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UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Developing strategies for alleviating caregiver burden among informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga province

Olindah Mkhonto Silaule

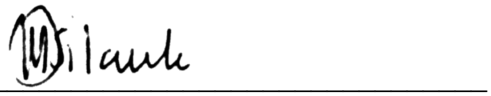
A thesis submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Doctor of Philosophy Johannesburg, South Africa.

May,2024

DECLARATION

I, Olindah Mkhonto Silaule, declare that this thesis is my own, unaided work. It is being submitted for the Degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other university.

I confirm lead authorship of the published articles included in this thesis.



Olindah Mkhonto Silaule

21 day of May 2024 in Cape Town

DEDICATION

This work is dedicated to my mother

Sibongile Silaule

PUBLICATIONS AND CONFERENCE PRESENTATIONS ARISING FROM THIS STUDY

Publications

ARTICLE ONE

(Objective 1: Published)



Rural and Remote Health

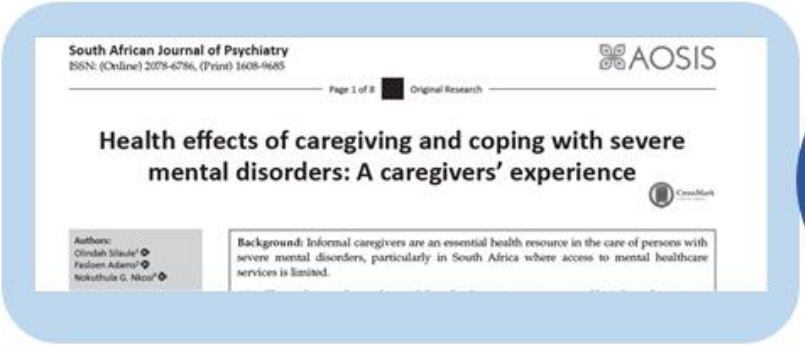
ORIGINAL RESEARCH

Extent of caregiver burden among informal caregivers of persons with severe mental disorders in rural South Africa

AUTHORS

CORRESPONDENCE

AFFILIATIONS



South African Journal of Psychiatry

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AOSIS

Page 1 of 8 Original Research

Health effects of caregiving and coping with severe mental disorders: A caregivers' experience

Authors:

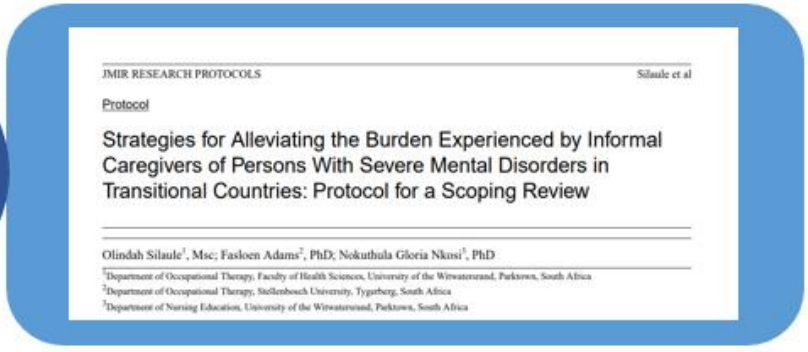
Background: Informal caregivers are an essential health resource in the care of persons with severe mental disorders, particularly in South Africa where access to mental healthcare services is limited.

ARTICLE TWO

(Objective 2: Published)

ARTICLE THREE

(Objective 3: Published)



JMIR RESEARCH PROTOCOLS Silaule et al

Protocol

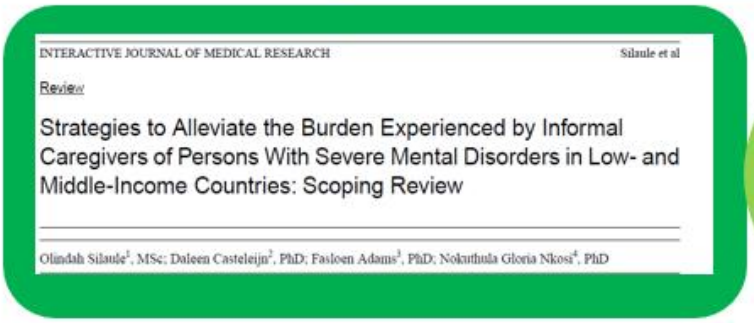
Strategies for Alleviating the Burden Experienced by Informal Caregivers of Persons With Severe Mental Disorders in Transitional Countries: Protocol for a Scoping Review

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INTERACTIVE JOURNAL OF MEDICAL RESEARCH Silaule et al

Review

Strategies to Alleviate the Burden Experienced by Informal Caregivers of Persons With Severe Mental Disorders in Low- and Middle-Income Countries: Scoping Review

Olindah Silaule[1], MSc; Daleen Casteleijn[2], PhD; Fasloen Adams[3], PhD; Nokuthula Gloria Nkosi[4], PhD

ARTICLE FOUR

(Objective 3: Published)

Articles submitted and under review

Study objective	Manuscripts titles	Submitted	Status
Objective 2	Experience of burden and support needs of informal caregivers of persons with severe mental disorders in rural South Africa: A qualitative study.	✓	Post-review corrections submitted
	What if I die? Existential crisis in caring for persons with severe mental disorders in rural South Africa	✓	Post-review corrections submitted
Objective 4	Service providers' perspectives on the challenges of informal caregiving and the need for caregiver-orientated mental health services in rural South Africa: A descriptive study	✓	Post-review corrections submitted
	Service providers' perspectives on strategies for alleviating burden of care among informal caregivers of persons with mental disorders in rural South Africa: A descriptive study		To be submitted to the journal

