993).

To assist us with accessing relevant publications, we consulted two mental health service providers working in the field of recovery while conducting an electronic search. A comprehensive search strategy (Gamieldien et al., 2020) was developed by the first author in collaboration with two librarians (MS and DB). The search strategy and filtering methods were tested using preliminary search terms to comply with searches across different databases. The main filtering methods related to the date range (January 1993–December 2019). ([Appendix G](#))

Databases described in the protocol were searched (Gamieldien et al., 2020). Grey literature sources were also pursued through Google Scholar searches, contacting study authors, and connecting with key personnel involved in recovery-focused programmes in LMICs. Reference lists of included full-text papers were hand-searched for additional sources. Policy documents, conference abstracts, reviews, opinion pieces and commentaries sourced from grey literature were excluded, although they were reviewed to identify published literature.

Stage 3.4.3 Literature selection

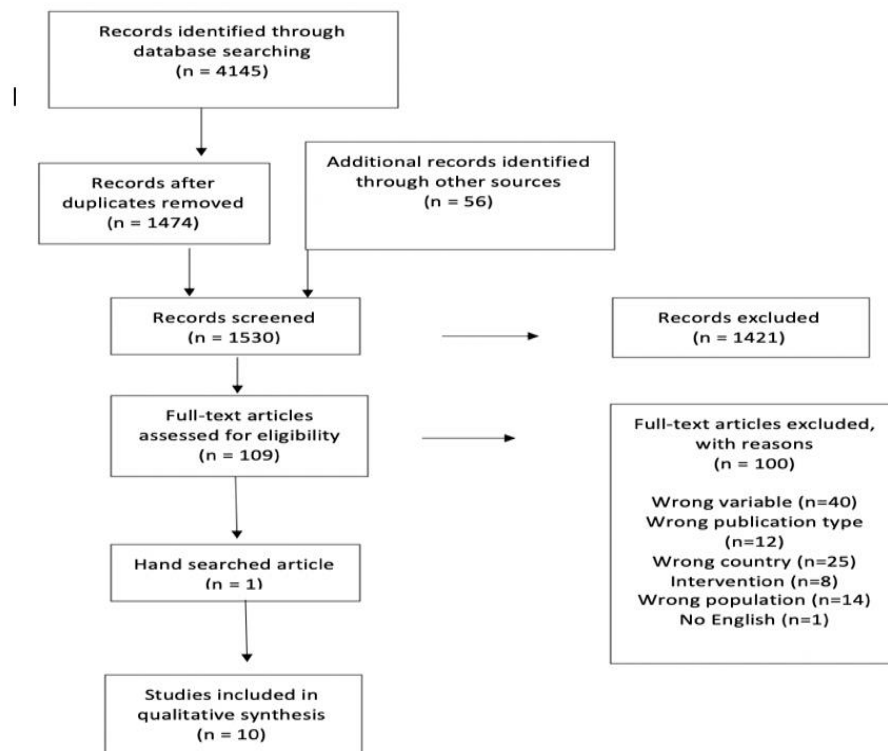
We followed two independent screening levels for selecting studies for inclusion: (1) title and abstract review, and (2) full-text review. For the first level of review, all citations from the database searches were downloaded into Endnote (Clarivate Analytics, 2018), and duplicates were removed. Thereafter, all citations were imported into Rayyan QCRI software (Ouzzani et al., 2016), which allowed reviewers (FG and ZS) to screen and select titles and abstracts independently according to the inclusion and exclusion criteria. Inter-rater agreement was assessed by calculating Cohen’s kappa. A score of 0.89 was attained, suggesting good inter-rater reliability (Blackman & Koval, 2000).

One hundred and nine articles ($n = 109$) were selected for full-text review and assessed to determine if they met the criteria for study inclusion. Disagreements on study selection were minimal ($n = 10$) and were based on interpretations of the outcome, diagnosis or intervention type described in the article. Disagreements were resolved

through consensus-seeking with a third rater (KS). At this level of screening, inter-rater agreement was calculated as 0.86. Figure 3.1 summarises the literature search and selection process.

Figure 3.1

Flow Diagram: PRISMA: Preferred Reporting for Systematic Reviews and Meta-Analyses (PRISMA)/PRISMA Extension for Scoping Review-(PRISMA-ScR)



Note: Copyright: Moher et al. (2015).

Stage 3.4.4 Charting the data

All 109 articles selected for full review were read. The two reviewers (FG and ZS) independently extracted and summarised data based on the Joanna Briggs Institute data extraction template (Arksey & O'Malley, 2005; Peters et al., 2015). Extracted information included: (1) study title, (2) author, (3) year of study, (4) country, (5) study population, (6) participant characteristics, (7) number of participants, (8) gender distribution, (9) research question and aim, (10) study methodology, (11) study description, (12) data collection methods, (13) data analysis, (14) outcome measures, (15) results, (16) summary of findings, and (17) definitions and conceptual links of recovery. [Appendix H](#) provides information on the questions applied when charting the

data. To ensure rigour, there was flexibility regarding emerging categories for data extraction. Ongoing consultation with the team occurred throughout the process.

The Mixed Methods Appraisal Tool (MMAT) V. 2018 (Hong et al., 2018) and the Critical Appraisal Skills Programme (CASP) qualitative checklist (Singh, 2013) were used to assess the quality of the included studies. Additionally, we assessed compliance to ethical standards as part of the quality appraisal process. Indicators included (a) obtaining human research ethics before study commencement, (b) documentation of consent to participate, and (c) management of vulnerability, given that the focus was on people living with an SMI.

Stage 3.4.5 Collating, summarising and reporting the results

Collated data were extracted and summarised into a descriptive and narrative synthesis of study characteristics that addressed the review questions. Data were summarised to answer the following questions from LMIC settings: how recovery is conceptualised, what the descriptors of recovery are, and what influences recovery. In consultation with KS, FG completed a qualitative data-driven thematic analysis where findings were coded using qualitative software, as recommended by Levac et al. (2010) using QSR's International NVivo 11 data analysis software (Castleberry, 2014). The codes were checked by KS, and the coding process was recorded in a memo, which was later reviewed by ZS and KS. All authors contributed to reporting the summarised results.

Stage 3.4.6 Consultation

During each stage of the review process, FG consulted with an advisory committee. This advisory committee comprised the research team and key stakeholders, including mental health service providers and service users from the public health and NPO sectors. This committee was constituted from the onset of the project, with some members being part of a pre-existing group of public mental health specialists. The advisory committee was consulted to gain their opinion on the relevance of the review. They guided access to grey literature, offered their perspectives on the data extraction and charting process and reviewed the findings. We included the inputs of an advisory committee in this review to enhance its relevance and support collaborative efforts to facilitate consumer participation and public involvement in mental health research research (Levac et al., 2010; Morgan, 2014).⁹

⁹ Patient and public involvement: There was no direct patient involvement in this scoping review. Mental health service user representatives were involved in designing the scoping review protocol and were part of the advisory committee.

3.5 Results

3.5.1 Search findings

Of the 1530 articles originally identified, 109 articles were selected for full-text review. Ten were deemed relevant to the research question. Figure 1 outlines the study selection and exclusion process.

The results are presented in two sections: (1) a summary of the characteristics and quality of the included studies, and (2) the results of the thematic analysis.

3.5.2 Description of included studies

Table 3.1 summarises the 10 studies included in this review. All studies were published between 2014 and 2019 and were conducted in: Turkey ($n = 2$), India ($n = 2$), China ($n = 1$), Swaziland ($n = 1$), Indonesia ($n = 1$), Egypt ($n = 1$), South Africa ($n = 1$) and Vietnam ($n = 1$). According to the World Bank classification system, this covered the range of LMICs. Four studies were conducted in upper-middle-income countries, and six in lower-middle-income countries.

The studies followed different study designs (qualitative: $n = 8$; quantitative $n = 2$). Qualitative studies were guided by the following approaches: grounded theory ($n = 1$), phenomenology ($n = 3$), ethnography ($n = 2$) and qualitative descriptive ($n = 2$). In all the qualitative studies, data were collected through semi-structured and unstructured interviews. Five studies focused solely on MHSUs' perspectives (De Wet et al., 2015; Gandhi et al., 2019; Güner, 2014; Nxumalo Ngubane et al., 2019; Soygür et al., 2017); one described perspectives of psychiatrists (Humphries et al., 2015); and three offered a combination of MHSUs and family members' perspectives (Chen et al., 2018; Gopal et al., 2019; Subandi, 2015). One study reported on multiple stakeholder perspectives by including a combination of MHSUs, family members, community members and healers (Rashed, 2015). Although there was heterogeneity across studies in terms of participants, MHSUs' perspectives were central to conceptualising recovery in most studies.

All participants were adults. The majority of studies focused on a diagnosis of schizophrenia ($n = 8$), while two studies looked at first-episode psychosis (De Wet et al., 2015; Subandi, 2015). The age of participants varied between 21 and 70 years, participants had been living with an SMI for between 1 and 40 years, and recovery was described as occurring over time (Chen et al., 2018; Gandhi et al., 2019; Gopal et al., 2019; Güner, 2014; Nxumalo Ngubane et al., 2019; Rashed, 2015; Soygür et al., 2017). The participants' gender profile was described in six studies (Chen et al., 2018; Gandhi

et al., 2019; Gopal et al., 2019; Güner, 2014; Nxumalo Ngubane et al., 2019; Soygür et al., 2017). In studies where the gender profile was reported, more males were included in the service user groups, except in one study in which there were more females (Gandhi et al., 2019). One study included only female service users (Nxumalo Ngubane et al., 2019). In the two quantitative studies, the majority of caregivers were female.

MHSUs in all of the studies were recruited either directly or indirectly from psychiatric services ($n = 7$) or schizophrenia associations ($n = 2$), with inclusion criteria stipulating a DSM or ICD-10 coding diagnosis. Two studies stipulated that medication adherence was required for participation in the study (Güner, 2014; Soygür et al., 2017). Table 3.1 provides further detail on included studies.

Table 3.1

Studies Included in the Review (N = 10)

	Authors (year)	Aim(s)	Country; Setting according to World Bank Classification; Recruitment site	Design and methods	Participants
1	Chen et al. (2018)	To develop an instrument to examine the opinions of consumers and their family members regarding autonomous decision making in family matters	Chengdu, China Upper-middle-income country Psychiatric Hospital	Quantitative Descriptive	MHSUs: N = 182 Female: <i>n</i> = 85 Male: <i>n</i> = 97 Family members: N = 182 Female: <i>n</i> = 103 Male: <i>n</i> = 79
2	De Wet et al. (2015)	To investigate how MHSUs with first episode psychosis experience their recovery	Cape Town, South Africa Upper-middle-income country Psychiatric Hospital research Unit	Qualitative Descriptive	MHSUs: N = 7 Gender not reported
3	Gandhi et al. (2019)	To explore patients' perspectives about factors affecting recovery from schizophrenia	Bengaluru, India Lower-middle-income country Psychiatric Hospital (Outpatients department)	Qualitative Grounded theory	MHSUs: N = 18 Males: <i>n</i> = 7 Females: <i>n</i> = 11
4	Gopal et al. (2019)	To identify clients and family members' perspectives of what constitutes recovery from schizophrenia in the Indian context and to examine gender differences in recovery indicators	Chennai, India Lower-middle-income country Psychiatric Hospital (Outpatients department)	Quantitative Descriptive	MHSUs N = 100 Males: <i>n</i> = 55 Females: <i>n</i> = 45 Caregivers: N = 80 Male: <i>n</i> = 43 Female: <i>n</i> = 37

	Authors (year)	Aim(s)	Country; Setting according to World Bank Classification; Recruitment site	Design and methods	Participants
5	Güner (2014)	To understand patients' views and experiences of schizophrenia	Istanbul, Turkey Upper-middle-income country Schizophrenia Association	Qualitative Descriptive	MHSUs: N = 9 Male: <i>n</i> = 8 Female: <i>n</i> = 1
6	Humphries et al. (2015)	To understand psychiatrists' views on outcomes for people with schizophrenia in a developing country	Danang, Hanoi, HoChi Minh City and Hue, Vietnam Lower-middle-income country Public hospitals	Qualitative Descriptive	Psychiatrists: N = 15
7	Nxumalo Ngubane et al. (2019)	To explore the experiences and meanings of recovery for Swazi women living with schizophrenia	Swaziland Lower-middle-income country Psychiatric Hospital (Outpatients department)	Qualitative Phenomenological	MHSUs: N = 15 Females only
8	Rashed (2015)	To explore the use of spirit-based frameworks to take control over symptoms in their cultural contexts	Dakhla, Western Desert Egypt Lower-middle-income country General Hospital with psychiatric service	Qualitative Ethnographic	MHSUs: N = 2 Male: <i>n</i> = 1 Female: <i>n</i> = 1 Family members <i>n</i> = not specified Healers: N = 11 Community members: N = 56
9	Soygür et al. (2017)	To identify the factors contributing to recovery, as observed from the perspectives of schizophrenia patients working at a supported employment project	Ankara, Turkey Upper-middle-income country Schizophrenia Association	Qualitative, Phenomenological;	MHSUs: N = 24 Male: <i>n</i> = 15 Female: <i>n</i> = 9

	Authors (year)	Aim(s)	Country; Setting according to World Bank Classification; Recruitment site	Design and methods	Participants
10	Subandi (2015)	To explore participants' experience of illness and recovery in a Javanese cultural context	Yogyakarta, Java Lower-middle-income country Psychiatric Hospital	Qualitative, Ethnographic	MHSUs: $N = 7$ Family members: $n =$ not specified

3.5.3 Themes from included studies

Table 3.2 provides a summary of the key findings of each of the 10 included studies. The thematic analysis yielded three themes describing recovery as a personal and complex social process involving healthcare providers, family and community members (Chen et al., 2018; De Wet et al., 2015; Gandhi et al., 2019; Gopal et al., 2019; Güner, 2014; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Rashed, 2015; Soygür et al., 2017; Subandi, 2015). These themes, namely (1) recovery is a personal journey occurring along a continuum; (2) aspects of social relationships supportive of recovery; and (3) finding meaning and hope through spirituality and religion, are elaborated upon in Table 3.2 below.

Table 3.2

Summary of Findings of Included Studies

	Title, Author, Year	Aim(s)	Country and Setting	Key Findings
1	Family decision making and self-determination among consumers with schizophrenia in China: Cross-cultural implications. Chen et al. (2018)	To develop an instrument to examine the opinions of consumers and their respective family members about autonomous decision making in family matters	Chengdu, China	-Autonomy in decision making contributes to the MHSUs functioning during recovery. -In Asian contexts it is accepted practice that family members make decisions on behalf of the MHSUs, especially with regard to money management, and community and daily living. -Decisions related to psychiatric care are often deferred to health professionals. -The concept of autonomy for MHSUs includes situations where they endorse and agree with decisions made by family members on their behalf.
2	Hearing their voices: The lived experience of recovery from first episode psychosis in schizophrenia in South Africa. De Wet et al. (2015)	To investigate how MHSUs with first episode psychosis experience their recovery	Cape Town, South Africa	-Caring for others and being cared for was identified as the biggest contributor to recovery of persons with schizophrenia. Spirituality was seen to build resilience more so than adherence to medication. Understanding the mental illness and managing associated stigma influenced disclosure, especially at work.
3	Perspectives of consumers in India on factors affecting recovery from schizophrenia. Gandhi et al. (2019)	To explore patients' perspectives about factors affecting recovery from schizophrenia	Bengaluru, India	-MHSUs in India indicated that recovery was affected by facilitators and barriers related to individual, familial and societal influences. -Holding valued roles in a supportive family structure facilitated the recovery of MHSUs. -MHSUs reported that spirituality and their engagement in prayer and religious rituals anchored them and contributed towards their recovery.

	Title, Author, Year	Aim(s)	Country and Setting	Key Findings
				-Engaging in activities with others was important for MHSUs as they reported that having meaningful social relationships helped them combat loneliness. - Barriers to recovery included side effects of medication, inconsistent treatment approaches and religious beliefs which delayed access to treatment.
4	What constitutes recovery in schizophrenia? Client and caregiver perspectives from South India. Gopal et al. (2019)	To identify clients and family members' perspectives of what constitutes recovery from schizophrenia in Indian context and examine gender differences in recovery indicators	Chennai, India	-Recovery, according to caregivers and MHSUs, entailed being symptom free; being able to work; and being independent. -Recovery was equated with no longer needing medication. -Recovery was based on MHSUs' subjective feelings and experiences and not on the opinions of family members and health professionals.
5	Illness perception in Turkish schizophrenia patients: A qualitative explorative study. Güner (2014)	To understand patients views and experiences of schizophrenia	Istanbul, Turkey	-Recovery was variably defined and included a lack of symptoms; being able to work; getting married and having opportunities to become part of community networks. - MHSUs took ownership for their own personal recovery by engaging in meaningful occupations, hobbies and religious practices, including prayers. -In Turkey, almost all MHSUs with schizophrenia live with their families. - For some, having a supportive family facilitated recovery, but recovery was hindered when the family was overprotective. -Recovery was further hindered by difficulties accessing mental health services. -MHSUs did not disclose their mental illness for fear of stigma.

	Title, Author, Year	Aim(s)	Country and Setting	Key Findings
6	Psychiatrists' perceptions of what determines outcomes for people diagnosed with schizophrenia in Vietnam. Humphries et al. (2015)	How psychiatrists view outcomes for people with schizophrenia in a developing country	Danang, Hanoi, HoChi Minh City and Hue, Vietnam	-Access to contemporary treatment was seen as influencing the outcomes for people with schizophrenia. Contemporary treatment is defined as including generic second-generation antipsychotics, staff, facilities and psychosocial interventions. -Psychosocial interventions were not described. -MHSUs feared stigma; and this influenced help-seeking behaviour. - Psychiatrists reported that, in families who hold traditional beliefs, mental illness was attributed to spiritual causes; families access traditional treatment before seeking medical assistance, especially in rural areas. - The extended family system allows family members to share the burden of caring for a MHSU, especially in the absence of formal services. -MHSUs were able to access unskilled work in rural parts of Vietnam more readily than MHSUs in urban settings.
7	The experiences and meanings of recovery for Swazi women living with "schizophrenia". Nxumalo Ngubane et al. (2019)	To explore the experiences and meanings of recovery for Swazi women living with schizophrenia	District not specified, Swaziland	-In Swaziland, MHSUs referred to any mental illness as "an illness of the brain". -Schizophrenia is not a known term in Swaziland. -Diagnostic labels such as schizophrenia were used by health professionals but not shared with MHSUs. -Families and significant others provided emotional and financial support to MHSUs. -The presence of therapeutic rapport between MHSUs and health professionals contributed to personal recovery.
8	From powerlessness to control: Psychosis, spirit possession & recovery in the Western desert of Egypt. Rashed (2015)	Exploration of the use of spirit-based frameworks to take control over symptoms in their cultural contexts	Dakhla Western Desert, Egypt	-Mental illness was contextualised through spirit-based understandings of the illness and its symptoms. -The relationship MHSUs had with the spirit world was used as a means of describing their recovery journeys.

	Title, Author, Year	Aim(s)	Country and Setting	Key Findings
				- Clinical recovery was contested as it suggested that mental illness can be cured, whereas personal recovery was described as an ongoing process that did not require medical intervention. -Personal recovery involved MHSUs gaining control over their symptoms. -MHSUs were positioned as being actively involved in their recovery rather than as passive recipients of services. -Spirituality was foregrounded through the religion of Islam and Quranic healing in the lives of people with schizophrenia. -This study was located in a therapeutic community and supported employment setting. - Long-term relational support between MHSUs and stakeholders involved in health service delivery was seen as being central to recovery. -Recovery was promoted through a number of factors which were embedded in supportive relationships and unrestrictive environments. -MHSUs reported that having work gave them a sense of purpose, responsibility and motivation which added meaning to their lives.
9	Lessons learned from experiencing Mavi at Café (Blue Horse Café) during six years: A qualitative analysis of factors contributing to recovery from the perspective of schizophrenia patients. Soygur (2016)	“To identify the factors contributing to recovery, as observed from the perspectives of schizophrenia patients working at The Blue Horse Café”	Ankara, Turkey	
10	Bangkit: The processes of recovery from first episode psychosis in Java. Subandi (2015)	To explore participants’ experience of illness and recovery in a Javanese cultural context	Yogyakarta, Java	-MHSUs viewed their recovery in the cultural context in which they lived. -Recovery had different aspects to it and involved medical treatment, family care in the home and integration into natural community settings. -MHSUs reported being guided by spirituality which required their active participation in the performance of Islamic religious practices.

3.5.3.1 Recovery is a personal journey occurring along a continuum

The majority of studies included in this review conceptualised recovery as an ongoing, non-linear process rather than as an event with a finite end (De Wet et al., 2019; Gandhi et al., 2019; Gopal et al., 2019; Güner, 2014; Nxumalo Ngubane et al., 2019; Rashed, 2015; Soygür et al., 2017; Subandi, 2015). The age at onset of illness and duration of illness was highlighted (Chen et al., 2018; Gandhi et al., 2019; Gopal et al., 2019; Güner, 2014; Nxumalo Ngubane et al., 2019; Rashed, 2015; Soygür et al., 2017) as being a signal of when the recovery process began. Onset of illness was usually noticed by family members first, and they facilitated health-seeking behaviour on behalf of the MHSU.

Some studies (Chen et al., 2018; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Rashed, 2015; Subandi, 2015) defined the starting point for the recovery process as being from the time that people were back in their homes and communities and not from the start of their hospital admission. This was confirmed by the methodological decisions taken in all of the included studies not to include inpatients or make reference to inpatient services as facilitating recovery. One study described an outpatient service where the programme included psychosocial skills training, family and group therapy sessions and group outings (Güner, 2014). It is notable that recognising symptoms as cues of relapse was not explored since it appeared that the emphasis was on managing symptoms within the home and community settings after the onset of illness (De Wet et al., 2015; Gandhi et al., 2019; Gopal et al., 2019). This approach occurred after a diagnosis had been established for affected MHSUs (Chen et al., 2018; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Rashed, 2015; Subandi, 2015).

Since the process of recovery was described from the point of discharge, coping strategies related to managing symptoms of their illness and their reintegration within their families and communities emerged as critical facilitators to recovery. MHSUs needed strategies to facilitate this recovery process. Strategies identified in the studies included the development of self-awareness; being able to self-regulate; spirituality, including prayer; attending to basic needs; understanding the mental illness; having purpose and hope for the future; gaining a sense of autonomy; engagement in meaningful occupations; contributing to community; and adopting a positive attitude to living with a mental illness (Chen et al., 2018; De Wet et al., 2015; Gandhi et al., 2019; Gopal et al., 2019; Güner, 2014; Nxumalo Ngubane et al., 2019; Rashed, 2015; Soygür et al., 2017). The studies did not describe the development of these coping strategies. It was also noted that learning to self-manage facilitated the recovery process (De Wet et al., 2015; Gopal et al., 2019; Güner, 2014; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Subandi, 2015). Key aspects that MHSUs had to learn to self-manage

included their temperament, learning to live with and derive meaning from having a mental illness and being hopeful for their future.

There was a lack of consensus across the studies regarding the use of medication as an indicator of recovery (Chen et al., 2018; Gandhi et al., 2019; Gopal et al., 2019; Güner, 2014; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Rashed, 2015; Soygür et al., 2017; Subandi, 2015). Some studies emphasised treatment adherence as the first step towards recovery (Chen et al., 2018; Gandhi et al., 2019; Güner, 2014; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Soygür et al., 2017), while others viewed the choice to stop taking medication as an indicator of recovery (Gopal et al., 2019; Rashed, 2015; Subandi, 2015). When describing recovery as it relates to the medical model and clinical recovery, studies appeared to focus on the individual and described contemporary treatment as including a combination of access to medication, health personnel, mental health services at health facilities and psychosocial interventions (Gandhi et al., 2019; Humphries et al., 2015). According to Rashed (2015), clinical recovery foregrounds biological aspects, implicitly highlighting a curative approach to the illness, often demonstrated through administering medication. However, in exploring psychosis and spirit possession. Rashed (2015) found that recovery was not dependent solely on medication or medical intervention. Instead, recovery was conceptualised as an opportunity to expand personal agency in the way MHSUs respond to their illness, with or without medication (Rashed, 2015).

In the study conducted by Subandi (2015), the recovery process involved different phases of participation and integration across social spheres. Recovery as an active process started as MHSUs gained insight into the social isolation that resulted from their mental illness. However, social isolation and withdrawal were viewed as the opposite of recovery as they represented inactivity and passivity (Rashed, 2015; Subandi, 2015). Across studies, the effort exerted by MHSUs to expand their social interactions from their immediate physical environment to engaging with family members and other stakeholders in health and community spaces was seen as an indicator of recovery (Chen et al., 2018; De Wet et al., 2015; Gandhi et al., 2019; Gopal et al., 2019; Güner, 2014; Nxumalo Ngubane et al., 2019; Rashed, 2015; Soygür et al., 2017; Subandi, 2015).

From the aforementioned, it can be seen that the people involved in the recovery process included healthcare providers, family and community members. It is also noteworthy that personal recovery required action in a range of interconnected social and cultural contexts. MHSUs' ability to navigate these different environments indicated what was considered as successful recovery. Indicators of recovery described in the selected articles included being symptom-free, returning to work or supported employment, being independent, getting married, being self-sufficient, making decisions, integrating into social or community networks, and involvement in

spiritual and religious activities. Through this, recovery was described as active participation in daily activities. This participation was viewed as an indicator of recovery (Chen et al., 2018; De Wet et al., 2015; Gandhi et al., 2019; Gopal et al., 2019; Güner, 2014; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Rashed, 2015; Soygür et al., 2017; Subandi, 2015).

3.5.3.2 Aspects of social relationships supportive of recovery

Across included studies, the perspectives and contributions of healthcare providers, family and community members were identified as crucial to the MHSUs' recovery process. From these studies, it seems that the ways in which these stakeholders engaged with the recovery process potentially facilitated or hindered the recovery journey (Chen et al., 2018; De Wet et al., 2015; Gandhi et al., 2019; Gopal et al., 2019; Güner, 2014; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Rashed, 2015; Soygür et al., 2017; Subandi, 2015).

Relational support from health professionals was identified as a facilitator of recovery (Chen et al., 2018; De Wet et al., 2015; Güner, 2014; Nxumalo Ngubane et al., 2019; Soygür et al., 2017). Access to service providers was influenced by the availability of and access to psychiatric treatment (Chen et al., 2018; Humphries et al., 2015). Health professionals supported recovery when they communicated clearly, spent time with service users, offered alternative medication options and provided opportunities for engagement in activities (Güner, 2014; Nxumalo Ngubane et al., 2019). On the contrary, the poor continuity of psychiatric care, together with limited and brief consultations with a doctor and a focus on access and adherence to medication, was seen to limit the recovery process (Gandhi et al., 2019; Güner, 2014; Nxumalo Ngubane et al., 2019; Rashed, 2015).

Sociocultural values and variations in explanatory models of mental illness between the MHSUs and health professionals, as well as family members, influenced views of recovery (Chen et al., 2018; Humphries et al., 2015; Rashed, 2015). Family members were more likely to seek help from traditional or spiritual healers before seeking contemporary psychiatric treatment (Humphries et al., 2015; Subandi, 2015). The differences between socio-cultural values and explanatory models of mental illness included perceived causes of mental illness, traditional beliefs attributing mental illness to spiritual causes, fear of stigma and community attitudes. For example, discrepancies in the language used to refer to mental illness obscured a common understanding of recovery (Nxumalo Ngubane et al., 2019). MHSUs referred to any mental illness as an "illness of the brain" (Nxumalo Ngubane et al., 2019, p. 156), while health professionals used the diagnostic label of schizophrenia. For one participant, the voice of her grandmother was soothing to her but unacceptable to her family and health service providers (Nxumalo Ngubane et al., 2019). There was an element of

dissonance between how the MHSUs, their families and service providers made sense of the mental illness, with a disconnect occurring around how their symptoms were understood by different parties (Rashed, 2015). When the family, community or health professionals held different understandings and attitudes towards mental illness, recovery was obstructed.

The studies reported that all participants lived with family members or significant others (De Wet et al., 2015; Gandhi et al., 2019; Gopal et al., 2019; Güner, 2014; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Rashed, 2015). Although the complexity of large families was acknowledged (Gandhi et al., 2019; Humphries et al., 2015), the extended family supported recovery through sharing the burden of care in the absence of formal health services. The studies highlighted that family and cultural beliefs, along with societal values and expectations, were used as indicators of recovery (Chen et al., 2018; Gandhi et al., 2019; Subandi, 2015). These indicators were described in different ways and included whether the individual could take care of or provide for their family as they recovered (De Wet et al., 2015; Gandhi et al., 2019; Gopal et al., 2019; Güner, 2014; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Rashed, 2015).

Families provided the emotional and financial support needed by the MHSUs for daily living during their journey of recovery (De Wet et al., 2015; Gandhi et al., 2019; Gopal et al., 2019; Güner, 2014; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Rashed, 2015; Soygür et al., 2017; Subandi, 2015). While the family assumed responsibility for decision-making when the MHSUs were acutely ill, they gave up some of this responsibility as the MHSUs recovered (Chen et al., 2018; Güner, 2014; Rashed, 2015). The families' role as stewards of recovery continued in different ways as they provided flexible access to social networks for MHSUs on an ongoing basis (De Wet et al., 2015; Gandhi et al., 2019; Gopal et al., 2019; Güner, 2014; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Rashed, 2015; Soygür et al., 2017; Subandi, 2015). Once MHSUs started engaging in spheres such as personal and social functioning, community and daily living and money management, the family's decision-making in these spheres decreased (Chen et al., 2018; De Wet et al., 2015; Gopal et al., 2019; Humphries et al., 2015; Nxumalo Ngubane et al., 2019).

The importance of social support was recognised as a facilitator of recovery. MHSUs accessed support from different sources, including professionals, family members, therapeutic community networks and supported employment (Güner, 2014; Humphries et al., 2015; Rashed, 2015). Peer support was mentioned once as an important facilitator of recovery (Gandhi et al., 2019). Professional support was symptom-related; family support involved assisting with tangible aspects such as financial management or with support for community reintegration. Different networks thus facilitated recovery as they provided relational and emotional support to MHSUs.

MHSUs described having social connections and being able to engage in activities alone and with others as key components of personal recovery (Gandhi et al., 2019; Gopal et al., 2019). The MHSUs' social identity and social position in relation to their family, their community and broader society were seen to influence their functioning and social inclusion (Gandhi et al., 2019; Gopal et al., 2019). Stigma was mentioned as a barrier to recovery, but it was not elaborated on in the studies (De Wet et al., 2015; Güner, 2014; Humphries et al., 2015; Nxumalo Ngubane et al., 2019).

In four studies, MHSUs reported that being able to work facilitated access to social networks (De Wet et al., 2015; Güner, 2014; Nxumalo Ngubane et al., 2019; Soygür et al., 2017). For MHSUs, recovery meant becoming part of a social network where they felt valued and which allowed them to contribute meaningfully to their family and community, whether this was in paid employment or not (De Wet et al., 2015; Güner, 2014; Nxumalo Ngubane et al., 2019; Soygür et al., 2017). One study focused on MHSUs working in a therapeutic community and supported employment setting (Soygür et al., 2017). The emphasis in this study (Soygür et al., 2017) was on the relational support and social interactions provided to MHSUs via the supported employment project. While employment was important as it gave MHSUs the opportunity to contribute to the financial situation of the family, its role as a facilitator of social support networks was foregrounded. Recovery as a social process which is influenced positively by collaboration between MHSUs and stakeholders through long-term relational support and encouragement was emphasised (Soygür et al., 2017).

3.5.3.3 Finding meaning and hope through spirituality and religion

In eight of the ten studies, spirituality and religion emerged as resources that the MHSUs and caregivers used for understanding mental illness and the recovery process (Chen et al., 2018; De Wet et al., 2015; Gandhi et al., 2019; Güner, 2014; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Rashed, 2015; Subandi, 2015). Five studies (Chen et al., 2018; De Wet et al., 2015; Gandhi et al., 2019; Güner, 2014; Humphries et al., 2015) referred to the significance of spirituality and religion. Regarding religion, Islam was referred to in two studies (Rashed, 2015; Subandi, 2015) and Christianity in one study (Nxumalo Ngubane et al., 2019). Across these studies, spiritual and religious practices were seen to build resilience and were identified as contributing to recovery when they were equally valued by MHSUs, their families and the community (Chen et al., 2018; De Wet et al., 2015; Gandhi et al., 2019; Güner, 2014; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Rashed, 2015; Subandi, 2015).

While in recovery, MHSUs underwent internal spiritual struggles when participating in religious practices outside of their homes. The ways in which this was enacted included directly sharing feelings with God through prayer and not through an intermediary; use of religious rituals to relieve stress; surrendering healing to God's will; resisting spirit

possession as an act of faith and personal struggle; and by practically supporting places of worship through engaging in cleaning chores as part of church maintenance (De Wet et al., 2015; Gandhi et al., 2019; Güner, 2014; Nxumalo Ngubane et al., 2019; Rashed, 2015; Subandi, 2015).

MHSUs' relationship with and understanding of the spirit world was seen as an indicator of recovery in one study (Rashed, 2015). Recovery was aided by MHSUs' ability to manage the psychotic symptoms of the mental illness while drawing on the philosophical explanations offered by spirituality. In Egypt, spirit possession featured as part of the experience of a psychotic phenomenon and psychosis was not necessarily viewed as a medical problem (Rashed, 2015). According to this study, when MHSUs actively engage in accepted individual and communal religious practices, they are acknowledged as positively navigating personal recovery.

MHSUs reported that spirituality and religious practices provided an anchor for MHSUs and their families as it offered hope for recovery through their own efforts, while also demonstrating faith and trust in a divine power. Engaging in spiritual practices offered MHSUs structured opportunities to relax, relieve their stress and be hopeful about their future (Gandhi et al., 2019; Subandi, 2015). Being hopeful about the future required MHSUs to have faith in themselves and their religion, as this allowed them to find peace while living with the challenges of having a mental illness (De Wet et al., 2015; Güner, 2014; Nxumalo Ngubane et al., 2019; Rashed, 2015). Furthermore, spirituality was viewed as a resource which contributed positively to the recovery process when MHSUs used it to instil hope for the future and as a mechanism for making sense of the mental illness.

The views held by MHSUs and their family members regarding the influence of spirituality and religious practices on recovery differed from the views held by health professionals (Gandhi et al., 2019; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Rashed, 2015; Soygür et al., 2017). In one study, psychiatrists indicated that religious beliefs and practices could hinder the recovery process, particularly where symptoms were attributed to spiritual causes and where traditional treatment was sought before psychiatric treatment (Humphries et al., 2015). MHSUs viewed professional explanations of mental illness as unhelpful when they discounted the role of spirituality or religion in recovery, especially if they used coercion to support their own ideas of recovery (Nxumalo Ngubane et al., 2019; Rashed, 2015). Relying only on medication dispensed by healthcare providers positioned MHSUs as patients and service recipients, while adopting a spiritual and cultural interpretation of mental illness allowed MHSUs to be viewed as people who were in control of their illness and who were agents in their own personal recovery process (Rashed, 2015; Subandi, 2015). The focus on clinical recovery and the medical interpretation of mental illness minimised the contribution of spirituality to personal recovery.

3.6 Discussion

This review contributes to the growing body of research exploring the meaning of recovery from SMI (Llewellyn-Beardsley et al., 2019; Mathew et al., 2018; Tew et al., 2012) by synthesising qualitative and quantitative research from LMICs. The ten articles selected for inclusion were published between 2014 and 2019, suggesting recent and possibly growing interest in understanding perceptions of recovery in these contexts. While there was heterogeneity in terms of design and setting, all studies endorsed the power of individual narrative accounts of recovery. This review highlighted commonalities but also differences between how studies from HICs and LMICs (1) conceptualise the recovery process; (2) outline the individual, interpersonal and social factors that facilitate or impede recovery; (3) define indicators of recovery; and (4) view the role of spirituality and religion in the recovery process, and as an indicator of recovery.

Findings suggest that recovery for MHSUs is conceptualised as a personal, non-linear, and complex process. While this view is echoed in the literature from HICs (Deegan, 1988; Leamy et al., 2011; Mathew et al., 2018; Slade & Longden, 2015), the starting point of the process differs between HICs and LMICs. In HICs, MHSUs generally have access to specialised inpatient mental health care and their recovery journeys were thought to begin pre-discharge (Van Weeghel et al., 2019). In the included studies, none of the MHSUs were inpatients at the time of the study; their recovery journeys were described post-discharge. The conceptualisation of recovery as being non-linear in nature incorporates the frequent occurrence of relapses among this populations (Petersen, Lund, et al., 2011) and explains the growing interest in the sociocultural contexts where recovery takes place (Doroud et al., 2018), particularly in LMICs.

Given the variability in sociocultural contexts, a range of individual, interpersonal and social factors were found to facilitate or impede the process of recovery among stakeholders. First, these publications highlighted the role of explanatory models of mental illness, including pathways to care and perceptions regarding the use of medication in the process of recovery. Explanatory models of mental illness (Makanjuola et al., 2016) provide a framework for understanding SMI and treatment-seeking behaviour in a particular context. Systematic reviews have highlighted how, in many instances, traditional healers are often the first point of contact in many LMICs, including African countries (Burns & Tomita, 2015; Green & Colucci, 2020). Unlike literature from HICs, views were mixed regarding the role of clinical recovery, emphasising medication adherence. While some studies highlighted the role of medication in facilitating recovery (Chester et al., 2016; Le Boutillier et al., 2015; Winsper et al., 2020), others emphasised the additional importance that health professionals have an awareness of sociocultural values and variations in explanatory

models of mental illness as these factors influence MHSUs, caregivers and community members' social relationships and cultural norms which can either facilitate or impede recovery (Bhikha et al., 2012; Green & Colucci, 2020; Thornicroft et al., 2016).

Second, included studies highlighted how recovery requires long-term relational and emotional support provided by family and friends. The role of the family in MHSUs' recovery journeys is emphasised differently in studies from HICs and those from LMICs. In HICs, the deinstitutionalisation process shifted care for MHSUs from hospital to community care. This increased the responsibility placed on family members (Ward-Griffin et al., 2005), but in LMICs, access to mental healthcare is a challenge which necessitates that families are involved in the MHSUs' recovery journey from the onset, given the limited availability of community care services (Aldersey et al., 2017).

According to several of the included studies (Chen et al., 2018; Gandhi et al., 2019; Gopal et al., 2019; Güner, 2014; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Subandi, 2015), the family members, including significant others, are responsible for the establishment of supportive living arrangements which involved living with family members, another key facilitator in the process of recovery. These living arrangements seem to reflect norms embedded in particular cultures globally and were not viewed as a lack of independence or aspiration. In some African and Asian contexts, collaborative decision-making based on family involvement was seen by MHSUs as a source of support rather than a lack of autonomy, especially in terms of financial support. This contrasts with Western society, where gaining independence is seen as an indicator of recovery (Deegan, 1988). Additionally, in some LMIC contexts, living with a supportive family provided MHSUs with opportunities for social cohesion, which improved their recovery outcomes (Aldersey et al., 2017; Chan et al., 2019; Ran et al., 2019). Although supported housing is viewed as a key facilitator of recovery in HICs (Carpenter-Song et al., 2012; Doroud et al., 2018; McPherson et al., 2018), it was not mentioned in any of the included studies described here. Studies in LMICs have examined supported housing for people who are homeless (Padmakar et al., 2020), in the absence of family support. Despite the potentially important role that families can play in the recovery of MHSUs, there is limited literature available on how living with family or extended family facilitates recovery in LMICs (Gopal & Henderson, 2015).

Similar to HICs, accessing opportunities to build social connectedness and community relationships emerged as a facilitator to recovery. Although research indicates that people with SMI have poorer social connections than the general population (Leamy et al., 2011), social relationships allow MHSUs to connect with their family, community and work environments. Employment in the skilled or unskilled labour market was found to promote personal recovery of people with SMI (Doroud et al., 2015; Gamielidien & Van Niekerk, 2017; Humphries et al., 2015; Lund et al., 2018; Thomas et al., 2019; Young et al., 2019). Although MHSUs have difficulty accessing employment

opportunities, in a number of included studies (Chen et al., 2018; Gopal et al., 2019; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Soygür et al., 2017; Subandi, 2015), the ability to work was described as a significant indicator of recovery, as well as a means of accessing social networks and supportive relationships which facilitated recovery.

Third, spirituality emerged not only as an important facilitator of the recovery process but a significant indicator of recovery for MHSUs in LMICs. This is in keeping with a review on religion, spirituality and mental health (Borthwick, 2001) in HICs and LMICs, which concluded that engagement in religious practices was a facilitator of recovery. On an individual level, religion was seen as a source of emotional support (Koenig, 2009); but the influence of religion on family and cultural perspectives and practices, even for ethnic minorities in HICs was not reported on in this review. Included studies in the current review described community religious groups as accessible social networks which provide support to MHSUs and their families (Griffith et al., 2016). As a facilitator of recovery, spirituality was also seen as a way of finding meaning and hope for MHSUs and their families through the rituals and social connections embedded in practice (Abdaleati et al., 2016; Bhikha et al., 2012).

The findings of this scoping review need to be considered in light of some limitations. The review aimed to analyse conceptual and theoretical underpinnings of recovery from SMI in LMICs, as such interventions and intervention outcomes were not focused on. Data synthesis was limited to full-text articles available in English and published between January 1993 and December 2019. This practical decision may have led to potentially relevant unpublished papers in other languages being excluded.