Conferences:
18th World Federation of Occupational Therapy Congress. Paris. Oral presentation: Extent of caregiver burden amongst the informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga province. August 2022
The Consortium of Advanced Research Training in Africa (CARTA) for Joint Advanced Seminar 4 Conference. Makerere University Uganda. Oral presentation: Extent of caregiver burden amongst the informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga province. July 2022
Research seminars:
Research seminar. University of Queensland Australia: What if I die? Existential crisis in caring for persons with severe mental disorders in rural South Africa. September 2023
Book chapters:
Improving health and access to health services through Community Based Rehabilitation. Occupational Therapy in Psychiatry and Mental Health 6th Ed. 2023 (Last review revisions submitted)
Supporting informal caregivers of persons with mental disorders in sub-Saharan Africa. The Palgrave Handbook of Mental Health Practice in sub-Saharan Africa. 2024(Last review revisions submitted)

Agreement by co-authors

By signing this declaration, the co-authors listed below agree to the use of the article by the student as part of her thesis.

Article	1st Author	2nd Author	3rd Author	4th Author
Extent of caregiver burden among informal caregivers of persons with severe mental disorders in rural South Africa	O Silaule	NG Nkosi	F Adams	[redacted]
Strategies to alleviate the burden experienced by informal caregivers of persons with severe mental disorders in transitional countries: A protocol for scoping review	O Silaule	F Adams	NG Nkosi	
Strategies to alleviate the burden experienced by informal caregivers of persons with severe mental disorders in developing countries: A scoping review	O Silaule	D Casteleijn	F Adams	NG Nkosi
Experience of burden and support needs of informal caregivers of persons with severe mental disorders in rural South Africa: A qualitative study.	O Silaule	NG Nkosi	F Adams	[redacted]
Health effects of caregiving and coping in severe mental disorders: a caregivers' experience	O Silaule	F Adams	NG Nkosi	
What if I die? Existential crisis in caring for persons with severe mental disorders in rural South Africa	O Silaule	NG Nkosi	F Adams	
Service providers' perspectives on the challenges of informal caregiving and the need for caregiver-orientated mental health services in rural South Africa: A descriptive study	O Silaule	NG Nkosi	F Adams	
Service providers' perspectives on strategies for alleviating burden of care among informal caregivers of persons with mental disorders in rural South Africa: A descriptive study	O Silaule	NG Nkosi	F Adams	

ABSTRACT

Background: Globally, implementation of deinstitutionalisation led to a shift from institutional to community care of persons with severe mental disorders. This move calls for informal caregivers including families, relatives, friends, or neighbours to become key role players in the care and management of persons with severe mental disorders. The role of informal caregiving results in stress that consequently leads to caregiver burden. In South Africa, limited evidence exists on the extent of the burden experienced by the informal caregivers of persons with severe mental disorders and strategies for supporting these informal caregivers in their role are lacking. This study aimed to explore the burden of care to inform the development of strategies for alleviating burden among informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga province.

Methods: This study used a three-phased mixed methods approach with a multiphase design to facilitate a comprehensive investigation of caregiver burden among informal caregivers and to develop the multilevel strategies for alleviating the burden. Sequential and concurrent methods were combined to collect quantitative and qualitative data across five studies that were conducted to address the study objectives.

Results: The established extent of burden revealed that most informal caregivers (44.7%) reported moderate-to-severe levels of objective burden, and 35.9% reported moderate-to-moderate levels of subjective burdens. Objective burden levels were significantly associated with age, gender and residence ($p = 0.025$, $p = 0.034$, and $p = 0.038$, respectively), while subjective burden was significantly associated with daily caregiving ($p = 0.012$). The exploration of lived experiences revealed that most informal caregivers experienced burden with subsequent impact on their emotional, mental, and physical health. The subsequent burdens were attributed to dealing with the chronic nature of severe mental disorders, role and financial strain, and stigmatisation from family and community. To deal with their caregiving demands informal caregivers expressed reliance on their internal resources, including resilience and resourcefulness. Expressed support needs included access to mental health services, and empowerment and social support from family, government, and religious and community organisations. The findings identified the need for conducting health screenings among the informal caregivers, as well as the need for strategies to support informal caregivers to complement their internal coping resources. The findings of the

scoping review revealed that most studies were conducted in Asian countries. Psychoeducation and support group interventions were identified as predominant strategies for alleviating caregiver burden. The service provider's perspectives revealed that the current state of formal and informal community mental health services is inadequate to meet the needs of the informal caregivers.

Conclusion: The study's findings informed the development of strategies for alleviating caregiver burden among informal caregivers in a low-resourced setting. The complexity of caregiver burden requires multilevel strategies, namely caregiver-driven, health worker-driven, community-based, intersectoral, policy, and legislature strategies across the individual, interpersonal, organisational, community, and policy levels. Caregiver empowerment, family and peer support, development of caregiver-orientated institution and community-based services, task sharing, and task shifting were identified as overriding strategies relevant for alleviating informal caregiver burden in a low-resourced setting.

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ACRONYMS AND ABBREVIATIONS

ADLs	Activities of Daily Living
IADLs	Instrumental Activities of Daily Living
BMD	Bipolar Mood Disorder
CHW	Community Health Worker
CMHS	Community Mental Health Services
CR	Care recipient
FG	Focus Group
HICs	High income countries
LMICs	Low- and Middle-income Countries
MHC	Mental health Coordinator
MHCU	Mental Healthcare User
MHP	Mental Health Professional
PHC	Primary Health Care
PHCS	Primary Healthcare Supervisors
PI	Primary Investigator
SAPS	South African Police Services
SMD	Severe Mental Disorder
SSI	Semi-structured Interview
SUD	Substance Use Disorder
WHO	World Health Organization

DEFINITION OF TERMS

- **Caregiver burden:** The strain or load borne by a person who cares for a chronically ill or disabled person who is unable to care for themselves (Liu et al., 2020).
- **Deinstitutionalisation:** refers to the process of relocating care for people with mental disorders from traditional mental health facilities to care in community-based facilities, group homes and families(Pillay, 2017).
- **Formal community mental health services:** refers to services that are provided by primary health workers in health and social development. This may include services offered in day centres, rehabilitation facilities, community centres, home help, and outpatient services at primary healthcare facilities (WHO, 2008a).
- **Informal caregiver:** Family, and at times friends, neighbours, or a good Samaritan, who are often unpaid and provides ongoing care (Roth et al., 2015).
- **Informal community mental health services:** refers to non-specialised community-based services including care provided by traditional healers, religious organisations, village workers, lay community workers, non-governmental organisations, families and friends(WHO, 2008a).
- **Lay health worker:** a lay health worker "is a member of the community who has received some training to promote health or to carry out some healthcare services, but is not a healthcare professional"(Lewin *et al.*, 2010:2).
- **Objective burden:** objective burden refers to those effects of informal caregiving that are tangible and observable, including financial constraints and restrictions on social and leisure activities (Chadda, 2014).
- **Severe Mental Disorder:** A mental, behavioural, or an emotional disorder that results in a serious functional impairment that substantially interferes with major life activities (del Barrio, 2017).
- **Subjective burden:** subjective burden relates to the caregivers' negative appraisal of the caregiving experience that results in feelings of guilt, anger, loss and shame (Chadda, 2014).

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FORMAT OF THE THESIS

The thesis structure follows the integrated format outlined in the University of the Witwatersrand's Faculty of Health Sciences guide for PhD thesis formats.

Phase of the study	Name of the chapter/study objectives	Articles/description of the chapter	Chapter
	Background of the study	The introduction chapter outlines the background of the study, the rationale for the study, the study objectives, the study's significance, and the methods used in the study.	Chapter 1
	Concepts and conceptual framework	This chapter describes the key concepts and conceptual framework used to answer the research question	Chapter 2
Phase 1	To describe the extent of subjective and objective caregiver burden among the informal caregivers of persons with severe mental disorders	Article 1: Extent of caregiver burden among informal caregivers of persons with severe mental disorders in rural South Africa	Chapter 3
	To describe the lived experiences of informal caregivers of persons with severe mental disorders	Article 2: Experience of burden and support needs of informal caregivers of persons with severe mental disorders in rural South Africa: A qualitative study.	
		Article 3: Health effects of caregiving and coping in severe mental disorders: A caregivers' experience	
		Article 4: What if I die? Existential crisis in caring for persons with severe mental disorders in rural South Africa	
Phase 2	To describe existing strategies for alleviating caregiver burden in developing countries through a scoping review	Article 5: Strategies to alleviate the burden experienced by informal caregivers of persons with severe mental disorders in developing countries: a scoping review	Chapter 4
	To describe stakeholder's perceptions of the formal and informal community mental health services for alleviating caregiver burden among the informal caregivers within a low-resourced community in Mpumalanga province, South Africa	Article 6: Service providers' perspectives on the challenges of informal caregiving and the need for caregiver-orientated mental health services in rural South Africa: A descriptive study.	Chapter 5
		Article 7: Service providers' perspectives on strategies for alleviating burden of care among informal caregivers of persons with mental disorders in rural South Africa: A descriptive study	

Phase of the study	Name of the chapter/study objectives	Articles/description of the chapter	Chapter
Phase 3	To identify individual, organisational, and policy strategies for alleviating caregiver burden among informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga province	This chapter describes the triangulation of findings from Phase 1 and 2 to guide the development of strategies for alleviating burden	Chapter 6
	Integrative discussion	In this chapter, key study findings are discussed to outline the proposed strategies for alleviating burden	Chapter 7
	Conclusion and recommendations	This chapter presents limitations, strengths, and recommendations.	Chapter 8

CHAPTER 1
BACKGROUND OF STUDY

1.1 INTRODUCTION

This chapter gives a brief overview of the burden experienced by the informal caregivers of persons with severe mental disorders (SMDs). The rationale, study aim, and objectives are outlined along with the methodology.

Mental disorders are consistently recognised as a leading cause of disability and a prominent contributor to the increasing global disease burden (Patel et al., 2018). These disorders account for 14% of the global burden of disease, and more than 80% of those affected are reported to reside in low- and middle-income countries (LMICs) (Amuyunzu-Nyamongo, 2013; Rathod et al., 2017). In LMICs, including South Africa, mental disorders are estimated to contribute 8.8–16.6% to the total burden on disease, with SMDs, including schizophrenia, bipolar mood disorders (BMDs), depressive disorders and substance use disorders (SUD), among the top 10 leading causes of disability (WHO, 2017).