3.7 Strengths and limitations of the study

- 3.7.1 A comprehensive search strategy was used, which allowed the literature to be mapped as a basis for further exploration of the concept of recovery in low- and middle-income countries (LMICs) to inform research, policy and practice.
- 3.7.2 The review aimed to analyse conceptual and theoretical underpinnings of recovery from severe mental illness (SMI) as a construct in LMICs and, as such, interventions and intervention outcomes were not focused on.
- 3.7.3 Data synthesis was limited to full-text articles available in English only and published between January 1993 and December 2019.
- 3.7.4 Grey literature and unpublished studies not available in English were excluded from the scoping review, and this practical decision means that potentially relevant papers were excluded.

- 3.7.5 Future reviews should search the grey literature extensively as there are non-government organisations active in providing recovery-oriented support and care to people with SMI in LMICs but do not publish in the peer-reviewed literature.
- 3.7.6 The scoping review included no studies from low-income or Latin-American countries. Research from these countries could shed light on how recovery is conceptualised in different social and cultural contexts.

3.8 Conclusion

This review aimed to examine the literature on how recovery of people with SMI is conceptualised in LMICs, and factors thought to facilitate the recovery process. In this review, we found that understanding of recovery overlapped with those from HICs, but there were important differences. Unlike HICs, where independence and autonomy were emphasised, social connectedness and interdependence were emphasised as important indicators of recovery in LMICs (Aldersey et al., 2017). In addition, family support played a much larger role in LMICs than in HICs, where peer support as a strategy for supporting the recovery process is emphasised. Additionally, spirituality emerged as both a facilitator and an indicator of recovery. In HICs, spirituality is rarely considered in the context of recovery, whereas interdependence with the spiritual realm is viewed as an important indicator and facilitator of recovery in LMICs. These differences highlight the importance of assessing whether tools and measures of recovery from SMI developed in HICs capture all of the key indicators of recovery that are important for MHSU living in LMICs. In conclusion, this review highlights the need to expand the recovery concept to be more inclusive of cultural conceptualisations of recovery and illness in LMICs that extend beyond the individual.

Chapter Four: Service Providers' Perspectives on Personal Recovery from Severe Mental Illness¹⁰ in Cape Town, South Africa: A Qualitative Study¹¹

4.1 Chapter outline

In Chapter Three, I presented the scoping review examining the literature on how recovery from SMHCs is conceptualised and facilitated in LMICs. This chapter reports on a qualitative, descriptive study on service provider perspectives of personal recovery from SMHCs in Cape Town, South Africa. More research is needed on service provider views on recovery from SMHCs in LMICs, such as South Africa. This chapter addresses this gap and fulfils Objective Two of this thesis. The background, methods, results and conclusion of the qualitative, descriptive study on service provider perspectives on recovery from SMHCs are presented here.

4.2 Abstract

Severe mental illnesses (SMIs) contribute significantly to the global disease burden. In low- and middle-income countries (LMICs), the treatment gap impacts the clinical and personal recovery of people living with a SMI. The drive to reduce this treatment gap in LMICs makes it pertinent to understand service providers' views on recovery from SMI. In this qualitative study, semi-structured interviews and focus groups were conducted with service providers from health services and non-profit organisations in the Western Cape Province, South Africa. Seventeen participants were purposively selected, and data were thematically analysed. Three major themes emerged: delineating recovery, available services supporting recovery from SMI, and facilitators and barriers to recovery at the service level. Health services favoured clinical over personal recovery. Participants thought that many service users' personal recovery from SMI was hindered

¹⁰ The term Severe Mental Illness (SMI) was used in this publication and, for alignment with the publication, it has been retained here.

¹¹ As per the DDB recommendations for including publications in the dissertation, this chapter includes the following publication, verbatim: **Gamielien, F.**, Galvaan, R., Myers, B., & Sorsdahl, K. (2021). Service providers' perspectives on personal recovery from Severe Mental Illness in Cape Town, South Africa: A qualitative study. *Community Mental Health Journal*. <https://doi.org/10.1007/s10597-021-00904-8>

by intersecting social, economic, cultural, and political inequalities that extended beyond the influence of the health sector.

4.3 Introduction

Severe mental illnesses (SMI) (schizophrenia spectrum disorders, non-organic psychotic disorders, and bipolar affective disorder) are some of the main causes of years lived with disability (YLDs) (Vos et al., 2017). Despite schizophrenia being a low prevalence disorder, the Global Burden of Disease study (2016) ranked it as the 12th most disabling disorder out of 310 injuries and diseases (Vos et al., 2017), contributing 1.7% of total YLDs globally, equivalent to 13.4 million YLDs (Charlson et al., 2018). The burden associated with these disorders is four times greater in low- and-middle-income countries (LMICs) than high-income (HICs) due to the substantial treatment gap (Charlson et al., 2018). Additionally, people living with SMI require complex interventions to address the social and economic difficulties they face (Charlson et al., 2018).

In many LMICs, available treatment for SMI is primarily biomedical and provided at specialised psychiatric facilities on an inpatient or outpatient basis. However, as many LMICs allocate insufficient resources to SMI services in primary levels of care, treatment for SMI remains inadequate in these settings (Iseselo & Ambikile, 2017), and there is little integration between hospitals and community-based services (Eaton et al., 2011). Services at primary levels of care are limited to the collection of medication at clinics, but community-based services which facilitate community integration are limited (Lund, Oosthuizen et al., 2010). Inadequate care for people with SMI holds negative consequences for the person with the SMI, family, and community. These consequences include human rights violations (Asher et al., 2017), high relapse rates (Lund et al., 2010), homelessness (Smartt et al., 2019), risks of restraint and assault (A. Fekadu et al., 2019), adverse intergenerational effects on family members (W. Fekadu et al., 2019), caregiver burden (Shibre et al., 2012), premature mortality (Teferra et al., 2011), poverty and food insecurity (Jenkins et al., 2010; Teferra et al., 2013), stigma and discrimination (Egbe et al., 2014), and economic strain on carers (Addo et al., 2018), and unemployment (Ebuenyi et al., 2018).

Inadequate care also impacts mental health service users' (MHSUs) community integration and recovery (Aldersey et al., 2017). Biomedical approaches to SMI focus on symptom remission as the main indicator of (clinical) recovery. In contrast, personal recovery approaches emphasise functional improvement, social inclusion, community integration, illness management, access to employment and family support as crucial markers of recovery alongside symptom remission (Aldersey et al., 2017; Slade, 2009). While there is no universally applicable definition of personal recovery from SMI, there

is agreement that it involves developing meaning and purpose while living with an SMI (Mathew et al., 2018; Slade, 2009).

There is growing interest in understanding the meaning of recovery from multiple stakeholder perspectives, not just from the perspectives of MHSUs as experts by experience (Swerdfager, 2016). Several studies have explored the views of service providers on recovery-oriented practice. A systematic review identified three major conceptualisations of recovery-oriented practice: clinical recovery, personal recovery and service-defined recovery (Le Boutillier et al., 2015). Service-defined recovery is of interest to health system reform as the goals and financial needs of the organisation influence how recovery translates into practice (Le Boutillier et al., 2015). Of the 22 studies included in this review, only one study came from a LMIC. The interest in research on recovery from SMI in LMICs is relatively new. A scoping review exploring the recovery of people living with SMI in LMICs (Gamieldeen et al., 2021) found similarities but also contextual differences in how stakeholders from high-income countries and LMICs frame personal recovery from SMI.

There is a shortage of research on service provider perspectives of recovery from SMI in Africa. In Nigeria, a qualitative study conducted with 312 doctors across eight health institutions found that provider stigma was a barrier to recovery (Adewuya & Oguntade, 2007). A qualitative study conducted in Ethiopia revealed that healthcare workers favoured a biomedical approach to recovery, while other stakeholders saw medication as only one care component (Mall et al., 2017). A qualitative study exploring social worker perspectives of recovery from SMI was conducted in Tshwane, South Africa, revealed a lack of knowledge and skills around recovery-oriented practices, a biomedical focus on illness and deficits, and stereotypical attitudes towards mental illness, which influenced practice (Bila, 2019). Research indicates that the attitudes of healthcare providers (Egbe et al., 2014) impede recovery, and this needs to be better understood (Egbe et al., 2014). Yet perspectives of recovery from SMI from a multidisciplinary team perspective have rarely been reported. Addressing this gap is important as providers from different disciplines may have different views on illness and recovery. This paper aims to explore the diverse views of a range of healthcare providers in the public health and non-profit organisation (NPO) sectors on (i) their understanding of recovery, (ii) the services in the Western Cape that support recovery and (iii) the barriers and facilitators to recovery.

4.4 Method

This paper adheres to the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007). In this qualitative, descriptive study (Kim et al., 2017; Lambert & Lambert, 2012; Neergaard et al., 2009; Sandelowski, 2010), we used the

framework method (Gale et al., 2013; Ritchie & Spencer, 2002) as it is a pragmatic approach to systematically analyse qualitative data. This study was executed by the first author (FG) and supervised by the co-authors (KS, RG and BM).

4.4.1 Study context

Cape Town, which includes a large area outside the city centre, is a densely populated city in the Western Cape Province. The outer area is referred to as the Cape Flats. During apartheid, people designated as Black and Coloured (Erasmus, 2000) were forcibly removed from their homes and relocated to the Cape Flats, which is characterised by high levels of violence, crime, and poverty (Bowers-Du Toit, 2014). Specialised mental health services in the Western Cape Province of South Africa are rendered from three psychiatric hospitals: Valkenberg, Lentegeur and Stikland Hospitals. These hospitals each cater for different parts of the Cape Flats. MHSUs with an SMI are often referred directly to these psychiatric hospitals for interventions (Lund, Oosthuizen et al., 2010). Once admitted, they are treated by multidisciplinary team (MDT) members. MHSUs are discharged from the hospital to the outpatient service of the admitting tertiary hospital. After that, they are discharged and collect their psychotropic medication from their closest community health centre (CHC). In Cape Town, a few NPOs are offering community-based mental health services to MHSUs. These NPOs are located on or close to the premises of the psychiatric hospitals and not on the Cape Flats, where many MHSUs live. The NPO services provide supported living options, day programmes and in-hospital activities not included in the hospital rehabilitation programme. These NPO-run services are staffed by health professionals, including social workers, registered counsellors, occupational therapists, auxiliary workers and MHSUs.

4.4.2 Participants

All service providers and service managers in the public mental health and NPO sectors involved in providing services for people with SMI were eligible for participation in the study. Service providers and service managers were identified using purposive sampling, and maximum variation was sought to ensure that stakeholders at different levels of service and emanating from a range of public health and NPO sectors were included. Participants included service managers, heads of institutions, multidisciplinary team members and community-based service providers. Participants trained as health professionals included psychiatrists, occupational therapists, social workers, psychologists and nurses. All participants who were approached agreed to participate. In total, 17 participants were recruited for the study.

4.4.3 Procedure

The interviews and focus group discussions (FGDs) (Bradshaw et al., 2017) were conducted by the main researcher (FG), a female occupational therapist from the Cape Flats with experience in conducting qualitative research in mental health. Potential participants were contacted via email, informing them of the study and inviting them to participate. A convenient time and location were identified to conduct the interviews and FGDs, each of which ran for one hour. Eleven individual interviews were conducted, and participants were interviewed once only. Additionally, two FGDs were held for participants, affiliated with the same organisation, who were unable to meet individually. One FGD had two participants, and the other had four. This pragmatic approach to data collection allowed for flexibility in FGD to accommodate participants' availability in their natural service provision settings (Bradshaw et al., 2017). Having a smaller group allowed for rich participant discussion, which was guided by FG (Gill et al., 2008; Morgan, 2012; Ritchie & Spencer, 2002). An interview guide ([Appendix I](#)) was used (Bradshaw et al., 2017), and participants were invited to share their views on (a) the mental health services they offer to MHSUs; (b) their understanding of clinical vs personal recovery; (c) available services for SMI; (d) accessibility of services; (e) caregiver inclusion in services; and (f) benefits and gaps in current services. All participants provided written informed consent before inclusion in the study ([Appendix J](#)). The interviews and FGDs were conducted in English, in a private room at the participants' workplace. The discussions were audio-recorded and transcribed verbatim. FG made field notes during and after each interview and FGD. Each participant received a USB storage flash drive to compensate for their time. This study adheres to the tenets of the Declaration of Helsinki. Ethical approval for the study was provided by the University of Cape Town's Faculty of Health Sciences Research Ethics Committee (HREC 655/2018) ([Appendix K](#)) and the Western Cape Government Health Research Committee (WC_201902_010) ([Appendix L](#)).

4.4.4 Data analysis

NVivo12 software aided data analysis. The framework approach allowed us to analyse the data in a systematic manner (Gale et al., 2013). The five key stages of framework analysis were followed, namely: (i) familiarisation with data, (ii) identifying a thematic framework, (iii) indexing, (iv) charting, and (v) mapping and interpretation of the data. The analytical framework consisted of codes and categories that were developed from the research question and its key concepts, and this was used to sift, chart and sort the data (Ritchie & Spencer, 2002). The coding framework developed was based on the research questions. The initial coding and identification of preliminary categories and themes were conducted by the first author (FG). After that, the first and second author (KS) familiarised themselves with the data and developed a thematic framework. The

framework was then used to analyse the data deductively. FG and KS then coded the first five transcripts independently. The two authors met regularly to refine the codes and gain consensus to establish an intercoder agreement (Creswell & Poth, 2018). FG continued coding the remaining eight transcripts. Coding continued until no new information emerged from the transcripts. Once themes were identified, member checks were done, allowing participants to comment on the interpretation of the data (Nowell et al., 2017). FG emailed the themes to participants for their comments and feedback. Member checking did not yield new information. As a reflexive practice, FG kept a research journal to document her thoughts and views on participants' personal recovery during the interview and coding process.

To ensure trustworthiness, FG employed reflexivity, peer debriefing, and an audit trail to promote the quality, authenticity, and truthfulness of findings. As part of peer debriefing, FG engaged with a colleague who was not involved in the study to discuss the research process, data interpretation and emerging findings. These engagements challenged FG's thinking, strengthened reflexivity, and exposed FG's assumptions or biases (Creswell & Poth, 2018). After coding was complete, FG met with colleagues in a PhD programme group where she presented the themes and categories. These colleagues questioned FG's reasoning to help her identify blind spots and overlooked patterns. This external feedback on analysis helped with the credibility of the research.

To ensure dependability and confirmability, FG maintained an audit trail. This audit trail included detailed documentation on methodological decisions, interview protocols, coding frameworks, NVivo memos and notes on theme development (Creswell & Poth, 2018).

4.5 Results

The demographic characteristics of the study participants are described in Table 4.1. In total, 17 service providers agreed to participate in interviews and FGDs. The following health professionals were represented: occupational therapists (3); social workers (5); psychologists (2); psychiatrists (2); and nurses (2). Two participants were community rehabilitation workers, and one was a volunteer with a finance background. Of the 17 participants, nine were employed in the NPO sector; the rest were employed in the public health sector. In terms of gender, three participants were male. The majority of participants were female ($n=14$, 82%). Regarding race and religion, the 17 participants identified as follows: Coloured ($n=9$), White ($n=6$), Black ($n=1$), and Indian ($n=1$). Most participants indicated that they were Christian ($n=12$). Four participants said they were Muslim; and one said she was Jewish.

Table 4.1

Demographic Characteristics of Participants (N = 17)

No.	Participant ID	Gender	Race	Religion	Profession	Sector
1	OT 1	Female	Coloured	Islam	Occupational Therapist	Health
2	OT 2	Female	Coloured	Islam	Occupational Therapist	NPO
3	OT 3	Female	White	Christianity	Occupational Therapist	NPO
4	SW 1	Female	White	Christianity	Social Worker	Health
5	SW 2	Female	White	Jewish	Social Worker	NPO
6	SW 3	Female	Coloured	Islam	Social Worker	NPO
7	SW 4	Female	Coloured	Christianity	Social Worker	NPO
8	SW 5	Female	White	Christianity	Social Worker	NPO
9	P 1	Female	Coloured	Christianity	Psychologist	Health
10	P 2	Female	Coloured	Christianity	Psychologist	Academia
11	D 1	Male	White	Christianity	Psychiatrist	Health
12	D 2	Male	Indian	Islam	Psychiatrist	Health
13	N 1	Female	Coloured	Christianity	Nurse	Health
14	N 2	Male	Black	Christianity	Nurse	Health
15	C 1	Female	Coloured	Christianity	Community Rehabilitation Worker	NPO
16	C 2	Female	Coloured	Christianity	Community Rehabilitation Worker	NPO
17	V 1	Female	White	Christianity	Volunteer manager	NPO

Results are reported according to the three major themes identified in the framework analysis: 1) delineating recovery, 2) available services supporting recovery from SMI in the Western Cape, and 3) facilitators and barriers to personal recovery within services. Quotes are attributed to participants using the following abbreviations: Social workers (SW), Psychologists (P), Psychiatrists (D), Occupational therapists (OT), Nurses (N), Volunteer managers (V), and Community rehabilitation workers (C).

4.5.1 Delineating recovery

When asked about the definition of recovery, the importance placed on personal and clinical recovery depended on the providers' work setting. Service providers indicated that health services favoured clinical over personal recovery. According to several service providers (from different professions), focusing on clinical recovery allowed them to measure MHSUs' progress objectively, especially while MHSUs were in the psychiatric hospital:

The clinical things are given because this is a psychiatric hospital; it is the clinical model. It is a medical model. It is about medication and symptoms, that is almost like the baseline. (SW3)

Clinical recovery was linked to MHSUs' mental state and their behaviour: "if they adhere to their medication, take it on time, and they actively participate in groups, maybe then they can recover" (C1). According to service providers, clinical recovery starts in the hospital, where the focus is to give medication and intervene to alleviate MHSUs' acute symptoms:

To get a person clinically well has to be our priority as a [psychiatric] hospital. That is what we are here for. And if it is medication, then we must push that and support it because, I mean, I believe in pot plants, and I believe in nice duvets, but I do not think that makes sense alone when you are hearing things, seeing things and feeling at your most disconnected as a human can ever feel. (P1)

According to these providers, personal recovery followed clinical recovery and was viewed as an extension of clinical recovery that started with MHSUs understanding their diagnosis.

And I think an integral part of that actual recovery starts with the client in terms of insight, in terms of intellectually and on a personal level having the insight into exactly what your diagnosis is about. How your diagnosis works, your chances

for recovery and then coupled with internal motivation and all of those things.

(OT2)

All service providers expressed the sentiment captured by one service provider who said that the journey of personal recovery involves a “slow, complex and cyclical process”. Service providers associated personal recovery with the following: the ability to set goals, engage in self-care, exercise choice and autonomy, and access resources. While service providers believed in the importance of personal recovery, this concept was not embedded in the hospital’s services or communicated in the physical environment of the hospital:

So, the other thing about recovery is accepting the complexity. It is realising that as important as your therapy or medication is, looking after what you eat, doing a bit of exercise and having friendships and relationships and working on something important to you. So, clinical recovery is seen as this endpoint with a whole lot of measurables. Recovery with a capital R is how I like to refer to personal recovery. (D1)

Your journey is a long journey, you understand, we cannot do it all here, but we start putting back the pieces. (N2)

Engaging in the journey of personal recovery “is about finding meaning and purpose in your life, and that is an endless process”. Service providers described some indicators of personal recovery. MHSUs highlighted vital features such as “quality of life” and “being an active member of the community”. According to the service providers, indicators of recovery varied, and they acknowledged the reality of relapses along the way:

So recovery for me is probably equal to someone having a good quality of life, maintaining a sense of commitment towards sobriety, and being an active member of society. Certainly, the need to have a family, to be loved, and to be independent is still something that they view as significant for them. They do recover, which means that they will, at a certain point, experience symptoms again. (D2)

4.5.2 Lack of available services supporting recovery from SMI in the Western Cape

According to all participants, the public health services available for MHSUs tended to focus primarily on clinical recovery, irrespective of whether the services are offered at tertiary, secondary or primary levels of care. The participants highlighted that services within psychiatric hospitals were limited to medical stabilisation:

So, psychiatric treatment does not think beyond the stabilisation, does not think how is this person going to get back into work and support themselves? So we [are] dealing with stabilisation, but the person does not live in a psychiatric hospital; they are only there for stabilisation. They have to go out into their family, community and work, but where is the further treatment and support? It is basically absent. (OT3)

Service providers reported that the physical environment of the hospital prioritizes practical safety precautions to minimise the risk of bodily harm for the MHSUs over creating a healing space conducive to personal recovery:

Often when you come into the environment, there is nothing. There is a table, and there is a chair, and they try to give the heaviest chair because they are assuming that the patient is going to pick up this chair and throw it at somebody. So, furniture everything is designed for safety, which is something big that you need to consider. (OT3)

Tertiary hospitals also experience pressure for space when they have MHSUs needing urgent admissions while they cannot discharge others. As a result, service providers used the phrase “bed blockers” when referring to MHSUs stuck in the hospital system. The reasons for this varied:

We were saying to our bosses [that] there is an elephant in this room, and the elephant is our bed blockers, our increasing burden, our patients staying longer in our hospital because families do not want them. There are no families. (P1)

What I have heard about Valkenberg is that substance use is a massive problem in terms of why people get admitted, drug-induced psychosis and things. I have heard in the past resentment from the staff in the wards. It is like they are taking bed space from people who is just an ordinary schizophrenic who needs that

bed. There is some resentment. 'It is your fault that you are here' kind of stuff.

(SW3)

Participants indicated that the integration of mental health into primary levels of care “requires investment in mental healthcare at primary level, and there is no investment”. Once discharged, services available to MHSUs were reported to be primarily limited to collecting medication from a clinic at the primary healthcare level, where much time is spent waiting to be attended to:

The story of arriving there at 4 o'clock in the morning because otherwise, you are not going to be seen that day, I hear over and over again. (D1)

Once discharged from the psychiatric hospital, those MHSUs with an SMI who are at risk of relapse are seen in their homes by the assertive community team (ACT). A participant who was previously on the ACT team shared that, “the focus was trying to manage compliance to medication because obviously medication was a big part of why patients were relapsing”. Thus, according to participants, the focus of this service was to facilitate medication adherence:

The main function was the home visit programme, so we went to the client's home, assess the home circumstances and the families and then looked around medication compliance. (OT1)

According to a few stakeholders, the non-profit sector offers personal recovery-focused services for “people who have been formally diagnosed with mental conditions like schizophrenia, depression, mood disorders”. Services provided by NPOs have a range of elements that service providers see as contributing towards personal recovery. One service provider shared their service package:

Recovery is such a multi-faceted thing. Our services range from practical support, like clothing and food parcels and bus-fare through to life skills type projects, like cooking and projects that help with relaxation, leisure, stress management, perhaps art, and sport. Then we have our skills development side of things, and that, again is a multifaceted space. They all have a thread running through them of the sort of basic things about hope for recovery, hope for something better, communication, social engagement and interaction, self-esteem, and confidence building; there is a common thread. (SW3)

4.5.3 Facilitators and barriers to personal recovery

The participants highlighted several facilitators and barriers to personal recovery. These factors varied and included: i) service-related barriers; and ii) difficulties with MHSUs' community reintegration.

4.5.3.1 Service-related barriers

To begin with, participants identified services' focus on clinical recovery as a significant barrier to personal recovery. Service providers lamented that services lacked a "recovery-based focus", and they noted a shortage of "intersectoral collaboration and partnerships" that could extend their work beyond clinical recovery. This is illustrated in the following quote:

We only do the stabilisation and the other things; then outside of the multidisciplinary team is all the sectors – social services, education, and labour. All those other departments speak to the recovery of the person with mental illness in the community [but] we have not got there yet. (D2)

Second, the lack of consistent, long-term relational support offered to MHSUs by service providers acts as a barrier to personal recovery. According to service providers, support through long-term relationships between MHSUs and service providers was essential, especially for MHSUs living in supported living environments with limited family contact. In these environments, service providers can promote personal recovery through the therapeutic relationships they have with MHSUs:

But it's also because psychiatric patients, they want that. They want that reliable person. They want the consistency. They don't want to have to repeat their story every time. (N1)

Third, service providers shared that a lack of flexibility and openness to MHSUs' cultural beliefs can serve as a barrier to personal recovery. Providers described how, "in Xhosa culture, if you get ill and if you do strange things and behaviours, these symptoms could be directly correlated with schizophrenia, but it is viewed that the ancestors are calling you to become a sangoma" [traditional healer]. Service providers, therefore, need to discern between cultural practices, cultural beliefs and symptoms of mental illness. For example, one participant, an occupational therapist, shared:

So, if the guy says, 'I am becoming a sangoma', I will ask him: where are you going to practise, and who are you going to practise on? If they can give me detail, then for me, there is a basis of truth. If there is no detail except, 'I am going to kill

everyone with my hands and heal everyone’, then I am like, okay, delusion, right?

(OT1)

Consulting with colleagues was seen as an opportunity to expand service providers’ understanding of the MHSUs’ cultural context. Given the cultural nuances in the way symptoms are expressed and the cultural beliefs and understandings regarding the causes of these symptoms, many service providers highlighted the importance of consulting with colleagues when their backgrounds differed from that of the MHSUs they were seeing.

Our Xhosa colleagues would say his family is very traditional, so it would not be outside the cultural norm to learn to become a sangoma. So, we have to see and do a little more investigation, and if it was appropriate, it isn’t a delusion. (OT1)

4.5.3.2 Difficulties with community reintegration

Service providers shared their perceptions of facilitators and barriers to personal recovery that MHSUs experienced once discharged from psychiatric services.

First, while the family was part of the MHSUs support network, service providers described how family dynamics and “toxic relationships that often exist” impacted on recovery and caused “an inevitable relapse” if not dealt with:

And then, I met the family, and I realised the illness was not limited to the patient. So, people exist in systems and invariably, not invariably, but usually, the entire system is dysfunctional. (D1)

The families are not always supportive; they’re problematic families. So you don’t get the family that is supporting you in taking your medication or ensuring that you don’t go back to the substances or, you know, try and support recovery for that person. (SW1)

Second, service providers highlighted unhealthy community environments as un conducive to personal recovery, stating that MHSUs “are going straight back to the community where all their problems started”, and there is a recognition that family holidays can also hinder recovery:

Our patients will say to us: ‘I do not want to go home for Christmas because I know what is going to happen. Everyone is drinking or taking drugs. I will rather go [home] after Christmas’. (SW3)

Third, socio-economic factors such as a lack of financial control, dependence on social grants and unemployment were perceived as some of the factors influencing MHSUs' personal recovery. Service providers are mindful that MHSUs' financial contributions from disability grants are essential to their household's economic survival, and they ask themselves: "Does the family depend on the grant?" as a determiner of whether the family wants the MHSU at home:

I think for people who are fairly impoverished, the grant is quite an important source of income for families. But that is often the sole income in that house.
(SW4)

Service providers report on the dilemma faced by MHSUs when they need the income but are not allowed financial control over their social grant. For some MHSUs, not claiming eligibility for social assistance keeps the MHSUs and their family safe:

He says: 'if I get my disability grant, my family will take it away from me, and they will buy drugs with the money'. So he does not want a disability grant. (V1)

Fourth, for those MHSUs not in receipt of a social grant, service providers reflected on the "struggle with unemployment" that MHSUs faced when they are on their personal recovery journeys and want to reintegrate back into their communities:

So many of our clients get to a point where they are clean; they are doing what they need to do, but now what? Is this a worth it sort of thing? 'So I am not employed, I do not have experience, no one wants to hire me, I am just sitting around doing nothing', and there is that lack of integration back into society and the community. And that is where we struggle the most, I think. (D2)

Fifth, comorbid substance abuse was reported to impact personal recovery as it influenced how MHSUs managed themselves. For example, the comorbid diagnosis contributed to "the very high readmission rate because of the substances". One participant indicated that "60% of our admissions" were due to substances, and relapses occurred "between six to 18 months" after discharge. One of the causes of this relapse was MHSUs' inability to cope with difficulties they faced and who then "self-medicate when they are getting unwell then they will use [substances] again". This was reiterated in the following quote:

They are self-medicating the feeling away. 'So, tik makes me happy, weed makes me happy', and in a clinical perspective, I find that the instant gratification of that

outweighs the consequences of coming back to the hospital and getting sick again. (OT1)

Finally, service providers shared that the personal recovery of men is hindered by how they manage their problems or how society views their behaviours. Service providers suggest that “males take longer to present themselves, and that’s why they take longer to recover”. The personal recovery of men is also compromised by societal norms around masculinity and what it means to be a man, which says that “males are not supposed to have problems”. The stigma attached to having an SMI also impedes recovery, as all behaviours displayed by male MHSUs are attributed to their SMI:

Men do not access help. Men with mental illness very seldom go, ‘I need help’. They get drunk and beat someone up or get hooked on tik and becomes psychotic, and so on. (D1)

It is expected for a female to have all the emotions and be hyper and feisty. But once you are a male with mental illness, you raise your voice, and the police will come and fetch you. And we have seen clients being readmitted with no psychotic features. (OT1)

4.6 Discussion

This study resulted in several significant insights into how South African healthcare providers perceive personal recovery from SMI. First, results highlighted that, although participants valued personal recovery, this is rarely addressed in available services which largely target clinical recovery. Second, personal recovery was viewed as a cyclical, complex process that takes place over time. Finally, barriers and facilitators to personal recovery from SMI in the South African context were highlighted.

To begin with, the findings echo the predominant focus on clinical recovery in healthcare settings in other parts of the world (Le Boutillier et al., 2015; Slade, 2009), including LMICs (Adewuya & Oguntade, 2007; Bila, 2019; Humphries et al., 2015; Rashed, 2015). Although service providers are aware of personal recovery, they focus on clinical recovery. Service providers manage competing demands concerning clinical versus personal recovery-focused interventions. This is influenced by the priorities of their working environments which favour a biomedical perspective because of resource constraints within the health system. In a systematic review exploring clinician and manager understanding of recovery-oriented mental health practice (Le Boutillier et al., 2015), service providers were seen as the health experts shaping their interventions and favouring a focus on stabilising or improving mental state through the use of

medication. In LMICs, mental health service providers are in short supply and are predominantly based at specialised psychiatric facilities (Eaton et al., 2011). In South Africa, the public mental health budget makes up 5.0% of the public health budget and 86% of mental health care expenditure goes to inpatient care (Docrat et al., 2019; Petersen et al., 2019).

Despite efforts to integrate mental health into primary healthcare services in LMICs, like South Africa, progress remains slow due to existing infrastructure, budget and human resource shortages (Eaton et al., 2011). The limited resources allocated to primary levels of care results in a focus on managing SMI through psychotropic medication (Docrat et al., 2019). Although all the service providers in the study supported the South African Mental Health Policy and Strategic Plan 2013–2020 (Dept of Health, 2014) that advocates for mental health to be integrated into primary healthcare, they reflected upon the lack of financial and human resources to offer these services. Challenges faced by mental health services in the primary care setting relate to inadequate infrastructure, poor organisation, shortage of medication, insufficient staff with mental health training, limited out-patient services for people with SMI, stigma towards people with SMI, long waiting times, lack of rehabilitation and mental health promotion services, limited psychosocial services and insufficient community-based services (Baker & Naidu, 2020; Sorsdahl et al., 2020; Wakida et al., 2018). Collaborative care models for common mental disorders have been explored to address these gaps, but the capability to implement these models varies considerably among primary care facilities and is driven mainly by attitudinal and resource differences across settings (Myers et al., 2019). Further, the application of these care models for managing SMI needs to be investigated, especially in light of specialist resource shortages and the proposed benefits of utilising existing human resources within communities. Collaborative efforts across levels of care provide opportunities to transform mental health services and promote personal recovery. Collaboration with diverse stakeholders, including outside the health sector (Fitts et al., 2020), emerged as a way to expand mental health services.

Service providers described personal recovery from SMI as a cyclical, complex process that takes place over time. These findings are consistent with definitions of personal recovery as described in previous research conducted in HICs and LMICs (Chen et al., 2018; Güner, 2014; Leamy et al., 2011; Llewellyn-Beardsley et al., 2019; Mathew et al., 2018; Nxumalo Ngubane et al., 2019; Rashed, 2015; Slade & Longden, 2015; Soygür et al., 2017; Subandi, 2015). Although service providers in this study supported personal recovery as a concept, they did not clarify how mental health services at primary and tertiary levels of care could support personal recovery from SMI in practice, given that their focus was on biomedical models of care. Instead, they saw clinical recovery as part of, and sometimes a pre-requisite for, personal recovery. As a result, service

providers prioritise clinical over personal recovery resulting in few resources being allocated to support personal recovery. An area of further consideration is the binary manner in which clinical and personal recovery is viewed. In South Africa, as in other LMIC countries, personal recovery starts once the MHSU is discharged back into their communities (Chen et al., 2018; Humphries et al., 2015; Nxumalo Ngubane et al., 2019; Rashed, 2015; Subandi, 2015), and not while they are in hospital. It would thus be beneficial if service providers were trained to support personal recovery.

Given the limited availability of personal recovery-focused services in the community, many people with an SMI experience multiple relapses. Service providers described high relapse rates amongst MHSUs and attributed relapses to crisis discharges, pressure for inpatient beds and non-adherence to medication (Botha et al., 2010). A recent study reported that 24% of mental health inpatients are readmitted within three months of a previous admission (Docrat et al., 2019). Frequent relapses are costly and result from various barriers MHSUs face, which impede their recovery. Some of the reasons for frequent readmissions have been cited in the literature. They include premature discharges, insufficient community resources, poor integration of mental health into primary healthcare, non-adherence to medication, homelessness, substance abuse, inadequate family support and diverse cultural responses to SMI (Botha et al., 2010; Habtamu et al., 2015; Jacob & Coetzee, 2018; Lazarus, 2005; Smartt et al., 2019).

Service providers shared their views on some of the environmental and contextual barriers to personal recovery faced by MHSUs when returning to their communities. These included gender-based norms related to societal expectations of roles and responsibilities that differed between males and females, stigma, family conflict, substance abuse, lack of long-term relational support, lack of money and unemployment. A scoping review on intersectional inequalities in mental health in HICs (Fagrell Trygg et al., 2019) included 20 studies that considered gender, socio-economic position, race, ethnicity, and sexual orientation. The findings suggest that intersectional inequalities in mental health across different population groups and settings hinder recovery. This is not surprising, given the available literature indicating that social determinants of mental health play a role in personal recovery. In a systematic review of reviews conducted by Lund et al. (2018), social determinants of mental disorders were mapped according to the Sustainable Development Goals (SDGs) endorsed by all United Nations member states in 2015. They included the following domains: demographic, economic, neighbourhood, environmental, social and cultural (Lund et al., 2018). The results indicated that coordinated intervention efforts between government services, civic societies and the private sector are needed when considering mental health system reforms.

Given that personal recovery includes being able to participate in everyday life and everything that holds meaning and purpose for an individual, the factors influencing recovery extend past the confines of services offered by the health sector or the abilities of an individual with SMI. A scoping review on recovery from SMI in LMICs found that social networks and supportive relationships with others facilitated social inclusion and recovery (Gamieldien et al., 2021). If personal recovery happens in the community and requires long-term relational support, then service providers must consider where and how MHSUs can access this network once they have been discharged from hospital.

4.7 Implications for future research

This is one of the first studies in South Africa looking at personal recovery from SMI. Service providers recommend that diverse stakeholders and service sectors be involved in understanding and generating opportunities for personal recovery. Given that traditional healers and religious advisors are a pathway to mental health care in LMICs, including South Africa, further exploration of traditional healers' perspectives on mental health conditions might be helpful, as their views could offer culturally grounded understandings and practices which support recovery (Burns & Tomita, 2015; Nortje et al., 2016, Sorsdahl et al., 2010). Mental health reform must be cognisant of MHSUs' social, economic, cultural and political environments, as intersectional inequalities hinder personal recovery and community integration. Promoting personal recovery requires policies that advocate for and support the development of recovery-based mental health services across the continuum of care.

4.8 Strengths and limitations

A diverse range of mental health professionals was recruited for this study from the government-funded health services and the NPO sector. The study aimed to provide a detailed description of service providers' understanding of the complex nature of recovery from SMI. The findings offer focused insights into service providers' views on recovery, along with possibilities for future research. We identify several limitations. First, although the sample included service providers from different disciplines, participants were likely not representative of mental health service providers in other sectors or other parts of South Africa. Second, the sample size was small. Third, we did not observe any practice; all findings were based on service provider reports. Fourth, the definition of recovery is contested, and the sample recruited might have had more knowledge of personal recovery than providers in other levels of health care.

4.9 Conclusion

This study contributes to the growing interest in understanding service provider perspectives on personal recovery from SMI in LMICs. The findings highlight the distinction drawn by service providers regarding clinical and personal recovery. This distinction is primarily influenced by models of care and human resource constraints in mental health service delivery. While participants focused on clinical recovery, they acknowledged the importance of personal recovery, sharing their views on the multiple systemic challenges and contextual influences faced by MHSUs on their journeys towards personal recovery. Given the constraints in mental health service delivery, innovative interventions, such as peer support (Chien et al., 2019), collaborative care models (Petersen et al., 2019), task sharing (Brooke-Sumner et al., 2017; Hanlon, 2017) and telehealth (Medalia et al., 2020) offer opportunities to extend the reach of services.

Chapter Five: Mental Health Service Users and Their Caregivers' Perspectives on Personal Recovery from Severe Mental Health Conditions in Cape Town, South Africa: A Qualitative Study¹²

5.1 Chapter outline

In Chapter Four, service provider perspectives on recovery from severe mental health conditions (SMHCs) in Cape Town, South Africa, were presented. As mentioned in previous chapters, there needs to be more research involving persons with lived experience of SMHCs in LMICs. This chapter addresses this gap and meets Objective Three of this thesis. The qualitative, descriptive study exploring what recovery is for men with SMHCs and their caregivers is presented here as a publication.

5.2 Abstract

Severe mental health conditions (SMHCs) significantly contribute to the global disease burden. In low- and middle-income countries (LMICs) like South Africa, the long-term impact of SMHCs on individuals and their families is serious. However, mental health services focus on clinical recovery, with little attention given to the personal recovery needs of mental health service users (MHSUs) and their caregivers. The CHIME framework outlines five domains characterising personal recovery: connectedness, hope and optimism about the future, identity, meaning in life, and empowerment. This qualitative, descriptive study sought insights from male MHSUs and their caregivers on their perspectives of personal recovery from SMHCs. Four male MHSUs and three of their caregivers were purposively selected from Cape Flats communities in the Western Cape. Data were collected using visual participatory methods, including photovoice, life graphs, community maps, and photo-elicitation interviews with MHSUs. In addition, semi-structured interviews were held with caregivers. Data were thematically analysed, and two main themes emerged: Finding meaningful participation and Affirming agency. These themes describe how diverse contextual, socioeconomic, political, cultural, demographic, and spiritual factors help and hinder personal recovery. MHSUs and their

¹² As per the DDB recommendations for including publications in the dissertation, this chapter includes the following publication, verbatim: **Gamielien, F., Galvaan, R., Myers, B., & Sorsdahl, K. (2023).** Mental health service users and their caregivers' perspectives on personal recovery from severe mental health conditions in Cape Town, South Africa: A qualitative study. *Journal of Psychosocial Rehabilitation and Mental Health*, 1-19. <https://doi.org/10.1007/s40737-023-00341-8>

caregivers sought support from mental health non-profit organisations (MH-NPOs) because of stigmatising attitudes from their communities. MH-NPOs provided MHSUs with long-term relational support and opportunities to build their capacities, which helped them access living, learning, working and socialising opportunities. Understanding the diverse needs of MHSUs and including MH-NPOs in scaling up community-based mental health services in LMICs will enable more accessible services that support personal recovery.

5.3 Introduction

Severe mental health conditions (SMHCs), including schizophrenia spectrum disorders, psychotic disorders, and bipolar affective disorders, contribute significantly to the global disease burden (Charlson et al., 2018; Rehm & Shield, 2019). In low- and middle-income countries (LMICs) such as South Africa (SA), many people with SMHCs are undetected and do not receive the treatment they need (Demyttenaere et al., 2004; Kohn et al., 2004). This treatment gap is further exacerbated because people living with SMHCs require complex interventions to address their social and economic difficulties (Charlson et al., 2018). Additionally, the long-term impact on individuals and their families is substantial (Docrat et al., 2019; Vigo et al., 2016). In the public sector, mental health care for SMHCs is rendered predominantly through inpatient specialist psychiatric services (Docrat et al., 2019), with limited availability of community services. In addition, available services tend to focus on clinical recovery, giving little attention to the personal recovery needs of mental health service users (MHSUs) (Gamieldien et al., 2022; Kleintjes et al., 2013).

Both clinical and personal recovery are critical components of mental health service provision. However, clinical recovery tends to be limited as it focuses on treating SMHCs symptoms, with the clinician positioned as the expert (Gamieldien et al., 2022; Llewellyn-Beardsley et al., 2019; Rennick-Egglestone et al., 2019; Slade, 2009). While personal recovery values clinical recovery (Slade, 2009), it focuses on experiences and actions taken to live a meaningful life with SMHCs (Anthony, 1993; Chamberlin, 2007; Deegan, 1988). Furthermore, personal recovery positions MHSUs as experts by experience who should inform the design and implementation of mental health services (Kakuma et al., 2010; Ørjasæter & Almvik, 2022; Sullivan et al., 2017). To describe the complexity of the recovery process better, several frameworks have been developed. One such framework is the widely endorsed CHIME Framework (Leamy et al., 2011; Leendertse et al., 2021).

The CHIME Framework was conceptualised by Leamy et al. (2011) and includes five domains used to organise the dimensions of recovery. The CHIME framework consists of a network of interlinking concepts to operationalise recovery (Leamy et al., 2011;

Leendertse et al., 2021; Vogel et al., 2020). These domains are connectedness, hope and optimism about the future, identity, meaning in life, and empowerment. CHIME was developed following a systematic review and narrative synthesis on conceptualisations of personal recovery from mental illness, which included 97 papers from 13 high-income countries (HICs). Leamy et al. (2011) acknowledge the limitations of CHIME and its applicability in diverse settings. They advocate for more research with culturally diverse ethnic groups because the black and minority ethnic (BME) groups included in their study had different perspectives on recovery. The emphasis placed on family and community involvement, spirituality, and overcoming stigma highlights that culture-specific factors in BME groups differ from the views on recovery from non-BME (Brijnath, 2015; Leamy et al., 2011; Van Weeghel et al., 2019) or HIC perspectives. There is a need to understand better how contextual barriers and access to resource influences recovery in LMICs.