Severe mental disorders are chronic and disabling in nature. Those afflicted by SMDs often exhibit long-term symptoms that affect their ability to function and become contributing members of society. These disorders results in serious functional impairments that influence one's ability to perform activities that the individual wishes to perform in order to pursue their life goals as well as fulfil their social roles (Rudnick, 2014). Depending on the severity of their disorders, individuals with SMDs often struggle to lead independent lives and often require assistance with basic self-care, healthy eating, following daily routine, medication management and compliance, engagement in meaningful activities, and community integration (Roth, Fredman and Haley, 2015; Vigo, Thornicroft and Atun, 2016).

Globally, the growing burden of mental disorders has been faced with persistent challenges, and one prominent challenge is the treatment gap between the need and provision of mental health services (Thornicroft & Semrau, 2019). In high-income countries, about a third of the people with mental disorders receive treatment, but in LMICs, less than 5% of people with mental disorders receive treatment (Thornicroft et al., 2017; Alonso et al., 2018). In African countries, including

South Africa, limited funding, poor policy implementation, lack of infrastructure, limited institutional support, and staff shortages exacerbate the treatment gap (Monteiro, 2015). In a deinstitutionalised mental health system, the inadequate access to mental health services calls for informal caregivers to become key role players in the recovery of persons with mental disorders, particularly for those with SMDs who often require long-term care and management (Ndikuno et al., 2016; Paruk & Ramdhial, 2018). The role of being an informal caregiver is often occupied by family, friends, neighbours, or a good Samaritan, who are often not remunerated for providing care, and often provide continuous care to a person with a SMD (Roth et al., 2015; Akbari et al., 2018).

Previous studies established informal caregiving to be a fertile ground for stress as many caregivers are untrained and ill prepared to occupy this role (Pearlin et al., 1990; Souza et al., 2017). This is because informal caregivers are expected to deal with the distressing behaviours exhibited by the mental healthcare users (MHCUs), structure their routine, assume responsibility for help-seeking, monitor medications, and provide financial care for their care recipients (Chadda, 2014; Souza et al., 2017). Occupying this role has adverse effects on the quality of life of the caregiver as it is associated with several negative experiences that results in objective and subjective caregiver burden (Chadda, 2014; Mokgothu et al., 2015). Objective burden refers to those effects of informal caregiving that are tangible and observable, including financial constraints and restrictions on social and leisure activities (Chadda, 2014). The subjective burden relates to the caregivers' negative appraisal of the caregiving experience that results in feelings of guilt, anger, loss and shame (Chadda, 2014). Understanding these burdens in research is critical as it "gives a full account of what caregiver burden entails and how it can be alleviated" (Bastawrous, 2013: 433). It is therefore necessary to understand the extent of these burdens as this forms a basis for planning of support strategies and experience that not only benefit MHCUs but also their informal caregivers (Addo et al., 2018).

1.2 THE RATIONALE OF THE STUDY

1.2.1 Epidemiology of severe mental disorders

To develop support strategies that are responsive to the needs of the informal caregivers, it is crucial to understand the epidemiology of SMDs and the implications they have on the informal

caregiver. Mental disorders are complex and encompass various forms, ranging from mild, moderate to SMDs. SMDs include depressive disorders, schizophrenia, bipolar mood disorder(BMD), and substance use disorder (SUD) (WHO, 2011).

According to the World Health Organization (2023), depressive disorders are the largest contributor to disability, affecting 5% of the global population. About 80% of the population affected by depressive disorders resides in LMICs, with 16% in Africa (Herman et al., 2009; Seedat et al., 2009). In South Africa, the prevalence of depressive disorders is estimated to be between 14.7–38.8%, thus making these disorders a major contributor to the disease burden in the country (Craig et al., 2022). Depressive disorders are characterised by prolonged feelings of sadness, guilt, and reduced energy levels, which hinder participation in daily living and work-related activities. Consequently, individuals affected by a depressive disorder struggle to function independently, requiring long-term care (Global Burden of Disease Study 2013 Collaborators, 2015). A study by Olawale et al., (2014) highlighted that 45% of Nigerian caregivers of persons with depression experienced moderate-to-severe burden. Age of onset, increased number of hospitalisation, time spent on caregiving, and severity of the disorder are identified as the top determinants of burden among caregivers of persons with depressive disorder (Olawale et al., 2014; Katsuki et al., 2018).

Similar to depressive disorders, schizophrenia contributes heavily to the global disease burden (Mhaule & Ntswana-Lebang, 2009; Addo et al., 2018). This disorder affects about 24 million people in the world, indicating that 1% of the population suffers from schizophrenia (WHO, 2022). In South Africa, schizophrenia is estimated to contribute 2.1% to the overall burden of disease (Jack et al., 2014). Schizophrenia is characterised by positive and negative symptoms (WHO, 2022). Positive symptoms include persistent delusions, hallucinations, and disorganised thinking; and negative symptoms include apathy, social withdrawal, mood changes and cognitive impairments, resulting in deterioration of social and occupational functioning (Asmal et al., 2014; WHO, 2022). This disorder manifests itself in the early adulthood and persists throughout until old adulthood, and therefore, it affects individuals' ability to earn a livelihood and form meaningful relationships, resulting in a need for prolonged care and management (Arun et al., 2018). Consequently, informal caregivers of persons with schizophrenia are likely to experience emotional and physical burden, lifestyle changes, inadequate support, and relationship burden (Mhaule & Ntswana-Lebang, 2009; Ukpong, 2012; Lippi, 2016). A study conducted in Malawi

indicated that 25.5% of caregivers spent 1–32 hours per week providing care, and 60% spent more than 32hours per week caring for their loved one with schizophrenia (Sefasi et al., 2008). Prolonged time spent in caregiving, lack of knowledge about schizophrenia, and the chronic nature of the disorder have been identified as top determinants of caregiver burden among informal caregivers providing care for people with schizophrenia (Roick et al., 2007; Sefasi et al., 2008).