Research on personal recovery has emerged mainly from the perspectives of HICs, with few descriptions emerging on personal recovery from LMIC perspectives (Gamieldeen, Galvaan, Myers, et al., 2021). A recent scoping review (Gamieldeen, Galvaan, Myers, et al., 2021) emphasised the relational aspect of personal recovery for MHSU from LMICs. This was less salient in reviews of personal recovery for MHSUs in HICs (Mathew et al., 2018). Although numerous studies advocate for a greater understanding of how personal recovery occurs for MHSUs in LMICs, including in South Africa (De Wet & Pretorius, 2020; Docrat et al., 2019), studies on the lived experience and contextual factors impacting MHSUs' personal recovery journey remain sparse (Gamieldeen et al., 2022). There has been little exploration of MHSUs' experiences, or the systemic and socio-economic barriers MHSUs face to personal recovery in their communities (Gamieldeen, Galvaan, & Duncan, 2021; Gamieldeen et al., 2022). These understandings are important to build personal recovery assets and services which address the diverse needs of MHSUs.

Given that SMHCs are characterised by gender differences and behavioural problems that vary between men and women (Vázquez-Reyes et al., 2021), adopting a gendered perspective to explore personal recovery may help tailor personal recovery supports for the different needs of men and women (Smith et al., 2018; Vázquez-Reyes et al., 2021). Gender is important to consider since men are less likely to seek help for mental health difficulties, resulting in an under-utilisation of services (Sagar-Ouriaghli et al., 2019). Although specialist psychiatric hospitals in SA allocate more emergency inpatient beds for men, how men with SMHCs navigate their recovery once they return to their communities has not been explored (Botha et al., 2020). This impacts our ability to design interventions to support the personal recovery journeys of men with SMHCs. This study explored and described the views on personal recovery and access to

services from the perspectives of men with SMHCs and their caregivers in Cape Town, South Africa.

5.4 Study context

This study was situated in Cape Town, a densely populated city in South Africa. Cape Town is a diverse city which includes the poorly resourced Cape Flats, a vast region outside the city centre notorious for a high prevalence of poverty, gangsterism, and violence (Bowers Du Toit, 2014; Mncube & Madikizela-Madiya, 2014). During apartheid, people designated as Black and Coloured¹³ were forcibly moved to the Cape Flats. Due to the demand for psychiatric beds, MHSUs residing on the Cape Flats have poor access to the three psychiatric hospitals that provide specialist, inpatient services for SMHCs in the Western Cape (Docrat et al., 2019). After being discharged from the hospital, MHSUs receive follow-up clinical care through psychiatric hospital outpatient departments or local community health centres (CHCs). MHSUs receive their psychotropic medication at these sites and are monitored for medication adherence. They do not receive any other services at this level of care as efforts to integrate mental health into primary healthcare remain slow (Jacob & Coetzee, 2018). To address this treatment gap, a few mental health non-profit organisations (MH-NPOs) offer community-based mental health services. Staff at these MH-NPOs include health professionals, auxiliary workers, community members and MHSUs. MH-NPOs provide supported living, supported employment, daily activity-based programmes, support groups and in-hospital activities not included in the hospital rehabilitation programme (Grobbelaar, 2010). These services are inaccessible to the majority of MHSUs since they are mostly situated in areas that are far from the communities where MHSUs live. Those MHSUs who access the services benefit from the long-term relational support that they need once discharged from the hospital (Gamielien et al., 2022).

5.5 Research design

This study uses a qualitative, descriptive research design (Bradshaw et al., 2017; Lambert & Lambert, 2012; Neergaard et al., 2009) to explore recovery from SMHCs from the vantage point of male MHSUs from Cape Flats communities. Photovoice (Wang & Burris, 1997) was implemented as a visual participatory method to provide insight into user experiences. Visual participatory methods are recognised in public health research as helpful for co-producing knowledge in under-researched areas and with

¹³ Coloured identity refers to people with mixed heritage and creolised identities shaped and re-shaped by historical practices in South Africa. Erasmus, Z. (2000). Recognition through pleasure, recognition through violence: Gendered coloured subjectivities in South Africa. *Current Sociology*, 48(3), 71-85.
<https://doi.org/https://doi.org/10.1177/0011392100048003006>

marginalised groups of people (Anderson Clarke & Warner, 2016; Cabassa et al., 2013; Lal et al., 2012; Wang & Redwood-Jones, 2001). The study reported on in this paper uses the Standards for Reporting Qualitative Research (SRQR) framework to enhance the transparency of the research (O'Brien et al., 2014).

5.6 Researcher characteristics

The first author, FG, is a woman of colour who lives on the Cape Flats. Her living experiences on the Cape Flats provided her with an intuitive understanding of the disadvantaged socio-economic communities in which participants lived. FG's professional and research experience strongly supports the need for a gendered lens on recovery from SMHCs. Her work as a public sector occupational therapist in male admission and forensic services revealed how institutional practices shape men's recovery pathways. Furthermore, her prior qualitative research has highlighted that, in the Western Cape, intermediate care facilities have been disproportionality allocated to male MHSUs who were inadequately prepared for community integration (Gamielien, Galvaan, & Duncan, 2021). These insights made FG curious about the role of gender in access to diverse services, the nature of support needed, the assumptions about recovery readiness and the influence of systemic factors on the recovery trajectories of men and women. Adding to these work experiences, her personal and professional commitment to human rights contributed to her strong belief in advocacy and self-representation of MHSUs. FG was especially interested in learning more about, and giving voice to, MHSUs' perspectives on recovery. FG's extensive work experience in the sector positioned her well for this study as she was very familiar with MH-NPOs servicing the Western Cape. She also knew some of the Programme Managers offering community-based mental health services as a result of having worked with them previously or being involved in similar networks.

5.7 Sample selection and recruitment

The following inclusion criteria were applied for purposive selection of eligible participants: (a) males aged between 18-60 years, (b) able to communicate in English or Afrikaans¹⁴ (c) diagnosed with an SMHC, (d) registered on the Public health services database, and (e) living in a Cape Flats community. Maximum variation sampling techniques (Creswell & Poth, 2018) were used to ensure the sample included diverse perspectives and a range of recovery experiences. The factors considered in maximum variation sampling were age, race, residential circumstances, employment status and

¹⁴ Due to resource constraints a translator was not involved in the study. However, this did not preclude MHSUs who spoke isiXhosa from participating as all MHSUs who were approached could communicate in English or Afrikaans.

time since relapse. MHSUs were invited to identify caregiver participants. Caregivers had to be connected to the MHSUs, and MHSUs had to consent to the caregivers' participation. An inclusion criterion was thus that the MHSU identified the caregiver as fulfilling this role in their lives.

All participants were recruited via an MH-NPO through the Programme Manager. The Programme Manager at the MH-NPO is a social worker by profession and is bound by principles of ethical and professional conduct. She identified MHSUs who met the inclusion criteria and explained the study to them. If they agreed to be contacted by FG, she contacted them telephonically and set up an in-person appointment. Participants' capacity to give consent was assessed using an informal, conversational approach drawing on the details provided in the consent form. This included checking participant's understanding of the purpose, process, risks and benefits of the study, their right to withdraw and information on how data would be used, as reflected on the consent form ([Appendix M](#)).

Of the 12 MHSUs who were eligible, four MHSUs consented to participate. Two MHSUs were not contactable at the time of recruitment. Six MHSUs declined to participate because of personal reasons upon which they did not elaborate ($n = 4$), and caregivers disapproved of their involvement ($n = 2$). MHSUs were invited to nominate their caregivers to participate in the study. Three caregivers, associated with two of the MHSU participants, agreed to participate ([Appendix N](#)). Two MHSUs did not have caregivers whom they felt comfortable nominating. A total of seven participants (four MHSUs and three caregivers) were recruited for this study.

In Table 5.1, the key characteristics of the four MHSUs and their caregivers are presented. The time that had elapsed since participants' last hospital admissions ranged between nine and 20 years. For all participants, the time graph since onset of illness also showed frequent admissions and relapses in the first few years following their diagnosis and when they were admitted involuntarily, often via the police.

At the time of the study, all participants were single. Only one participant had ever been married.

In the table, pseudonyms are used to protect participants' identities.

Table 5.1

Description of Participants (MHSUs)

Participant 's Pseudonym	Age	Age at first psychiatric hospital admission	Year of last psychiatric hospital admission (Range 9-20 years)	Living situation	Race	Employment status	Relationship status	History of Substance use	Caregivers
Patrick	50	21	2005	In supported housing with other MHSUs since 2006	Coloured	Employed as a cook in the education sector	Single, never married	Yes	Parents (Patrick's mother and father)
Globie ¹⁵	38	22	2012	In a family home on the Cape Flats with parents and siblings	Coloured	Employed as a shop assistant in the retail sector	Single, never married	Yes	Globie's mother
Siya	42	23	2008	In supported housing with other MHSUs since 2012	Black	Unemployed	Single, never married	Yes	None identified
Reggie	50	23	2000	In supported housing with other MHSUs since 2000	Coloured	Supervisor, employed in a supported employment project for adults with intellectual disabilities in the NPO sector	Single, divorced	No	None identified

¹⁵ Globe is a synonym for a lightbulb. "Globie" is a colloquial Afrikaans word for a globe. Globie is the nickname of this participant.

5.8 Procedure

Data collection was conducted by FG who has experience conducting qualitative research. The visual methods (Glaw et al., 2017) used included focused life graphs (Adriansen, 2012; Denicoff et al., 2002); production of a community map; and photovoice methods (Wang & Burris, 1997). A life graph was used to represent visually the significant events related to living with SMHCs (Adriansen, 2012; Denicoff et al., 2002). A community map is a drawing that shows places available in a sociocultural context (Sweet et al., 2018). Photo-voice methods involved MHSUs taking photos (Anderson Clarke & Warner, 2016; Cabassa et al., 2013; Wang & Burris, 1997) in their communities to express their personal recovery stories. These stories were discussed as part of a photo-elicitation interview. These methods were piloted with an MHSU (MM) on the study's advisory committee.

First, FG conducted an in-depth interview with each MHSU, during which the MHSU produced a life graph ([Appendix O](#)). By referring to the life-graph, participants were able to share important events in their lives such as these: a) onset of mental illness; b) experience of living with a mental illness; c) significant life events; d) exploration of substance use; e) their access to psychiatric services; and f) their future hopes and plans.

In the follow-up interview, participants discussed their recovery using their life graph as a prompt. After that, they were asked to develop a community map ([Appendix P](#)) in preparation for the photovoice exercise. Participants were reluctant to draw their maps in the session because they wanted more time on their own to think about crafting their maps. This led them to use the time during the session to gather their ideas and write down places of interest and to use these notes as prompts when they took their photos. The community map assisted participants with identifying the places, people, and activities that contributed to their recovery experiences. They could use this map to plan what photos to take to depict their recovery.

MHSUs captured their recovery stories using a digital camera (Wang & Burris, 1997). Before issuing the digital cameras to participants, the researcher discussed possible ethical issues that could emerge during the photovoice process, including the need to obtain consent from people being photographed ([Appendix Q](#) and [Appendix R](#)). MHSUs were shown how to use the digital camera ([Appendix S](#)). MHSUs had five weeks to take their pictures, allowing sufficient time to capture personally meaningful and contextually rich images of their recovery stories (Han & Oliffe, 2016). They brought these pictures to subsequent photo-elicitation interviews ([Appendix T](#)) where each participant explained their stories (Piat et al., 2017). MHSUs were issued digital copies

of their photographs and colour prints of their requested photos. The digital cameras were returned to FG.

FG also conducted semi-structured interviews in the homes of consenting caregivers. Using an interview guide ([Appendix N](#)), FG elicited discussion centred around living with someone with a mental illness, onset and duration of illness, access to psychiatric services for the MHSU, and MHSU and caregiver access to support in and outside of their communities. Caregivers were also asked about MHSUs' substance use histories and their (caregivers') understanding of recovery. They were probed about the factors that they thought would help or hinder recovery for MHSUs. All interviews lasted approximately one hour, were audio-recorded and transcribed verbatim. Interviews conducted in Afrikaans were translated into English after transcription. After every interview, each participant received a ZAR100 (\$6) supermarket voucher and a refreshment pack to compensate them for their time. Ethical approval was obtained from the Health Sciences Research Ethics Committee (HREC 655/2018) ([Appendix K](#)) at a large university in the Western Cape, as well as the Western Cape Province's Health Research Committee (WC_201902_010) ([Appendix L](#)).

5.9 Analysis

NVivo12 software was used to manage the data. Thematic data analysis (Creswell & Poth, 2018) guided engagement with the data. FG read the transcripts and reviewed the visual data sources to identify initial codes and preliminary themes. The second author, RG, and FG met regularly to refine the codes, categories, sub-themes and themes (Creswell & Poth, 2018; Saldaña, 2016) and reflexively analyse and interpret the data (Braun & Clarke, 2019). Themes were checked with MHSUs and their caregivers as part of member checking. FG met with participants individually after data analysis so that they could give feedback on the themes which had emerged. Participants agreed with the themes, and categories and this increased confidence in our interpretation of the data (Nowell et al., 2017). FG kept a research journal to promote reflexivity to document her thoughts and insights on personal recovery during the interview and coding process.

5.10 Results

Two main themes were identified: "Finding meaningful participation" and "Affirming agency". These two themes with corresponding sub-themes represented in Table 5.2 are discussed in detail in this section.

Table 5.2

Overview of Findings

Theme 1	Sub-theme
<i>Finding meaningful participation</i>	<i>1.1 Developing self-management strategies</i>
	<i>1.2 Securing places and activities that promote mental health</i>
Theme 2	Sub-theme
<i>Affirming agency</i>	<i>2.1 Maintaining relational support</i>
	<i>2.2 Making meaningful contributions</i>

5.10.1 Theme One: Finding meaningful participation

This theme describes how MHSUs experienced meaningful participation which supported their recovery journeys. MHSUs and their caregivers described their recovery as an evolving process in which personal change was needed to live with and manage the consequences of their SMHCs.

I was meeting new friends and learning new skills. Starting to wear new clothes again and travelling on my own to Garden Place [pseudonym] – the taste of independence. You must be willing to change. (Globie)

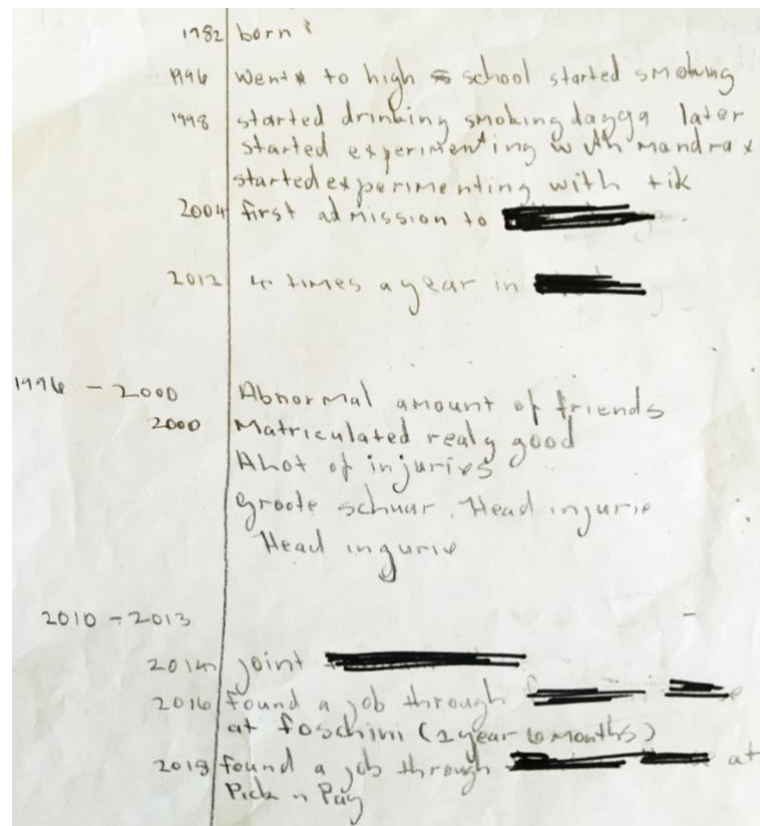
According to participants, these personal changes involved changing behaviours and social circles that posed an increased risk of relapse. Globie, for instance, reflected on how he needed to cut ties with his friends who used substances.

It is hard to break away from friends. It is very hard for people to get out of that life. I try. When you are trying to quit, the devil comes to you. So I adapt. Growing up, I went to Sunday school and stuff like that, so that put something in me. That guided me in life, having love for the Lord, you see, there is always something that is pulling you away from trouble and stuff like that. (Globie)

Globie's life graph (Figure 5.1) offers insights into the significant events related to living with a mental illness. Events referenced on his life graph included: experimenting with drugs when he started secondary school; peer pressure in adolescence; multiple psychiatric hospital admissions; and connecting with an MH-NPO for support. With time, this MH-NPO enabled him to access work opportunities.

Figure 5.1

Globie's Life Graph Showing His Significant Life Events



MH-NPOs offered psychoeducation to MHSUs and their caregivers as all parties engaged in learning to understand SMHCs and its challenges.

His dad and I went immediately to a workshop to understand what was wrong with him. He was at home, he had difficulty holding a job, got involved with gangsterism. And the first thing we let him do is start, let him take control of himself, and take his medication. Because at first, I had to give it to him. Every morning, I had to stand in front of him to take it and then eventually we got him to the stage where he went and took the medication himself. He had to take responsibility for what was wrong with him. (Patrick's mom)

Caregivers supported MHSUs as they learnt to cope with their SMHCs. MHSUs and caregivers recognised that knowledge about SMHCs was powerful in demystifying SMHCs, offering insights into how to cope. When caregivers sought knowledge on SMHCs, they did so to support and understand MHSUs, and this promoted everyone's mental health.

Finding meaning included learning to maintain their mental health and accept their SMHCs. MHSUs drew on their spirituality and belief in a higher power for sense-making during their recovery journeys.

I think also religion helps. To sustain any endurance that comes before you and not give up when things are too hard for you to overcome. (Siya)

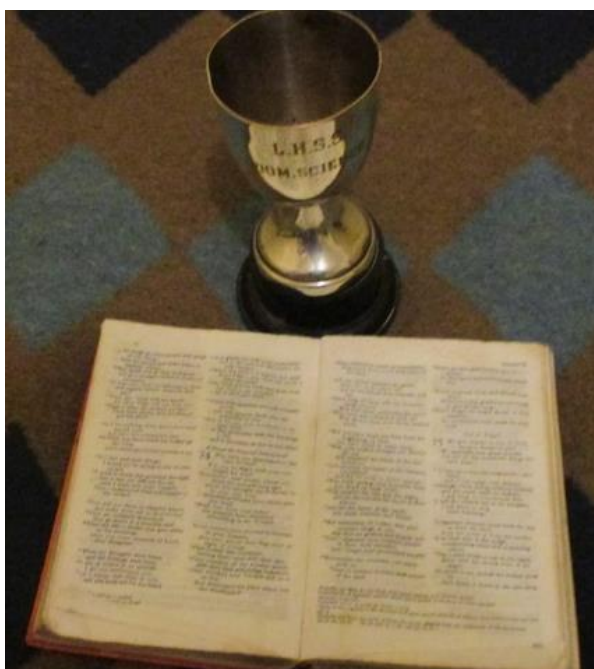
God, you must have a plan for me. (Reggie)

Reflecting on this, Reggie explained that he was first diagnosed with an SMHC at 23 years, and he had multiple clinical relapses and hospital admissions between the ages of 23 and 29 years old. After three suicide attempts, at the age of 31, Reggie decided to trust a higher power (Figure 5.2). He no longer questioned why he had a mental illness; instead, he accepted it as part of his life journey.

The diagnosis of SMHCs was overwhelming for MHSUs and their caregivers. Despite looking to their religious community for spiritual support, MHSUs and their caregivers reported being ostracised and unsupported by members of their religious communities.

Figure 5.2

Globie's Photo Showing His Spiritual Practice



Globie's mother shared her perspective on stigma:

When I look out of the window, I see religious people laugh at him. My heart was sore. For me, it was a terrible thing. I did not expect it from them. He was broken, dirty, up and down. He was in a bad condition. Religious people laughed at him. Oh, I was so disappointed. (Globie's mother)

The stigma surrounding SMHCs was cited as a reason for the lack of support offered to MHSUs and their caregivers by fellow congregants. This led MHSUs to practise their religions on their own.

I am a person who likes to go to church. But I do not go a lot now, but I love God, the word of God. And I respect the church, but I do not go. I will not lie to you. It is very long since I have gone to church. But what I do is I took a pic of my bible. My bible I read about three times a day. (Siya)

In the absence of this aid from religious institutions, MHSUs developed self-management strategies (sub-theme 1.1). They identified alternative places and activities to obtain the mental health support they needed (sub-theme 1.2).

5.10.1.1 Sub-theme: Developing self-management strategies

All MHSUs described developing self-management strategies that they likened to a game plan for staying organised, managing their finances, and diverting their attention from harmful activities that could lead to clinical relapse. Having a game plan also helped them manage their interpersonal relationships. Most participants invested in new ways to do their daily activities to maintain good interpersonal relations with others, particularly in communal living spaces. Patrick explained how he carefully organised himself to prepare for his workday (see Figure 5.3) to be considerate of others. While Patrick would not have been bothered with how his morning preparation activities impacted others in the past, it now mattered as maintaining his harmonious living arrangements was important to him. This meant that he carefully selected his clothing every evening to get dressed quietly in the dark every morning.

Figure 5.3

Patrick Manages Himself by Preparing for the Workday the Night before Work



MHSUs also developed strategies for responding to stigmatising responses to their diagnoses. Some MHSUs dealt with stigma proactively by pre-emptively managing other people's views. For example, Reggie explained how he makes his diagnosis accessible to others:

And that is the face of a person with Schizofriendly, not Schizophrenia. A lot of people do not know what Schizophrenia is; they think you are probably crazy. So, they do not get the stigma. You know I tweaked it a little. I would say, I am a Schizofriendly, and they say, 'What is that?' (Reggie)

Reggie and other participants created opportunities to educate others about SMHCs. Participants' capacities to design and implement their self-management strategy came from incrementally practising self-discipline as opportunities arose. MHSUs also learnt to accept that living with a mental illness requires self-acceptance and self-discipline:

Having a mental illness is not the end of the world; let your light shine. A reward of letting your light shine. The reward is a normal life, and it requires a lot of discipline. (Globie)

Another self-management strategy involved financial self-discipline. All participants received a social support grant (1890ZAR/122USD), and some received additional income from casual employment. They budgeted their income carefully to cover basic living costs and some lifestyle choices. For example, Reggie designed a plan to enjoy

gambling in a controlled manner. This involved allocating a small amount of money to playing the lottery a few times per month. He created a gambling game where he used marbles with numbers painted onto each marble for random selection of the lottery numbers he would play (Figure 5.4). This gave Reggie a sense of control and helped him resist the temptation to play more often. Reggie explained:

I budget myself R160.00 a month, which is R40.00 a week. I do not play horses or anything like that. I do not like how they do the lotto, but I still play because I like playing with the marbles. (Reggie)

Figure 5.4

Reggie's Lotto Number-Generating Invention



MHSUs also identified alternatives to socialising in environments where drugs and alcohol were readily available. These included watching sports at home with friends or fellow group home residents, enjoying quiet time on their own or creating prayer routines. For example, Globie shared that subscribing to a paid television broadcasting service (DSTV) allowed him to stay home, listen to music, watch movies and socialise with his family:

The small things like the other day my father would come and watch DSTV with me. Watch a soccer game together. It is the small things that mean a lot to the person with mental illness. (Globie)

Affording a DSTV subscription also elevated his status in his community. While these self-management strategies were practical, participants revealed that they also built

their mental endurance and stamina for new ways of being as part of their recovery journeys.

5.10.1.2 Sub-theme: Securing places and activities that promote mental health

MHSUs drew on different supports to find activities of interest to them. When they felt ready, they found new places and ways of performing their activities. MHSUs described their difficulty accessing opportunities to participate in meaningful activities since they were usually only referred to their local clinics to collect their repeat medication prescriptions and only sometimes were they informed about MH-NPOs that offered psychosocial support. Consequently, MHSUs and their caregivers only sought assistance from MH-NPOs after many relapses.

All the MHSUs in this study described the Garden Place (pseudonym) programme as pivotal to their recovery. MH-NPOs, like Garden Place, offered MHSUs different activities to promote their mental health while also allowing them to develop skills necessary to integrate into society (Figure 5.5). These services included psychoeducation; supported living in group homes; drop-in services, which MHSUs attend during weekday mornings; skills development programmes; and transitional employment learnerships.

Figure 5.5

The Garden and Skills Development Spaces at Garden Place (Globie)



MHSUs progressively developed their willingness and confidence to try these activities. Although challenging initially, participating in the MH-NPO programmes opened opportunities and built MHSUs' confidence:

First of all, when I started at Garden Place, I was a bit shy. So, it gave me a lot of confidence and positiveness and learning as well. So, I just want to tell you something. I was chairperson, and I went to Johannesburg and Pretoria [cities outside of the Western Cape Province] to stand for the rights of people with Schizophrenia and disabilities. (Siya)

These skills development opportunities allowed MHSUs to try different work opportunities. For example, Reggie held various jobs, eventually securing a job as a project supervisor at a supported employment project run by Garden Place. Garden Place provided a safe place where MHSUs could progress by learning from their experiences, developing new skills, building resilience, being flexible, recognising different possibilities to access networks and utilising available work opportunities. Reggie proudly shared his certificates of completion for courses he had accessed through Garden Place:

A picture on my wall of small achievements. While working for [Health Connected], I was sent on a few courses. I was sent to a first aid course, where I achieved an 80 per cent pass. I also did a business course at UCT Business School. I was sitting there, and the guys were arriving there with their Audis [luxury vehicle]. I did it for six months. It was a business course. I thought it was okay, but some of the things just went over your head. (Reggie)

The urging from their caregivers facilitated MHSUs' uptake of unfamiliar opportunities. Patrick explained how his mother coaxed him to take advantage of work opportunities:

*She [Patrick's mother] gave me a look as if to say, "You don't wanna f*cking stop. You don't wanna stop. We've had it". And after a while, they told me, "No, we're not gonna support you anymore". And with that look she gave me, I decided here I better make a change in my life, here I must make a success, here I must survive. I must show these people that I'm worth it, and I can still be a productive member of society, and then they [Garden Place] got me a job which is very therapeutic, especially when you're a criminal. (Patrick)*

Through their participation at MH-NPOs, MHSUs developed work readiness which assisted them in the relational aspects that MHSUs with SMHCs have difficulty with, as Siya detailed:

That also empowered me because what I enjoyed most was Garden Place. There's a life skill for everybody, every bloody problem you have on the earth. So, they made me go through many life skills about how to appropriately act in a workplace. When people are rude to you, what are the procedures? Was I work ready? Papers, certificates to prove that you went on a course for work readiness. So, there I learned a lot of life skills and how to cope and defend myself without acting out or acting violently because now you're using knowledge, and knowledge gives you more power, man. (Siya)

As MHSUs increased their participation in activities offered by MH-NPOs, they required less support from their caregivers and sought opportunities to be more independent. As Patrick's parents described, some MHSUs transitioned from their homes to supported living houses with fellow MHSUs:

Patrick's mother: *There was always an offer from Garden Place's side that if they wanted to apply, they could apply to go and live in those houses. Patrick never wanted to move away from us. He was going to be here for the rest of his life; mentally, that is what he thought. I kept saying to him; you will have to go live on your own and become independent. You cannot live with us for the rest of your life, but I never forced it. I felt he needed to do it when he was ready.*

Patrick's father: *He said: "No, I'm not going anywhere! I'm not going to go live on my own. No, I'm not leaving this house!"*

Patrick's mother [Laughing]: *He just wouldn't think of it, and he is so happy now, you know what I mean, that he had taken that step, and as I said, he was about thirty-eight when he took that step to go and, to apply, and he got the place you know. He got a room there.*

Through these opportunities, MHSUs become less reliant on their caregivers for their basic needs and could find new ways of living, working and socialising.

5.10.2 Theme Two: Affirming agency

All the MHSUs repeatedly experienced public humiliation associated with their behaviours while they had acute clinical symptoms of SMHCs. Theme Two describes how MHSUs overcame this public humiliation and reinvented themselves in their community.

All the MHSUs came from Cape Flats communities, with high levels of visible policing due to crime. Most families relied on the police to assist when the MHSUs required hospital admission. This resulted in MHSUs being involuntarily transported to the hospital in a police van. This violent way of containing the MHSU and facilitating their hospital admission often took place in full view of their neighbours. It was traumatic for everyone involved. Globie photographed a police van to show this (Figure 5.6).

Figure 5.6

Globie Emphasises the Role of Police, Showing a Van in front of His Gate



These interactions with the police when they were acutely ill contributed to MHSUs' lingering feeling of not being good enough in the eyes of the public. These humiliating experiences created a need for MHSUs to find new ways of demonstrating and affirming their agency. Being able to show that their life did not stop after a hospital admission was important to MHSUs. Securing a job and owning items such as name-branded clothing and sneakers were a source of pride and a sign of progress for MHSUs.

Now I have moved from a gangster to a productive member of society.

Sometimes I feel proud of the man that I have become. Working has given me financial freedom and has taught me to fend and stand on my own two feet. A job is therapeutic, especially if you are a criminal. A job gives you meaning and purpose. (Patrick)

MHSUs developed their sense of agency through relationships with people who promoted their sense of mental well-being (sub-theme 2.1) and by contributing meaningfully to their households and communities (sub-theme 2.2).

5.10.2.1 Sub-theme: Maintaining relational support

MHSUs identified that MH-NPO staff and their caregivers provided them with much-needed, ongoing relational support, which helped build resilience, despite clinical relapses:

My mother is always there, and people are there for me. Again, like my social worker, Garden Place, the staff of Garden Place, the managers at work, my supervisors at work. I always have a good relationship with them, which keeps me motivated. (Globie)

MHSUs and their families did not always have the ongoing support needed to navigate the stigma and trauma associated with the way that involuntary readmissions to a psychiatric hospital occurred. MHSUs recognised that they needed enabling environments that included supportive people for their recovery. Reggie used a photograph of a tree-lined road to explain.

I think every year was a road for me. Every year, you know, if I had my cycle and got sick, I had to go back, and I believe there is no way back in life. So I am looking forward. I do not really want to go from the pavement into the gutter or something like that. Basically, my medication, my support system that I get at home, and my colleagues at work. We are very close, we are like a very close-knit family, but you know, in the work sense. (Reggie)

People who believed in participants when they had difficulty believing in themselves or gave participants a chance were valued as enablers. For example, Patrick's psychiatrist's efforts enabled him to access MH-NPO services when they were not offering services to MHSUs in the forensic psychiatry system.

I would just like to thank Horizon, and I would like to thank Garden Place for giving me a chance and for believing in me because you know Garden Place do not take people with criminal records because it is against their policy, but Dr R wrote such a beautiful letter to them, and they said they would give me a chance. (Patrick)

Having meaningful work and a stable home environment helped participants move forward. Growing and developing in supportive environments allowed MHSUs to have hope in new possibilities and live meaningful lives, despite their diagnosis of SMHCs.

With lots of love and the ability to learn, everything is possible (Reggie)

5.10.2.2 Sub-theme: Making meaningful contributions

By contributing financially or volunteering their services in meaningful ways, MHSUs felt a sense of citizenship. Patrick is a cook at a creche, and his kitchen is his "*pride and joy*" (Figure 5.7). Patrick's stable living environment, supportive champions, and job contributes to his sense of fulfilment and agency. He said he felt he added value and positively contributed to the spaces he engaged in.

Figure 5.7

Pictured in The Kitchen at the Crèche



The children are beautiful to work with. The one child comes up and says, "Thank you, Mom". I said, "I'm not your mom". [Giggling]. Because of the food, the Chairperson of the Board says: "And in the kitchen, we have an excellent chef".

Children are very honest man. So, you have to know what you're doing, and then you have to put some effort and some love into it, and it's not just about throwing potatoes in a pot. It's done with some sense of pride. (Patrick)

MHSUs were pleased that, as men, they could assist their parents, siblings and others financially. Globie helped his father and paid for home improvements to their family home and luxury entertainment items (Figure 5.8). His entire family benefitted from his contributions. By supporting home improvements, MHSUs could showcase their successful recovery to their communities.

Figure 5.8

Globie's Picture Showcasing the Kitchen Renovation He Paid for in the Family Home



When MHSUs could access work, they generously shared what they could with other MHSUs. Patrick explained:

JP [a fellow group home resident] always does me a favour, you know, and I always give him something because he doesn't work. He installed that whole bloody decoder for me. And I gave him 50 rand just to say thank you because he had to climb up the roof to attach it to the dish. (Patrick)

The theme of Affirming agency captures how MHSUs progress towards living successfully in the public eye. They do this by accessing MH-NPOs' support services, which allow them to find their purpose and participate meaningfully as citizens in their chosen communities. Thus, individuals navigated personal recovery in their daily experiences through intrapersonal, interpersonal and group interactions with the rest of their community and society. Through doing well in different spaces, MHSUs were affirmed as people. Their ability to work further supported their recovery. Additionally, MHSUs measured their success by the symbolic status acquired through their material possessions and by contributing to improve the lives of others.

5.11 Discussion

The findings of this study yielded significant insights into how South African men and their caregivers experience personal recovery from SMHCs. First, the stigma faced by MHSUs led them to seek opportunities for support and meaningful participation outside of their community and the social institutions that are traditional sources of support. Second, MHSUs built their capacities for personal recovery by participating in MH-NPO activities which offered them long-term relational support. Third, accessing work opportunities and making meaningful contributions to others is an integral part of the recovery journey for MHSUs. The findings resonated with existing research identifying recovery as an active, complex process grounded in the daily life challenges MHSUs face (Krupa et al., 2009; Leamy et al., 2011; Mathew et al., 2018; Sommer et al., 2021; Sullivan et al., 2017). The CHIME framework foregrounds the positive and individual aspects of recovery (Stuart et al., 2017), though its optimistic themes do not reflect the difficulties and struggle MHSUs face as part of their recovery process. To focus solely on the personal strengths of the individual (Brijnath, 2015) and without due consideration of contextual barriers influencing their recovery is reductionist.

Ongoing research into the social, economic, cultural and political environments which help or hinder recovery is needed for mental health reform (Gamielien, Galvaan, Myers, et al., 2021). The participants included three Coloured and one Black individual, with no representation from other race groups, including White and Indian. The manner in which some MHSUs accessed services, including being escorted by police, warrants further exploration as the demographic distribution may reflect the racial profile of service users in the catchment area serviced by the MH-NPOs. It also signals the need to consider the historical, racial, and geographic factors which shape access to services (Kleintjes & Schneider, 2023).

The results of this study make an essential contribution to the CHIME framework from a LMIC perspective. Stigmatising attitudes of others, including from traditional support structures like organised religious structures, limited MHSUs' opportunities to engage

in meaningful activities in their local community. MHSUs faced stigma due to their community's poor understanding of mental illness. This adversely affected MHSUs and their caregivers, resonating with the dimensions of CHIME which identify that a cultural group or a community can either help or hinder recovery (Leamy et al., 2011). In HICs, spirituality is not reported in relation to religion and belonging to a collective through faith-based organisations. Instead, it is framed as an individual practice where MHSUs use their beliefs to make sense of their mental illness (Brijnath, 2015; Jaiswal et al., 2020). This differs from MHSUs in LMICs, BME and ethnic majority groups, where belonging to faith-based communities and having a religious affiliation were essential components of the spiritual aspects of their recovery (Brijnath, 2015; Gamieldeen, Galvaan, Myers, et al., 2021; Leamy et al., 2011). There is a growing interest in using faith-based organisations to offer community-based mental health services (Scheid & Smith, 2021). However, in this study, the stigmatising attitudes of congregants in faith-based organisations meant that MHSUs and their caregivers did not view or use these organisations as recovery partners. Instead of relying on their local communities and religious affiliations, the MHSUs in this study sought support from MH-NPOs.

MHSUs and caregivers in this study accessed MH-NPOs, such as those implementing a clubhouse model (Kinn et al., 2018; McKay et al., 2018), because it offered them a sense of community and provided varied, long-term relational support. Similar to other studies (Bitter et al., 2020; Onken et al., 2007), the support offered by the MH-NPOs facilitated the MHSUs to participate in socialising, learning, living and working environments. The MH-NPOs adopted recovery-oriented practices by addressing the elements of recovery which resonate with the CHIME domains (Leamy et al., 2011). These MH-NPOs provided multi-stakeholder support after discharge from the hospital. A scoping review on recovery from severe mental illness in LMICs (Gamieldeen, Galvaan, Myers, et al., 2021) reported that MHSUs personal recovery drew mostly on similar such community spaces for support. For MHSUs in this study, the MH-NPOs acted as inclusive communities that provided long-term relational support through various services, including access to alternate living arrangements, day programmes and work opportunities. Since their living, learning, socialising and working needs were supported to varying degrees by the MH-NPOs, it is acknowledged that participants could have foregrounded the utility of the MH-NPO in this study. Further studies with MHSUs who are not associated with MH-NPOs will provide insight into possible alternative modes of support.

Supported housing offered by MH-NPOs is an alternative to living with family or alone. When MHSUs' socio-economic constraints forced them to live with family, they often experienced an extended childhood (Gamieldeen, Galvaan, & Duncan, 2021). By moving from the family home into communal living, MHSUs in this study experienced success and independence. Moving out of the Cape Flat and having a place to live separate from

family allowed MHSUs to explore new opportunities. Their affiliation with the MH-NPO facilitated their access to resources that developed their skills in the societal, personal, functional, lifestyle and cultural aspects of recovery (Bitter et al., 2020).

Independent living is often cited as an essential recovery indicator for HICs; but in LMIC settings, it is not as heavily weighted (Gamielidien, Galvaan, Myers, et al., 2021). For participants in this study, living on their own was not an option due to socio-economic and cultural constraints, such as low income, and dependence on social grants. Independent living was mostly unaffordable or inaccessible to participants in this study; however, moving out of the family home to live with others was viewed as a step towards independence and gave MHSUs the opportunity to become more autonomous.

Realising a different life meant that MHSUs constantly had to weigh their options and strategies to achieve mental, emotional and spiritual health and well-being (Llewellyn-Beardsley et al., 2019). MHSUs developed insights into how their identity and their views on masculinity influenced their recovery; and they needed to be courageous and follow their path, despite setbacks while balancing feeling secure and taking risks (Deegan, 1996). One aspect of their masculinity was connected to their views that men are the financial providers in their families. To build their capacities to live consistently purposeful and personally meaningful lives as part of their recovery, MHSUs invested in their personal growth. Adopting a learning spirit and being open to change and new opportunities were notable characteristics of navigating recovery.

As part of their recovery journeys, MHSUs actively resisted peer pressure to engage in health-compromising activities that were prevalent in their poor socio-economic environments. While being patient and tolerant of themselves, they sought alternative places to make connections, such as the MH-NPO which supported their recovery. The role of context as critical for recovery is well recognised in literature from HICs (Llewellyn-Beardsley et al., 2019; Roe et al., 2020; Slade, 2021; Slade et al., 2021; Sommer et al., 2021). MHSUs fluctuated in how they exercised choice and autonomy in choosing contexts which either helped or hindered their recovery. A meta-synthesis reporting on the role of place in recovery (Doroud et al., 2018) showed that context was an anchor for daily living in HICS, but contextual factors can have negative or positive outcomes for MHSUs living in LMICs.

The contribution of work to the mental health and well-being of people living with SMHC is well documented in the literature (Devine et al., 2020). In this study, MHSUs used their ability to work and contribute to their households to demonstrate masculinity and agency. Opportunities to work in supported employment or the open labour market allowed male MHSUs to find meaning and develop confidence in themselves as contributing members of society. Being tactical when taking up interpersonal and skills development chances from MH-NPOs helped male MHSUs in this study to consider a

range of flexible, self-paced learning and employment opportunities. In a LMIC setting like South Africa, with a high unemployment rate, developing entrepreneurial skills would also help MHSUs access more varied occupations (Gamieldien, Galvaan, & Duncan, 2021; Gamieldien & Van Niekerk, 2017).

5.12 Strengths and limitations of the study

The research was conducted with persons with lived experience who are part of a difficult-to-reach population. Combining visual methods and interviews over multiple data collection sessions allowed numerous opportunities to ensure the research's credibility. The contextual detail offered through the visual techniques would have been difficult to describe if data collection relied on interviews only (Han & Oliffe, 2016). Member checking (Lincoln & Guba, 1985; Nowell et al., 2017; Thomas, 2017) was done during the final interview by discussing the data presented in the life graph alongside the photographs taken by MHSUs. The findings offer some insights on recovery for men with SMHC and their caregivers and provide possibilities for future research. There were some limitations of the study. First, the sample size was small as it was a qualitative study, but rich insights were gained with these experts by experience. Second, the study included MHSUs connected to two MH-NPOs following a clubhouse model based in Cape Town, not to other organisations from other parts of South Africa. As members who had benefited positively from their involvement in the MH-NPO, they might have been more inclined to participate. Third, because of failed recruitment attempts with this difficult-to-reach population of people living with SMHC, all MHSUs were recruited via an MH-NPO. Fourth, due to resource constraints, we did not have access to translation services and thus did not set out to recruit MHSUs who were unable to converse in either English or Afrikaans. Fifth, the voice of caregivers is not widely reflected as the study foregrounded MHSU perspectives on personal recovery, although caregivers are important stakeholders who should be the focus of future research.