BMD is estimated to affect 45 million people worldwide, with a lifetime prevalence of 2.4% in high income countries (HICs) (Merikangas et al., 2011; GBD 2017 Disease and Injury Incidence and Prevalence Collaborators, 2018). In South Africa, 4 million people are estimated to suffer from BMD, indicating that 3–4 % of the population are affected (South African Depression and Anxiety Group, 2019). Individuals who are diagnosed with BMD experience considerable impairments at work and in the family and often struggle to form and maintain social relationships. These symptoms are likely to persist even when managed with medication, and reportedly, 55–70% of adults with BMD have recurring episodes within 2 - 4years of initial diagnoses even when maintained on pharmacotherapy (Miklowitz et al., 2003; Reinares et al., 2016).

The rate of recurrences and persistent symptoms frequently lead to functional impairments that places emotional strain on the patient and their families (Hubbard et al., 2016; Reinares et al., 2016). Therefore, those diagnosed with BMD require long-term care and management. According to Berk et al. (2011), 93% of informal caregivers of BMD mental healthcare users in high-income countries experience moderate caregiver burden during acute bipolar episodes while 54% experience more severe forms of burden (Berk et al., 2011). Similarly, a study conducted in India identified prolonged time spent in caregiving, low literacy levels, and low socioeconomic status to be associated with high levels of burdens among the informal caregivers of those with BMD (Gania et al., 2019). Currently, there is a paucity of research on caregiver burden in BMD within the LMICs, and therefore, the extent of this burden and the qualitative experiences of caregivers on their burden remains unknown.

Like the other SMDs, SUDs contribute significantly to the global disease burden. It is estimated that a quarter of a billion people worldwide used illicit drugs, and of this number, 29 million are reported to suffer from a SUD (United Nations, 2016). In South Africa, there is limited demographic data on substance use; however, it is estimated that 8.6% of people use illicit drugs, which include cannabis, mandrax, methamphetamine, and opiates (Pasche & Myers, 2012;

Pengpid et al., 2021). Based on available evidence, it is estimated that 13.3% of South Africans meet the diagnostic criteria for SUDs (Herman et al., 2009). Some of the inherent symptoms of SUDs include poor memory and concentration, impaired ability to learn and work, and behavioural disturbances such as aggression, and therefore, in the long term, those affected exhibit chronic functional limitations (Pasche & Myers, 2012). Comorbidity has been established between SUDs and other SMDs such as schizophrenia, and this has been associated with poor medical and functional outcomes (Tekin Uludağ & Güleç, 2016). Studies report that those with schizophrenia and comorbid SUDs have poor compliance to treatment and are likely to experience high relapse rates with recurrent readmissions (Soyka, 2000; Tekin Uludağ & Güleç, 2016). The uniqueness of the difficulties encountered by the caregivers of people with SUDs have been highlighted to include high risk of mental and physical conditions, dealing with a high frequency of aggression, death, and frequent problems with law enforcement (Marcon et al., 2012). According to Daley (2013), families of those with SUDs experience high levels of emotional burden, which is associated with the feelings of anger and frustration, and economic burden caused by reckless spending on substances and job loss. In addition, these families face relationship distress and family instability caused by violence and abuse (Daley, 2013).

1.2.2 Policy background in mental health

The last few decades have seen a shift in the management of people with SMDs. Central to this transformation was the deinstitutionalisation policy that was adopted in HICs, including the USA and Europe, during the 1950s (Parker, 2014). Deinstitutionalisation refers to the shift in the care of MHCUs from traditional mental health institutions to care within community-based facilities, group homes and families in order to encourage independent functioning (Pillay, 2017). One of the top drivers for deinstitutionalisation were the high financial costs associated with in-patient care and the pressure to reduce such costs (Chow et al., 2019). Deinstitutionalisation was seen as a cost reduction strategy (Chow et al., 2019). The WHO endorsed deinstitutionalisation as a viable, cost-effective strategy to address the mental health treatment gap, particularly in LMICs where general access to health is limited (WHO, 2013a, 2014a; Addo et al., 2018). In addition, deinstitutionalisation was identified as an effective way of promoting the human rights of those afflicted by mental disorders as it allowed MHCUs to be treated closer to their families and the civil society (Pillay, 2017). Subsequently, deinstitutionalisation has been commended largely for

bringing services close to where persons with SMDs live and work, and therefore, improving access to mental health services and promoting community reintegration among these MHCUs (Lund & Flisher, 2009; Robertson & Szabo, 2017).

Talbott (1979) proposes 'commandments' for successful implementation of deinstitutionalisation, which includes the provision of adequate community services, adequate funding, continued care, and a commitment from the state and local governments. To facilitate this, the WHO (2013b, 2014a) proposes that a shift towards community care be done systematically as ineffective adoption can lead to adverse effects. Subsequently, the downsizing of long-term mental health institutions should be complemented by strengthening community mental health services (CMHS).