5.13 Conclusion

This study has provided insights into the contextual, social, economic, political, demographic, cultural, ethnic, spiritual and intersectional factors which help or hinder recovery from SMHCs. Promoting personal recovery should include a human rights-based approach to mental health service design and delivery which addresses contextual factors, including stigma and social belonging (Desai et al., 2021), while also involving all the stakeholders involved in supporting recovery from SMHCs (Ørjasæter & Almvik, 2022; Sullivan et al., 2017). Understanding MHSUs' experiences is vital to building personal recovery assets and services that address the diverse needs of MHSUs. Scaling up mental health services that include MH-NPOs will enable MHSUs to access services outside the public health sector that support their recovery in their communities.

Chapter Six : The Psychometric Properties of the Recovery Assessment Scale (RAS) among Persons with Severe Mental Health Conditions in South Africa¹⁶

6.1 Chapter introduction

The previous chapter presented qualitative data regarding male MHSUs and their caregivers' perspectives on recovery from SMHCs, generating insights into their views and dimensions of the construct of recovery vital to them. As pointed out in Chapter One, there is a need to ensure that current measures of recovery developed in the Global North capture key elements of recovery and are appropriate and valid for persons with SMHCs in LMICs, including South Africa. In Chapter Two, I presented critical concepts and a foundational literature review for this thesis. I prefaced the prevalence and burden of SMHCs and co-morbid SUDs. After that, I discussed the disabling impacts of SMHCs on individuals and their caregivers. I then highlighted the structure and function of public mental health services globally before honing in on public mental health services in the Western Cape Province (WCP) of South Africa and support for the recovery model as a philosophy for public mental health service reform in LMICs. I concluded Chapter Two with a section on the utility of recovery outcome measures in generating evidence for strengthening public mental health services. The study presented in Chapter Six addresses this the gap in recovery outcome measure by investigating the reliability, construct validity, and convergent validity of the Recovery Assessment Scale (RAS) within a South African population of mental health service users.

6.2 Methods

This quantitative, cross-sectional study consisted of two phases. Phase One involved adapting the RAS for a South African population with input from an advisory committee, followed by cognitive testing ([Appendix U](#) and [Appendix V](#)). Phase Two involved assessing the psychometric properties of the RAS.

¹⁶ This chapter has been adapted from a paper submitted for publication. **Gamielien, F.,** Galvaan, R., Myers, B., Garman, E & Sorsdahl, K. (in preparation). The psychometric properties of the Recovery Assessment Scale (RAS) among persons with severe mental health conditions in South Africa.

6.2.1 Study setting

This study was undertaken in the geographic catchment areas of three state-run psychiatric hospitals in the Western Cape Province. MHSUs in the Western Cape Province can access mental health services at different levels of care. These include formal primary health care services (clinics), secondary care offered by district hospitals, mental health non-profit organisations, and specialist psychiatric services. MHSUs who are acutely ill and who cannot be managed by primary care providers are admitted to district hospitals for a 72-hour assessment, after which they may be referred to the tertiary psychiatric hospital in their catchment area. Depending on the complexity of the condition, MHSUs admitted to inpatient services at psychiatric hospitals are either discharged to intermediate care facilities, to their homes with referral to the nearest primary health care clinic for ongoing medication access, or to continuing care from the hospital's outpatient department for a three-month period before their care is devolved to the primary health care clinic. MHSUs are also referred to mental health non-profit services, depending on their needs, provider knowledge of available resources and if these services are available in their communities.

6.2.2 Participants

This study was conducted with MHSUs who had SMHCs and had been admitted to one of the aforementioned psychiatric hospitals between January 2007 and January 2022. This period was selected to ensure that persons with chronic and newly diagnosed SMHCs were included. To be eligible for study inclusion, people had to be at least 18 years of age, diagnosed with an SMHC (schizophrenia spectrum disorders, bipolar affective disorder, major depressive disorder, substance-induced psychotic disorder or related psychotic disorders), and conversant in English or Afrikaans. These two languages were selected as they are currently the language mediums in which mental health services are delivered in the Western Cape. Individuals were excluded if they had symptoms of psychosis at the time of the interview, if they were assessed as not having capacity to consent at that time, or if they were unable or unwilling to provide informed consent. Where possible, service providers at multiple sites assisted with suitability screening based on MHSUs' participation in other programmes or services. MHSUs were invited to participate, and a recruitment flyer detailing information on the study was given to potential participants ([Appendix W](#)). Interviews were conducted by the lead researcher (FG) and three trained research assistants who were occupational therapists by profession and could assess participants' mental state and ability to consent. Capacity to provide consent was assessed and included willingness to participate, ability to make decisions, capacity to understand the nature of the interview and knowledge about the research project (Dalal, 2020) ([Appendix X](#)).

6.3 Procedure

6.3.1 Phase One: Adapting the RAS for the South African context

To identify where contextually relevant modifications to RAS items were required to increase its comprehensibility, we formed a project advisory committee comprising content experts and service users. The advisory committee provided oversight and advice on refining the data collection tools before commencing the research. Although South Africa is a multilingual society, this committee advised that the RAS be administered in its original English form as this is the second language of many participants, as well as the main language in which mental health services in the Western Cape are offered. No translation or back translation of the RAS was thus necessary. FG worked with the advisory committee for initial adaptations to item wording ([Appendix U](#) and [Appendix V](#)). As part of the initial item adaptation, the AC was guided by the work of Flaherty et al. (1988) to identify the five forms of equivalence which must be considered when selecting, adapting and translating research instruments for use in different cultures: (i) content, (ii) semantic, (iii) technical, (iv) criterion, and (v) conceptual equivalence. The advisory committee discussions focused on linguistic aspects, colloquial language, cultural adaptation, and cognitive issues (Biringer & Tjoflåt, 2018). Following advisory committee feedback, minor adaptations and wording adjustments were made to four of the 24 RAS items to improve comprehension and linguistic aspects (as reflected in Table 6.1), while retaining semantic equivalence with the original RAS items ([Appendix V](#)). The RAS domains reflected in Table 6.1 are Goal and success orientation (GSO), Reliance on others (ROO), Personal confidence and hope (PCH), No domination of symptoms (NDS), and Willingness to ask for help (WAH).

Table 6.1

RAS Domains and Items with Modifications

Item	Domain	Original RAS items	Revised RAS items
1	GSO	I have a desire to succeed.	I can make something of myself.
2	GSO	I have my own plan of how to stay or become well.	
3	GSO	I have goals in life that I want to reach.	
4	GSO	I believe I can meet my current personal goals.	
5	GSO	I have a purpose in life.	
6	ROO	Even when I don't care about myself, other people do.	
7	PCH	Fear doesn't stop me from living the way I want to.	
8	PCH	I can handle what happens in my life.	

9	PCH	I like myself.	
10	PCH	If people really knew me, they would like me.	
11	PCH	I have an idea of who I want to become.	I have an idea of who I want to become in the future.
12	PCH	Something good will eventually happen.	
13	PCH	I'm hopeful about my future.	
14	PCH	I continue to have new interests.	
15	NDS	Coping with my mental illness is no longer the main focus of my life.	
16	NDS	My symptoms interfere less and less with my life.	My symptoms interfere less and less with my experiences
17	NDS	My symptoms seem to be a problem for shorter periods of time each time they occur.	
18	WAH	I know when to ask for help.	
19	WAH	I am willing to ask for help.	
20	WAH	I ask for help, when I need it.	
21	PCH	I can handle stress.	
22	ROO	I have people I can count on.	
23	ROO	Even when I don't believe in myself, other people do.	
24	ROO	It is important to have a variety of friends.	It is important to have different friends.

Next, 10 MHSUs living in supported housing affiliated with a local MH-NPO were recruited to participate in the cognitive testing of the initially adapted RAS. The sample included both Afrikaans and isiXhosa speakers. Seven of the MHSUs were men, and three were women, with a mean age of 47 years (range 32 to 60 years). Cognitive testing involved one-on-one interviews with participants to assess each item's relevance, comprehensibility and acceptability. First, each item of the RAS was read to the participant before asking questions to gauge their comprehension, recall, and judgement, as per Miller et al. (2014). For each item, participants were asked: (i) Did you find this question easy to understand? If not, what part was difficult?; (ii) Can you say what the question was asking in your own words?; (iii) What were you thinking of when you answered the question?; (iv) Did you find the question easy to answer?; and (v) Is there anything we can change to make the question easier to answer? Participants' verbal responses, response time, and comments were documented. All interviews were audio-recorded. Responses were collated to check for issues around acceptability and comprehensibility. Overall, the participants found the questions easy to understand. No further changes were made to the RAS items.

6.3.2 Phase Two: Investigating the psychometric properties of the RAS

Recruitment of participants

Participants were recruited from mental health non-profit organisations specialising in inpatient psychiatric services and outpatient departments servicing the Western Cape Province. Initially, we had planned to use systematic random sampling to select patients from outpatient department registers to participate in this study. However, just as recruitment was set to commence, the COVID-19 pandemic began so face-to-face research was suspended until December 2020. In January 2021, the Ethics Committee granted permission for face-to-face research to resume. However, when outpatient department appointments resumed, they were restricted to MHSUs with follow-up appointments, and we could not randomly select MHSUs from patient registries for study activities. Instead, we recruited a convenience sample using the outpatient department booking list to contact potential participants, and we simultaneously extended recruitment to include mental health non-profit organisations and circulated recruitment flyers ([Appendix W](#)) at these organisations. We also recruited MHSUs from forensics long-stay wards and step-down facilities of two psychiatric hospitals.

Data collection

Data were collected from January 2021 to January 2022. The research team visited different sites to meet potential participants, describe the study and arrange times for questionnaire completion among eligible persons who consented to participate. As part of the consent process, participants were informed about the confidentiality and anonymity of the process, assured that participation was voluntary and of their right to withdraw from the study. Thereafter, the RAS and other questionnaires were administered to consenting participants in a face-to-face interview format, with the interviewer recording participants' responses on a hard copy of the questionnaire ([Appendix X](#) and [Appendix Y](#)). The questionnaires were administered in private offices or rooms at various recruitment sites, private homes, or supported living facilities where participants lived in the community. Questionnaire administration lasted 45 to 60 minutes. If participants needed to participate in a therapeutic group or see a healthcare worker as part of the service programme, data collection was temporarily suspended until their return. After completing these procedures, participants needing additional support were referred to the mental health provider at the referral agency. Each participant received a ZAR100 (\$6) supermarket voucher and a refreshment pack to compensate for their time. Reimbursement for any incurred travel costs was also provided.

A subset of participants ($n = 65$) were randomly selected to complete the RAS again two to four weeks after the initial interview. This process allowed the temporal reliability of the RAS to be evaluated. Procedures were identical to those of the initial interview. The study was approved by the Health Sciences Research Ethics Committee (HREC 655/2018) ([Appendix K](#)) and the Western Cape Province's Health Research Committee (WC_201902_010) ([Appendix L](#)).

6.3.3 Measures

A number of measures were used to collect data ([Appendix Y](#)). Sociodemographic variables such as age, gender identity, race, home language, education level, and employment were included. Further, mental health-related variables such as diagnosis, previous admissions, time living with a mental health condition, medication type, and substance use were included.

Recovery Assessment Scale (RAS)

The RAS contains 24 items across five domains (Corrigan et al., 2004). The *Personal confidence and hope* (PCH) domain consists of nine items and reflects MHSUs' hope for the future and their ability to manage stress. The *Willingness to ask for help* (WAH) domain is related to MHSUs' disposition to seek help from others, and includes three items. The *Reliance on others* (ROO) domain consists of four items and assesses social networks as part of recovery. The five-item *Goal and success orientation* (GSO) domain assesses MHSUs' ability to meet goals and their desire for success. The domain *No domination of symptoms* (NDS) has three items that focus on whether psychiatric symptoms are at the centre of the person's life. See Table 6.1 for a description of domains and items.

Each item is rated on a 5-point Likert scale, from 1 "Strongly disagree" to 5 "Strongly agree". A composite total score is calculated by summing responses for the 24 items, with total scores ranging from 24 to 120. Domain scores are calculated by summing responses for the items contained in each domain. For each domain, possible total scores are influenced by the number of items in that domain, with GSO domain scores ranging from 5 to 25, PCH ranging from 9 to 45, ROO ranging from 4 to 20, NDS ranging from 3 to 15, and WAH domain scores ranging from 3 to 15. The RAS does not have a cutoff score. Instead, it is used to measure an individual's perception of their recovery from SMHCs, with higher scores indicating a greater sense of recovery (Corrigan et al., 2004).

WHO Quality of Life Assessment (WHOQOL- BREF) (The WHOQOL Group, 1998)

The WHOQOL-BREF is an internationally validated questionnaire which produces a quality-of-life profile (QOL) (The WHOQOL Group, 1998) with a cross-culturally consistent factor structure (Lin & Yao, 2022). The WHOQOL-BREF comprises 26 items organised into four domains: (i) physical health (seven items), (ii) psychological health (six items), (iii) social relationships (three items), and (iv) environmental health (eight items). It also has two items which measure overall QOL and general health. Each item was scored on a five-point ordinal scale from 1 (low) to 5 (high), with a total score calculated for each domain, as well as a total score (sum of domain scores). The four domain score totals were then transformed linearly to a scale from 0 to 100 using a syntax file for SPSS in the user manual of the WHOQOL-BREF (The WHOQOL Group, 1998). This allowed us to calculate a total score. The higher the total score, the higher the QOL.

Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988)

The MSPSS is a 12-item scale that assesses social support from three sources: family, friends and significant others. It is widely used and is psychometrically sound, with good internal and test-retest reliability, factorial validity and moderate construct reliability (Zimet et al., 2016). There are seven possible answers to each of the 12 statements, ranging from 1 (very strongly disagree) to 7 (very strongly agree). Item scores are summed to create a total score, with higher scores indicating higher levels of perceived social support.

6.4 Data analysis

Phase Two analyses were conducted on a realised sample of 250 participants. Initially, 300 participants were recruited, 50 of which did not complete data collection procedures. These participants either withdrew from the study (due to fatigue or no interest in participating) or were withdrawn (due to an inappropriate referral, intellectual disability, or for being psychotic at the time of data collection). Statistical analysis was conducted using the IBM Statistical Package for Social Sciences (SPSS), Version 28.0.1.1(14). Descriptive statistics were calculated using frequencies and percentages for categorical variables and the mean and standard deviation for continuous variables.

For the psychometric validation of the RAS, we first undertook an exploratory factor analysis (EFA) to explore the RAS's construct validity and understand if the factors present within the data aligned with the original factor structure of the RAS. While there is some debate in the literature regarding sample size calculations for factor analysis,

the generally accepted gold standard for validation studies is five to ten participants per item, with at least 100 participants for optimal results (MacCallum et al., 1999; Pearson & Mundform, 2010). Our sample of 250 participants met the recommended guideline of 10 participants per item (De Winter et al., 2009; Williams et al., 2010). We were also guided by the Consensus-based Standards for selecting Measurement Instruments (COSMIN) when considering the sample size (Mokkink et al., 2018). According to COSMIN, a sample of $n > 100$ is very good (Prinsen et al., 2018).

We examined the suitability of the data for factor analysis by assessing the data for normality, linearity, outliers and factorability. We assessed normality by visually examining histograms and evaluating the skewness and kurtosis. Linearity was assessed with inspections of scatterplots. A visual inspection of boxplots was used to identify outliers.

Using SPSS, we ran a Kaiser-Meyer-Olkin (KMO) (Kaiser, 1974) measure of sampling adequacy and Bartlett's Test of Sphericity to assess factorability (Williams et al., 2010). A KMO value close to 1 indicates the data is suitable for factor analysis. The KMO in this study was 0.881, indicating meritorious sampling adequacy. Bartlett's Test of Sphericity was significant at $p < .001$, suggesting a correlation between the variables and confirming factorability. After confirming that the correlation matrix was factorable, principal component analysis (PCA) and varimax rotation with Kaiser Normalisation were chosen to extract factors. Factor adequacy was assessed using Kaiser's criteria (eigenvalue > 1) (Kaiser, 1992), visual inspection of the scree plot, and other factor characteristics: at least three salient item loadings on each factor and whether the factors were meaningful and distinct (Williams et al., 2010).

Item performance was evaluated based on factor loading values and patterns, with a factor loading value greater than 0.60 considered high and 0.30 considered acceptable (Kline, 2014). Factor loadings below 0.30 were excluded, and only items with factor loadings of 0.30 or higher (in absolute value) were considered. Each item was loaded onto the factor with the higher loading, which differed by more than 0.15, and the loadings were meaningful. Only two RAS items required decisions because they loaded on multiple factors.

Next, reliability was assessed. For the total sample, the internal consistency of the RAS domains was assessed by calculating Cronbach's alpha coefficient. While an alpha value of 0.90 is considered excellent, a Cronbach's alpha higher than 0.70 is considered acceptable (Tavakol & Dennick, 2011). For the retest sample, we used the intraclass correlation coefficient (ICC) to determine the test-retest reliability of the RAS domains. ICC values less than 0.50 indicate poor test-retest reliability, values between 0.50 and 0.75 indicate moderate reliability, values between 0.75 and 0.90 indicate good

reliability and values greater than 0.90 indicate excellent test-retest reliability (Koo & Li, 2016).

Finally, convergent validity was investigated by exploring the relationship between the RAS, quality of life, and social support, as we were interested in assessing whether the RAS aligned with other measures of related constructs (Bjorkedal et al., 2023; Yu et al., 2022). The psychometric properties of the WHOQOL-BREF and the MSPSS have been explored in validation studies in South Africa (Bruwer et al., 2018; Cronje et al., 2017). Although not core to the concept of recovery, these measures reflect some recovery constructs. The assumption was that those who scored high on the RAS would also score high on these two measures. All analyses were based on two-tailed tests, with Cronbach alpha level of $p < .05$ for statistical significance.

6.5 Results

6.5.1 Socio-demographic and mental health characteristics of participants

Table 6.2 depicts the sociodemographic characteristics of the 250 participants. Most participants were male (72.0%), with a mean age of 40 ($SD = 11.6$), with ages ranging between 20 and 69 years. Afrikaans was the home language for 108 participants (43.2%), followed by English ($n = 104$, 41.6%). The majority were recipients of social grants ($n = 191$, 76.4%) and unemployed ($n = 168$, 67.2%). Over half the participants had only completed primary school ($n = 145$, 58.0%). Most participants reported being single and not in a relationship ($n = 215$, 86.0%), and only nine lived alone ($n = 3$, 3.6%). The characteristics of the test-retest sample ($n = 65$) were similar to those of the overall population. The average age in the test-retest group was 43 years ($SD = 0.34$). In this sample, most were English-speaking ($n = 39$, 60.0%), and most were males ($n = 52$, 80.0%). The majority were social grant recipients ($n = 54$, 83.1%) who lived with others ($n = 61$, 93.8%).

Table 6.2

Sociodemographic Characteristics of Participants (N = 250)

Variable	Total (N = 250) N (%)	Male (n = 180) n (%)	Female (n = 70) n (%)
Age (m, sd)	40 (11.6)	39 (10.9)	43 (12.8)
18-24	30 (12.0)	23 (12.8)	7 (10.0)
25-34	58 (23.2)	45 (25.0)	13 (18.6)
35-44	71 (28.4)	54 (30.0)	17 (24.3)
45-54	64 (25.6)	46 (25.6)	18 (25.7)
> 55	27 (10.8)	12 (6.7)	15 (21.4)
Race			
Black	47 (18.8)	39 (21.7)	8 (11.4)
Coloured	152 (60.8)	107 (59.4)	45 (64.3)
Indian	6 (2.4)	3 (1.7)	3 (4.3)
White	40 (16.0)	26 (14.4)	14 (20.0)
Other	5 (2.0)	5 (2.8)	
Home language			
Afrikaans	108 (43.2)	76 (42.2)	32 (45.7)
English	104 (41.6)	69 (38.3)	35 (50.0)
IsiXhosa	33 (13.2)	30 (16.7)	3 (4.3)
Other	5 (2.0)	5 (2.8)	
Religion			
Christian	206 (82.4)	149 (82.8)	57 (81.4)
Muslim	25 (10.0)	15 (8.3)	10 (14.3)
Other	19 (7.6)	16 (8.9)	3 (4.3)
Relationship status			
Not in a relationship	215 (86.0)	155 (86.1)	60 (85.7)
In a relationship	35 (14.0)	25 (13.9)	10 (14.3)
Living arrangements			
Live alone	9 (3.6)	5 (2.8)	4 (5.7)
Live with others	241 (96.4)	175 (97.2)	66 (94.3)
Type of dwelling			
Government housing	46 (18.4)	36 (20.0)	10 (14.3)
Private home	84 (33.6)	53 (29.4)	31 (44.3)
Group home	51 (20.4)	40 (22.2)	11 (15.7)
Tertiary hospital	43 (17.2)	31 (17.4)	12 (17.1)
Other	26 (10.4)	20 (11.1)	6 (8.6)
Educational level			
Incomplete primary school	16 (6.4)	13 (7.2)	3 (4.3)
Completed primary school	145 (58.0)	109 (60.6)	36 (51.4)
Completed high school	76 (30.4)	51 (28.3)	25 (35.7)
Tertiary education	13 (5.2)	7 (3.9)	6 (8.6)
Employment status			
Employed	82 (32.8)	57 (31.7)	25 (35.7)
Unemployed	168 (67.2)	123 (68.3)	45 (64.3)
Social grant			
No	59 (23.6)	40 (22.2)	19 (27.1)
Yes	191 (76.4)	140 (77.8)	51 (72.9)

Note. 'Coloured' refers to people with mixed-race ancestry and creolised identities shaped and reshaped by historical practices in South Africa (Erasmus, 2001).

The mental health characteristics of participants, stratified by gender, are presented in Table 6.3. Schizophrenia accounted for most diagnoses ($n = 163$, 65.2%), followed by Bipolar Affective Disorder ($n = 41$, 16.4%). Most were diagnosed between 18 and 34 years old ($n = 178$, 71.2%) and had lived with a SMHC for over 10 years ($n = 153$, 61.2%). In total, just more than half ($n = 137$, 54.8%) had experienced a psychiatric admission in the last two years, and the majority ($n = 239$, 95.6%) had experienced a psychiatric admission over their lifetime. The retest sample showed a similar pattern of mental health problems.

Table 6.3

Mental Health Characteristics of Participants

Variable	Total ($N = 250$) N (%)	Male ($n = 180$) n (%)	Female ($n = 70$) n (%)
Age at diagnosis			
< 17 years	38 (15.2)	24 (13.3)	14 (22.9)
18-34 years	178 (71.2)	139 (77.2)	39 (55.7)
> 35 years	34 (13.6)	17 (9.4)	17 (24.3)
Years living with mental illness			
< 9 years	97 (38.8)	67 (37.2)	30 (42.8)
Between 10-19 years	81 (32.4)	63 (35.0)	18 (25.7)
> 20 years	72 (28.8)	50 (27.8)	22 (31.4)
Psychiatric admissions in the last 2 years			
None	113 (45.2)	78 (43.3)	35 (50.0)
One	78 (31.2)	58 (32.3)	20 (28.6)
> 2	59 (23.6)	44 (24.4)	15 (21.4)
Psychiatric hospital admissions in life			
None	11 (4.4)	9 (5.0)	2 (2.9)
One	57 (22.8)	45 (25.0)	12 (17.1)
2-5	106 (42.4)	69 (38.3)	37 (52.9)
> 6	76 (30.4)	57 (31.7)	19 (27.1)
Medication collection services			
Clinic	135 (54.0)	98 (54.4)	37 (52.9)
Psychiatric hospital	83 (33.2)	57 (31.7)	26 (37.1)
Other	32 (12.8)	25 (13.9)	7 (10.0)
Received treatment for substance use			
No	195 (78.0)	135 (75.0)	60 (85.7)
Yes	55 (22.0)	45 (25.0)	10 (14.3)
Lifetime substance use			
Tobacco	175 (70.0)	150 (83.3)	25 (35.7)
Alcohol	84 (33.6)	72 (40.0)	12 (17.1)
Cannabis	81 (32.4)	72 (40.0)	9 (12.9)
Methamphetamine	52 (20.8)	39 (21.7)	13 (18.6)
Methaqualone (Mandrax)	39 (15.6)	29 (16.1)	10 (14.3)
*Other	40 (16.0)	34 (18.9)	6 (8.6)

Note: Other: cocaine, inhalants, sedatives, hallucinogens, opioids, and drugs not listed.

Overall, the majority of participants reported lifetime use of tobacco ($n = 175$, 70.0%), and more men ($n = 150$, 83.3%) than women reported its use. Approximately a third of participants reported the lifetime use of cannabis ($n = 81$, 32.4%); and one in five reported the lifetime use of methamphetamine ($n = 52$, 20.8%), substances known to be associated with substance-induced psychoses.

6.5.2 Factor structure of the RAS

Descriptive statistics for each RAS item and subscales are provided in [Appendix V](#). The suitability of the data set for factor analysis was confirmed with KMO indices of 0.88, and Bartlett's Test of Sphericity was highly significant ($\chi^2 = 2208$, $p < .001$), indicating adequacy for factor analysis. No missing data were identified in the data set. The results indicated five factors for the South Africa dataset that cumulatively accounted for 55.87% of the variance. Table 6.4 provides a summary of the factor loadings for each RAS item; these ranged from 0.48-0.83. All 24 items loaded onto a factor.

Table 6.4

Factors Derived from the South African Version of the RAS in the Total Sample (N = 250)

		EFA	Alpha	ICC
Factor 1	Personal Confidence (PC)		0.81	0.70
9	I like myself.	0.59		
10	If people really knew me, they would like me.	0.52		
13	I'm hopeful about my future.	0.65		
14	I continue to have new interests.	0.48		
18	I know when to ask for help.	0.70		
19	I am willing to ask for help.	0.74		
20	I ask for help, when I need it.	0.66		
Factor 2	Goal and Success Orientation (GSO)		0.84	0.72
1	I can make something of myself.	0.67		
3	I have goals in life that I want to reach.	0.79		
4	I believe I can meet my current personal goals.	0.76		
5	I have a purpose in life.	0.68		
11	I have an idea of who I want to become in the future.	0.54		
12	Something good will eventually happen.	0.54		
Factor 3	Reliance on Others (ROO)		0.66	0.54
6	Even when I don't care about myself, other people do.	0.62		
22	I have people I can count on.	0.74		
23	Even when I don't believe in myself, other people do.	0.67		
24	It is important to have different friends.	0.66		
Factor 4	Empowerment and Inner Strength (EIS)		0.72	0.52
2	I have my own plan of how to stay or become well.	0.66		
7	Fear doesn't stop me from living the way I want to.	0.69		
8	I can handle what happens in my life.	0.75		
21	I can handle stress.	0.50		
Factor 5	No Domination of Symptoms (NDS)		0.76	0.61
15	Coping with my mental illness is no longer the main focus of my life.	0.68		
16	My symptoms interfere less and less with my experiences.	0.83		
17	My symptoms seem to be a problem for shorter periods of time each time they occur	0.82		

Factor 1 comprised seven items related to "Personal confidence" that explained 30.26% of the total variance, with factor loadings from 0.58 to 0.74. Factor 1 had an eigenvalue of 7.26. Factor 2 comprised six items related to "Goal and success

orientation”, with factor loadings ranging from 0.54 to 0.79. This factor had an eigenvalue of 1.83, explaining 7.61% of the total variance. Reliance on others loaded as Factor 3; and it comprised four items that explained 7.42% of the total variance, with factor loadings ranging from 0.62 to 0.74. Factor 3 had an eigenvalue of 1.78. Four items (with factor loadings of 0.50 to 0.75) loaded onto Factor 4. This new factor, which we named “Empowerment and inner strength”, had an eigenvalue of 1.39 and accounted for 5.79% of the variance. “No domination of symptoms” emerged as Factor 5, which comprised three items (with factor loadings ranging from 0.68 to 0.83). The eigenvalue for Factor 5 was 1.15, accounting for 4.77% of the total variance. Of the five factors, four were closely aligned with the original factors proposed by the RAS.

A significant difference was that four items from the original RAS domain, “Personal confidence and hope”, loaded onto the new factor, “Empowerment and inner strength” that emerged in this South African sample (Factor 4). Additionally, the original RAS domain, “Willingness to ask for help”, did not emerge as a distinct domain in this sample. Instead, the three items comprising this domain in the original RAS loaded onto Factor 1 (Personal confidence). For this sample, the resulting factor structure was: Factor 1 (Personal confidence), comprising items #9, #10, #13, #14, #18, #19, and #20; Factor 2 (Goal and success orientation), which included items #1, #3, #4, #5, #11 and #12; Factor 3 (Reliance on others), which included items #6, #22, #23 and #24; Factor 4 (Empowerment and inner strength) with items #2, #7, #8 and #21; and Factor 5 (No domination of symptoms) comprising items #15, #16 and #17 (see Table 6.4 and [Appendix Z](#)).

6.5.3 Internal consistency and test-retest reliability of the RAS

Using Cronbach’s alpha coefficient and intraclass correlations (ICC), the internal consistency and test-retest reliability were assessed on the five factors that emerged from the EFA, with findings presented in Table 6.4. Internal consistency for the total RAS was also examined. No items were deleted and, as a whole, the RAS had a Cronbach’s alpha of 0.89, with four subscales having a Cronbach’s alpha of > 0.7 , indicating acceptable internal consistency. Factor 1 (Personal confidence) had a Cronbach’s alpha of 0.81, while Factor 2 (Goal and success orientation) had a Cronbach’s alpha of 0.84. Factor 3 (Reliance on others) showed moderate internal consistency with a Cronbach’s alpha of 0.66. The Cronbach’s alpha for Factor 4 (Empowerment and inner strength) was 0.72, and for Factor 5 (No domination of symptoms), it was 0.76.

Test-retest reliability of the new factors was assessed using the initial sample of 250 participants and the retest sample ($n = 65$) (see Table 6.4). The intraclass correlations for the total RAS scores showed moderate test-retest reliability. The total scale had a correlation coefficient of 0.73, and when the subscales were considered, the temporal

stability of individual subscales ranged between 0.52 and 0.72, indicating moderate reliability.

6.5.4 Convergent validity of the RAS

Convergent validity was explored by examining the correlation between the RAS and the MSPSS and the RAS with the WHOQOL. Table 6.5 presents the results of these analyses.

Table 6.5

Correlations between the RAS-SA, Social Support and Quality of Life Dimensions

	Total RAS
RAS	1.00
MSPSS	.372**
WHOQOL	.516**

Note: **Correlation is significant at 0.01 level (2-tailed)

The RAS was moderately correlated with the MSPSS ($r = 0.372$, $p < 0.01$), such that as perceptions of personal recovery increased, as did perceived social support. The correlation between RAS and the WHOQOL-BREF was statistically significant ($r = 0.516$, $p < 0.01$) such that as perceptions of personal recovery increased, so did perceived quality of life.

6.6 Discussion

This study aimed to explore the psychometric properties of the RAS in a population of persons with SMHCs. Our findings suggest that, for the most part, the RAS has adequate internal consistency, temporal stability and convergent validity among South African MHSUs with SMHCs.

Previous studies carried out in Japan, Australia, Spain, and Argentina respectively (Chiba et al., 2010; McNaught et al., 2007; Saavedra Macías et al., 2021; Zalazar et al., 2017), have supported the five latent domains represented in the original RAS (Corrigan et al., 2004). In contrast, two studies conducted in the USA and Portugal proposed four factors, given the overlap between the domains PCH and GSO (Gonzales et al., 2015; Jorge-Monteiro & Ornelas, 2016). The EFA in the reported research supported a five-factor structure. Two factors in this study (ROO and NDS) were aligned to the original factors identified (Corrigan et al., 2004), with the same items loading on these domains. The domain ROO considers the involvement of others in supporting recovery. The

domain ROO considers the involvement of others in supporting recovery. Although its Cronbach's alpha score was the lowest of all the subscales, these findings are consistent with those from previous studies, which also reported that the internal consistency was lowest for ROO, ranging between 0.60 and 0.67 (Biringer & Tjoflåt, 2018; Cavelti et al., 2017; Saavedra Macías et al., 2021; Zalazar et al., 2017).

The other domains differed from the original RAS domains in five ways. First, WAH (Willingness to ask for help) did not emerge as a separate factor; surprisingly, all three items assigned to WAH (#18, #19, #20) loaded onto PC (Personal confidence). Second, although PC emerged with seven items, only four were aligned with the original RAS; and items related to hope did not feature in this factor. The inclusion of WAH-related items into PC could mean that participants in the South African sample perceived a "willingness to ask for help" as being a sign of having confidence to ask for help and so getting the help they needed when they asked for it. PC thus speaks broadly to self-confidence in accessing help; and the alpha coefficient for the seven items comprising this domain was 0.81, suggesting a relatively high internal consistency.

Third, the original factor, GSO (Goal and success orientation), emerged with six items, two of which were on the factor PCH in the original RAS. This could mean that South African respondents perceived hope for the future to be closer to GSO than to PC. Although not clear, these discrepancies in the factor structure could be explained in how recovery is understood differently in different cultures and communities (Chiba et al., 2010; Zalazar et al., 2017).

Fourth, a new factor with four items emerged in this study. This factor consisted of one original GSO item (I have my own plan of how to stay or become well) and three items from the original PCH domain (Fear doesn't stop me from living the way I want to; I can handle what happens in my life; and I can handle stress). We called this factor "Empowerment and inner strength" (EIS), as it speaks to moving beyond the mental health condition and having the courage and confidence to stay well, the ability to cope in the future and the belief in having access to tools to support personal recovery. The EIS domain had a Cronbach's alpha of 0.72, indicating acceptable internal consistency. The items in this domain seem to relate to the unpredictability of the future *and* MHSUs' views that they have the knowledge to manage and survive future relapses.

A reason for items loading onto different factors could be that these items having varied meanings in the South African context, showing that recovery dimensions cannot be understood in isolation and that understandings of recovery are influenced by context. Differences in the factor structure could be attributed to how recovery is explained and understood in different countries and across cultures. For example, in other cross-cultural studies (Chiba et al., 2010), the authors suggested that cultural differences between how individualism and collectivism are understood in different parts of the

world could explain why items load onto different factors. This is an important consideration for a multicultural and multilingual country like South Africa. With its legacy of apartheid, conceptualisations of recovery might be influenced by historical experiences, collective trauma, marginalisation, economic hardship and resilience, and where recovery occurs in a communal, relational way rather than as an individualistic journey towards autonomy (Essel-Gaisey et al., 2023; Kpanake, 2018). In this sample, only two factors (ROO and NDS) aligned with the original RAS (Corrigan, 2004). Other factors diverged, with items from WAH loading onto PCH rather than emerging as a separate factor as in the original. The emergence of EIS, a new factor comprising items related to PCH and GSO, may reflect resilience and confidence in accessing support systems when needed. This might suggest that local understandings of mental health and recovery contributed to these differences. The divergence from the original factor structure could further suggest that certain constructs of recovery measured by the RAS may not map neatly onto the South African experience (Kleintjes & Schneider, 2023). These differences highlight the importance of developing culturally responsive and locally meaningful recovery conceptualisations as they speak to the complexity and interwoven relationship between recovery and the broader social and historical context.

This study confirmed the reliability of the 24-item RAS. In this sample, the RAS had a Cronbach's alpha coefficient of 0.89, indicating that the RAS has a high internal consistency comparable to other studies (Chiba et al., 2010; Corrigan et al., 2004; Saavedra Macías et al., 2021; Zalazar et al., 2017). The RAS also had an overall good test-retest reliability in this sample, with an ICC of 0.73, indicating strong temporal stability, despite three domains scoring below 0.70. In addition, the RAS had good convergent validity, providing additional evidence for the RAS being a psychometrically sound measure of recovery for persons with SMHCs in South Africa. Specifically, the RAS corresponded well to other validated measures of social support and quality of life, which are embedded in conceptualisations of recovery (Salzer & Brusilovski, 2014).

The factor structure of the RAS covers many elements of recovery related to the mental health of the individual (such as hope, self-determination, agency, meaning, purpose and potentiality) and the environmental barriers to social integration and community inclusion that persons with SMHCs face (Onken et al., 2007). However, the RAS does not cover domains related to spirituality and religion, finding meaningful roles and valued social connections, cultural dimensions, and reliance on caregivers, all of which are important in how recovery is conceptualised and facilitated in LMICs (Gamielien et al., 2023; Gamielien, Galvaan, Myers, et al., 2021). In LMIC contexts, traditional healers and spiritual advisors form part of the unacknowledged mental health care pathway (Burns & Tomita, 2015); but they hold differing explanatory models for SMHCs, which influence their treatment practices (Asher et al., 2018; Sorsdahl et al., 2010).

In some contexts, the focus is less on the individual's achievements and more on the successful relationships born from family and friendship ties. Seeking help outside the family is a last resort, and families are expected to be the caregivers of persons with any mental health condition (Silaule, Casteleijn et al., 2024; Zalazar et al., 2017). In South Africa, the social and cultural dimensions of recovery are essential elements in MHSUs' recovery journeys (Gamieldien, Galvaan, & Duncan, 2021; Gamieldien et al., 2022; Gamieldien et al., 2023; Gamieldien, Galvaan, Myers, et al., 2021). Earlier chapters discussed how MHSUs' recovery needs intersect across social, economic, cultural and political spheres.

Findings from this study are potentially significant as few studies examine the psychometric properties of the RAS in LMICs, despite its widespread use as a tool for measuring recovery (Burgess et al., 2010; Shanks et al., 2013). The South African public health policy and its drive to develop mental health services that support recovery offers service providers the opportunity to interrogate the relevance and applicability of recovery measures for use in the South African context. Equipping South African service providers with tools, such as the RAS, to assess some of the dimensions of recovery will advance the mental health reform agenda and facilitate the development of recovery-focused mental health services across the continuum of care. This study provides empirical evidence that the RAS is a useful tool for measuring aspects of personal recovery from SMHCs. However, it does not fully encompass the breadth of recovery dimensions relevant to the South African context. MHSUs recovery needs intersect across social, political, economic, spiritual and cultural spheres (Essel-Gaisey et al., 2023; Kleintjes & Schneider, 2023; Kpanake, 2018) and the findings of this study underscore the importance of adapting assessment tools which reflect contextual realities, enabling a more holistic approach to developing recovery-focused mental health services.

6.7 Limitations

Some possible limitations should be considered. First, despite the large and diverse sample, it is likely that it only represented part of the population living with SMHCs in South Africa. Participants were also drawn through convenience sampling and were either part of inpatient programmes or affiliated with mental health non-profit organisations, creating further difficulties in generating a representative sample and rendering the study's findings generalisable to all MHSUs. Second, the RAS was only administered in English, despite Afrikaans being the first language of 43.2% of the sample. The implications of using only an English version of the RAS need to be explored. Additionally, further development work is necessary to translate the RAS into Afrikaans and isiXhosa to reach the speakers of all three official languages of the Western Cape Province of South Africa. Third, the study was partially conducted during

the COVID-19 pandemic, and the results may be unique to this time, thus limiting the study's external validity when generalising the findings pre- and post-pandemic conditions. Finally, this study was undertaken in a single province with a health system that may differ from others in the rest of the country.

6.8 Conclusion

Overall, this study shows that the 24-item RAS is a reliable and valid measure of recovery among those with SMHCs in South Africa. While the EFA revealed a five-factor structure in this sample, the emergence of a new factor gives us some insights into variations of meaning attributed to recovery in a South African population. Further studies are needed to explore other language versions of the RAS. Findings support using the RAS for assessing personal recovery among persons living with SMHCs in South Africa. The brevity, practicality, and simplicity of the 24-item RAS make it useful for mental health services to include as part of routinely collected outcomes data. This would advance our understanding of the extent to which services promote personal recovery and may advance the mental health reform agenda by facilitating the development of recovery-focused mental health services.

Chapter Seven: Bringing it Together: Findings, Recommendations and Future Directions

7.1 Chapter overview

In this thesis, I explored recovery from severe mental health conditions (SMHCs) from the perspective of a low- and middle-income country (LMIC). The overall research question underpinning this study was: What constitutes and facilitates recovery for persons with SMHCs in South Africa? This question was answered in four empirical studies. In Chapter Three, a scoping review examined the conceptualisation of personal recovery in LMICs. Chapters Four and Five qualitatively explored the perspectives on recovery from SMHCs among service providers, men living with SMHCs, and their caregivers, respectively. Chapter Six evaluated the psychometric properties of the Recovery Assessment Scale (RAS) for measuring recovery among individuals living with SMHCs in South Africa. Since each chapter provides an in-depth discussion of the findings, this closing chapter synthesises results through the proposed Recovery Mandala for recovery-focused care. The implications for policy and practice across the four studies, as well as recommendations and future directions for research, training and service provision, are also discussed.

7.2 The Recovery Mandala: Highlighting elements of recovery-focused care

Several models and frameworks in the literature describe recovery from mental health conditions, each offering different perspectives and essential components of the recovery process. Recovery models and frameworks extend the medical model across the continuum of care and are not limited to hospital-based services and interventions. Recovery frameworks offer opportunities to operationalise recovery as the recognised outcome of public policy, services and research (SAMSA, 2006). The Substance Abuse and Mental Health Services Administration (SAMHSA) proposes ten widely endorsed components of recovery: (i) self-direction, (ii) individualised and person-centred services, (iii) empowerment, (iv) holistic, (v) non-linear, (vi) strength-based, (vii) peer support, (viii) respect, (ix) responsibility, and (x) hope (SAMSA, 2006). Some or all of these components feature in different recovery frameworks (Ellison et al., 2018; Gyamfi et al., 2022). For example, the Tidal Model (Barker, 2001) reflects MHSU's fluid experience of health and illness and the role of support networks in empowering MHSUs to take charge of their lives (Barker, 2001). Other frameworks in the literature include the REFOCUS model for recovery-oriented practice (Slade et al., 2015), the

Integrated Recovery Model (Frost et al., 2017), and the previously discussed CHIME framework (Leamy et al., 2011).

Recovery models challenge the medical model that frames mental health conditions as solely a clinical condition. Rather, these frameworks call for the consideration of recovery as a social, relational and rights-based process; and the Social Model of Disability provides a useful lens for understanding recovery from SMHCs (Barnes, 2019; Kinn, 2016; Shakespeare, 2006). Disability activism and the recovery movement challenge the medical model that focuses on individual pathology and symptom reduction, highlighting instead the impact of social, cultural and political barriers (Slade, 2015). The recovery process involves MHSUs reclaiming agency, dignity and full participation in society (Leamy et al., 2011). The Social Model of Disability frames disability as a right-to-access issue, and it looks at ways of removing barriers that limit the choices of people with disabilities, including those with SMHCs (Kinn, 2016). By using a social and rights-based approach to mental health reform, we can conceptualise recovery as a transformative process influenced by inclusion, access and freedom from coercion (Kinn, 2016).

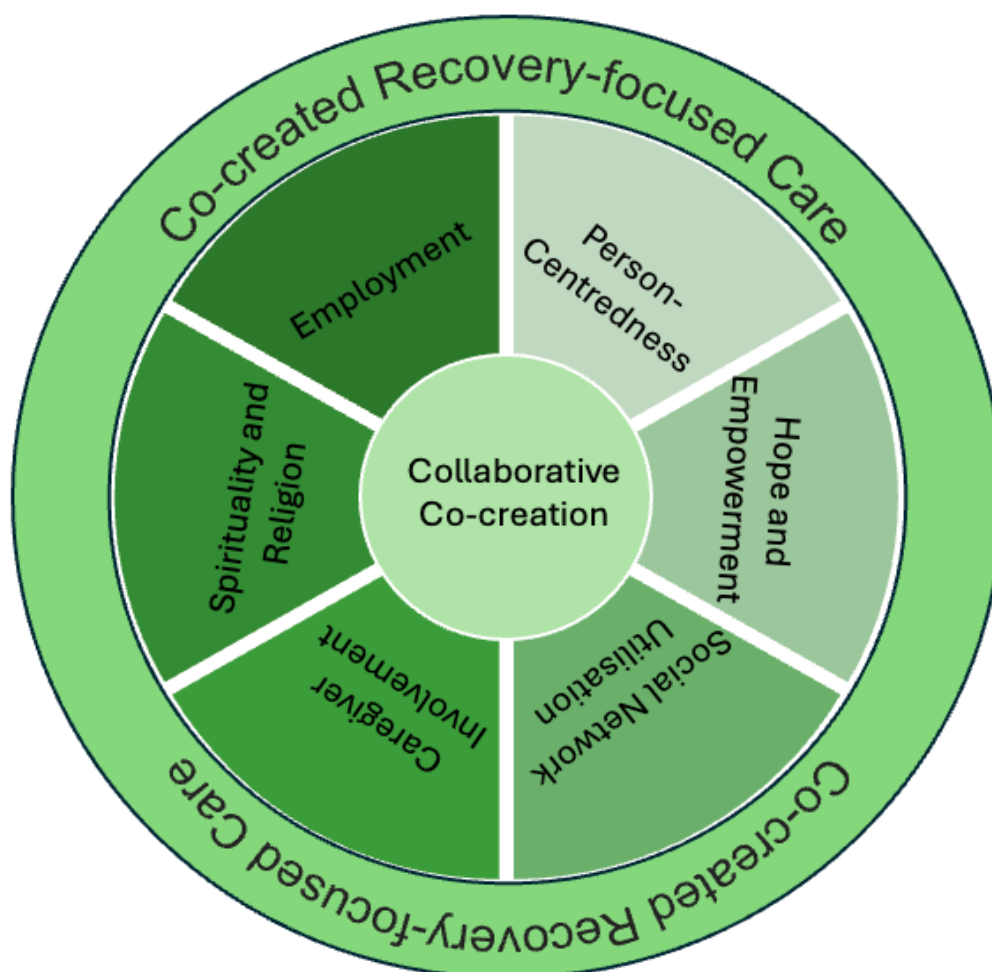
Results from Chapter Five extend the CHIME framework by looking beyond the individual to include contextual factors, struggles, stigmatising attitudes, and difficulties that influenced the recovery of four MHSUs and their caregivers in the Western Cape Province of South Africa. While the CHIME framework effectively illustrates the interconnected dimensions of recovery, I found it limiting as it primarily emphasises positive individual strengths that facilitate recovery without adequately considering external factors that may impact recovery. The findings further illustrate the importance of the meaningful inclusion of persons with lived experience in recovery-focused research, policy and service provision. The CHIME framework conceptualises recovery, allowing for application to recovery-focused care.

The elements of the recovery journey that emerged from this thesis are graphically illustrated by the Recovery Mandala, highlighting elements that should form a part of recovery-focused care (Figure 7.1). The word mandala means circle or centre in Sanskrit; and some view it as a spiritual or ritual symbol of existence and revelation (Blume, 2024; Sepehri, 2022). The mandala is one of the earliest symbols of humankind, often used to depict the cycle of birth, life, and death. It is also used to show the interconnectedness of all living things. Thus, it symbolises unity, harmony, and spiritual exploration (Sepehri, 2022). Since the circles making up a mandala are unending, I have used these circles to symbolise the continuous, non-linear nature of recovery. Indeed, the temporal nature of the recovery journey emerged in all elements of this thesis.

The Recovery Mandala represents the interface between the elements embedded in co-created recovery-focused care. In this way, the Recovery Mandala showcases what (i) constituted recovery and (ii) facilitated recovery in this study. As shown in Figure 7.1, the seven elements making up the Recovery Mandala are (i) Collaborative Co-creation, (ii) Person-centred Care, (iii) Fostering Hope and Empowerment, (iv) Accessing Social Support, (v) Caregiver Involvement, (vi) Spirituality and Religion, and (vii) Employment. The inner core of the mandala reflects the central element of collaborative co-creation with diverse stakeholders; and the outer circle includes six interconnected recovery elements. I did not set out to explore each element individually, and the elements are not necessarily new to the recovery literature as they are featured in various models (Gyamfi et al., 2022). However, through the Recovery Mandala, the elements reflect the main findings derived from this thesis and represent recovery holistically in one South African context. What follows is a discussion of these elements.

Figure 7.1

Recovery Mandala



7.2.1 Collaborative co-creation with diverse stakeholders (Element #1)

Across the empirical studies reported in Chapters Three to Five, the importance of co-production, collaboration, and meaningful engagement with diverse stakeholders, including persons with lived experience of SMHCs in LMICs, emerged as a central element of recovery-focused care. In Chapters Four and Five, this element became apparent as a necessary foundation that is precursive and central to all of the elements in the Recovery Mandala. The data indicated that stakeholders across the studies view recovery as a personal journey which occurs across a continuum alongside others. However, resource constraints in the current public mental health systems meant that there was a lack of continuity of care and involvement of others, and these shortcomings impeded recovery.

The WHO's global drive to close the treatment gap includes involving persons with lived experience (PWLE) in scaling up community-based mental health services to ensure person-centred, human rights-based, recovery-focused care (Bhugra et al., 2017; Sorsdahl et al., 2023; World Health Organization, 2003, 2022b). There has been a global call to prioritise lived experience perspectives into mental health research, training, service development, implementation, and monitoring, given past oppression and injustices in this area (Hawke et al., 2023; Sunkel & Sartor, 2022). The literature points to consensus that collaboration and meaningful engagement involving PWLE as experts by experience enhances the quality, relevance, and impact of public mental health research, service orientation, and available interventions (Nature Mental Health, 2023; Sartor, 2023b; Subandi et al., 2023; Thornicroft et al., 2022; Vera San Juan et al., 2021). When engaging PWLE in research and service design, key considerations involve fostering inclusivity, knowledge co-creation, active involvement, flexibility, agency, and support (Dray et al., 2024; Hamilton et al., 2018; Sunkel & Sartor, 2022). Connecting with PWLE and incorporating their lived experience into research studies can lead to better health outcomes for MHSUs and a satisfying care experience for service providers (Vojtila et al., 2021).

Despite the South African National Mental Health Policy Framework and Strategic Plan (National Department of Health, 2023) highlighting the importance of involving PWLE, much work must be done to achieve this. There are some international guidelines and organisations for co-creation with lived experience experts that offer us valuable lessons. The Global Mental Health Peer Network (GMHPN) is a South African-based international organisation focusing on building lived experience leadership from diverse perspectives. The GMHPN also showcases lived experience in service delivery to demonstrate that MHSUs can be meaningfully employed as part of the mental health workforce and research networks (Hawke et al., 2022; Sunkel & Sartor, 2022). Senior members of the GMHPN are PWLE, who also provide mental health care such as virtual

support group facilitators, online peer support platform creators, peer support specialists, social workers, advanced lived experience practitioners and psychiatrists (Sunkel & Sartor, 2022). Models of lived experience that may be useful in the South African context include the Cape Consumer Advocacy Body (CCAB), a platform hosted by Cape Mental Health which allows MHSUs to be proactive in their care by giving them a voice on various platforms (Kakuma et al., 2010).

In spite of the Element no. 1 of collaborative co-creation being essential for recovery-focused care, some challenges may exist. First, the partnership between service providers, caregivers and PWLE must be collaborative and not swayed by power dynamics favouring the service provider (Bird et al., 2020; Dray et al., 2024). Second, collaboration must be intentional and receive ongoing attention and effort, not an element that is considered once-off (Dray et al., 2024). Third, the provision of compensation for MHSUs and caregivers needs to be explored (Sartor, 2023b). If we are to offer co-created recovery-focused care in research, service design, implementation and training, then we must embed the element of collaboration in all aspects of public mental health.

7.2.2 The provision of person-centred care (Element #2)

Across Chapters Three to Five, the importance of providing person-centred care (PCC) at all levels of services was highlighted as a key element of recovery. In Chapter Three, which focused on LMICs, the recovery journey started once MHSUs were discharged from hospitals to their communities. MHSUs indicated that accessing PCC ensured their unique service needs and preferences were addressed and facilitated their recovery. As highlighted in Chapter Four, despite service providers' awareness of the importance and evidence for PCC, the healthcare settings where many worked did not foster this element. MHSUs received some PCC when accessing a few MH-NPO settings beyond the health sector. In Chapter Five, a key theme was the importance of MHSUs receiving services and interventions focused on individualised care and autonomy. In this chapter, MHSUs reported that the involuntary and restrictive manner in which they were admitted to the hospital violated their autonomy and human rights.

The significance of PCC is well documented in the literature. WHO views PCC as an important element of community-based services because it includes freedom and human rights (World Health Organization, 2021b). PCC involves providing holistic services that promote living a meaningful life for service users. This involves considering service users' goals, aspirations, and preferences and identifying support systems to facilitate recovery (Davidson et al., 2021; Davidson & Tondora, 2022; Håkansson Eklund et al., 2019; Kilbourne et al., 2018). The WHO provides guidance and direction on providing PCC that supports recovery while maintaining relevance to the social and economic context (World Health Organization, 2021b). These guidelines

affirm the WHO's commitment to the protection of human rights. The recovery movement is also embedded in human rights, so mental health systems need to protect and commit to PCC within formal and informal mental health services (Davidson & Tondora, 2022).

Several conceptual frameworks exist for defining PCC. Despite the range of approaches to PCC, common aspects should be considered for care planning and provision of care. These include shared decision-making, individualised care, participation and involvement of service users, the relationship between the service user and the team, and holistic services in a range of contexts (Davidson & Tondora, 2022; Hummelvoll et al., 2015; Scholl et al., 2014; World Health Organization, 2021b). Shared decision-making and opportunities for personal growth and development, as identified by the person, are central to PCC and are personalised and tailored to the needs and preferences of individuals (Davidson & Tondora, 2022). My findings are consistent with literature outlining the benefits of PCC, including shared decision-making. As found in Chapter Five, when MHSUs actively participated in shared decision-making, they reported being more engaged in their recovery journeys, which motivated them to stay well and decreased readmission rates. PCC also recognise MHSUs' expertise, values their perspectives, respects the choices of PWLE, addresses stigma and discrimination and engages MHSUs to be active participants in their recovery and the broader stakeholder community (Anthony, 1993; Rudnick, 2020; Sunkel, 2022; Thornicroft et al., 2022; Veldmeijer et al., 2023). Additionally, services should include evidence-based interventions in diverse community settings aligned with PWLEs' recovery goals at different stages of their lives.

Several studies have shown the benefits of PCC and shared decision-making. For example, a study by Banfield and Forbes (2018) evaluating the Partners in Recovery care coordination initiative focused on forming partnerships and linkages with services through a network of support facilitators. In the Partners in Recovery Programme, MHSUs, carers, and service providers benefited from the stability and relational continuity provided by care coordinators to facilitate coordinated access to health and social care aligned to MHSUs' recovery goals (Banfield & Forbes, 2018). A practical application of PCC, which supports shared decision-making, involves the creation of advance directives. This intervention involves the development of a co-constructed contingency plan which acts as a tool for discussing intervention options, relapse management, and goals which can sustain recovery in context (Davidson & Tondora, 2022; Martinelli & Ruggeri, 2020; Suhas & Rao, 2021).

Some models that could be applied to LMICs integrate PCC into service delivery. These include the previously mentioned Partners in Recovery Program (Banfield & Forbes, 2018) and the Integrated Recovery Model (IRM) (Frost et al., 2017). The IRM considers that people change and grow, and access to services should be tailored to involve the

PWLE in establishing, achieving, and maintaining their recovery-oriented goals. Frost proposes the IRM because it involves collaborations in diverse service contexts and with service providers that are integral to supporting recovery. The IRM considers three components offered at different times and levels of care: remediation of functioning; restoration of skills in collaboration with others; and reconnection with the community. The three levels of service provision are aligned with these three components: acute mental health care, specialist clinical rehabilitation, and non-profit organisations that provide community integration services. The interaction of the three components is seen as a tripartite agreement that promotes hope in living a meaningful and satisfying life beyond the MHC (Frost et al., 2017). In a context such as South Africa, service providers could consider the IRM as it accommodates the temporal nature of recovery by providing recovery-focused services in an integrated and seamless manner across three levels of care.

Another example of PCC is strengths-based approaches that promote individual strengths and resources which facilitate recovery (Bird et al., 2012; Davidson & Tondora, 2022; McKay et al., 2018). Some MH-NPOs provided MHSUs with opportunities to develop and practise self-management strategies to help them understand who they are beyond their diagnosis. The Strengths Model is a recovery-oriented approach to mental health care that originated in social work (Rapp & Goscha, 2011). This model is both a set of tools and methodologies and a philosophy of clinical practice (Martinelli & Ruggeri, 2020) that shifts the focus away from deficits, symptoms, and pathologies (clinical recovery) to focus on the strengths and resources that promote health, well-being, and life satisfaction (Bird et al., 2012; Keyes, 2014; Rapp & Goscha, 2011; Xie, 2013). Given that MHSUs' experience of the health system is focused on discussing their problems, the Strengths Model involves a strengths assessment to identify different types of strengths. These include environmental factors, personal qualities, aspirations, and talents (Rapp & Goscha, 2011). In Chapter Four, service providers using a clinical recovery lens viewed relapses as unfavourable. However, relapses are anticipated in the Recovery Mandala, given the non-linear nature of recovery, and should be factored into recovery plans as part of the recovery journey. Healthcare providers are encouraged to reorient their interventions and services to be responsive and respectful to health service users' abilities, resources, choices, needs, and values, including plans for when they relapse (Davidson & Tondora, 2022; Van der Veen et al., 2023).

Despite its benefits, implementing PCC poses some challenges in our context. First, healthcare workers might resist change as PCC is seen as adding to the workload. Second, time constraints and short admissions mean that it is difficult to account for the temporal aspects of recovery in public mental health settings. This is further reinforced by the focus on clinical recovery in hospital settings, which results in service

providers missing the use of PCC as a tool for relational continuity with PWLE (Banfield & Forbes, 2018). Third, restrictive and involuntary hospital admissions mean dignity and respect are not always at the centre of health care, despite PCC being connected to human rights (Davidson & Tondora, 2022). Given WHO guidance on mental health services, which “Promote Person-Centred and Rights-Based Approaches” (World Health Organization, 2021b), a reorientation of mental health care planning and provision must consider the rights of MHSUs and the protection of their rights in the services they receive (Davidson & Tondora, 2022). In conclusion, PCC is an important element of co-created, recovery-focused care, as evidenced in the existing literature and this thesis.

Next, I will explore the element of hope and empowerment that emerged from my research.

7.2.3 Fostering hope and empowerment (Element #3)

Across Chapters Three to Six, hope and empowerment were highlighted as key elements to promoting recovery. In Chapter Three, being hopeful about MHSUs' recovery potential was an important consideration for stakeholders in LMICs. Findings from Chapter Four indicated that, although service providers have different understandings of recovery, hope and empowerment are featured in their conceptualisations. Some service providers shared that, although this element was not evident in all public health service offerings, they believed that services and interventions which foster hope and empower MHSUs with skills to facilitate their recovery were important elements for recovery-oriented services to include. These findings are echoed in a synthesis of recovery-oriented practice where providers who render inpatient services indicated that supporting hope and promoting empowerment should be explored as alternative intervention options within predominantly medical models of practice (Waldemar et al., 2015). In Chapter Five, MHSUs and caregivers noted that fostering hope in the possibilities of recovery and empowering MHSUs to achieve their recovery goals were necessary ingredients offered by a few MH-NPO-run services. According to MHSUs, these MH-NPOs allow MHSUs to acknowledge their past, experience the present, and be hopeful in actively shaping their future. In Chapter Six, the RAS domain goal and success orientation (GSO) and a new factor, empowerment and inner strength (EIS), featured strongly. These factors were related to hope, agency and being in control of one's life.

First, hope is a multidimensional element; and the literature consistently emphasises the importance of cultivating hope as a critical step in clinical research and practice. Hope is an essential recovery principle and a strong determinant of recovery (Jaiswal et al., 2020; Laranjeira & Querido, 2022; Slade et al., 2021). Furthermore, fostering hope was the overarching principle that emerged in a review of guidelines for recovery-

oriented practice from Australia, Canada, Ireland, the UK and the US (Subandi et al., 2023). Hope and optimism, as well as empowerment, are included in the CHIME framework as two of five recovery processes forming part of the journey of recovery (Bird et al., 2014; Leamy et al., 2011).

Second, empowerment focuses on the PWLE exercising autonomy and agency in their lives to assert their rights, fulfil their dreams and aspirations, reach their potential, overcome obstacles, and manage themselves (Subandi et al., 2023). Empowerment is a fundamental component of recovery, as found in a comprehensive systematic review examining 97 articles on recovery elements (Leamy et al., 2011). Empowerment is pivotal in the recovery journey of individuals with mental health conditions as it helps MHSUs take control over their lives while striving to actualise their potential (Subandi et al., 2023; Venkatesan, 2019). This is featured strongly in Chapter Five, where MHSUs shared how they developed self-management strategies to affirm their agency, and in Chapter Six, through the new RAS domain, which I refer to as EIS.

In the CHIME framework (Leamy et al., 2011), hope and optimism about the future are separate from empowerment. However, the results from this thesis conceptualised hope and empowerment as one element: the one could not exist without the other as they were interconnected. My findings indicate that having a positive expectation of their future motivated MHSUs to join MH-NPOs, which supported recovery. These MH-NPOs were flexible and responsive to accommodate MHSUs' changing needs and preferences while providing them with opportunities for self-determination, empowerment, and active participation in their recovery.

Although there are no specific targeted interventions for fostering hope and empowerment, the literature highlights several guidelines that foster this element in their recovery programmes (Marshall et al., 2024; Mousavizadeh & Jandaghian Bidgoli, 2023; Sartor, 2023a). An example of an empowering intervention is the Living Libraries project, which involves PWLE telling their stories of living with a SMHC and then answering questions from the listener(s) (Marshall et al., 2024). The South African-based Global Mental Health Peer Network focuses on empowering PWLE in their personal and professional capacity development and leadership skills so they can thrive in all aspects of their lives (Sartor, 2023a). In the qualitative studies included in this thesis, fostering hope was a precursor to recovery, as hope ignited the belief that change was possible. This possibility encouraged agency; and, when supported through access to resources, relationships, and affirming spaces, MHSUs were empowered, as capable experts by experience, who could influence their circumstances. The findings of this thesis resonate with the literature that views hope and empowerment as essential elements in recovery from SMHCs (Jaiswal et al., 2020; Mousavizadeh & Jandaghian Bidgoli, 2023; Penas et al., 2021; Slade, 2021).

Offering interventions that foster hope and empowerment presents some challenges. First, there might be differences in how various communities and cultures conceptualise hope and empowerment (Subandi et al., 2023). Second, standardised programmes that lack dialogue and collaboration will not be able to manage the varied ways that MHSUs might respond to interventions fostering hope and empowerment (Jaiswal et al., 2020).

I will now discuss the element of accessing supportive social networks.

7.2.4 Accessing social networks (Element #4)

The findings across Chapters Three to Six indicate that, in LMICs such as South Africa, for MHSUs and their caregivers, access to social networks was a vital element of recovery. This element is connected to the concept of interdependence, which emerged as a key facilitator of recovery in LMICs, including South Africa. This finding differed from studies in HICS, which viewed independence as an important marker of recovery (Mousavizadeh & Jandaghian Bidgoli, 2023; Slade et al., 2014). In this thesis, MHSUs' access to social networks was facilitated through the relationships and connections between stakeholders in the public mental health and MH-NPO sectors. The involvement of the Department of Social Development (DSD) was limited to the provision of social grants, and no other programmes from other government departments emerged from my research as sources of access to social support networks.

Several chapters of this thesis highlighted the element of social support. In Chapter Three, long-term relational support from service providers was viewed as a facilitator of recovery. However, this was hampered by the focus on clinical recovery and the limited availability of support services. This finding was echoed in Chapter Four, where the lack of access to resources offering social support once they were discharged from hospitals hindered MHSUs' recovery. Locally, the integration of mental health into primary levels of care was limited to the collection of medication from CHCs without access to stable, continuous support and services, which stakeholders indicated facilitated their recovery. This finding was extended in Chapter Five, where MHSUs indicated that they did not rely on romantic relationships or family for support; instead, they accessed supportive social networks through their involvement with a few MH-NPOs. These MH-NPOs allowed MHSUs to interact with various people in their living, learning, working and socialising environments. MH-NPOs facilitated social inclusion and community integration because they offered a few marginalised MHSUs equal opportunities to access resources, advocate for their rights, and allow for meaningful participation in their community lives (Davidson et al., 2021; Filia et al., 2022). The data generation methods and findings reported in Chapter Five allowed me to explore how social networks connected to people, places and activities helped or hindered recovery

(Sweet et al., 2018). In Chapter Six, I found that, in the South African sample, the original RAS domain, Willingness to ask for help (WAH), loaded in the domain of Personal confidence (PC), showing that the social aspects of recovery and having supportive people to count on are important domains in my sample.

My findings are consistent with the literature, which emphasises that support networks are an important element of recovery (Leamy et al., 2011; Pope et al., 2019; Sweet et al., 2018; World Health Organization, 2021b). Some MH-NPOs that offered support networks that were accessible to MHSUs adopted the international best practice clubhouse model (McKay et al., 2018; Raeburn et al., 2013). MH-NPOs who adopted the clubhouse model were seen as safe spaces that facilitated recovery by offering positive social connections in supportive and restorative environments away from the struggles of the outside world (Desai et al., 2021). The clubhouse model follows a work-ordered day where the range of activities provided, such as sharing and preparing meals, participating in creative groups, contributing to the upkeep of the club, finding ways to honour members' talents, learning new skills and daily acts of kindness all foster a sense of fellowship and positive social connections (Desai et al., 2021). A recent review of community mental health services offering social and rehabilitation services found that different levels and types of social support exist and are offered by service providers, peers, and caregivers (Bjørlykhaug et al., 2022). Social support-based services include direct strategies such as recovery-oriented communities, clubhouses, and activity-based programmes, including soccer and gardening. In contrast, indirect social interventions include financial support, housing support, context-specific support and support for specific life circumstances (Bjørlykhaug et al., 2022). Recovery depends on different stakeholders supporting MHSUs in their immediate and extended social networks across the continuum of care (Pope et al., 2019).

Interventions offering peer support to MHSUs and caregivers do exist. Loneliness is prevalent amongst MHSUs, and social support programmes, including those with an element of peer support, could mitigate against social isolation (Jenkins et al., 2023). A randomised controlled study on the feasibility and accessibility of peer-led recovery groups for people with psychosis in South Africa (PRIZE) found that these groups were an acceptable means of accessing social interactions, sharing stories, problem-solving and support (Asher et al., 2023). This task-shared model involved groups run by social worker auxiliaries and PWLE. Another South African study nested in the PRIZE study found that the restrictions during the COVID-19 pandemic prevented service users and their caregivers from accessing and providing support in different contexts, and this increased their social isolation (Brooke-Sumner et al., 2023). While peer support programmes did not emerge as a key finding across our studies, in the study reported on in Chapter Five, we found that MH-NPO-affiliated mid-level workers, such as auxiliary social workers, offered MHSUs access to enduring social relationships. These

service providers' consistency in the lives of MHSUs was a facilitator of recovery. As unemployment and economic disparities are high in South Africa (Kleintjes & Schneider, 2023), and the treatment gap is large, it is necessary to extend the network of people who can support MHSUs in their communities for an extended period (Philip & Chaturvedi, 2018). Different cadres of staff (from health and non-health settings) to which tasks can be shifted include mid-level workers, lay health workers, social work auxiliary workers, registered counsellors, peer support workers and case management by non-specialised healthcare workers trained in mental health and supervised by specialists in LMIC settings (Academy of Science of South Africa, 2021; Chibanda, 2017; Jacob & Coetzee, 2018; Petersen, Ssebunnya, et al., 2011; Stein et al., 2022).

There are contestations in the literature about the value and effectiveness of peer support programmes (Chien et al., 2019; Eddie et al., 2019; Lyons et al., 2021; Puschner et al., 2019). A systematic review and meta-analysis on group peer support for persons with MHCs reported that, while peer support had some benefits in promoting recovery, it has not yet been identified as a routine intervention for MHSUs (Lyons et al., 2021). Interestingly, peer support from fellow MHSUs was only mentioned in one study (Chien et al., 2019) which was included in the scoping review discussed in Chapter Three. In South Africa, the previously mentioned PRIZE intervention (Peer-led recovery groups for people with psychosis) is a task-sharing strategy to make recovery groups available in health and social care settings (Asher et al., 2023). Formative work on the PRIZE intervention is complete, but a randomised feasibility trial exploring these groups' acceptability and potential benefits is underway (Asher et al., 2023). While MHSUs shared social support networks with peers in their living, learning, socialising, and working spaces, no formalised peer-support services emerged in the findings reported in Chapter Five. The literature reports on the efficacy, effectiveness and cost-benefits of support services involving peers (Eddie et al., 2019). Intervention studies indicated that peer support initiatives amongst PWLE reduced stigma and offered hope in recovery when MHSUs witnessed their own success and that of others (Chien et al., 2019; Kwon et al., 2023). Given that the help-seeking behaviour of men and women differs, a gender-sensitive approach to accessing social support could reduce men's disengagement with mental health services (Kwon et al., 2023; Sagar-Ouriaghli et al., 2019).

The literature highlights several challenges that persons with SMHCs face regarding their social networks. First, research in LMICs indicates that MHSUs face stigma from communities and services, which leads to difficulties in help-seeking behaviour and relationships, including getting or staying married (Hailemariam, Ghebrehiwet, et al., 2019; Javed et al., 2021). When MHSUs face stigma and discrimination from different stakeholders, including service providers and caregivers, their access to social support networks is hindered, resulting in social isolation and exclusion (Jenkins et al., 2023;

Thornicroft et al., 2022). Second, so far, stigma interventions in LMICs have relied chiefly on strategies from HICs, and African perspectives on stigma, social integration, and recovery from SMHCs have been under-researched (Thornicroft et al., 2022). Third, WHO recognises that loneliness and social isolation are new epidemics affecting people, including MHSUs, and they advocate for expanding opportunities for community engagement to decrease social exclusion (Jenkins et al., 2023; Wang et al., 2018). Fourth, mental health professionals' workload in clinical recovery-oriented settings limits their ability to engage with the social networks available for MHSUs and carers (Davidson & Tondora, 2022; Gamiieldien et al., 2022; Sánchez, 2022; Yu et al., 2022). The Academy of Science in South Africa (ASSAf) published a consensus study report on “Provider core competencies for improved mental health care of the nation” (Academy of Science of South Africa, 2021). Given the diversity of disciplines in health services, the ASSAf report indicates that the Occupational therapist category (inclusive of occupational therapists, community rehabilitation workers, occupational therapy assistants, and occupational therapy technicians) could be the best placed to connect with community structures and facilitate access to longitudinal social support as part of community-based rehabilitation (Academy of Science of South Africa, 2021). Fifth, financial and human resource constraints impede the scaling up of community-based services such as MH-NPOs (Chisholm et al., 2019; Razzouk, 2019).

The lack of consistently available for long-term relational support for MHSUs is a barrier to recovery, especially in circumstances where caregiver support is limited. Facilitating supportive relationships within families, communities, and peer networks can enhance social integration, reduce stigma, and provide MHSUs and their caregivers with access to supportive networks and programmes that integrate with recovery (Ndeti et al., 2023; Silaule, Casteleijn, et al., 2024). Peer support for caregivers of MHSUs was cited in the literature as a frequently used but under-researched intervention that has long-term benefits in alleviating caregiver burden in LMICs (Silaule, Casteleijn, et al., 2024).

Next, we will explore caregiver involvement as an important element of recovery.

7.2.5 Caregiver Involvement (Element #5)

The nature of caregiver relationships impacts recovery and should always be considered. In the scoping review reported in Chapter Three, we found that caregivers were the main source of support for MHSUs in LMICs. Caregivers were the first to seek help for MHSUs and were involved in the subsequent long-term care of MHSUs. It was rare for MHSUs to live on their own in LMICs. MHSUs often lived with family or extended family as determined by cultural norms or socioeconomic and contextual factors. Besides providing MHSUs with accommodation, caregivers offered support, monitored treatment adherence, and facilitated social and community reintegration. Caregivers, in the studies reported in Chapters Three and Five, offered financial, practical and

emotional support to MHSUs as they navigated their recovery journeys. These findings are consistent with the available literature in LMICs, where family members are typically the primary unpaid source of support for MHSUs (Bakhshy & Schizophrenia Awareness Association, 2022). In Chapter Four, service providers indicated that where supportive family involvement was absent, MHSUs were hospitalised for longer as there were no alternative places to discharge MHSUs. The lack of family involvement and support thus impacted negatively on relapse and discharge rates and placed additional strain on public mental health services.

In the study discussed in Chapter Five, we found that MHSUs affiliated with MH-NPOs preferred living in supported housing as opposed to living at home. Where MHSUs had poor relationships with their caregivers, the MH-NPO fulfilled that role. This arrangement allowed MHSUs to determine the nature of their contact with their families. The socio-demographic data generated from the study reported in Chapter Six show that while most participants reported being single ($n = 215$, 86.0%), only nine (3.6%) lived independently. Most MHSUs in this study lived at home with their families ($n = 130$, 52.0%), and 51 (20.4%) participants lived in group homes. This echoes our scoping review findings and the literature, which point to caregivers being part of the 'invisible healthcare system' in overburdened, resource-constrained settings, including those in South Africa (Yerriah et al., 2022).

There is evidence demonstrating the involvement of family and caregivers as a necessary element for the recovery of persons with SMHCs. A systematic review exploring the effectiveness of family-based interventions for psychosis found that all included studies ($n = 27$) recommended family-based interventions in LMICs (Morillo et al., 2022). The family was viewed as an underutilised resource whose involvement was key to the recovery of MHSUs. Effective family interventions were adapted to religious and cultural contexts and included psychoeducation and task-sharing components (Morillo et al., 2022). Research emanating from Nigeria indicates that family involvement and MHSUs' perception of caregiver support create opportunities for recovery, despite the treatment gap and the absence of recovery-focused mental health services (Adeponle et al., 2009; Aldersey et al., 2017). Recovery in the Nigerian setting occurs through everyday socio-cultural practices which help MHSUs access social spaces (Adeponle et al., 2009). Caregivers in our study were interested in psychoeducation interventions to help them understand the diagnosis and treatment of SMHCs. This finding also emerged in the literature where caregivers seek support in understanding clinical recovery through psychoeducation and family interventions to reduce stress (Norton & Cuskelly, 2021; Vera San Juan et al., 2021).

A scoping review on interventions to alleviate caregiver burden in LMICs found that psychoeducation and support group interventions were the most common strategies identified for alleviating the burden of care among caregivers of persons with SMHCs

(Silaule, Casteleijn, et al., 2024). Additional interventions included cognitive behavioural therapy, spirituality-based interventions, mindfulness, mental health care, collaborative interventions, provision of financial and social support, counselling, and occupation-based interventions (Silaule, Casteleijn, et al., 2024). Further strategies are needed to support caregivers in facilitating the community integration of MHSUs with SMHCs (Silaule et al., 2023). In the study reported in Chapter Five, when MHSUs had poor relationships with their caregivers, MH-NPOs stepped into the caregiver role when and as needed. We posit that MH-NPOs can leverage their access to caregivers by incorporating contacts with family, community, and work environments into their services to further build MHSUs' social connections and caregiver support.

Caregivers are untapped resources that can help MHSUs access health and social support if service providers include them in the social support network. However, despite advocating policies, the implementation of caregiver involvement and interventions in mental health care remains a challenge because it is often overlooked, misunderstood and not addressed (Eckardt, 2022). There is a paucity of knowledge on what caregiver-focused interventions should entail, despite caregiver involvement being touted as a cost-effective means to decrease the mental health treatment gap (Norton & Cuskelly, 2021; World Health Organization, 2008). While caregivers can be a means of expanding the mental health workforce through task-sharing, local research in South Africa indicates that caregiver burden negatively impacts the caregiver's quality of life (Brooke-Sumner et al., 2023; Eckardt, 2022; Silaule, Adams, et al., 2024; Silaule et al., 2023; Yerriah et al., 2022), and more women than men take on caregiving roles in the home and community (Monnapula-Mazabane & Petersen, 2021; Silaule et al., 2023; Yerriah et al., 2022). The WHO's Mental Health Action Plan recommends providing care and support to families and carers across the levels of care (World Health Organization, 2011a).

Despite the importance of caregiver involvement as a key element of recovery, caregiver burden is a challenge as there is limited support for caregivers in LMICs, including in South Africa. A review of the burden of MHCs and healthcare interventions in the Western Cape Province did not identify any interventions targeting caregivers (Jacob & Coetzee, 2018). Aspects of caregiver burden include a negative impact on caregiver health and well-being, decreased quality of life, food insecurity, caregiver relocation for work opportunities, violence, substance abuse, feeling obligated to provide care, peer pressure, and MHSUs' limited insight (Sibeko et al., 2016; Silaule, Adams, et al., 2024; Yerriah et al., 2022).

In the next section, I will discuss spirituality and religion, which emerged as an important component of relatedness and connectedness between family and community life in LMICs.

7.2.6 Spirituality and religion (Element #6)

Spirituality and religion is another important element that emerged in my study. In Chapters Three and Five, I found that spirituality and engagement in religious practices were essential elements of recovery for some MHSUs and their caregivers in LMICs, including South Africa. The scoping review reported in Chapter Three revealed that spirituality was a resource that helped some MHSUs and their caregivers to develop a framework to make sense of the SMHC. Additionally, a few MHSUs and caregivers indicated that being spiritual offered emotional support. When MHSUs were able to engage in meaningful rituals and social connections at the individual, family, and community levels, they experienced a sense of community. However, as described in Chapter Five, a few MHSUs and caregivers reported that the stigmatising attitudes held by some members of their religious communities meant that they did not feel supported by faith-based organisations. For these MHSUs, spirituality was something they practised on their own and included as part of their self-management strategies.

Both recovery and spirituality are conceptualised in terms of finding meaning and purpose in life (Anthony, 1993; Milner et al., 2019). A systematic review comprising 38 studies from 15 countries found that spirituality plays a vital role in the lives of persons living with MHCs (Milner et al., 2019). A framework with six themes emerged from this review: Meaning-making, Identity, Service provision, Talk about it, Interaction with symptoms, and Coping (MISTIC). The authors suggest that service providers must be aware of and prepared to support the spiritual dimension of MHSUs (Milner et al., 2019). They recommended that service providers include traditional healers and spiritual advisors as part of their service provision and community support network.

Religious and traditional healers often hold explanatory models for SMHCs; and these models differ from those of mental health providers whose views on SMHCs influence their treatment practices (Asher et al., 2018; Sorsdahl et al., 2010). A South African study on the health-seeking behaviour of persons with common mental health conditions in a 12-month period reported that traditional healers and spiritual advisors were part of the care pathway and were consulted 9% and 11% respectively (Sorsdahl et al., 2009). Traditional healers and spiritual advisors are part of the mental health workforce as they are perceived to have knowledge of traditional medicine, cultural practices, and spiritual beliefs; therefore, their advice is sought as part of the mental health pathway (Burns & Tomita, 2015; Nortje et al., 2016). In LMICs such as South Africa, traditional healers and religious advisors are important components of informal mental health care (Herman et al., 2009; Sorsdahl et al., 2023; Sorsdahl et al., 2009; South African Society of Psychiatrists, 2020). While the South African Stress and Health (SASH) study (Herman et al., 2009) focused on common mental health conditions, they reported that South Africans are likely to consult traditional healers before accessing

formal mental health services. Others have shown that alternative or traditional medicine is widely used among South Africans (Green & Colucci, 2020). Traditional healers are often the first port of call for families of persons with SMHCs because their communities hold them in high esteem. While attention has been given to the effectiveness of traditional healers in treating common mental health conditions (Nortje et al., 2016), the involvement of traditional healers as a resource that can offer MHSUs and their caregivers long-term relational support over the course of their recovery journeys warrants further exploration. Given these findings and the pathways to mental healthcare in LMICs, it will be beneficial for traditional healers and health service providers to make efforts to understand differing conceptualisations of MHCs and collaborate with each other, as this will improve access to mental healthcare (Asher et al., 2018; Green & Colucci, 2020).

Challenges to including spirituality in recovery-focused services do exist. First, service providers need to consider how cultural practices, beliefs and symptoms of mental illness influence recovery (Asher et al., 2018). Second, the mental health literacy of spiritual and traditional healers needs to be improved so that they can support MHSUs in accessing help timeously (Green & Colucci, 2020). Third, different explanatory models for SMHCs influence MHSUs' experiences of stigma and their access to evidence-based care (Asher et al., 2018). Fourth, religious groups can be a source of social support, but internal and societal stigma must be addressed (Baxter et al., 2019; J. Griffith et al., 2016). Fifth, some research shows that there is a 'religiosity gap' between the value placed on spirituality by MHSUs and their caregivers, and that of service providers (Milner et al., 2019), and this leads to a gap in understanding how MHSUs' ability to participate in religious occupations influences health outcomes (Thompson et al., 2018). Sixth, traditional healers play an important role in the lives of some MHSUs, but faith-based organisations and traditional healers have not been formally integrated into health services in South Africa (Academy of Science of South Africa, 2021).

Finally, I will explore how the element of work influences MHSUs' recovery.

7.2.7 Employment (Element #7)

The findings reported in Chapter Three indicated that access to employment opportunities was an important element of recovery where the value of work extended beyond economic benefits. In Chapter Four, service providers reported how unemployment and dependence on social grants negatively impacted MHSUs' recovery. Chapter Five offered insights from MHSUs affiliated with a few MH-NPOs who benefited from accessing skills development and work opportunities. These work opportunities allowed MHSUs to participate meaningfully as citizens in their chosen communities, to help others in need, and to acquire material possessions reflecting

symbolic status and success. Furthermore, the provision of work opportunities for MHSUs to represent PWLE in advocacy spaces emerged as a critical element connected to making meaningful contributions to service delivery. These findings corroborated assertions made in the literature regarding the importance of work as a means of social inclusion for persons with SMHCs (Devine et al., 2020; Pai et al., 2021; Read et al., 2020; Saavedra et al., 2016). Obtaining and maintaining employment are considered essential indicators of recovery (Pai et al., 2021). As echoed in the literature, the findings in Chapter Five also indicate that socioeconomic factors, including racial disparities, further impact MHSUs' ability to pursue work and educational opportunities (Delman & Adams, 2022; Gamieldien et al., 2023). In Chapter Six, I found that the majority of participants were social grant recipients (76%) and unemployed (67%).

There is substantial evidence demonstrating the importance of employment in the recovery of persons with SMHCs. Employment is a multifaceted element that impacts individuals, their caregivers and society (Topor et al., 2019; Van Weeghel et al., 2019; Yanos et al., 2010). Employment provides people with financial benefits, a sense of purpose, social interaction, and routine (Pai et al., 2021). A scoping review conducted in HICs recommended that mental health services could support PWLEs in meeting their employment goals by focusing on offering sustained support over the work journey and involving family and friends to facilitate early exposure to employment-related interventions (Gmitroski et al., 2018). According to the World Bank data on the top ten countries with the highest unemployment rate, South Africa features second at 28% (World Population Review, 2023). Given the high unemployment rate in South Africa, MHSUs need help developing work skills, access to alternative income-generation opportunities, and employment support (Ebuenyi et al., 2018; Gamieldien & van Niekerk, 2017; Kinoshita et al., 2013).