CMHS are divided into formal and informal mental health care. Formal CMHS are specialised services provided by staff in health and social welfare, including care in day centres, rehabilitation facilities, community centres, home help, and outpatient services at primary health care facilities (WHO, 2008b). Informal CMHS refers to mental health services provided by sectors other than health and/or social development services, such as care from families, friends, traditional healers, religious organisations, village workers, lay community workers, and NGOs (WHO, 2008c; Mugisha et al., 2017). Informal CMHS are deemed essential in the management of SMDs as they provide cost-effective mental health care and reduce relapses for the MHCU as well as increase support for caregivers (WHO, 2008c).

In South Africa, the adoption of deinstitutionalisation took place in the mid-1990s in response to the calls for advancing the human rights of MHCUs to have access to mental health services closer to their homes (Lazarus, 2005; South African Department of Health, 2023). The move was further motivated by the transformation of the healthcare system, which began with a clear political commitment to increase equity in resource allocation (Pillay, 2001). This called for the restructuring of the National Health System to decentralise to a district-based healthcare system and ensure the delivery of healthcare services through the principles of the primary health care approach (Pillay, 2001; Vergunst, 2018). Deinstitutionalisation was escalated further by the promulgation of the Mental Health Care Act 17 of 2002, which placed more emphasis on the rights of MHCUs to have access care within their communities (South Africa, 2002;). Subsequently, deinstitutionalisation progressed rapidly and this adoption was done without the development of necessary CMHS to support both the MHCUs and their informal caregivers

(Pillay, 2017). As a result, there has been an increase in homelessness and imprisonment among the MHCUs, as well as an increase in the revolving door patterns of care which places substantial burden on the current mental health system(Robertson *et al.*, 2018).

The rapid adoption of deinstitutionalisation in SA resulted in adverse effects when over 100 MHCUs lost their lives following the untimely move from Life Esidimeni to non-governmental organisations (NGOs) that were ill-prepared to provide the required care and management (Makgoba, 2016). This tragedy represented a poorly planned deinstitutionalisation and highlighted the need for effective CMHS (Robertson *et al.*, 2018). According to Makgoba, (2016) CMHS should consist of an integrated primary mental healthcare and community-based psychiatric services. They need to include specialised psychiatric care for persons with SMDs, primary care for those with common mental disorders and general health care for the MHCUs. These services should support the NGOs by offering outreach rehabilitation services, education and offer supervision for caregivers (Makgoba, 2016).

To date, the CMHS in SA remain under-funded and under-resourced as the limited mental health funds are directed towards hospital-based care (South African Department of Health, 2023). Robertson *et al.*, (2018) highlighted that mental health budget is scattered across the different programmes, as result most of the budget is directed by the historical institution-based principles. Over the last few years there has been an increase in the budget for psychiatric hospitals while the budget for CMHS has decreased(Robertson *et al.*, 2018). This is despite the positive intent of the National Mental Health Policy Framework and Strategic Plan 2023–2030 that embraces CMHS as a viable option to address the mental health treatment gap in the country (South African Department of Health, 2023). It should be acknowledged that the dysfunctional mental health system in South Africa fails to meet the needs of the MHCUs with mental disorders (Makgoba, 2016). These unmet needs have a 'negative spillover' effect on the informal caregivers, and therefore, caregiver support is necessary to ensure recovery and care of MHCUs within communities (Scazufca, 2002).

The WHO (2008b) proposed the integration of mental health services into existing primary healthcare (PHC) systems and the mobilisation of community resources to enable the development of CMHS to support MHCUs and their informal caregivers. However, in resource-constrained contexts like in Bushbuckridge, Mpumalanga province, in South Africa adopting this strategy has

proven to be ineffective (Braathen et al., 2013). As a result, the need for innovative strategies to deliver CMHS has been recommended as a viable option for addressing the treatment gap in these contexts (Alem et al., 2008). This calls for the development of interventions that move beyond formal health care and acknowledges the important role played by informal CMHS in the management of mental disorders (Vergunst, 2018). The following strategies are suggested as effective in developing CMHS: Empowerment of MHCUs and their caregivers to take part in the planning and implementation of services; training of non-specialists, including community health workers (CHWs), to provide support to the MHCUs and their caregivers; and developing collaborations between formal and informal mental health services providers (Campbell-Hall et al., 2010; DeSilva et al., 2014; Vergunst, 2018). While such strategies have been proven effective in managing MHCUs with SMDs within communities in LMICs, the evidence indicating the use of these strategies to support the informal caregivers of these MHCUs is limited within South Africa (Asher et al., 2016; Pillay, 2017; Jacob & Coetzee, 2018; Kohrt et al., 2018).

1.3 PROBLEM STATEMENT

Strategies aimed at alleviating burden of care among the informal caregivers of those with SMDs are lacking within South Africa. It is widely acknowledged that informal caregivers play a vital role in mental health service and that there comes a burden with occupying such a role; however, there is limited evidence of strategies that can be employed to support them in their role, particularly in LMICs like South Africa (Mokgothu et al., 2015; Ndikuno et al., 2016). The burdened informal caregiver is likely to display expressions of criticisms and hostility towards a care recipient, and this can aggravate relapses as it affects the quality of care received by these MHCUs (Berk et al., 2011). Thus, it is a complex issue for which no simple intervention/one size fits all intervention is likely to apply.