The recovery movement has explored interventions to support employment as an important element of recovery. Intervention models include supported employment, individual placement, vocational rehabilitation, and entrepreneurship (Gamieldien & Van Niekerk, 2017; Gmitroski et al., 2018; Pai et al., 2021). A study on the impact of the Wellness Recovery Action Plan (WRAP) found that recovery happened through employment that was facilitated by WRAP strategies (Olney & Emery-Flores, 2017). WRAP strategies include self-management activities and tools, such as (i) a daily wellness maintenance plan, (ii) a toolbox of strategies the person can use, (iii) understanding personal triggers, (iv) seeking support from family and friends, and (v) advance crisis planning (Copeland, 2024; Olney & Emery-Flores, 2017). Another intervention to support employment is the work-ordered day, an integral aspect of the clubhouse model, as it offers MHSUs the opportunity to develop work skills in a structured environment as part of their recovery journeys (McKay et al., 2018). In

Ghana, there has been a recent focus on policies that foreground social activism to promote the rights of PWLE by enabling opportunities for participation in work (Read et al., 2020).

While employment is a significant element of recovery, some obstacles hinder MHSUs' access to work opportunities. First, when MHSUs are recipients of social grants, they risk losing their grant once they are employed, even if the employment is temporary (Read et al., 2020). Second, stigma and discrimination impacted by low mental health literacy means that businesses are reluctant to offer work opportunities due to the perceived increase in employee support needs (Read et al., 2020). Third, underexplored employment dimensions – supported employment, vocational rehabilitation, transitional work, and entrepreneurship – are not widely available in South Africa nor are they well understood (Gamieldien & Van Niekerk, 2017; Gmitroski et al., 2018). Fourth, some health practitioners do not view employment as an element of recovery, which means they do not refer MHSUs to services and programmes which can help them find and retain employment (Olney & Emery-Flores, 2017)

In summary, as outlined in the Recovery Mandala (Figure 7.1), the key elements which emerged from my thesis as essential elements of recovery are: (i) Collaborative Co-creation, (ii) Provision of Person-centred Care, (iii) Fostering Hope and Empowerment, (iv) Accessing Social Networks, (v) Caregiver Involvement, (vi) Spirituality and Religion, and (vii) Employment. These seven elements are not mutually exclusive; they are intertwined components that comprise and support recovery. The interconnectedness and interdependence between what recovery is and the key facilitators of recovery, which stakeholders must consider, emphasises the relational theme that emerged as a fundamental ingredient of co-created, recovery-focused research, policies, services and interventions. My findings are echoed in the literature, which states that recovery is both a means and an end, as it involves promoting relationships, meaningful participation and measuring recovery elements (Davidson et al., 2010; Dell et al., 2021; Jaiswal et al., 2020).

I will now discuss the implications for policy and practice across the four studies, as well as recommendations and future directions for research, training and service provision, are also discussed.

7.3 Recommendations from the thesis

This study explored the meanings, experiences and contexts that facilitate recovery from SMHCs in South Africa. As highlighted in this thesis, mental health discourse has been dominated by a biomedical model which views mental health conditions through a clinical lens, that is, as something within the individual that needs to be treated. While the Recovery Mandala reflects elements of recovery found in recovery literature,

findings across the thesis illuminate conceptualisations of personal recovery as a socially constructed process. Applying the Social Model of Disability (Shakespeare, 2006) to SMHCs reframes recovery as a collective, rights-based process and not an individual pursuit of normality and functional ability (Kinn, 2016). The Social Model of Disability highlights that MHSUs are not only disabled by the SMHC but also by the stigma, poverty, lack of access to recovery-focused services and structural barriers which they face (Barnes, 2019; Kinn, 2016).

If we are to engage with PWLE meaningfully, we must embrace the principle of personhood as the transcendent principle in recovery work (Anthony, 2004). I am calling for more investment into recovery-focused care packages tailored to the preferences, needs, and context of PWLE of SMHCs in the Western Cape. Co-creating knowledge on recovery-focused care requires us to embed collaboration with stakeholders into our research, training, policy development, service delivery, and service evaluation. Given the limited literature on recovery in LMICs, I offer some recommendations for future directions:

7.3.1 Practice and service provision

Multiple stakeholders, including MHSUs and caregivers, must be involved in co-designing community mental health services that promote recovery (Rocelli et al., 2024). To address resource constraints, co-created community-based recovery-focused services should include peer support (Kwon et al., 2023; Lyons et al., 2021) and task-sharing initiatives (Adams et al., 2023; Sorsdahl et al., 2023; Stein et al., 2022). Task sharing to expand the mental health workforce has been used to scale up mental health services in other LMICs (Adams et al., 2023; Chibanda et al., 2016; Hanlon, 2017; Javadi et al., 2017; Javed et al., 2021; Spedding et al., 2014; Stein et al., 2022; Ventevogel, 2014) and is a feasible strategy which needs further exploration in South Africa. Task-sharing facilitated the provision of mental health care across various settings, including MH-NPOs, which are part of the community-based network that provides accessible recovery-focused services to MHSUs (Brooke-Sumner et al., 2022; Sorsdahl et al., 2023).

In Chapter Four, MHSUs were asked to draw community maps to help them identify the people, places and things which help or hinder their recovery. While I used this as part of data collection, its use as an asset mapping intervention could be explored. Asset mapping is a powerful tool for stakeholders to map out recovery-promoting and recovery-compromising networks that will sustain recovery in context (Mall et al., 2017; Selamu et al., 2015; Sweet et al., 2018).

My study adds to the body of literature by providing evidence that interventions which foster hope and empowerment facilitate recovery. Based on this, I suggest that service

providers include strategies fostering hope and empowerment in their interventions. Further exploration of how this element is different between men and women may be helpful in the development and testing of interventions, given that gender influences help-seeking behaviour and resource allocations (Hailemariam, Fekadu, et al., 2019; Huff et al., 2020).

Spirituality and religion featured as an important element of recovery, which was often overlooked by service providers in LMICs. I propose that stakeholders in South Africa further explore the role that spirituality and religion play in the lives of MHSUs. First, stakeholders could include a spiritual dimension in their assessments and interventions to explore if spirituality, faith, and prayer facilitated MHSUs' recovery (Rafiuddin & Sami, 2024). Second, by integrating culture, religion, and spirituality into the training and practice of service providers and improving collaborations between health practitioners and traditional healers (Green & Colucci, 2020), more can be done to support the role of spirituality in recovery (Janse van Rensburg, 2014; Milner et al., 2019). Third, interventions aimed at improving the mental health literacy of traditional healers and spiritual advisers should be developed and assessed (Sorsdahl et al., 2010). Fourth, spirituality was an important element of relatedness and connectedness between family and community life in the Global South, which could be further explored with first-person accounts (Rafiuddin & Sami, 2024). Sixth, more research is needed on evaluations of collaborations between health service providers and traditional healers (Asher et al., 2018) as they could both be a valuable resource offering long-term support to MHSUs and their caregivers.

7.3.2 Policy implementation gaps

The limited expenditure on mental health care in South Africa (Chisholm et al., 2019) hinders the implementation of policies such as the National Mental Health Policy Framework and Strategic Plan 2023–2030 (National Department of Health, 2023). Despite this, intersectoral commitment is a cornerstone of the policy, which is essential to address the needs of MHSUs. Intersectoral collaborations require strengthening communication and written agreements across and between sectors, including, but not limited to, Social Development, Labour, Human Settlements and Non-profit Organisations (Brooke-Sumner et al., 2016; National Department of Health, 2023). To implement the National Mental Health Policy, key government departments and organisations could focus on implementing the following roles and responsibilities:

Department of Labour (DOL)

The DOL must play a role in livelihood creation, skills development and work rehabilitation for persons with SMHCs (National Department of Health, 2023). DOL policies and programmes must include training in improving the mental health literacy

of staff, providing reasonable accommodations for SMHCs, and developing supported employment opportunities (National Department of Health, 2023).

Department of Social Development (DSD)

The DSD must offer assistance and support for housing, employment, and access to social assistance programmes. Collaboration with the services of the National Department of Health (DOH) is needed to integrate mental health into existing DSD services. The DSD must give attention to services for dual diagnosis of SMHCs and comorbid substance use disorders (SUDs) and clarify roles and responsibilities between the DOH and the DSD (National Department of Health, 2023).

Department of Human Settlements (DHS)

Subsidised supported housing and group homes for persons with SMHCs need to be accessible and available to MHSUs so they can live in communities with peers, if not with caregivers. The DHS must include policies to accommodate the housing needs of persons with SMHCs to ensure equitable access to transitional and permanent housing (National Department of Health, 2023)

Mental Health Non-Profit Organisations (MH-NPOs)

In my study, MH-NPOs were significant contributors to community mental health services. Amongst their contributions, MH-NPOs empowered MHSUs by allowing them to participate in advocacy and lobbying strategies promoting civil rights and active citizenship. Advocacy and lobby initiatives and organisations can influence policy and legislation to improve access to local mental health services, and these strategies should be explored further (Stein et al., 2022; Sunkel, 2022; Thornicroft et al., 2022).

There is a need to fast-track intersectoral collaboration as a pivotal strategy to address the treatment gap, which includes community-based mental health services such as MH-NPOs who can support recovery from SMHCS. Clearly defined and operational referral pathways should be developed to ensure timely and appropriate referrals of MHSUs and their caregivers to community-based resources. Even though stakeholders are encouraged to work with other sectors to align services and interventions with the recovery goals of MHSUs (Van Rensburg & Brooke-Sumner, 2023), these partnerships remain challenging for a number of reasons. First, services are siloed, and mental health services are seen as the responsibility of the National Department of Health. Second, there are limited guidelines to promote collaboration, and individual MH-NPOs and service providers are expected to forge their own collaborations without institutional support. Third, government funding models under-fund mental health services at institution and NPO levels, and this limits the expansion of community-based services as partners in recovery.

7.3.3 Research and training

This thesis offers preliminary findings on the utility of the RAS as a recovery outcome measure for use in a South African population. Further research opportunities include the large-scale roll-out of the RAS as a validated recovery measure for use in public mental health services. However, more work is needed to assess contextual dimensions that shape recovery outcomes in different Western Cape communities, such as substance use, violence, culture, poverty, unemployment, and gangsterism (Achoki et al., 2022; Bowers Du Toit, 2014; Lund et al., 2013; Sherry, 2014).

The Recovery Mandala offers stakeholders an overview of the elements embedded in recovery-focused care in the Western Cape Province. Training service providers in the elements identified in the Recovery Mandala could help them move from foregrounding symptoms or deficits (clinical recovery) to identifying MHSUs' recovery goals, skills, abilities, and potential (Davidson et al., 2021; Hummelvoll et al., 2015; Kwon et al., 2023; Starnino et al., 2014; Subandi et al., 2023). I found that recovery was facilitated when services could identify and build on MHSUs' strengths, resources and resilience. Additionally, the Recovery Mandala sensitises stakeholders to the interconnected elements that influence MHSUs' recovery journeys over time and within different settings. Future research should continue to explore the inclusion of mental health services in the deliverables of government departments and NPOs in non-health settings in South Africa (Jacob & Coetzee, 2018; National Department of Health, 2023; World Health Organization, 2021b).

While this study is context-specific, the insights might be transferable to other South African contexts where MHSUs face similar structural barriers. In a country where race and history have shaped access to mental health services, it is important to include more diverse racial perspectives intentionally, especially in Black communities, to ensure a fuller understanding of recovery across diverse contexts (Kleintjes & Schneider, 2023). Given that access to MH-NPOs varies across settings, this study from an urban area could offer opportunities to juxtapose services for rural and underserved areas. The findings may also contribute to furthering our understanding of how recovery is shaped by complex intersections of race, culture and historical trauma (Whitley, 2016). This underscores the need for culturally grounded and contextually relevant recovery frameworks. Additionally, coordinated efforts to address the broader social determinants of health, such as health, housing, education, social development, traditional healers, and faith-based organisations, are needed (National Department of Health, 2023).

Although this study did not set out to focus exclusively on men, a significant proportion of participants were male, and their narratives highlighted gendered dynamics, a feature which merits further exploration. A more balanced and nuanced analysis of gender in future

research could deepen our understanding of how masculinity and gender norms shape pathways to mental health care, recovery and access to support. Some participants' experiences of criminalisation, gangsterism, and incarceration show how normative expectations of masculinity intersect with systemic exclusion (Baranyi et al., 2019). Such insights are essential for tailoring recovery-focused services that meet the distinct needs of men and women in South Africa.

7.4 Limitations

In Chapters Three to Six, we discussed the limitations of the studies reported in these chapters. This study offers insights into the needs and experiences of PWLEs of SMHCs in the Western Cape Province and the stakeholders involved in supporting their recovery journeys. As a whole, this thesis explores what constitutes and facilitates recovery for persons with SMHCs in LMICs, including in one province in South Africa. The Western Cape is a reasonably well-resourced province compared to other regions. As the findings are specific to the Western Cape, findings in other provinces may differ. However, my research offers insights into working with PWLE and building knowledge on conceptualisations and facilitators of recovery in a small sample.

Only men with SMHCs and their caregivers were interviewed for Objective Three. More work needs to be done on the recovery of women with SMHCs to meet the diverse needs of MHSUs. Currently, there is a severe shortage of psychiatric beds in the Western Cape, and more hospital beds are allocated to men than women (Thebus, 2022). We need to understand where and how women with SMHCs are engaging in their recovery journeys, as this will shed light on the gendered nature of recovery in the community.

Given that caregivers are often the unpaid providers of support, especially in LMICs, more research on interventions that support caregivers is needed. Further research examining the link between caregiver burden and community-based services and interventions that promote caregivers' quality of life could offer insights into the lived experience of caring for MHSUs.

7.5 Situated knowledge and researcher identity

As a Muslim woman, an occupational therapist, and a mental health practitioner in academic, public mental health and non-profit sectors, my worldview and professional experiences have deeply informed my engagement with this study. Reflexivity has been a critical practice throughout the research process, particularly given the prominence of themes such as spirituality, recovery, gender, and systemic marginalisation. I kept a research diary throughout the study and my journal entries allowed me to record how the research process unfolded. I used the diary to reflect on events, how I reacted to

them, and what I had learnt, thereby providing context for my research. Additionally, I discussed issues raised with my supervisors during data collection, analysis and the writing up of the thesis.

My Islamic faith provided both a lens and an ethical grounding for engaging with participants' narratives, especially as many described spiritual and religious practices as central to their recovery journeys. In Islam, a holistic understanding of health encompasses the body, mind, and soul—a worldview that resonates with the recovery frameworks explored in this study. While I was mindful not to impose my beliefs, my appreciation for faith as a legitimate source of meaning and resilience may have sensitised me to these themes and shaped my openness to non-biomedical interpretations of recovery.

At times, I recognised how my spiritual practices paralleled participants' descriptions of prayer, surrender, or the search for purpose. I also had a life-threatening illness during this study and, as a health service user myself, this experience created within me a sense of empathy and resonance, but my researcher positionality also required that I maintain a distance to ensure the authenticity of MHSUs' lived experience, untainted by a projection of my personal meaning.

My training and practice as an occupational therapist influenced both the framing of the research questions and the interpretation of data. Occupational therapy emphasises function, meaning, purpose and participation, which positioned me to notice not only symptoms of illness but also expressions of agency, adaptation, and resilience. My prior engagement with mental health non-profit organisations (MH-NPOs) helped me recognise the nuanced tensions they face between biomedical imperatives and human rights frameworks. This knowledge deepened my understanding of how organisational culture, access to resources, and local recovery discourses interact to shape the lives of service providers, service users and caregivers. During data analysis, particularly in Chapters Four and Five, I remained attuned to how daily routines, roles, and environments either constrained or supported recovery, aligning with occupational therapy's ecological and social justice lens.

Chapters Four and Five reference how my work as a public sector occupational therapist exposed me to a gendered perspective on recovery, and this requires further clarification. In my clinical work, I observed how gender norms shaped access to care and experiences of illness. Women were often overburdened with caregiving responsibilities and more likely to be diagnosed with mood disorders, while men who expressed emotional vulnerability were frequently stigmatised. While more beds were allocated to men than women in specialist hospitals, institutional settings often failed to accommodate the needs of mothers, survivors of gender-based violence, or

transgender individuals, reinforcing the need for gender-sensitive approaches to mental health recovery.

As a woman practitioner operating within these systems, I experienced the intersection of professional authority and gendered expectations. These experiences sensitised me to the multiple layers of gendered disadvantage, which surfaced in participants' narratives and the organisational cultures I studied. This informed my interpretation of recovery as a socially and structurally embedded process rather than a purely individual or clinical one.

7.6 Conclusion

In this thesis, I explored how recovery is described and understood in LMICs, including South Africa. I foregrounded multiple stakeholders' conceptualisation of recovery and their involvement in recovery-focused care in one South African province. Further, I evaluated the utility of the RAS as a recovery outcome measure for use in South Africa. My study contributes knowledge on seven key elements that support recovery-focused care in the Western Cape Province. I found that long-term relational support outside of hospital settings unlocked potential in MHSUs. Thus, investing in “people” as recovery facilitators in community-based mental services is critical. The relational nature of recovery involves support from diverse stakeholders; hence, scaling up mental health services requires inter- and multi-sectoral collaborations across the continuum of care within and beyond the health sector.

My study sheds light on the experiences of persons living with SMHCs. Their stories of navigating the mental health system made them integral research partners as experts by experience. Spirituality and religion were an overlooked element of recovery-focused care, yet it featured strongly across my study as a facilitator and indicator of recovery. Stigma from members of faith-based communities limited access to support for some MHSUs and their caregivers. However, service providers could benefit from collaborating with traditional healers and spiritual advisors to explore further how cultural practices, beliefs and symptoms of mental health conditions influence recovery from SMHCs. Using the Recovery Mandala as a framework, I plan to inform future research, policy and practice to elucidate the recovery elements that emerged in an LMIC context like South Africa. This thesis supports the assertions that recovery-focused care packages should take a life course approach and involve MHSUs, caregivers, service providers, local leaders, religious leaders, and traditional healers to harness community support (Hanlon, 2017; Lund et al., 2018; Sánchez, 2022).

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Appendices

[Appendix A](#) Approval from the Doctoral Degrees Board for inclusion of publications in the thesis

[Appendix B](#) Published article: An exploration of recovery of people living with severe mental illness in low- and- middle-income countries: A scoping review

[Appendix C](#) Published article: Service providers' perspectives on personal recovery from severe mental illness in Cape Town, South Africa: A qualitative study

[Appendix D](#) Published article: Mental health service users and their caregiver's perspectives on personal recovery from severe mental health conditions in Cape Town: A qualitative study

[Appendix E](#) Exploration of recovery of people living with severe mental illness (SMI) in low-income and middle-income countries (LMIC): A scoping review protocol

[Appendix F](#) Publication draft: The psychometric properties of the Recovery Assessment Scale (RAS) among persons with Severe Mental Health Conditions in South Africa

[Appendix G](#) Scoping review search strategy

[Appendix H](#) Scoping review data charting questions

[Appendix I](#) Interview guide for mental health service providers

[Appendix J](#) Informed consent and information sheet (Mental health service provider)

[Appendix K](#) Human Research Ethics Committee approval (HREC655/2018)

[Appendix L](#) Western Cape Government Health Research Committee (WC_201902_010) Ethical approval

[Appendix M](#) Information and informed consent sheet (Mental health services user)

[Appendix N](#) Information, informed consent sheet and interview guide (Caregiver)

[Appendix O](#) Interview guide for MHSU life graph

[Appendix P](#) Interview guide for community map

[Appendix Q](#) Camera issue consent form

[Appendix R](#) MHSU Information sheet and photo release form

[Appendix S](#) Digital camera training guide sample

[Appendix T](#) Photo elicitation interview guide

[Appendix U](#) Sample cognitive testing questionnaire

[Appendix V](#) Original and Adapted 24-item Recovery Assessment Scale and Descriptive statistics

[Appendix W](#) Recruitment flyer

[Appendix X](#) Information sheet, consent form and standard operating procedure for COVID screening

[Appendix Y](#) Study questionnaire

[Appendix Z](#) Factors derived from the South African version of the RAS in the total sample

Appendix A: Approval from the Doctoral Degrees Board for inclusion of publications in the thesis

Friday, March 24, 2023 at 18:37:29 South Africa Standard Time

Subject: Permission to include publications in your PhD thesis | Fadia Gamieldien GMLFAD001
Date: Wednesday, 15 June 2022 at 12:29:17 South Africa Standard Time
From: DOCTORAL DEGREES BOARD
To: Fadia Gamieldien, Fadia Gamieldien
CC: Katherine Sorsdahl, Lynette Correia, Dianne Pryce, FHS PG ADMIN
Priority: High
Attachments: Declaration_InclusionPublications.docx, image.png

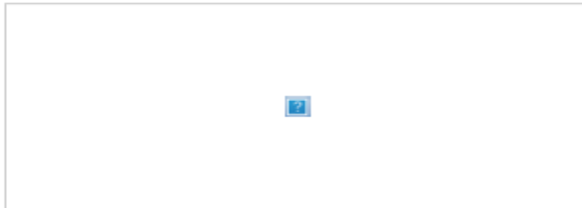
Dear Fadia Gamieldien

I hereby confirm that the Deputy Chair of the Doctoral Degrees Board has **approved** your request to include the specified publications in your PhD thesis.

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Appendix B: Published article: An exploration of recovery of people living with severe mental illness in low- and middle-income countries: a scoping review

Open access

Original research

BMJ Open Exploration of recovery of people living with severe mental illness (SMI) in low/middle-income countries (LMICs): a scoping review

Fadia Gamielien^{1,2}, Roshan Galvaan², Bronwyn Myers^{3,4}, Zarina Syed², Katherine Sorsdahl¹

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ABSTRACT

Objective To examine the literature on how recovery of people with severe mental illness (SMI) is conceptualised in low/middle-income countries (LMICs), and in particular what factors are thought to facilitate recovery.

Design Scoping review.

Data sources and eligibility We searched 14 electronic databases, hand searched citations and consulted with experts during the period May–December 2019. Eligible studies were independently screened for inclusion and exclusion by two reviewers. Unresolved discrepancies were referred to a third reviewer.

Data extraction and synthesis All bibliographical data and study characteristics were extracted using a data charting form. Selected studies were analysed through a thematic analysis emerging from extracted data.

Results The Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram offers a summary of the results: 4201 titles, 1530 abstracts and 109 full-text articles were screened. Ten articles were selected for inclusion: two from Turkey, two from India, and one each from China, Swaziland, Indonesia, Egypt, South Africa and Vietnam. Although most studies used qualitative methods, data collection and sampling methods were heterogeneous. One study reported on service provider perspectives while the rest provided perspectives from a combination of service users and caregivers. Three themes emerged from the data analysis. First, studies frame recovery as a personal journey occurring along a continuum. Second, there was an emphasis on social relationships as a facilitator of recovery. Third, spirituality emerged as both a facilitator and an indicator of recovery. These themes were not mutually exclusive and some overlap exists.

Conclusion Although there were commonalities with how high-income countries describe recovery, we also found differences in conceptualisation. These differences in how recovery was understood reflect the importance of framing the personal recovery concept in relation to local needs and contextual issues found in LMICs. This review highlighted the current sparse evidence base and the need to better understand recovery from SMI in LMICs.

INTRODUCTION

Mental, neurological and substance use (MNS) disorders are significant contributors to the global burden of disease, including

Strengths and limitations of this study

- A comprehensive search strategy was used which allowed the literature to be mapped as a basis for further exploration of the concept of recovery in low/middle-income countries (LMICs) so as to inform research, policy and practice.
- The review aimed to analyse conceptual and theoretical underpinnings of recovery from severe mental illness (SMI) as a construct in LMICs and as such interventions and intervention outcomes were not focused on.
- Data synthesis was limited to full-text articles available in English only and published between January 1993 and December 2019.
- Grey literature and unpublished studies not available in English were excluded from the scoping review and this practical decision means that potentially relevant papers were excluded.
- Future reviews should search the grey literature extensively as there are non-government organisations active in providing recovery-oriented support and care to people with SMI in LMICs but do not publish in the peer-reviewed literature.

severe mental illness (SMI). The lifetime prevalence of SMI ranges between 1% and 4%.¹ Although this is relatively low in comparison with the prevalence of common mental disorders, people with SMI require complex, long-term interventions.² Historically, most resources to respond to MNS were allocated to specialised psychiatric hospitals, with limited provision of mental health services at primary levels of care.³

Deinstitutionalisation initiatives in high-income countries (HICs) shifted people out of institutions to community living. The goal of deinstitutionalisation was to promote social inclusion for people with MNS disorders, a goal which remains in progress in low/middle-income countries (LMICs). The drive to decentralise services has led to an increase

Appendix C: Published article: Service providers' perspectives on personal recovery from severe mental illness in Cape Town, South Africa: A qualitative study

Community Mental Health Journal
https://doi.org/10.1007/s10597-021-00904-8

ORIGINAL PAPER



Service Providers Perspectives on Personal Recovery from Severe Mental Illness in Cape Town, South Africa: A Qualitative Study

Fadia Gamielidien^{1,2} · Roshan Galvaan² · Bronwyn Myers^{3,4,5} · Katherine Sorsdahl¹

Received: 18 November 2020 / Accepted: 6 October 2021
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Abstract

Severe mental illnesses (SMI) contribute significantly to the global burden of disease. In low-and-middle-income countries (LMICs), the treatment gap impacts the clinical and personal recovery of people living with an SMI. The drive to reduce this treatment gap in LMICs makes it pertinent to understand service providers' views on recovery from SMI. Semi-structured interviews and focus groups with service providers from health services and non-profit organisations in the Western Cape Province, South Africa, were conducted in this qualitative study. Seventeen participants were purposively selected, and data were thematically analysed. Three major themes emerged: delineating recovery, available services supporting recovery from SMI, and facilitators and barriers to recovery at the service level. Health services favoured clinical over personal recovery. Participants thought that many service users' personal recovery from SMI was hindered by intersecting social, economic, cultural, and political inequalities that extended beyond the influence of the health sector.

Keywords Recovery · Severe mental illness · Low-and-middle-income countries · Service providers

Introduction

Severe mental illnesses (SMI) (schizophrenia spectrum disorders, non-organic psychotic disorders, and bipolar affective disorder) are some of the main causes of years lived with disability (YLDs) (Vos et al., 2017). Despite schizophrenia being a low prevalence disorder, the Global Burden of Disease study (2016) ranked it as the 12th most disabling disorder out of 310 injuries and diseases (Vos et al., 2017), contributing 1.7% of total YLDs globally, equivalent to 13.4 million YLDs (Charlson et al., 2018). The burden associated with these disorders is four times greater in low-and-middle-income countries (LMICs) than high-income (HICs) due to the substantial treatment gap (Charlson et al., 2018). Additionally, people living with SMI require complex interventions to address the social and economic difficulties they face (Charlson et al., 2018).

In many LMICs, available treatment for SMI is primarily biomedical and provided at specialised psychiatric facilities on an inpatient or outpatient basis. However, as many LMICs allocate insufficient resources to SMI services in primary levels of care treatment for SMI remains inadequate in these settings (Iseselo & Ambikile, 2017), and there is little integration between hospitals and community-based services (Eaton et al., 2011). Services at primary levels of

To our knowledge, there is limited qualitative studies on service provider views on personal recovery from SMI in South Africa. The findings suggest that mental health service transformation must be informed by multiple stakeholder perspectives if it is to take on a recovery-focused approach.

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Published online: 20 October 2021

Springer

Appendix D: Published article: Mental health service users and their caregiver's perspectives on personal recovery from severe mental health conditions in Cape Town: A qualitative study

J. Psychosoc. Rehabil. Ment. Health
<https://doi.org/10.1007/s40737-023-00341-8>



ORIGINAL ARTICLE

Mental Health Service Users and Their Caregivers Perspectives on Personal Recovery from Severe Mental Health Conditions in Cape Town, South Africa: A Qualitative Study

Fadia Gamiieldien · Roshan Galvaan · Bronwyn Myers · Katherine Sorsdahl

Received: 8 December 2022 / Accepted: 25 March 2023
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Abstract Severe mental health conditions (SMHCs) significantly contribute to the global disease burden. In low-and-middle-income countries (LMICs) like South Africa, the long-term impact of SMHCs on individuals and their families is serious. However, mental health services focus on clinical recovery, with little attention given to the personal recovery needs of mental health service users (MHSUs) and their caregivers. The CHIME framework outlines five domains characterising personal recovery: connectedness, hope and optimism about the future, identity, meaning in life, and empowerment. This qualitative, descriptive study sought insights from male MHSUs and their caregivers on their perspectives of personal recovery from SMHCs. Four male MHSUs and three of their caregivers were purposively selected from Cape Flats

communities in the Western Cape. Data were collected using visual participatory methods, including photovoice, life graphs, community maps, and photo-elicitation interviews with MHSUs. In addition, semi-structured interviews were held with caregivers. Data were thematically analysed, and two main themes emerged: Finding meaningful participation and affirming agency. These themes describe how diverse contextual, socioeconomic, political, demographic, cultural, and spiritual factors help and hinder personal recovery. MHSUs and their caregivers sought support from mental health non-profit organisations (MH-NPOs) because of stigmatising attitudes from their communities. MH-NPOs provided MHSUs with long-term relational support and opportunities to build their capacities which helped them access living, learning,

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Springer

Appendix E: Published article: Exploration of recovery of people living with severe mental illness (SMI) in low-income and middle-income countries (LMIC): A scoping review protocol

Open access

Protocol

BMJ Open Exploration of recovery of people living with severe mental illness (SMI) in low-income and middle-income countries (LMIC): a scoping review protocol

Fadia Gamielien¹,² Roshan Galvaan,² Bronwyn Myers,^{3,4} Katherine Sorsdahl¹

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ABSTRACT

Introduction The construct of recovery was conceptualised in high-income countries and its applicability in low-income and middle-income countries is underexplored. A scoping review is proposed to synthesise knowledge, review conceptual overlap and map key elements of recovery from severe mental illness in low-income and middle-income countries. We aim to appraise the literature so as to inform future recovery-oriented services that consider the cultural and contextual influences on recovery from severe mental illness.

Methods and analysis The following electronic databases: MEDLINE via PubMed, SCOPUS (which included contents of Embase), PsycINFO, CINAHL, Africa-Wide Information, PsycARTICLES, Health source: Nursing/Academic Edition, Academic Search Premier and SocINDEX all via the EBSCOHOST platform, the Latin American and Caribbean Health Sciences Literature, the Cochrane Centre Register of Controlled Trials and grey literature sources will be searched between May and December 2019. Eligible studies will be independently screened for inclusion and exclusion by two reviewers using a checklist developed for this purpose. Studies published between January 1993 and November 2019 that focus on recovery from severe mental illness in a low-income and middle-income country will be included. Findings will be compared and discrepancies will be discussed. Unresolved discrepancies will be referred to a third reviewer. All bibliographic data and study characteristics will be extracted and thematically analysed using a tool developed through an iterative process by the research team. Indicators will be classified according to a predefined conceptual framework and categorised and described using qualitative content analysis.

Ethics and dissemination The review aims to synthesise information from available publications, hence it does not require ethical approval. The results will be disseminated through publications, conference presentations and future workshops with stakeholders involved within the recovery paradigm of mental health policy and practice. The scoping review title is registered with the Joanna Briggs Institute.

INTRODUCTION

Mental, neurological and substance use (MNS) disorders contribute significantly to the global burden of disease. Whiteford

Strengths and limitations of this study

- This scoping review allows for the systematic synthesis of knowledge on recovery from severe mental illness in low-income and middle-income countries (LMICs) in a rigorous and methodological manner.
- This review will highlight the diversity of severe mental illness since there is no agreed on criteria for including mental illnesses into this category.
- Knowledge gaps related to recovery as a multidimensional construct in LMICs will be identified.
- Only conceptual and theoretical underpinnings of recovery as a construct in LMIC will be discussed without a focus on intervention outcomes.
- Data synthesis will be limited to full-text articles available in English only and published between January 1993 and November 2019. Grey literature and unpublished studies in Latin America will be affected by the decision to exclude articles not available in English.

*et al.*¹ report that MNS disorders account for 10% of disability-adjusted life years (DALYs). However, it has been argued that the true global burden of mental health problems may be underestimated by more than one-third and that DALYs are closer to 13%.² The lifetime prevalence of severe mental illness (SMIs) ranges between 1% and 4%.³ Although this is relatively low in comparison to common mental disorders, SMIs are more disabling and require complex, long-term interventions for the person and their family.² Given the move towards the deinstitutionalisation of people with psychiatric disorders, shorter hospital stays are resulting in premature discharge rates and repeated relapse, creating a revolving door phenomenon.⁴ These frequent hospital readmissions are costly to the healthcare system.⁵

In low-income and middle-income countries (LMICs), many people living with an SMI are not detected and as a result do not receive the treatment they need.^{3,6,7} In a service

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Appendix F: Publication draft: The psychometric properties of the Recovery Assessment Scale (RAS) among persons with Severe Mental Health Conditions in South Africa

The psychometric properties of the Recovery Assessment Scale (RAS) among persons with severe mental health conditions in South Africa

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These authors contributed equally to this work.

Author contributions:

This quantitative study involved the intellectual contributions of all the authors. All authors were involved in developing the study design and conceptualising the approach. Fadia Gamielien prepared all the material and collected and captured the data. Fadia Gamielien and Katherine Sorsdahl ran the statistics, and Emily Garman supported them. Fadia Gamielien wrote the first draft of the manuscript with significant input from Katherine Sorsdahl, Bronwyn Myers, Roshan Galvaan and Emily Garman. Katherine Sorsdahl and Bronwyn Myers commented on previous manuscript drafts and provided substantial critique and review of the article which was then revised, based on feedback from the other authors.

Appendix G: Scoping review search strategy

Recent queries in pubmed			
Search	Query	Items found	Time
#14	Search ((((((Afghanistan OR Albania OR Algeria OR American Samoa OR Angola OR Armenia OR Azerbaijan OR Bangladesh OR Belarus OR Byelarus OR Belorussia OR Belize OR Benin OR Bhutan OR Bolivia	2999	05:28:45
#15	Search ((((((afghanistan OR albania OR algeria OR american samoa OR angola OR armenia OR azerbaijan OR bangladesh OR belarus OR byelarus OR belorussia OR belize OR benin OR bhutan OR bolivia OR	2938	05:27:31
#13	Search (((Afghanistan OR Albania OR Algeria OR American Samoa OR Angola OR Armenia OR Azerbaijan OR Bangladesh OR Belarus OR Byelarus OR Belorussia OR Belize OR Benin OR Bhutan OR Bolivia	4445394	05:25:40
#12	Search (Afghanistan OR Albania OR Algeria OR American Samoa OR Angola OR Armenia OR Azerbaijan OR Bangladesh OR Belarus OR Byelarus OR Belorussia OR Belize OR Benin OR Bhutan OR Bolivia OR	4162588	05:25:07
#11	Search (Deprived Countries OR Deprived Population OR Deprived Populations OR Developing Countries OR Developing Country OR Developing Economies OR Developing Economy OR Developing Nation OR	457184	05:23:39
#10	Search (((((Recovery OR recover OR psychosocial rehabilitation OR mental health rehabilitation OR psychiatric rehabilitation))) OR Recovery of Function(MeSH Terms) OR Mental Health Recovery(MeSH Terms	517175	05:22:56
#9	Search (Recovery OR recover OR psychosocial rehabilitation OR mental health rehabilitation OR psychiatric rehabilitation)	517175	05:22:04
#8	Search Recovery of Function(MeSH Terms)	47633	05:21:05
#7	Search Mental Health Recovery(MeSH Terms)	69	05:20:40
#6	Search Psychiatric Rehabilitation(MeSH Terms)	282	05:19:52
#5	Search (((((Severe mental illness OR bipolar OR delusional disorder OR delusional disorders OR major depressive disorder OR major depressive disorders OR schizophrenia OR manic OR manic-depressive OR	416890	05:17:41
#4	Search (Severe mental illness OR bipolar OR delusional disorder OR delusional disorders OR major depressive disorder OR major depressive disorders OR schizophrenia OR manic OR manic-depressive OR ps	416861	05:16:48
#3	Search Depressive disorder, Major(MeSH Terms)	27852	05:16:25
#2	Search (Bipolar and Related Disorders(MeSH Terms))	38718	05:15:59
#1	Search (Schizophrenia Spectrum and Other Psychotic Disorders(MeSH Terms))	142529	05:15:35

Population, Concept, Context (PCC)

Population:		
#1	MeSH terms:	Schizophrenia Spectrum and Other Psychotic Disorders Bipolar and Related Disorders Depressive disorder, Major
#2	Free text:	Severe mental illness OR bipolar OR delusional disorder OR delusional disorders OR major depressive disorder OR major depressive disorders OR schizophrenia OR manic OR manic-depressive OR paranoid disorder OR paranoid disorders OR psychoses OR psychosis OR psychotic disorder OR psychotic disorders OR schizoaffective disorder OR schizoaffective disorders OR Schizophreniform OR serious mental disorder OR serious mental disorders
#3	#1 OR #2	
Concept:		
#4	MeSH terms:	Psychiatric Rehabilitation Mental Health Recovery Recovery of Function
#5	Free text:	Recovery OR recover OR psychosocial rehabilitation OR mental health rehabilitation OR psychiatric rehabilitation
#6	#4 OR #5	
Context: Low and Middle Income Countries (LMICS)		
#7	Free text:	Deprived Countries OR Deprived Population OR Deprived Populations OR Developing Countries OR Developing Country OR Developing Economies OR Developing Economy OR Developing Nation OR Developing Nations OR Developing Population OR Developing Populations OR Developing World OR LAMI Countries OR LAMI Country OR Less Developed Countries OR Less Developed Country OR Less Developed Economies OR Less Developed Nation OR Less Developed Nations OR Less Developed World OR Lesser Developed Countries OR Lesser Developed Nations OR LMIC OR LMICS OR Low GDP OR Low GNP OR Low Gross Domestic OR Low Gross National OR Low Income Countries OR Low Income Country OR Low Income Economies OR Low Income Economy OR Low Income Nations OR Low Income Population OR Low Income Populations OR Lower GDP OR lower gross domestic OR Lower Income Countries OR Lower Income Country OR Lower Income Nations OR Lower Income Population OR Lower Income Populations OR Middle Income Countries OR Middle Income Country OR Middle Income Economies OR Middle Income Nation OR Middle Income Nations OR Middle Income Population OR Middle Income Populations OR Poor Countries OR Poor Country OR Poor Economies OR Poor Economy OR Poor Nation OR Poor Nations OR Poor Population OR Poor Populations OR poor world OR Poorer Countries OR Poorer Economies OR Poorer Economy OR Poorer Nations OR Poorer Population OR Poorer Populations OR Third World OR Transitional Countries OR Transitional Country OR Transitional Economies OR Transitional Economy OR Under Developed Countries OR Under Developed Country OR under developed nations OR Under Developed World OR Under Served Population OR Under Served Populations OR Underdeveloped Countries OR Underdeveloped Country OR

#7	Free text:	Deprived Countries OR Deprived Population OR Deprived Populations OR Developing Countries OR Developing Country OR Developing Economies OR Developing Economy OR Developing Nation OR Developing Nations OR Developing Population OR Developing Populations OR Developing World OR LAMI Countries OR LAMI Country OR Less Developed Countries OR Less Developed Country OR Less Developed Economies OR Less Developed Nation OR Less Developed Nations OR Less Developed World OR Lesser Developed Countries OR Lesser Developed Nations OR LMIC OR LMICS OR Low GDP OR Low GNP OR Low Gross Domestic OR Low Gross National OR Low Income Countries OR Low Income Country OR Low Income Economies OR Low Income Economy OR Low Income Nations OR Low Income Population OR Low Income Populations OR Lower GDP OR lower gross domestic OR Lower Income Countries OR Lower Income Country OR Lower Income Nations OR Lower Income Population OR Lower Income Populations OR Middle Income Countries OR Middle Income Country OR Middle Income Economies OR Middle Income Nation OR Middle Income Nations OR Middle Income Population OR Middle Income Populations OR Poor Countries OR Poor Country OR Poor Economies OR Poor Economy OR Poor Nation OR Poor Nations OR Poor Population OR Poor Populations OR poor world OR Poorer Countries OR Poorer Economies OR Poorer Economy OR Poorer Nations OR Poorer Population OR Poorer Populations OR Third World OR Transitional Countries OR Transitional Country OR Transitional Economies OR Transitional Economy OR Under Developed Countries OR Under Developed Country OR under developed nations OR Under Developed World OR Under Served Population OR Under Served Populations OR Underdeveloped Countries OR Underdeveloped Country OR underdeveloped economies OR underdeveloped nations OR underdeveloped population OR Underdeveloped World OR Underserved Countries OR Underserved Nations OR Underserved Population OR Underserved Populations
#8	Free text:	Afghanistan OR Albania OR Algeria OR American Samoa OR Angola OR Armenia OR Azerbaijan OR Bangladesh OR Belarus OR Byelarus OR Belorussia OR Belize OR Benin OR Bhutan OR Bolivia OR Bosnia OR Botswana OR Brazil OR Bulgaria OR Burma OR Burkina Faso OR Burundi OR Cabo Verde OR Cape Verde OR Cambodia OR Cameroon OR Central African Republic OR Chad OR China OR Colombia OR Comoros OR Comores OR Comoro OR Congo OR Costa Rica OR Côte d'Ivoire OR Cuba OR Djibouti OR Dominica OR Dominican Republic OR Ecuador OR Egypt OR El Salvador OR Equatorial Guinea OR Eritrea OR Ethiopia OR Fiji OR Gabon OR Gambia OR Gaza OR Georgia OR Georgia Republic OR Ghana OR Grenada OR Grenadines OR Guatemala OR Guinea OR Guinea- Bissau OR Guyana OR Haiti OR Herzegovina OR Hercegovina OR Honduras OR India OR Indonesia OR Iran OR Iraq OR Ivory Coast OR Jamaica OR Jordan OR Kazakhstan OR Kenya OR Kiribati OR Democratic People's Republic of Korea OR Kosovo OR Kyrgyz OR Kirghizia OR Kirghiz OR Kyrgyzstan OR Lao PDR OR Laos OR Lebanon OR Lesotho OR Liberia OR Libya OR Macedonia OR Madagascar OR Malawi

Appendix H: Scoping review data charting questions

Supplementary file 2

Questions applied when charting the data

Study characteristics • What is the title of the publication? • Who are the authors? • In which year was the publication published? • In which journal does the publication appear? • In what field was the article published? • From which country were participants recruited? • What is the research question and aim(s) of the study?
Participant characteristics • Who is the study population (mental health services, caregivers, stakeholder or a combination)? • Are participant characteristics shared? • How many participants were included in the study? • What is the gender distribution? • What is the age distribution? • What is the most frequently reported diagnosis? • How were participants recruited?
Methodology, data collection and results • Is this a qualitative, quantitative or mixed methods study? • How were data collected? • How were data analysed? • What are the relevant results of the study? • Overall theme and objectives ○ What is recovery? ○ How is it conceptualised? ○ What are the descriptors of recovery? ○ What influences recovery? ▪ Facilitators and barriers

Appendix I: Interview guide for mental health service providers

Stakeholder Interview Schedule

Introductions and job description

Please Read: "Please remember that what you say in this interview will remain confidential. Our discussion will last about 60 minutes. I will record the discussion and take notes so that I capture the points that you make."