Montgomery et al. (1985) argue that subjective and objective burdens are influenced by different factors, and as a result, strategies aimed at alleviating subjective burden cannot be used for objective burden, and vice versa. Most studies conducted on caregiver burden in mental health in HICs and LMICs fail to distinguish between these types of burdens, and consequently, there is very limited evidence on effective strategies for alleviating both types of caregiver burden (Oshodi et al., 2012; Shaji & Reddy, 2012; Bastawrous, 2013; Sessions et al., 2017).

In South Africa, the extent of objective and subjective burden among caregivers of persons with SMDs is unknown. Most studies focus on investigating the generic experiences of caregiving rather than on implementing measures to capture the dimensions of these types of burden (Mokgothu et al., 2015; Vukeya et al., 2022). Additionally, attention has been directed on the difficulty that surrounds caregiving but not on the development of strategies for alleviating caregiver burden.

1.4 RESEARCH QUESTION

The current study was guided by the following research question:

- How can strategies for alleviating burden among informal caregivers of persons with SMDs in Bushbuckridge, Mpumalanga province be developed?

1.5 STUDY AIM

This study aimed to explore the burden of care to inform the development of strategies for alleviating caregiver burden among informal caregivers of persons with SMDs in Bushbuckridge, Mpumalanga province.

1.6 RESEARCH OBJECTIVES OUTLINED FOR EACH PHASE OF THE STUDY

1.6.1 Phase 1: Conceptualisation of caregiver burden

In order to conceptualise the burden of care among the informal caregivers, the following objectives were important,

- To describe the extent of subjective and objective caregiver burden among the informal caregivers of persons with SMDs; and
- To describe the lived experiences of informal caregivers of persons with SMDs in Bushbuckridge, Mpumalanga province.

1.6.2 Phase 2: Exploration of the strategies for alleviating caregiver burden

In order to explore the strategies for alleviating caregiver burden among the informal caregivers, the following objectives were important:

- To describe existing strategies for alleviating caregiver burden in developing countries through a scoping review; and
- To describe stakeholders' perceptions of the formal and informal CMHS for alleviating caregiver burden among the informal caregivers within a low-resourced community in Mpumalanga province, South Africa.

1.6.3 Phase 3: Development of strategies for alleviating caregiver burden

In order to develop strategies for alleviating caregiver burden among informal caregivers, the following objectives were important:

- To identify individual, organisational, and policy strategies for alleviating caregiver burden among informal caregivers of persons with SMDs in Bushbuckridge, Mpumalanga province.

1.7 STUDY METHODS

In this study, a three-phased mixed methods approach with a multiphase design was used. The use of a mixed methods approach allowed for qualitative and quantitative data collection, which facilitated comprehensive investigation and interpretation of the factors related to caregiver burden among informal caregivers in mental health (Cresswell, 2014; Schoonenboom & Johnson, 2017; Shorten & Smith, 2017). The multiphase design was selected as it provided an opportunity for combining the concurrent and sequential collection of data in answering a research question (Schoonenboom & Johnson, 2017).

Data for Phases 1 and 2 were collected and analysed concurrently to inform the subsequent Phase 3 (Schoonenboom & Johnson, 2017). In Phase 1, a cross-sectional descriptive research design was used, and a quantitative aspect (Chapter 3, section 3.2) was employed in the form of a pre-existing interview-administered burden measure (objective data) that informed qualitative (Chapter 3, section 3.3) semi-structured interviews to gain an in-depth understanding (subjective data) of the lived experiences of the informal caregivers. This allowed for an in-depth exploration of caregiver burden and the identification of the informal caregivers' needs. In Phase 2, a cross-sectional descriptive research design was used, and a quantitative research approach was followed in the scoping review (Chapter 4.2), and this informed the qualitative aspect (Chapter 5.2) in the form of

semi-structured interviews (Appendix P) and focus group discussions (Appendix R and S) that were conducted with various stakeholders to identify existing formal and informal mental health services for alleviating caregiver burden within Bushbuckridge municipality. A conceptual framework was adapted from merging the conceptual framework for caregiver stress by Pearlin et al. (1990) and the socioecological framework by Mcleroy et al. (1988), and was used to triangulate the findings from Phases 1 and 2. Phase 3 was completed by triangulating the findings from Phases 1 and 2 to develop strategies for alleviating caregiver burden among the informal caregivers. This process is set out in the diagram in Figure 1.1.