Can you tell me a bit about the work that you do with people who have a severe mental illness?

(Probes: How long have you been doing this work, do you enjoy the work, what are some of the challenges; positives and negative aspects of job.)

Thinking about these problems, tell me what you think causes them, or makes them worse for men.

(Probes: Why do they start? Why do they continue? What makes men more prone to severe mental illness? Or what makes them more likely to abuse substances?)

What do you understand by the word recovery?

(Probe: What is recovery? What is the difference between clinical and personal recovery?)

Do people with mental illness recover?

(Probe: What does that look like?)

What about alcohol problems? Drug problems? What else do you know about these problems?

Tell me about the services available for people with a severe mental illness and those with comorbid substance use disorders.

(Probes: And in your community? What about formal or professional services?)

(Probes: NPOs, clinics, schools, recreational facilities, religious places)

How helpful do you think these services are?

(Probes: Are they accessible, being used?)

What do you consider the gaps to be?

What do you consider the role of the family/caregivers to be?

What support is available for family/ caregivers and what should there be?

In an ideal world, what resources do you think should be available to MHSUs, their carers and communities?

"Thank you very much for your participation. Are there any questions, comments or concerns that you would like to add, before we end?"

Appendix J: Informed consent and information sheet (Mental health service provider)



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Information letter and consent form

Study Title	An exploration of recovery among South African men with a severe mental illness.
Activity	In-depth interviews
Participants	Stakeholders providing services to people with severe mental illness
Principal Investigator:	Professor Katherine Sorsdahl: Alan J. Flisher Centre for Public Mental Health (021 650 4798) or Fadia Gamielien: AMARI PhD Fellow (0210 650 5852) or fadia.gamielien@uct.ac.za

Introduction.

My name is Fadia Gamielien and I am an AMARI PhD candidate at the Alan J. Flisher Centre for Public Mental Health (UCT). You are being asked to participate in an interview as part of a study that I am conducting. Before you agree to take part, you should understand what it involves. This letter is to help you decide if you want to take part in this study. Participation is voluntary and you should agree to take part only if you are happy with all it entails.

The goal of the research project is to understand what recovery from severe mental illness means to mental health service users, caregivers and stakeholders. It is hoped that this study will help people understand what recovery means for men with a severe mental illness who live in Cape Town. I am asking you to take part in an interview as part of the study.

The purpose of this interview is to better understand the mental health services that are available to people with severe mental illness including those with comorbid substance use disorders, barriers to accessing services, what helps or hinders recovery and your opinions on what services are needed to support recovery, where it should be provided, and who should provide it.

What is being asked of you.

If you agree to be interviewed, you will be one of up to 15 stakeholders interviewed. You will be asked questions about your experiences of providing services to people with severe mental illness and those with a dual diagnosis and the barriers to service delivery. I will also ask you about the legislation, policies and protocols that in your view helps and hinders recovery. I am asking for your permission to audio-record the interview so that I can transcribe it and analyse the data. The interview will last about an hour. The information you provide will help me better understand what it means to provide services for people living with severe mental illness.

Potential risks and discomforts of participating in this study

There are no foreseeable risks to participating in this interview. All information provided by you will be kept confidential. Your participation is entirely voluntary and there is no penalty for not answering questions. You are free to decline to participate and if you say no, this will not affect you negatively in any way.

Potential benefits of participating in this study

There are no direct benefits to you participating in this interview. Your participation may help us better understand what helps and hinders recovery of people living with severe mental illness, and this could help us design interventions that promote recovery in the future.

Confidentiality and privacy.

Any information obtained during the interview will remain confidential. The interview will be audio-recorded, transcribed and stored on a password protected computer for one year, after which they will be destroyed.

Stakeholder information and consent form

1

The only confidential information will be on the consent forms, which will be stored in a locked filing cabinet. The consent forms will be destroyed after five years of completion of these activities. The UCT Health Research Ethics Committee (HREC) will however have access to all data. I will use the information you provide to write and publish papers in academic journals but this data will be anonymised. Your name will not appear anywhere in any published material and your identity will remain anonymous as pseudonyms will be used.

Participation and withdrawal.

Participation is voluntary. You can choose not to participate. If you decide to participate, you may choose to stop your participation at any time. There will be no consequences. You may also refuse to answer any questions you do not want to answer.

Who is funding the study?

The study is being conducted through the Alan J. Flisher Centre for Public Mental Health (UCT) and the African Mental Health Research Initiative (AMARI). It is funded by the AMARI consortium whose overall goal is to build and support research in mental, neurological and substance use in Africa. For more information you can visit <https://amari-africa.org/> or contact info@amariconsortium.org

Reimbursement

You will receive a small gift to show our appreciation.

Rights of participants

This study has been approved by the University of Cape Town's Health Research Ethics Committee and its reference number is HREC 655/2018. It will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, and the South African Guidelines for Good Clinical Practice.

Who to contact with question

If you have any questions about your rights as a participant, concerns or complaints, please call the chairperson of the HREC, Prof Marc Blockman on (021) 406 6496

This research will be supervised by Professor Katherine Sorsdahl (021 650 4798). You are welcome to contact her if you have additional queries.

Please contact me, Fadia Gamielien, directly with any research related questions. I am available on (021) 650 5852

Indicating consent.

Please let me know if you have any questions before checking this consent form. Please check each item to show that you agree to what is required (leave blank if you do not agree):

Agree	
	I agree to take part in this interview which has been fully explained to me.
	I understand that my participation in this interview is completely voluntary, and there will be no penalty if I choose not to participate.

Please also provide a full signature to show whether you agree to this focus group being audio-recorded.

Agree	
	I agree to the interview being audio-recorded

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

Participant (Signature and Printed Name) Date

Person Obtaining Consent (Signature and Printed Name) Date

Witness (Signature and Printed Name) Date

*A witness is required if the research participant cannot read (e.g. blind or illiterate) or if it is required by the study plan. The witness should participate in all of the discussions with regards to the participant research during the consent process. By signing this consent form, the witness guarantees that all the information within the consent has been explained to the participant, and that the consent seemed to have been understood and given by free will.

Appendix K: Human Research Ethics Committee approval (HREC655/2018)



UNIVERSITY OF CAPE TOWN
UNIVERSITEIT VAN KAAPSTAD

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee



HUMAN RESEARCH ETHICS COMMITTEE

27 JAN 2023

HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
☒ Approved	Annual progress report	Approved until/next renewal date	28/01/2024
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee			Date Signed 27/1/2023

Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.

Please clarify your plan for research-related activities during COVID-19 lockdown.

Please use the latest form found on our website:

<http://www.health.uct.ac.za/fhs/research/humanethics/forms>

Comments to PI from the HREC

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	27 January 2023		
HREC REF Number	655/2018	Current Ethics Approval was granted until	28/02/23
Protocol title	An exploration of recovery among South African men with a severe mental illness		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?		☐ Yes	☒ No
If yes, could you please provide the HREC Reference number for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Prof K Sorsdahl		



Department / Office Internal Mail Address	Alan J Flisher Centre for Public Mental Health, Department of Psychiatry, UCT, Sawkins Road, Rondebosch

1.1 Does this protocol receive US Federal funding?	☐ Yes	☒ No
1.2 If the study receives US Federal Funding, does the annual report require full committee approval?	☐ Yes	☐ No
Note: Any annual approvals for Full Committee review MUST be submitted on the monthly HREC submission dates. (Please send electronic copy for full committee review to hrec-submission@uct.ac.za)		

If yes in 1.2 please complete section 1.3 below for invoicing purposes

1.3 Ethics Renewal Fee

Please (tick ✓) appropriate box for billing purposes:

<u>Submission Type</u>	<u>Description</u>	<u>New fee (Vat Incl.)</u>	<u>tick ✓</u>
<i>Research funded solely from UCT departmental/divisional/group budget</i>	Annual evaluation of research progress report for re-certification	R0,00	☐
<i>Non-sponsored student research for degree purposes at UCT/Other Universities & Colleges</i>	Annual evaluation of research progress report for re-certification	R0,00	☐
<i>Annual re-certification / Progress report (FHS016 Form)</i>	Clinical Trial & International Grant Funded Research - Annual evaluation of research progress report for re-certification for Full Committee Approval	R7000,00	☐
<i>Annual re-certification / Progress report (FHS016 Form)</i>	Clinical Trial & International Grant Funded Research - Annual evaluation of research progress report for re-certification for Expedited review	R3 710.00	☐
<i>Annual re-certification / Progress report (FHS016 Form)</i>	National grant funded research - Annual evaluation of research progress report for re-certification for Full Committee Approval	R6000.00	☐
<i>Annual re-certification / Progress report (FHS016 Form)</i>	National Grant funded research for Annual evaluation of research progress report for re-certification for Expedited review	R1 500,00	☐

NB: Protocols funded by UCT (e.g. departmental funding / student research) and by certain grant funding organizations (e.g. MRC, NRF, CANSA,) are exempt from these charges.

Please provide details for Invoicing, either complete section 1 or 2 :

1. Invoice billing – Directly to Sponsor	
Sponsor's name	
Billing Address of Sponsor:	
Vat Number:	



Contact person	
Telephone number	
Email Address	
2. Internal Journal Billing:	
Fund Number:	
Cost Centre Number:	
Account Holder Name:	
Division of Account Holder:	

2. List of documentation for approval

3. Protocol status (tick ✓)

☐	Open Enrolment
☐	Closed to enrolment (tick ✓)
☐	Research-related activities are ongoing
☐	Research-related activities are complete, long-term follow-up only
☒	Research-related activities are complete, data analysis only
☐	Main study is complete but sub-study research-related activities are ongoing
☐	Study is closed → Please submit a Study Closure Form (FHS010)

4. Enrolment

Number of participants enrolled to date	300
Number of participants enrolled, since last HREC Progress report (continuing review)	0
Additional number of participants still required	0

5. Refusals

Total number of refusals (participants invited to join the study, but refused to take part)	8

6. Cumulative summary of participants

Total number of participants who provided consent	
Number of participants determined to be ineligible (i.e. after screening)	
Number of participants currently active on the study	
Number of participants completed study (without events leading to withdrawal)	
Number of participants withdrawn at participants' request (i.e. changed their mind)	
Number of participants withdrawn by PI due to toxicity or adverse events	
Number of participants withdrawn by PI for other reasons (e.g. pregnancy, poor compliance)	
Number of participants lost to follow-up. Please comment below on reasons for loss of follow-up.	
Number of participants no longer taking part for reasons not listed above. Please provide reasons below:	

7. Progress of study

Please provide a brief summary of the research to date including the overall progress and the progress since the last annual report as well as any relevant comments/issues you would like to report to the HREC:

Objective one of the study was to conduct a scoping review on recovery from severe mental illness (SMI) in low- and -middle- income countries. This objective was concluded, and a scoping view protocol (2020) and a scoping review (2021) was published in BMJ Open

The second objective of the study was to explore stakeholders' views on recovery from SMI. One-on-one interviews and focus groups were conducted with service users, caregivers and service providers. All data collection is complete and has been analysed. The findings of the service providers views was published in the Community Mental Health Journal and the service user article is awaiting feedback from the reviewers.

The final objective of the study was to conduct a survey with 300 mental health service users from the catchment areas of the three psychiatric hospitals. This aspect of the study is related to adapting the Recovery Assessment Scale (RAS) for use in the South African population. Data was collected in the period December 2020- December 2021.

Comments:

Data collection was suspended during the hard lockdown of the Covid -19 pandemic (March 2020- December 2020). Thereafter data was collected intermittently as HREC approved face to face research and when lockdown restrictions eased.

The researcher, FG, fell ill in September 2021 and this delayed progress on the study.



8. Protocol violations and exceptions (tick ✓ all that apply)

☒	No prior violations or exceptions have occurred since the original approval
☐	Prior violations or exceptions have been reported since the last review and have already been acknowledged or approved
☐	Unreported minor violations that have occurred since the last review, as well as significant deviations not yet reported, are attached for review

9. Amendments (tick ✓ all that apply)

☐	No Prior amendments have been made since the original approval
☒	Prior amendments have been reported since the last review and have already been approved
☐	New protocol changes/ amendments are requested as part of this continuing review (See note below)

Note: If new protocol changes are being requested in this review, please complete an amendment form (FHS006).

Specific changes in the amended protocol and consent/assent forms must be **bolded**, *italicised* or tracked and all changes must include a rationale.

10. Adverse events

10.1 Please provide below or attach a narrative summary of serious adverse events and/ or unanticipated problems since the last progress report. Please indicate changes made to the protocol and informed consent document(s) as a result (if not already reported to the HREC). Please comment on whether causality to any study procedure or intervention could be established.

10.2 Have participants received appropriate treatment/ follow-up/ referral when indicated (e.g. in the case of abnormal or incidental clinical findings, distress or anxiety)?

☒ Yes	☐ No	☐ Not applicable

If yes, please describe:

All interviews were conducted by qualified occupational therapists. If participants were assessed as needing follow up they were referred to the mental health nurse who referred them to the study and the research assistant also made this referral.

11. Summary of Monitoring and Audit Activities (tick ✓)

11.1 Was this study monitored or audited by an external agency (e.g. SAHPRA, FDA)?

☐ Yes	☐ No	☒ Not applicable

11.2 Did a Data and Safety Monitoring Board publish a report?



☐ Yes	☐ No	☒ Not applicable

11.3 If yes, please identify the agency and attach a summary of the findings.					
Agency Name		Report attached	☐ Yes	☐ No	☐ Not applicable
		DSMB report attached	☐ Yes	☐ No	☐ Not applicable

11.4 Has there been any agency, institutional or other inquiry into non-compliance in this study, or any finding of non-compliance concerning a member of the research team?	
☐ Yes	☐ No
If yes, please explain:	

12. Level of risk (tick ✓)

12.1 In light of your experience of this research, please indicate whether the level of risk to participants has:	
☐	Increased
☐	Decreased
☒	Shown no change
If there has been a change, please explain:	

12.2 Please provide a narrative summary of recent relevant literature that may have a bearing on the level of risk.



13. Insurance

Please confirm that valid no fault insurance is still in place? (tick ✓)			
☐ Yes	☐ No	☒ Not Applicable – N/A	
If yes, please complete the following:			
Insurer's name:			
Policy no.		*Coverage Period:	
For UCT sponsored studies please liaise the Insurance office via fhs.sponsorship@uct.ac.za regarding the required documentation and information required obtain a renewed UCT No-fault Insurance Certificate.			

14. Statement of conflict of interest

Has there been any change in the conflict of interest status of this protocol since the original approval? (tick ✓)	
☐ Yes	☒ No
If yes, please explain and if necessary, attach a revised conflict of interest statement (Section #7 in the New Protocol Application Form FHS013):	

15. Signature

My signature certifies that the above is complete and correct.			
Signature of PI	<i>Katherine Sorsdahl</i>	Date	January 27 th , 2023

Appendix L: Western Cape Government Health Research Committee (WC_201902_010) Ethical approval



Health Impact Assessment Health Research Sub- Directorate

Health.Research@westerncape.gov.za
Tel: +27 21 483 0866: fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_201902_010
ENQUIRIES: Dr Sabela Petros

University of Cape Town

Anzio Road

Observatory

Cape Town

7925

For attention: Ms Fadia Gamielien, Prof Katherine Sorsdahl, Prof Roshan Galvaan, Dr Brownwyn Myers

Re: An exploration of recovery among South African men with a severe mental illness

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to following people to assist you with any further enquiries in accessing the following sites:

Stikland Hospital

Dr Liezl Koen

021 940 4455

Lentegeur Hospital

Mary Jacobs

021 370 1314

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. By being granted access to provincial health facilities, you are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of your project. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the *estimated completion date* which was submitted, researchers are expected to complete and submit a progress report

(Annexure 8) to the provincial Research Co-ordinator

(Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR M MOODLEY

DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 03-06-2019



**Western Cape
Government**

Health

**Health Impact Assessment
Health Research Sub- Directorate**

Health.Research@westerncape.gov.za
Tel: +27 21 483 0866: fax: +27 21 483 9895
5th Floor, Norton Rose House,, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_201902_010
ENQUIRIES: Dr Sabela Petros

University of Cape Town

Anzio Road

Observatory

Cape Town

7925

For attention: Ms Fadia Gamielien, Prof Katherine Sorsdahl, Prof Roshan Galvaan, Dr Brownwyn Myers

Re: An exploration of recovery among South African men with a severe mental illness

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to following people to assist you with any further enquiries in accessing the following sites:

Valkenberg Hospital

Mapitsi Photo

021 826 5801

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. By being granted access to provincial health facilities, you are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of your project. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the *estimated completion date* which was submitted, researchers are expected to complete and submit a progress report

(Annexure 8) to the provincial Research Co-ordinator
(Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR M MOODLEY

DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 19.03.2019

Appendix M: Information and informed consent sheet (Mental health services user)



Information letter and informed consent for community mapping and photo discussion interviews

Activity	Community mapping and photo discussion interviews
Participants	Key informants
Principal Investigator:	Professor Katherine Sorsdahl: Alan J. Flischer Centre for Public Mental Health (021 650 4798) or Fadia Gamieldien: AMARI PhD Fellow (021) 650 5852 or fadia.gamieldien@uct.ac.za

Introduction

My name is Fadia Gamieldien. I am a PhD student at the University of Cape Town. I would like to invite you to share in interviews as part of a study that I am conducting. Before you agree to take part, you should understand what it involves. The purpose of this letter is to give you information so that you can decide if you want to take part in this study. Participation is voluntary, and you should agree to take part only if you are happy with all it involves.

The goal of the research project is to understand what recovery from severe mental illness means to mental health service users, caregivers and stakeholders. It is hoped that this study will help people understand what recovery means for men with a severe mental illness who live in Cape Town.

What is being asked of you

If you agree to take part in this interview, you will be one of up to six (6) men interviewed. You will be required to attend three (3) interviews of approximately 60 minutes each. We are asking for your permission to audio-record every interview so that we can listen to and analyse the information. We will schedule the interview for a time and place that suits you.

Interview 1: Community mapping Interview: You will be asked questions about your views on living with severe mental illness in your community. You will also be asked to draw a community map of your area. This map will help us discuss the activities you do every day and reasons for doing them.

Interview 2 and 3: Photovoice uses photographs to help people talk about their experiences. At the end of the interview, you will be issued with a disposable camera. You will have some time to take photos of places, people and things of interest to you in your community.

If you are taking photos of other people you will have to ask their permission to do so. You will also have to ask them to sign the photo release form (attached) every time you take a photo of them. Try not to take a picture of their faces directly as we want to protect their identities. They can withdraw permission to use the photo at any time.

We will collect your camera from you and we will develop the photos and set up our follow-up photo discussion interview.

Photo discussion Interviews: During these interviews you will get some time to look at the printed photos and share them with the researcher. You will then discuss your photos and the experience of being a photographer in your community. We will meet twice to discuss your photos and the interviews will be arranged for a time and location that suits you. The information you provide will help us better understand what it means to live with a severe mental illness from service user perspectives.

Potential risks and discomforts of participating in this study

There are small risks to participating in the interview. One is connected to the time of the interview which might lead to you getting tired. Comfort breaks and refreshments will be part of the interview to decrease this. If any of the questions possibly make you uncomfortable, you do not have to answer these. There is no penalty for not participating or not answering questions. If you feel distressed during the interview process, then an appointment will be made for you to see a mental health professional at the clinic closest to where you live.

Potential benefits of participating in this study

There are no direct personal benefits to you participating in these interviews. Your participation may help us better understand recovery of people living with severe mental illness, and this could help us design interventions that promote recovery in the future.

Confidentiality and privacy

Any information obtained during the interview will remain confidential. Information will not be shared with your service providers or caregivers unless you are in danger of harming yourself or others. In this case we will be legally obliged to share information with your caregivers.

The interview will be audio-recorded, typed-out and stored in a locked cupboard in a secure office along with the photographs and community maps. Electronic copies of will be stored on computer but access will be password protected. We will erase any names from the audio-recordings and transcripts. The only confidential information will be on the consent forms, which will be stored in a locked filing cabinet. The consent forms and audio-recordings will be destroyed after five years of completion of the study. The UCT Health Research Ethics Committee (HREC) will have access to all data. We will use the information you provide to write and publish papers in academic journals, but your name or face will not appear anywhere in any published material and your identity will remain anonymous as pseudonyms will be used.

Participation and withdrawal

Participation is voluntary. You can choose not to participate in the interviews. If you decide to participate, you may choose to stop your participation at any time. There will be no consequences. You may also refuse to answer any questions you do not want to answer.

Who is funding the study?

The study is being funded through the Alan J. Flisher Centre for Public Mental Health (UCT) and the African Mental Health Research Initiative (AMARI). For more information you can visit <https://amari-africa.org/> or contact info@amariconsortium.org

Reimbursement

You will receive a R100 Shoprite/Checkers voucher and a full set of your photos. You will also be provided with refreshments.

Rights of participants

This study has been approved by the University of Cape Town's Health Research Ethics Committee, reference number **HREC 655/2018**. The study will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, and the South African Guidelines for Good Clinical Practice.

Who to contact with questions

If you have any questions about your rights as a participant, concerns or complaints, please call the chairperson of the HREC, Prof. Marc Blockman on (021) 406 6496.

This research will be supervised by Professor Katherine Sorsdahl (021 650 4798). You are welcome to contact her if you have additional queries.

Please contact Fadia Gamielidien directly with any research-related questions. She is available on (021) 650 5852.

Indicating consent

Please let us know if you have any questions before checking this consent form.

Please check each item to show that you agree to what is required (leave blank if you do not agree):

Agree	
	I agree to take part in the interviews which have been fully explained to me.
	I understand that my participation in these interviews is completely voluntary, and there will be no penalty if I choose not to participate.
	I understand that the camera issued to me is to be used to take photographs that will be discussed with me at a follow-up interview.
	I understand that I have to return the camera.
	I understand that I cannot take photos of anyone unwillingly and every photo I take of another person requires their permission and a signed photo release form.
	I understand that I will need to provide a contact number where the researcher can reach me for the duration of the project.

Please also provide a full signature to show whether you agree to this interview being audio-recorded.

Agree	
	I agree to the interviews being audio-recorded
	I agree to my photos being used for research purposes

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

Participant (Signature and Printed Name) Date

Person Obtaining Consent (Signature and Printed Name) Date

Witness (Signature and Printed Name) Date

*A witness is required if the research participant cannot read (e.g. blind or illiterate) or if it is required by the study plan. The witness should participate in all of the discussions with regard to the participant research during the consent process. By signing this consent form, the witness guarantees that all the information within the consent form has been explained to the participant, and that the consent seemed to have been understood and given by free will.

To safeguard you, recorded verbal consent and a fingerprint will be obtained when a witness has signed.

Fingerprint Date

Appendix N: Information, informed consent sheet and interview guide (Caregiver)



Alan J Flisher Centre for Public Mental Health

Department of Psychiatry and Mental Health

University of Cape Town

46 Sawkins Road, Rondebosch, 7700

Cape Town, South Africa

Tel. +27 21 685 0120

Fax +27 21 650 3054

Katherine.Sorsdahl@uct.ac.za

Fadia.Gamieldien@uct.ac.za

Information letter and informed consent form for in-depth interviews

Activity	In-depth interviews
Participants	Key informants: Caregivers/ Family Members/Friends or Family
Principal Investigator	Professor Katherine Sorsdahl: Alan J. Flisher Centre for Public Mental Health (021 650 4798) or Fadia Gamieldien: AMARI PhD Fellow (0210 650 5852 or fadia.gamieldien@uct.ac.za)

Informed Consent for Caregiver In-depth Interviews

Caregiver interviews and introduction

My name is Fadia Gamieldien. I am a PhD student at the University of Cape Town. I would like to invite you to share in interviews as part of a study that I am conducting. Before you agree to take part, you should understand what it involves. This purpose of this letter is to give you information so that you can decide if you want to take part in this study. Participation is voluntary, and you should agree to take part only if you are happy with all it involves.

The purpose of this interview is to get your views on caring for someone living with a severe mental illness. You have been identified as the caregiver of a male living with a severe mental illness and we would like you to share your experiences with us.

The goal of the research project is to understand what recovery from severe mental illness means to mental health service users, caregivers and stakeholders. It is hoped that this study will help people understand what recovery means for men with a severe mental illness who live in Cape Town.

What is being asked of you

If you agree, you will be one of up to 15 caregivers participating. You will be asked questions about your views on caring for someone who has a severe mental illness in your community. We are asking for your permission to audio-record the interview session so that we can listen to and analyse the discussion. The interview sessions will last about an hour each. We will schedule interviews at a suitable time and location.

Potential risks and discomforts of participating in this study

There are no foreseeable risks to participating in these interview sessions. Some of the questions and discussions may make you uncomfortable but you will not be forced to answer questions directly. Your participation is entirely voluntary and there is no penalty for not participating. Keeping things private and confidentiality will be discussed in the group.

Potential benefits of participating in this study

There are no direct individual benefits to you participating in these interview sessions. Your participation may help us better understand what helps and hinders recovery of people living with severe mental illness, and this could help us design interventions that promote recovery in the future. Additionally, you might find it helpful to share your experiences with us and hear others' experiences as well.

Confidentiality and privacy

Respecting people's privacy and confidentiality will be discussed in the group. Interview sessions will be audio-recorded, transcribed and transcriptions stored on a computer for one year, after which the information will be destroyed. We will erase any names from the audio-recordings and transcripts. The only confidential information will be on the consent forms which will be stored in a locked filing cabinet. The consent forms will be destroyed after five years of completion of these activities. The UCT Health Research Ethics Committee (HREC) will, however, have access to all data. We will use the information you provide to write and publish papers in academic journals, but your name will not appear in any published material and your identity will remain anonymous as pseudonyms will be used.

Participation and withdrawal

Participation is voluntary. You can choose not to participate in the interview session. If you decide to participate, you may choose to stop your participation at any time without fear of negative consequences. You may also refuse to answer any questions you do not want to answer.

Who is funding the study?

The study is being funded through the Alan J. Flisher Centre for Public Mental Health (UCT) and the African Mental Health Research Initiative (AMARI). For more information you can visit <https://amari-africa.org/> or contact info@amariconsortium.org

Reimbursement

You will receive a R100 Shoprite/ Checkers voucher for participating in the interview session.

Rights of participants

This study has been approved by the University of Cape Town's Health Research Ethics Committee; its reference number is **HREC 655/2018**. It will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, and the South African Guidelines for Good Clinical Practice.

Who to contact with questions

If you have any questions about your rights as a participant, concerns or complaints, please call the chairperson of the HREC, Prof. Marc Blockman on (021) 406 6496.

This research will be supervised by Professor Katherine Sorsdahl (021) 650 4798. You are welcome to contact her if you have additional queries.

Please contact Fadia Gamielien directly with any research-related questions. She is available on (021) 650 5852.

Indicating consent

Please let us know if you have any questions before checking this consent form. Please check each item to show that you agree to what is required (leave blank if you do not agree):

Agree	
	I agree to take part in the interview session which has been fully explained to me.
	I understand that my participation in these interview sessions are completely voluntary, and there will be no penalty if I choose not to participate.

Please also provide a full signature to show whether you agree to this interview session being audio-recorded

Agree	
	I agree to the interview session being audio-recorded

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

Participant	(Signature and Printed Name)	Date

Person Obtaining Consent (Signature and Printed Name)	Date

Witness (Signature and Printed Name)	Date

*A witness is required if the research participant cannot read (e.g. blind or illiterate) or if it is required by the study plan. The witness should participate in all of the discussions with regard to the participant research during the consent process. By signing this consent form, the witness guarantees that all the information within the consent has been explained to the participant, and that the consent seemed to have been understood and given by free will.

Caregiver interview guide

Introductions and job description (of facilitator/s)

Read:

“Please allow me to thank you once again for agreeing to participate in this study. Please remember that what you say in this interview will remain confidential. Our discussion will last about 60 minutes. I will record the discussion and take notes so that I capture the points that you make.”

We would like to know about your experience of being a caregiver of a man living with a severe mental illness.

What is it like living with someone who has a severe mental illness?

Probe

- How long has he had a SMI?
- What is your relationship to him?

What are some of the challenges you face living with a man who has a SMI?

Probe

- Relationships
- Work
- Stigma
- Contribution to the household

Are these challenges different to what they face?

What are some of the opportunities that have arisen because of the mental illness?

Do any of them struggle with substance use?

Probe:

- Have they been given a diagnosis related to their substance use?
- What in your opinion is more of a worry for you? Mental illness or substance use?

How were you told about their diagnosis?

What does the term recovery mean to you?

Probe:

- Do you think people with a SMI can recover?
- What are some of the things people might need to recover from?

Thinking about these problems, tell me what you think causes them, or makes them worse for men.

Probes: Why do they start? Why do they continue? What makes men more prone to severe mental illness? Or what makes them more likely to abuse substances?

What is your community's attitude towards people with SMI?

How has having someone in your care who has a mental illness impacted on your home situation and relationships with others?

Factual information to be collected when recruiting for focus group:

Regarding the MHSU is your care:

- Hospital Admission, where, how long, how many
- In patient services and programmes
- Outpatient services?
- After discharge, how did he receive treatment?
- Where is he followed up now?
- Are there services outside of health that he uses?
- Probe: Disability grant, NPO Fountain House, Comcare, Cape Mental health psychosocial group, Others
- As a caregiver, were you invited to any support groups while he was in hospital?

Does he struggle with substance use?

- Has he been given a diagnosis related to substance use?
- Has he been in trouble with the police? In what way?

Appendix O: Interview guide for MHSU life graph

Guided questions MHSUs In-Depth Interview

Introductions and job description (of facilitator/s)

Read: "Please allow me to thank you once again for agreeing to participate in this study. Please remember that what you say in this interview will remain confidential. Our discussion will last about 1 hour, and we might meet again on another date. I will record the discussion and take notes so that I capture the points that you make. We would like to know about your mental illness, what it means for you to have one and what recovery means for you".

Factual information to be collected when recruiting for interview:

- Hospital Admission, where, how long, how many
- In patient services and programmes
- Outpatient services?
- After discharge, how do you receive treatment?
- Where are you followed up now?
- Are there services outside of health that you use?
- Probe: Disability grant, NPO Fountain House, Comcare, Cape Mental health psychosocial group, Others

In-depth interview

I am asking you to draw a timeline to show your journey of living with a severe mental illness. You will have 20 minutes to draw your timeline and then you will share it with the researcher, who will ask you questions about your timeline.

Things to consider on the timeline are important dates, times or events in your life as a person with a SMI.

Timeline trigger guide to elicit discussion on:

- *onset of mental illness*
- *significant life events,*
- *an exploration of substance use,*
- *their access to psychiatric services, in and outside of hospital*
- *experience of living with a mental illness, what is it like living with a mental illness*
- *role of caregivers*
- *community members attitude to MHSUs*
- *their future plans*
- *do they have hope for the future*

Additional questions: Please tell me what you understand by the word recovery?

Probe: clinical recovery? E.g.: No more seeing or hearing things?

How do medical staff see recovery?

Some people think that recovery refers to the ability of a person to have meaning and purpose in his life even though he has a mental illness

Probe: What do you think of this description?

- What would you add?
- Why?
- What would make this description of recovery real for you as a man living with a mental illness?
- What gives you hope for the future?

Additional probes to clarify:

- Being employed
- Being able to participate in community activities and events
- Being able to buy goods and services
- Having social connections with community members
- Feeling a part of the community
- Being in a relationship

How has having a mental illness affected your view of yourself as a man?

As someone with a mental illness what are some of the things you have to recover from?

Probe: Services providers attitudes, Stigma, Social support, Challenges to integration

What in your opinion supports recovery?

What additional support do you need?

- What do you think we need to do to help you access this?
- How can we get there?

Do you struggle with substance use?

- Have you been given a diagnosis related to your substance use?
- Have you been in trouble with the police? In what way?

What is more of a problem for you- substances or mental illness?

Anything else you would like to share?

"Thank you very much for your participation. Are there any questions, comments or concerns that you would like to add, before we end?"

Appendix P: Interview guide for community map

Community Mapping Interview guide

Read: "Please allow me to thank you once again for agreeing to participate in this study. Please remember that what you say in this interview will remain confidential. Our discussion will last about 60 minutes. I will record the discussion and take notes so that I capture the points that you make"

Psychiatric admission

We are first going to talk about your admission to a psychiatric hospital

Please tell me about why you were admitted

Probe: How long have you had a mental illness? How did the experience of being in hospital affect you?

Community services

We are now going to talk about your access to mental health services outside of hospital.

Where do you collect your medication?

Probe: Do you see any other service providers? Do you attend any groups?

Recovery

We are now going to talk about recovery .

Please tell me if you thought some more about what was said in the last interview about recovery.

In today's session we are going to talk about mapping resources in your community and taking photos to help us understand what it is like to live with a mental illness in your community.

Community Map

You are now going to draw a map of important places or landmarks in your community you spend your time and what your interests are. This will help me understand your daily activities, the places you go to, the people you meet and the things you do. You have 15 minutes to draw the map and it would be helpful if you drew it in silence. Please tell me about your map

Probe

What are the particular resources (things) or people that stand out for you?

Where are these people and resources (things) based?

How do you use these resources?

Are there resources available to your caregivers? Should there be and what should they look like?

What are your hopes for the future? "Thank you very much for your participation. Are there any questions, comments or concerns that you would like to add, before we end?"

Appendix Q: Camera Issue consent



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University of Cape Town
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Cape Town, South Africa
Tel. +27 21 685 0120
Fax +27 21 650 3054
Katherine.Sorsdahl@uct.ac.za
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Camera Issue form

Activity	Camera issue and photography training
Participants	Key informants
Principal Investigator:	Professor Katherine Sorsdahl: Alan J. Flisher Centre for Public Mental Health (021 650 4798) or Fadia Gamieldien: AMARI PhD Fellow (021) 650 5852 or fadia.gamieldien@uct.ac.za

What is being asked of you

You have been selected to be a participant and photographer in this project. Thank you for agreeing to participate. **Photovoice** refers to the use of photos to help people talk about their communities.

I will explain the use of photos in research, how to use a camera and the ethics of taking photos of others. You will also be given a camera that you can use for to take photos of places, people and things of interest to you as a person living with a mental illness in your community. Please remember if you want to take photos of other people you, you will have to ask permission to do so. We ask that you not take of their faces to protect their identity. You will also have to ask them to sign the photo release form (attached) every time you take a photo of them. They can withdraw permission to use the photo at any time.

The camera remains the property of the AMARI project and must be returned to the researcher. Please supply a contact number so that I can reach you for the duration of the project.

Indicating consent

Please let us know if you have any questions before checking this consent form. Please check each item to show that you agree to what is required (leave blank if you do not agree):

Agree	
	I understand that the camera does not belong to me and I will return the camera to the researcher at the agreed upon time
	I understand that my participation in this is completely voluntary, and there will be no penalty if I choose not to participate
	I will respect the rights of others to not have their photo taken against their will
	I will provide a contact number for the researcher to reach me in order to collect the camera
	I understand that permission is granted to use my photo(s) for project related discussions, exhibits, articles and presentations.

Please also provide a full signature to show whether you agree to these interviews being audio-recorded.

Signature	
	I agree to the interviews being audio recorded

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

Participant (Signature and Printed Name) Date

Contact number

Person Obtaining Consent (Signature and Printed Name) Date

Witness (Signature and Printed Name) Date

*A witness is required if the research participant cannot read (e.g. blind or illiterate) or if it is required by the study plan. The witness should participate in all of the discussions with regards to the participant research during the consent process. By signing this consent form, the witness guarantees that all the information within the consent has been explained to the participant, and that the consent seemed to have been understood and given by free will.

To safeguard you, recorded verbal consent and a fingerprint will be obtained to when a witness has signed.

Fingerprint Date

Appendix R: MHSU Information sheet and photo release form



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Information sheet

Photo release form: When a community member has their photo taken

Why am I taking photos?

I am participating in a Public Mental Health research project which requires me to take photos of places and things of interest to me. These pictures will help us understand the public mental health needs of communities in which people live, learn, work and play.

I would like to ask your permission to take a picture of what we are doing together or a place we are visiting together.

How will the photos be used?

The photos are part of the research data and your name or face will not appear anywhere in any published material. Your identity will stay anonymous and where necessary, faces will be "blocked" out to protect your identity.

All photos taken for the research project remain the property of the project. As the photographer I will get a full set of photos for my participation in the project.

Do you have to allow your photo to be taken? No, you do not have to allow your photo to be taken.

Who is running this study? The study is being conducted by the Alan J. Flisher Centre for Public Mental Health (UCT) and the African Mental Health Research Initiative (AMARI). For more information you can visit <https://amari-africa.org/> or contact info@amariconsortium.org

If you are willing to have your photo taken then I need you to fill out a **PHOTO RELEASE FORM**.

Please read the form carefully, sign and date it and return it to the photographer

Instructions to photographer

Please return all photo release forms to the researcher along with the camera.

Photo release form

Please check each item to show that you agree to what is required (leave blank if you do not agree):

Agree	
	By signing this form, I agree to have my photo taken.
	I understand that my participation is completely voluntary, and there will be no penalty if I choose not to participate.
	I understand that permission is granted to use my photo(s) for project related discussions, exhibits, articles and presentations.

Signing this consent form indicates that you agree to your photo being taken and used in this research project.

Participant _____ (Signature and Printed Name) _____ Date _____

Photographer (Signature and Printed Name) _____ Date _____

Photo release form

Please check each item to show that you agree to what is required (leave blank if you do not agree):

Agree	
	By signing this form, I agree to have my photo taken.
	I understand that my participation is completely voluntary, and there will be no penalty if I choose not to participate.
	I understand that permission is granted to use my photo(s) for project related discussions, exhibits, articles and presentations.

Signing this consent form indicates that you agree to your photo being taken and used in this research project.

Participant _____ (Signature and Printed Name) _____ Date _____

Photographer (Signature and Printed Name) _____ Date _____

Appendix S: Digital camera training guide sample

HOW TO HOLD YOUR CAMERA

Use the right hand and body
position for sharper photos



1. Keep the palm of your left hand underneath to support the camera
2. Use your right hand to adjust camera settings and press the shutter.
3. Have at least one elbow in against your body.

better-digital-photo-tips.com

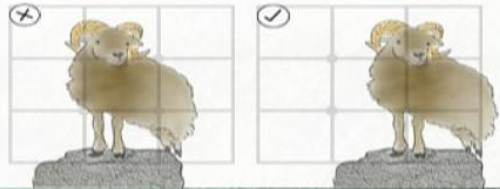
Lighting

Before raising your camera, try to work out where the light is coming from. Usually, you'll want the light to hit the front of your subject, not the back.



Follow the Rule of Thirds

For more visually pleasing photographs, use the rule of thirds; divide the frame into three horizontally and vertically (your camera should have a setting to do this for you), then position your subject at or near the intersection of any two lines.



Move Around

Think a picture of your pooch will look good from your level? Of course it will, but you can improve your snaps by moving around to ensure that you're always at the best angle for capturing your subject.



Capture the Moment

The best moments aren't choreographed, so have your camera on hand at all times when you're out and about to ensure that you capture the moments that matter.



Appendix T: Photo elicitation interview guide

MHSU Photo- Elicitation Interview Schedule

"Please allow me to thank you once again for agreeing to participate in this study. Please remember that what you say in this interview will remain confidential. Our discussion will last about 1 hour. I will record the discussion and take notes so that I capture the points that you make. We have developed the photos you took and here is the full set".

Please tell me how it felt to be a photographer in your community

Here is the full collection of photos. Please have a look at it and choose the ones that you would like to share with me. Let's start with 5 photos.

Now choose one of the five.

Please tell me about your photo

Probe

- If you had to write a heading or label for this photo what would it be?
- What are the particular things that stand out for you?
- Describe these a bit more for me.
- Do you have to spend time thinking about that?

Did you ever feel like you were in danger when taking the photo?

How did people respond to you asking them if you could take the photo

Probe

- Is there anything more you want to say about the photo
- Is there anything else this photo reminds you of that you would like us to know about?

Choose another until there are 5 photos that have been discussed

Do you have any questions you would like to ask me?

Thank you for sharing your photos with us. Here is a full set as a gift for you.

Appendix U: Sample cognitive testing questionnaire

RECOVERY ASSESSMENT SCALE

Cognitive Testing:

Interviewer:

Participant number:

Date:

Start time:

INSTRUCTIONS: Below is a list of statements that describe how people sometimes feel about themselves and their lives. Please read each one carefully and circle the number to the right that best describes the extent to which you agree or disagree with the statement. Circle only one number for each statement and do not skip any items.

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
	Question					
1.	I can make something of myself How do you understand the question? Can you repeat the question back to me in your own words? What were you thinking of when you answered the question? Is it difficult to plan ahead? RESPONSE	1	2	3	4	5

Name of person completing the form:	
Signature:	
Date:	
Start time:	
End time:	
How long did it take to complete this form?	
Over how many sessions:	

Appendix V: Original and Adapted 24-item Recovery Assessment Scale and Descriptive statistics

RECOVERY ASSESSMENT SCALE								
24 item factor loading								
Number	Original Item	Modified	Factor	Strongly disagree	Disagree	Not Sure	Agree	Strongly agree
1.	I have a desire to succeed	I can make something of myself	Goal and Success Orientation	1	2	3	4	5
2.	I have my own plan of how to stay or become well.		Goal and Success Orientation	1	2	3	4	5
3.	I have goals in life that I want to reach.		Goal and Success Orientation	1	2	3	4	5
4.	I believe I can meet my current personal goals.		Goal and Success Orientation	1	2	3	4	5
5.	I have a purpose in life.		Goal and Success Orientation	1	2	3	4	5
6.	Even when I don't care about myself, other people do.		Reliance on others	1	2	3	4	5
7.	I understand how to control the symptoms of my mental illness.			1	2	3	4	5
8.	I can handle it if I get sick again.	If I get sick again I know I'll be OK.		1	2	3	4	5
9.	I can identify what triggers the symptoms of my mental illness.			1	2	3	4	5
10.	I can help myself become better.			1	2	3	4	5
11.	Fear doesn't stop me from living the way I want to.		Personal confidence and hope	1	2	3	4	5
12.	I know that there are mental health services that do help me.			1	2	3	4	5
13.	There are things that I can do that help me deal with unwanted symptoms.	There are things that I can do that help me deal with unwanted symptoms (hallucinations).		1	2	3	4	5
14.	I can handle what happens in my life.		Personal confidence and hope	1	2	3	4	5
15.	I like myself.		Personal confidence and hope	1	2	3	4	5
16.	If people really knew me, they would like me.		Personal confidence and hope	1	2	3	4	5
17.	I am a better person than before my experience with mental illness.	Having a mental illness made me a better person.		1	2	3	4	5
18.	Although my symptoms may get worse, I know I can handle it.			1	2	3	4	5
19.	If I keep trying, I will continue to get better.			1	2	3	4	5
20.	I have an idea of who I want to become.	I have an idea of who I want to become in the future.	Personal confidence and hope	1	2	3	4	5
21.	Things happen for a reason.			1	2	3	4	5
22.	Something good will eventually happen.		Personal confidence and hope	1	2	3	4	5
23.	I am the person most responsible for my own improvement.	Getting better is my responsibility.		1	2	3	4	5
24.	I'm hopeful about my future.		Personal confidence and hope	1	2	3	4	5
25.	I continue to have new interests.		Personal confidence and hope	1	2	3	4	5
26.	It is important to have fun.			1	2	3	4	5
27.	Coping with my mental illness is no longer the main focus of my life.		No domination by symptoms	1	2	3	4	5
28.	My symptoms interfere less and less with my life.	My symptoms interfere less and less with my experiences.	No domination by symptoms	1	2	3	4	5
29.	My symptoms seem to be a problem for shorter periods of time each time they occur.		No domination by symptoms	1	2	3	4	5
30.	I know when to ask for help.		Willingness to ask for help	1	2	3	4	5
31.	I am willing to ask for help.		Willingness to ask for help	1	2	3	4	5
32.	I ask for help, when I need it.		Willingness to ask for help	1	2	3	4	5
33.	Being able to work is important to me.			1	2	3	4	5
34.	I know what helps me get better.			1	2	3	4	5
35.	I can learn from my mistakes.			1	2	3	4	5
36.	I can handle stress.		Personal confidence and hope	1	2	3	4	5
37.	I have people I can count on.		Reliance on others	1	2	3	4	5
38.	I can identify the early warning signs of becoming sick.	I know when I am getting ill.		1	2	3	4	5
39.	Even when I don't believe in myself, other people do.		Reliance on others	1	2	3	4	5
40.	It is important to have a variety of friends.	It is important to have different friends.	Reliance on others	1	2	3	4	5
41.	It is important to have healthy habits.			1	2	3	4	5
Scoring								
	Personal confidence and hope	Sum of 11, 14, 15, 16, 20, 22, 24, 25, 36						
	Willingness to ask for help	Sum of 30, 31, 32						
	Goal orientation and success	Sum of 1, 2, 3, 4, 5						
	Reliance on others	Sum of 6, 37, 39, 40						
	No domination by symptoms	Sum of 27, 28, 29						

Appendix V

Descriptive statistics of the RAS items, subscales and total

Descriptive statistics of the RAS items, subscales and total (n = 250)						
Items	RAS Questions	Range	Mean	SD	Skewness	Kurtosis
PCH	Personal Confidence and Hope	17-45	37.11	5.11	-0.54	0.87
7	Fear doesn't stop me from living the way I want to.	1-5	3.96	1.04	-1.05	0.54
8	I can handle what happens in my life	1-5	3.99	1.00	-1.09	0.88
9	I like myself.	1-5	4.43	0.72	-1.44	2.82
10	If people really knew me, they would like me	1-5	4.18	0.89	-1.21	1.60
11	I have an idea of who I want to become in the future	1-5	4.16	0.93	-1.18	1.26
12	Something good will eventually happen.	2-5	4.28	0.74	-0.98	1.10
13	I'm hopeful about my future.	1-5	4.28	0.78	-1.15	1.65
14	I continue to have new interests.	1-5	4.00	0.92	-0.90	0.55
21	I can handle stress	1-5	3.82	1.02	-0.86	0.19
WAH	Willingness to ask for help	6-15	12.72	1.91	-0.56	0.33
18	I know when to ask for help.	1-5	4.18	0.81	-1.18	1.73
19	I am willing to ask for help.	2-5	4.28	0.71	-1.15	2.17
20	I ask for help, when I need it.	1-5	4.26	0.72	-1.27	2.94
GSO	Goal and Succession Orientation	5-25	21.08	3.46	-1.14	1.96
1	I can make something of myself	1-5	4.26	0.89	-1.27	1.34
2	I have my own plan of how to stay or become well.	1-5	4.12	1.02	-1.20	0.83
3	I have goals in life that I want to reach	1-5	4.31	0.91	-1.73	3.27
4	I believe I can meet my current personal goals	1-5	4.07	0.94	-1.05	0.87
5	I have a purpose in life	1-5	4.28	0.87	-1.51	2.71
ROO	Reliance on Others	4-20	15.88	2.83	-0.84	1.69
6	Even when I don't care about myself, other people do.	1-5	4.02	0.98	-1.04	0.85
22	I have people I can count on	1-5	4.10	0.93	-1.36	2.02
23	Even when I don't believe in myself, other people do.	1-5	3.98	0.98	-0.85	0.14
24	It is important to have different friends	1-5	3.78	1.13	-0.83	-0.20
NDS	No domination by symptoms	3-15	10.58	2.97	-0.42	-0.30

15	Coping with my mental illness is no longer the main focus of my life.	1-5	3.36	1.31	-0.38	-1.09
16	My symptoms interfere less and less with my experiences	1-5	3.62	1.14	-0.66	-0.48
17	My symptoms seem to be a problem for shorter periods of time each time they occur	1-5	3.60	1.15	-0.72	-0.33
Total	Total RAS	61-120	97.45	12.09	-0.19	-0.27

Recovery from Severe Mental Illness in Cape Town



If you are 18 years or older and are living with an SMI then you may be eligible to participate to in a research study.

We would like to understand what recovery means for people living with a severe mental illness (SMI).

What will you have to do?
| Participate in one interview of approx. 40 minutes.

What are the risks and discomforts?
| There are no foreseeable risks, but if some questions make you uncomfortable, you do not have to answer them.

What are the benefits?
| There are no direct, personal benefits, but the information from this study will help us understand what recovery means for people living with an SMI.

Your participation will be kept confidential and private.

Participation is voluntary and you can withdraw at any time.

Participants will receive:

- Refreshments
- A voucher as a token of appreciation

LOCATION
In-person appointments at either OPD, OT, Group Home, Community Centre or a venue of your convenience.

ARE YOU ELIGIBLE?

- Are 18 years or older?
- Are you diagnosed with an SMI (Schizophrenia, Schizoaffective Disorder, Bipolar Affective Disorder, Major Depressive Disorder, Substance-Induced Psychotic Disorder or any psychotic disorder)?
- Are you willing and available to be interviewed?

If you are unsure if you meet the requirements, call or email a member of the study team:

- Direct any questions about your rights as a participant, concerns or complaints, to the chairperson of the HREC, Prof Marc Blockman on (021) 406 6496 or the Project Supervisor, Prof Katherine Sorsdahl on (021) 650 4798.
- Please contact Fadia Gamielien directly with any research- related questions. She is available on (021) 650 5852 or fadia.gamielien@uct.ac.za

Appendix X: Information sheet, consent form and standard operating procedure for COVID screening

COVID-19 Symptom Screener (Participants)

SCREENING QUESTIONNAIRE

Date:

Location/Suburb:

Surname:	
Name:	
Age:	
Date of Birth:	
Temperature:	

	Yes	No
Have you recently travelled internationally?		
In the past 2 weeks, have you interacted with anyone who has been COVID-19 positive?		
Are you suffering from any of the following symptoms?		
Fever		
Cough		
Sore throat		
Shortness of breath		
Loss of smell		
Loss of taste		
Body aches		
Nausea		
Vomiting		

Participant Number	For office use

COVID-19 SOP for study: An exploration of recovery among South African men with a severe mental illness

Fadia Gamielidien
Department of Psychiatry and Mental Health
University of Cape Town
HREC 655/2018

Date: 04/10/2020

Purpose: This SOP describes procedures to be followed during tracking and fieldwork in communities and study activities conducted at the three Psychiatric hospitals (Valkenberg, Lentegour and Stikland) and non-profit organisations (NPOs) in Cape Town, Western Cape

1. In-person tracking and fieldwork

Participant contact information will be updated using telephonic contact and tracking in the communities. In-person tracking will be used if participants are difficult to get hold of to invite for interviews (e.g. telephone on voicemail, telephone ringing with no answer) as this is a hard to reach target group (severe mental illness). All community tracking will be guided by the COVID-19 infection control and safety procedures outlined below.

2. Study activities at the Psychiatric Hospital and NPO Sites

The project managers and field workers will access psychiatric hospitals and NPOs to conduct participant interviews in person. See below for procedures at the site.

COVID-19 Infection Control and Safety:

We want to ensure everyone follows these guidelines to stay safe from COVID-19 at the office and when contacting their participants. Please follow these guidelines in communities:

- If you have any symptoms (see **Appendix A of this SOP**), DO NOT seek out any participants, and alert the researcher, Fadia Gamielidien ASAP).
- Wear a mask at ALL times when in the community, when travelling in a vehicle with other staff members and when sharing indoor spaces with other staff members or study participants.
- Ensure that indoor spaces are well ventilated.
- Let the participant put on a mask before you start the interview.
- Do not shake hands/touch/hug.
- Stay 1.5 metres apart at all times.
- Stay outside if possible.
- Sanitizer must be in the car and on your person at all times during community tracking.
- Sanitize your hands immediately after every visit.
- If you do community tracking, the study team member must fill out the COVID19 symptom screener (including temperature recording) for participants they come in contact with (see **Appendix B of this SOP**). These screeners are completed to establish contact and tracking in the event of a positive case. Screeners must be filed immediately upon return to the office.
- The temperature of the person you are making contact with must be measured by a thermometer gun (this will be provided to you) and recorded on the COVID19 symptom screener.

What to do if the participant screens positive:

- (a) If a participant screens positive for any of the symptoms above, please stop contact immediately.
- (b) Encourage the participant to contact the hotline (**Appendix C**).
- (c) It is not our responsibility to provide testing services, however, we will provide participants with a resource list with no-cost government-provided testing sites and contact details (**Appendix C**). *Note:* At the screening sites, not all patients will be tested. The criteria healthcare workers use to decide whether to test a patient include an assessment of symptom severity and the presence of other health conditions.

Other important information:

- All staff must ensure they dispose of the used or soiled PPE appropriately on returning to the site after going into communities for tracking purposes.
- Ensure that staff understand the importance of handwashing, sanitizing/ disinfecting surfaces and equipment.
- Staff must monitor their allocated PPE stock every week.
- Requests for the appropriate PPE and sanitising/ hand washing consumables required at the site should be communicated with **Fadia**, who will liaise with the UCT Safety Officer about such requests.

Please follow these guidelines at the Hospital and NPO sites:

- Complete the screener daily.
- Immediately upon entering the site please wash your hands following proper handwashing guidelines (see **Figure 1** below).
- Please wear masks while at the site.
- Wash your hands or use hand sanitizer every hour while at the site.
- Wipe down all workstation surfaces (especially phones) at the end of your workday with a bleach solution and paper towel.
- Only use offices with windows. Windows must be opened to allow for adequate natural ventilation.
- After wipe-down, wash your hands thoroughly before leaving the site for the day.

How to Handrub?

RUB HANDS FOR HAND HYGIENE! WASH HANDS WHEN VISIBLY SOILED

⌚ Duration of the entire procedure: 20-30 seconds



Figure 1: Hand Hygiene

Staff must be extremely cautious about infection control to protect themselves and their fellow team members. See Figure 2. Coronavirus prevention toolbox for an overview.

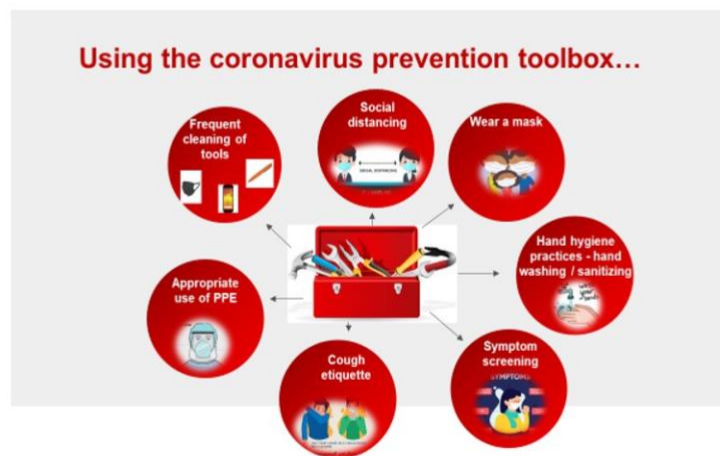


Figure 2: Coronavirus prevention toolbox



Appendix A: Possible COVID-19 Symptoms

If you have any of the symptoms below DO NOT make contact with any participants, and do not come to work (please inform Fadia ASAP).

Symptoms may appear 2-14 days after contact with a person who is COVID positive..

People with these symptoms may have COVID-19:

- ❖ Fever or chills
- ❖ Cough
- ❖ Shortness of breath or difficulty breathing
- ❖ Fatigue
- ❖ Muscle or body aches
- ❖ Headache
- ❖ New loss of taste or smell
- ❖ Sore throat
- ❖ Congestion or runny nose
- ❖ Nausea or vomiting
- ❖ Diarrhoea

COVID-19 Assessment Centres

Testing site	Address	Contact Details
Hotline number		021 928 4102 / 0809284102 (toll-free) / WhatsApp "Hi" to 0600123456
City of Cape Town Field Clinics (COVID-19 assessment & treatment) Opening hours Monday-Friday: 07h30-16h30		
Albow Gardens Field Clinic	Brooklyn Library Hall, Cnr Nahum and Albow Roads, Rugby	021 444 5943 / 021 444 5949 / 021 444 5950
Bloekombos Field Clinic	Bloekombos Clinic, Sam Njokazela Street, Bloekombos	021 444 5977 / 021 444 5973
Blue Downs Field Clinic	Bentley Road, Blue Downs	021 444 8313
Dr Ivan Toms Field Clinic	Dr Ivan Toms Clinic, Cnr Nqubelani and Umbashe streets, Ext 6, Mfuleni	021 400 3600
Eerste River Field Clinic	Eerste River Multi-Purpose Hall, Cnr Beverly Street and Bobs Way, Eerste River	021 444 7144
Ikhwezi Field Clinic	Ikhwezi Community Day Centre, 3 Simon Street, Lwandle	021 444 4778
Masiphumelele Field Clinic	Masiphumelele Community Hall, opposite Masiphumelele Clinic, Mayeza Road, Masiphumelele	021 444 4103 / 021 444 4101
Ocean View Field Clinic	Ocean View Civic Centre, opposite Ocean View CDC, Pollux Way, Ocean View	021 400 5474 / 021 400 5476
Phumlani Field Clinic	Phumlani Clinic, 3719 Stock and Mgqwani Road, Philippi East	021 444 6147 / 021 444 6162
Sarepta Field Clinic	Sarepta Community Hall, Rietvlei Road, Sarepta	021 900 2915 / 021 900 2910
Sir Lowry's Pass Field Clinic	Sir Lowry's Pass Clinic, Cnr Nolan and Brinkhuis streets, Sir Lowry's Pass	021 400 2996 / 021 400 2993
Tafelsig Field Clinic	Tafelsig CDC, Cnr Kilimanjaro and Pyrenees Streets, Tafelsig, Mitchell Plain	021 444 2024 / 021 444 3512
Town Two Field Clinic	Town Two CDC, Cnr Zibonele and Manyano streets, Town 2, Khayelitsha	021 444 2813 / 021 444 2838 / 021 444 2839
Weltevreden Valley Field Clinic	Weltevreden Valley Clinic, Rosewood Drive, Colorado	021 444 6502 / 021 444 6503

PARTICIPANT LOCATOR INFORMATION

Participant Number	For office use

PARTICIPANT DOB : | | | | | | |

CLINICOM NUMBER : | | | | | | | | |

DATE: | | | | | | | | | |

Day Month Year

LOCATION:

Instructions for Staff - Reviewing and/or Updating:

Please ask the questions below

Capture in writing as much detail as possible

Make sure to write legibly.

*This form should be reviewed and updated if necessary. Please complete another form with the date the update was made. **Do not** completely cross out any previous information, as this information may be useful in locating a participant.*

READ: *I am calling to ask if you would be prepared to participate in a research study on recovery from severe mental illness. Please note that giving us this information is voluntary and it will be kept private and locked up. We will use the information you give us to contact you by mail, email, phone, or in person to invite you to an interview in 2020/2021.*

What is your name?

FIRST NAME	MIDDLE NAME	MAIDEN/ANOTHER NAME	LAST NAME/ SURNANE

2) What is your cell phone number: _____

If for any reason, we can't get hold of you on this number is there another phone number that we could use?

Perhaps a number of someone that you see regularly?

NAME AND RELATION	MOBILE PHONE / HOME NUMBER
1.	1.
2.	2.
3.	3.
4.	4.

4) What do you consider your home address? – **MANDATORY (must give)**

NUMBER	STREET NAME	ST., AVE., ETC.

SUBURB	CITY	POSTAL CODE

5) If we cannot locate you by phone or mail, can we send a staff member to your home listed above?

☐ YES ☐ NO

Note to Staff: If "NO", please make a note on the front page of this form.

Any Closing comments

Date

Name of person

Signature of person

Research Assistant Symptom Screener

Before any staff member can enter the workplace, the following questions need to be answered and if any symptoms have been noted, please contact Fadia immediately and do not return to work before seeking advice from a medical professional asap.

Name: Period

Have you been in contact with anyone who has tested positive for COVID in the past ten days? Circle : **Y (yes)** **N (no)**

Symptoms Mark	Mark symptom with either a Y (yes) or N (no)									
	Monday	Tuesday	Wednesday	Thursday	Friday	Monday	Tuesday	Wednesday	Thursday	Friday
Fever										
Cough										
Sore throat										
Redness of the eyes										
Shortness of breath										
Did you have any of the following illnesses the last few days										
Body aches										
Loss of smell or taste										
Nausea										
Vomiting										
Diarrhoea										
Fatigue										
Weakness										
Tiredness										
Measured Body Temperature										

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Alan J. Flisher Centre for
Public Mental Health

Information letter and informed consent form for Interview Battery

Activity	Interview Battery
Participants	Key informants
Principal Investigator:	Professor Katherine Sorsdahl: Alan J. Flisher Centre for Public Mental Health (021 650 4798) or Fadia Gamieldien: AMARI PhD Fellow (0210 650 5852 or fadia.gamieldien@uct.ac.za)

Read

My name is.....and I am assisting with collecting data for a research project on living with a severe mental illness. I would like to invite you to take part in interviews as part of this study. Before you agree, you should understand what it involves. This letter is to give you information so that you can decide if you want to take part in this study. Your participation is voluntary, meaning that you should agree to take part only if you are happy with all it involves.

Purpose of the study and study requirements

The goal of the research project is to understand what recovery from severe mental illness means to mental health service users, caregivers and stakeholders. This study will increase understanding of what recovery means for people living with a severe mental illness in Cape Town.

Why have you been invited to take part? You have been invited to take part because you are an adult with a severe mental illness living in Cape Town.

What will happen if you take part? We will invite you to participate in a survey. This will be done by a trained research assistant in an interview format.

You will be asked questions from the following measures:

The Recovery Assessment Scale (RAS)

The Multidimensional Scale of Perceived Social Support

The WHO Alcohol, Smoking and Substance Involvement Screening Test (ASSIST)

World Health Organisation Quality of Life- BREF instrument (WHOQOL-BREF)

How long will the study last?

Each survey interview should take between 40-60 minutes to complete.

What are the potential risks and discomforts of participating in this study?

There are no foreseeable risks to participating in these interviews. It is possible that some survey questions or topics could make you feel uncomfortable. If we ask you a question that you do not want to answer, you can say no, and we will move to the next one.

What are the potential benefits of participating in this study?

There are no direct, personal benefits to you participating in this survey. Information from this study will be used to help us better understand what helps and hinders recovery of people living with severe mental illness, and this could help us design services that promote recovery in the future.

Will my participation in the study be kept confidential and private?

Any information obtained during the interview will remain confidential. Information will not be shared with your service providers or caregivers unless you are in danger of harming yourself or others. In this case we will be legally obliged to do so.

The study team will make every effort to protect your privacy. We will not use your name or other identifiers in the reports from this study nor will we link your name with the data provided. The only confidential information will be on the consent forms, which will be stored in a locked filing cabinet. The consent forms will be destroyed after five years of completion of these activities. The UCT Health Research Ethics Committee (HREC) will have access to all data.

We will use the information you provide to write and publish papers in academic journals, but your name will not appear anywhere in any published material and your identity will remain anonymous as pseudonyms will be used.

What are my rights as a research participant/subject? Participation is voluntary and you do not need to take part if you do not want to. You can also stop at any time. If you say yes now, and change your mind later, it will not affect your relationship with the research assistants or service providers you are associated with.

Who is funding this study?

The study is being funded through the Alan J. Flisher Centre for Public Mental Health (UCT) and the African Mental Health Research Initiative (AMARI). For more information you can visit <https://amariconsortium.org/> or contact info@amariconsortium.org

What will I receive for participating?

You will receive a R100 store (PnP or Shoprite) voucher for your time spent participating in the interview.

Rights of participants

This study has been approved by the University of Cape Town's Health Research Ethics Committee and its reference number is **HREC 655/2018**. It will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, and the South African Guidelines for Good Clinical Practice.

Who to contact with questions

If you have any questions about your rights as a participant, concerns or complaints, please call the chairperson of the HREC, Prof Marc Blockman on (021) 406 6496

This research will be supervised by Professor Katherine Sorsdahl (021) 650 4798. You are welcome to contact her if you have additional queries.

Please contact Fadia Gamiieldien directly with any research related questions. She is available on (021) 650 5852 or fadia.gamiieldien@uct.ac.za

Participant Number	For office use

Indicating consent

Please let me know if you have any questions before checking (✓) this consent form. Please check each item to show that you agree to what is required (leave blank if you do not agree):

Agree	
	I agree to take part in this survey interview which has been fully explained to me.
	I understand that my participation in this survey interview is completely voluntary, and there will be no penalty if I choose not to participate.

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

Participant (Signature and Printed Name) Date

Person Obtaining Consent (Signature and Printed Name) Date

Witness (Signature and Printed Name) Date

*A witness is required if the research participant cannot read (e.g. blind or illiterate) or if it is required by the study plan. The witness should participate in all of the discussions with regards to the participant research during the consent process. By signing this consent form, the witness guarantees that all the information within the consent has been explained to the participant, and that the consent seemed to have been understood and given by free will.

Fingerprint

Date

To safeguard you, recorded verbal consent and a fingerprint will be obtained when a witness has signed.

Appendix Y: Study questionnaire

Demographic Questionnaire

Please provide us with the following information

Venue	Community based venue Home Hospital NPO office Supported housing Other Please record name of venue	Date	
Participant Number	For office use		
1	Age (years)	DOB	DD-MM-YYYY
2	Gender	Female Male Nonbinary	
3	Home language	Afrikaans English IsiXhosa Other (specify)	
4	Population Group	Black South African Black African (specify) Coloured Indian White Other (specify)	
5	Your religion	Christian Muslim Hindu Jewish Rasta Other (specify)	
6	What is your highest level of education?	Primary school High school Specify highest grade passed After school qualifications No Yes Post school certificate Diploma	

		Degree Other (specify)
7	Are you employed?	No Yes
8	Type of employment	Full time Part time Self employed Unemployed Other (specify)
9	How many people receive an income in your home?	
10	What are the sources of income in your home? (<i>may select multiple sources</i>)	Family Wages/Salary Self-generated/own business Social grant Spouse/partner Other (specify)
11	Does your household have the same income every month?	No, it varies a lot Not sure/don't know Yes, every month Yes, most months
12	How many children do you have?	
13	Are you in a relationship?	No Yes
14	What type of relationship do you have?	Casual partner(s) Stable partner Divorced Married Widowed Other (specify)
15	Do you and your partner live together?	No Yes Some of the time
16	Does your partner provide financial support?	No Yes Some of the time
17	What area do you live in? (area/suburb)	
18	What type of dwelling do you live in?	Backyard dwelling Government housing Homeless

		Informal dwelling/ shack Private home Supported living/ Group Home Other (specify)
19	Do you pay rent?	No Yes Some of the time
20	Who else lives with you?	Children Grandchildren Parents Partner Siblings Tenants Other (specify)
21	What are the ages of people living with you?	Children (0-13years) Children (13-18 years) Over 18 Over 65?
22	Total number of people living in your home (including yourself)	
23	What is your mental health diagnosis?	
24	How old were you when you were diagnosed?	Child (0-13years) Child (13-18 years) Between 18-35 years 35 years and older
25	How long have you been living with a mental illness?	Under one year Between one -10 years Between 10-20 years 20 years and longer
26	How many admissions to a psychiatric hospital have you had in the past 2 years?	One admission Between 2-5 admissions More than 5 admissions
27	How many admissions to a psychiatric hospital have you had in your lifetime?	One admission Between 2-5 admissions More than 5 admissions
28	Are you taking pills or injections?	No Yes
29	What pills or injections are you taking?	
30	Where do you collect your medication?	Clinic Name of clinic..... Psychiatric hospital

		Other (specify)
31	Do you have any other health conditions?	Asthma Diabetes (High blood pressure) HIV Other (Specify)
32	Have you received treatment for alcohol or drug problems rather?	No Yes
33	Do you use any other services? (NPO, fountain house, support group, etc)	No Yes Name of service

ASSIST

READ: *I am going to ask you some questions about your experience of using alcohol and/or drugs during your lifetime and in the past three months. These substances could have been smoked, swallowed, snorted, inhaled, injected or taken in the form of pills. Some of the drugs listed may be prescribed by a doctor (like amphetamines, sedatives, pain medications). For this interview, we will not record medications that are used as prescribed by your doctor. However, if you have taken such medications for reasons other than prescription or taken them more frequently or at higher doses than prescribed, please let me know. While we are also interested in knowing about your use of various illicit drugs, please be assured that information on such use will be treated as strictly confidential.*

Question 1: In your life, which of the following have you used:

		YES	NO
1	Tobacco (Cigarettes, Okka pipe, twak pil)		
2	Alcoholic Beverages (beer, wine etc)		
3	Cannabis (dagga, weed, marijuana)		
4	Cocaine (rocks, coke, crack)		
5	Amphetamine Type Stimulants (Tik)		
6	Inhalants (nitrous glue, petrol)		
7	Sedatives or sleeping pills		
8	Hallucinogens (LSD, acid, mushrooms, PCP, special K)		
9	Opioids (heroin, morphine, methadone, unga)		
10	Mandrax (buttons, white pipe)		
11	Other (prescription medication, over the counter medication such as cough syrup, diet medication, etc)		

Question 2:

In the past three months, how often have you used the substances you mentioned (first substance, second substance, etc) <u>Please circle the number</u>	Never	Once or Twice	Monthly	Weekly	Daily or Almost Daily
Tobacco (Cigarettes, Okka pipe, twak pil)	0	2	3	4	6
Alcoholic Beverages (beer, wine etc)	0	2	3	4	6
Cannabis (dagga, weed, marijuana)	0	2	3	4	6
Cocaine (rocks, coke, crack)	0	2	3	4	6
Amphetamine Type Stimulants (Tik)	0	2	3	4	6
Inhalants (nitrous glue, petrol)	0	2	3	4	6
Sedatives or sleeping pills	0	2	3	4	6
Hallucinogens (LSD, acid, mushrooms, PCP, special K)	0	2	3	4	6
Opioids (heroin, morphine, methadone, unga)	0	2	3	4	6
Mandrax (buttons, white pipe)	0	2	3	4	6
Other (prescription medication, over the counter medication such as cough syrup, diet medication, etc)	0	2	3	4	6

Question 3:

During the past three months, how often have you had a strong desire or urge to use? <u>Please circle the number</u>	Never	Once or Twice	Monthly	Weekly	Daily or Almost Daily
Tobacco (Cigarettes, Okka pipe, twak pil)	0	3	4	5	6
Alcoholic Beverages (beer, wine etc)	0	3	4	5	6
Cannabis (dagga, weed, marijuana)	0	3	4	5	6
Cocaine (rocks, coke, crack)	0	3	4	5	6
Amphetamine Type Stimulants (Tik)	0	3	4	5	6

Inhalants (nitrous glue, petrol)	0	3	4	5	6
Sedatives or sleeping pills	0	3	4	5	6
Hallucinogens (LSD, acid, mushrooms, PCP, special K)	0	3	4	5	6
Opioids (heroin, morphine, methadone, unga)	0	3	4	5	6
Mandrax (buttons, white pipe)	0	3	4	5	6
Other (prescription medication, over the counter medication such as cough syrup, diet medication, etc)	0	3	4	5	6

Question 4:

During the <u>past three months</u> , how often has your use of substances led to health social, legal or financial problems? <u>Please circle the number</u>	Never	Once or Twice	Monthly	Weekly	Daily or Almost Daily
Tobacco (Cigarettes, Okka pipe, twak pil)	0	4	5	6	7
Alcoholic Beverages (beer, wine etc)	0	4	5	6	7
Cannabis (dagga, weed, marijuana)	0	4	5	6	7
Cocaine (rocks, coke, crack)	0	4	5	6	7
Amphetamine Type Stimulants (Tik)	0	4	5	6	7
Inhalants (nitrous glue, petrol)	0	4	5	6	7
Sedatives or sleeping pills	0	4	5	6	7
Hallucinogens (LSD, acid, mushrooms, PCP, special K)	0	4	5	6	7
Opioids (heroin, morphine, methadone, unga)	0	4	5	6	7
Mandrax (buttons, white pipe)	0	4	5	6	7
Other (prescription medication, over the counter medication such as cough syrup, diet medication, etc)	0	4	5	6	7

Question 5:

During the past three months, how often have you failed to do what was normally expected of you because of your use of substance use? <u>Please circle the number</u>	Never	Once or Twice	Monthly	Weekly	Daily or Almost Daily
Tobacco (Cigarettes, Okka pipe, twak pil)	0	5	6	7	8
Alcoholic Beverages (beer, wine etc)	0	5	6	7	8
Cannabis (dagga, weed, marijuana)	0	5	6	7	8
Cocaine (rocks, coke, crack)	0	5	6	7	8
Amphetamine Type Stimulants (Tik)	0	5	6	7	8
Inhalants (nitrous glue, petrol)	0	5	6	7	8
Sedatives or sleeping pills	0	5	6	7	8
Hallucinogens (LSD, acid, mushrooms, PCP, special K)	0	5	6	7	8
Opioids (heroin, morphine, methadone, unga)	0	5	6	7	8
Mandrax (buttons, white pipe)	0	5	6	7	8
Other (prescription medication, over the counter medication such as cough syrup, diet medication, etc)	0	5	6	7	8

Question 6:

Has a friend or relative or anyone else ever expressed concern about your use of specific substances? <u>Please circle the number</u>	No, Never	Yes, in the past 3 months	Yes, but not in the past 3 months
Tobacco (Cigarettes, Okka pipe, twak pil)	0	6	3
Alcoholic Beverages (beer, wine etc)	0	6	3
Cannabis (dagga, weed, marijuana)	0	6	3
Cocaine (rocks, coke, crack)	0	6	3
Amphetamine Type Stimulants (Tik)	0	6	3
Inhalants (nitrous glue, petrol)	0	6	3
Sedatives or sleeping pills	0	6	3
Hallucinogens (LSD, acid, mushrooms, PCP, special K)	0	6	3

Opioids (heroin, morphine, methadone, unga)	0	6	3
Mandrax (buttons, white pipe)	0	6	3
Other (prescription medication, over the counter medication such as cough syrup, diet medication, etc)	0	6	3

Question 7:

Have you <u>ever</u> tried and failed to control, cut down or stop using specific drugs? <u>Please circle the number</u>	No, Never	Yes, in the past 3 months	Yes, but not in the past 3 months
Tobacco (Cigarettes, Okka pipe, twak pil)	0	6	3
Alcoholic Beverages (beer, wine etc)	0	6	3
Cannabis (dagga, weed, marijuana)	0	6	3
Cocaine (rocks, coke, crack)	0	6	3
Amphetamine Type Stimulants (Tik)	0	6	3
Inhalants (nitrous glue, petrol)	0	6	3
Sedatives or sleeping pills	0	6	3
Hallucinogens (LSD, acid, mushrooms, PCP, special K)	0	6	3
Opioids (heroin, morphine, methadone, unga)	0	6	3
Mandrax (buttons, white pipe)	0	6	3
Other (prescription medication, over the counter medication such as cough syrup, diet medication, etc)	0	6	3

Question 8:

Have you <u>ever</u> used any drug by injection? <u>Please circle the number</u>	No, Never	Yes, in the past 3 months	Yes, but not in the past 3 months
	0	2	1

Total score PER substance

Score Substance 1: _____ Score Substance 3: _____ Score Substance 5:

Score Substance 2: _____ Score Substance 4: _____ Score Substance 6:

WHOQOL-BREF

Instructions

This questionnaire asks how you feel about your quality of life, health and other areas of your life. Please answer all the questions.

If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks.

	<i>(Please circle the number)</i>				
	Very poor	Poor	Neither poor nor good	Good	Very good
How would you rate your quality of life?	1	2	3	4	5

	<i>(Please circle the number)</i>				
	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your health?	1	2	3	4	5

	<i>(Please circle the number)</i>				
	Not at all	A little	A moderate amount	Very much	An extreme amount
To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5

How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
How much do you enjoy life?	1	2	3	4	5

		<i>(Please circle the number)</i>			
	Not at all	A little	A moderate amount	Very much	An extreme amount
To what extent do you feel your life to be meaningful?	1	2	3	4	5
How well are you able to concentrate?	1	2	3	4	5
How safe do you feel in your daily life?	1	2	3	4	5
How healthy is your physical environment?	1	2	3	4	5

	<i>(Please circle the number)</i>				
	Not at all	A little	Moderately	Mostly	Completely
Do you have enough energy for everyday life?	1	2	3	4	5
Are you able to accept your bodily appearance?	1	2	3	4	5
Have you enough money to meet your needs?	1	2	3	4	5

How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

	<i>(Please circle the number)</i>				
	Very poor	Poor	Neither poor nor well	Well	Very well
How well are you able to get around?	1	2	3	4	5

	<i>(Please circle the number)</i>				
	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your sleep?	1	2	3	4	5
How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
How satisfied are you with your capacity for work?	1	2	3	4	5

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your abilities	1	2	3	4	5
How satisfied are you with your personal relationships?	1	2	3	4	5
How satisfied are you with your sex life?	1	2	3	4	5
How satisfied are you with the support you get from your friends?	1	2	3	4	5
How satisfied are you with the conditions of your living place?	1	2	3	4	5
How satisfied are you with your access to health services?	1	2	3	4	5
How satisfied are you with your mode of transportation?	1	2	3	4	5

	<i>(Please circle the number)</i>				
	Never	Seldom	Quite often	Very often	Always

How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read and listen to each statement carefully. Indicate how you feel about each statement and mark with an X

RECOVERY ASSESSMENT SCALE

INSTRUCTIONS: Below is a list of statements that describe how people sometimes feel about themselves and their lives. Please read each one carefully and circle the number to the right that best describes the extent to which you agree or disagree with the statement. Circle only one number for each statement and do not skip any items.

For each of the following statements, please choose a smiley face that indicates how you feel about the statement.								
	Question	Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree
								
1	There is a special person who is around when you are in need.							
2	There is a special person with whom you can share your joys and sorrows.							
3	Your family really tries to help you.							
4	You get the emotional help and support you need from your family.							
5	You have a special person who is a real source of comfort to you.							
6	Your friends really try to help you.							
7	You can count on your friends when things go wrong.							

8	You can talk about your problems with my family.							
9	You have friends with whom you can share your joys and sorrows.							
10	There is a special person in your life who cares about your feelings.							
11	Your family is willing to help you make decisions.							
12	You can talk about your problems with your friends.							

		Strongly disagree	Disagree	Not Sure	Agree	Strongly Agree
	Question					
	I can make something of myself	1	2	3	4	5
	I have my own plan of how to stay or become well.	1	2	3	4	5
	I have goals in life that I want to reach	1	2	3	4	5
	I believe I can meet my current personal goals	1	2	3	4	5
	I have a purpose in life	1	2	3	4	5
	Even when I don't care about myself, other people do.	1	2	3	4	5
	I understand how to control the symptoms of my mental illness.	1	2	3	4	5
	If I get sick again, I know I will be OK	1	2	3	4	5
	I can identify what triggers the symptoms of my mental illness.	1	2	3	4	5
	I can help myself become better.	1	2	3	4	5
	Fear doesn't stop me from living the way I want to.	1	2	3	4	5
	I know that there are mental health services that do help me.	1	2	3	4	5
	There are things that I can do that help me deal with unwanted symptoms (hallucinations, etc)	1	2	3	4	5
	I can handle what happens in my life	1	2	3	4	5
	I like myself.	1	2	3	4	5
	If people really knew me, they would like me	1	2	3	4	5
	Having a mental illness made me a better person	1	2	3	4	5
	Although my symptoms may get worse, I know I can handle it.	1	2	3	4	5
	If I keep trying, I will continue to get better.	1	2	3	4	5
	I have an idea of who I want to become in the future	1	2	3	4	5
	Things happen for a reason.	1	2	3	4	5
	Something good will eventually happen.	1	2	3	4	5
	Getting better is my responsibility	1	2	3	4	5
	I'm hopeful about my future.	1	2	3	4	5
	I continue to have new interests.	1	2	3	4	5
	It is important to have fun.	1	2	3	4	5
	Coping with my mental illness is no longer the main focus of my life.	1	2	3	4	5
	My symptoms interfere less and less with my life	1	2	3	4	5
	My symptoms interfere less and less with my experiences	1	2	3	4	5

	I know when to ask for help.	1	2	3	4	5
	I am willing to ask for help.	1	2	3	4	5
	I ask for help, when I need it.	1	2	3	4	5
	Being able to work is important to me	1	2	3	4	5
	I know what helps me get better	1	2	3	4	5
	I can learn from my mistakes	1	2	3	4	5
	I can handle stress	1	2	3	4	5
	I have people I can count on	1	2	3	4	5
	I know when I am getting ill	1	2	3	4	5
	Even when I don't believe in myself, other people do.	1	2	3	4	5
	It is important to have different friends	1	2	3	4	5
	It is important to have healthy habits	1	2	3	4	5

Name of person completing the form:	
Signature:	
Date:	
Start time:	
End time:	
How long did it take to complete this form?	
Over how many sessions:	

Appendix Z: Factors derived from the South African version of the RAS in the total sample ($N = 250$)

		EFA
Factor 1	Personal Confidence	
9	I like myself.	0.59
10	If people really knew me, they would like me	0.52
13	I'm hopeful about my future.	0.65
14	I continue to have new interests.	0.48
18	I know when to ask for help.	0.70
19	I am willing to ask for help.	0.74
20	I ask for help, when I need it.	0.66
Factor 2	Goal and Success Orientation	
1	I can make something of myself	0.67
3	I have goals in life that I want to reach	0.79
4	I believe I can meet my current personal goals	0.76
5	I have a purpose in life	0.68
11	I have an idea of who I want to become in the future	0.54
12	Something good will eventually happen.	0.54
Factor 3	Reliance on Others	
6	Even when I don't care about myself, other people do.	0.62
22	I have people I can count on	0.74
23	Even when I don't believe in myself, other people do.	0.67
24	It is important to have different friends	0.66
Factor 4	Empowerment and Inner Strength (EIS)	
2	I have my own plan of how to stay or become well.	0.66
7	Fear doesn't stop me from living the way I want to.	0.69
8	I can handle what happens in my life	0.75
21	I can handle stress	0.50
Factor 5	No Domination of Symptoms	
15	Coping with my mental illness is no longer the main focus of my life.	0.68
16	My symptoms interfere less and less with my experiences	0.83
17	My symptoms seem to be a problem for shorter periods of time each time they occur	0.82

Green is Willingness to ask for help (WAH), which loaded on PC and did not emerge as a factor on its own.

Turquoise is Empowerment and inner strength (EIS), which is a new domain that emerged in this study.