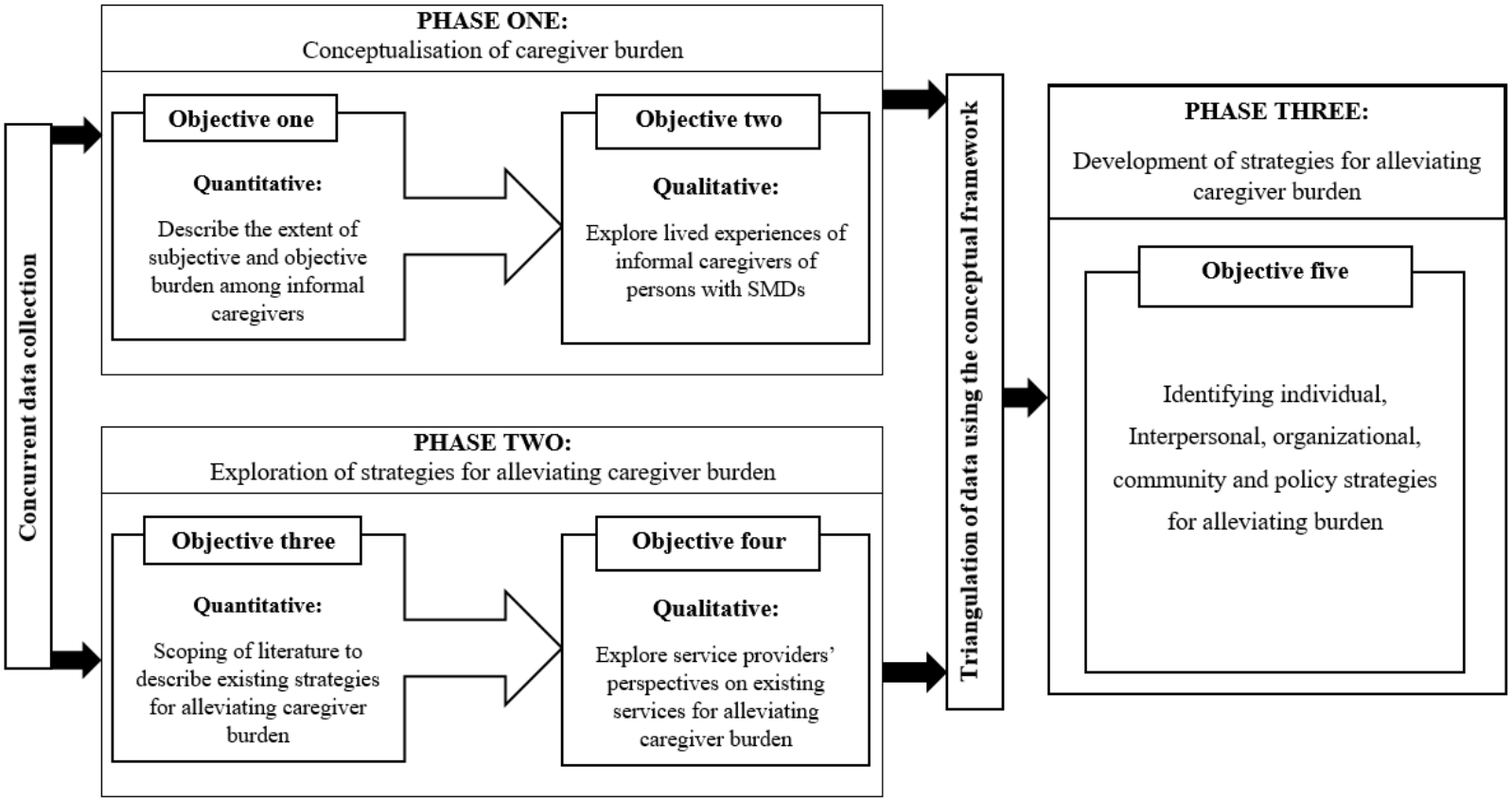


Figure 1.1 Multiphase mixed methods approach (adapted from Creswell, 2014)

1.8 REFLEXIVITY

Reflexivity is a crucial aspect of qualitative research as it enables the researcher to self-consciously critique, appraise, and evaluate the impact of their subjectivity and the research context on the research processes (Olmos-Vega et al., 2022). In this section, I critique, appraise, and evaluate the impact of my subjectivity on the research processes that I followed to answer the research question. To ensure comprehensiveness and better flow of information, the reflection is grouped into personal, interpersonal, methodological, and contextual factors (Olmos-Vega et al., 2022). The steps taken to overcome some of the challenges are outlined under the respective headings.

1.8.1 Personal reflexivity

I was born and bred in Bushbuckridge, Mpumalanga province. I relocated to Cape Town for work, where I now lecture and supervise students in the area of mental health. Part of my work duties include coordinating and supervising students in the community practice block in Bushbuckridge, Mpumalanga province. Prior to my career in academia, I worked in an acute mental health unit in a district hospital within Bushbuckridge municipality. My work entailed developing and implementing hospital- and community-based occupational therapy programmes within the local community of Bushbuckridge. I also conducted training programmes for mid-level workers, such as occupational therapy technicians, in the community to extend occupational therapy services to MHCUs in the community. In 2014, I enrolled for my master's degree during which I evaluated the effectiveness of the in-patient occupational therapy programme on the function of the MHCUs. The findings of my study revealed that MHCUs performed well while in hospital but regressed following discharge from the hospital. One of the established contributing factors was that families were not prepared to structure activities for the MHCUs. The findings of my master's research and my personal and clinical experiences helped shape my idea for this PhD project as I started to question the role of families in supporting MHCUs and their preparedness for taking up this role.

The conceptualisation of my PhD made me discover how uncomfortable various stakeholders are with the use of the word 'caregiver burden' as many think it captures negative experiences and negates some of the positive experiences informal caregivers encounter in their caregiving. This made me more cognisant of my own assumptions that caregiving in mental health is marked by difficulty and made me cautious of the fact that there must be a balance in terms of the questions

used to explore the experiences of the informal caregivers to ensure I provide them the opportunity to also express their positive experiences. Our exploration of the lived experiences in their caregiving role aimed specifically to allow caregivers to share both their challenges and the positive aspects of their caregiving based on their subjective experiences.

One of the crucial steps in my personal reflexivity involved reflecting on and managing my assumptions that caregiving in mental health is only marked by burden and difficulty and that the healthcare system is responsible for providing solutions to help overcome these difficulties. During data collection and analysis, I had to be cautious of how I framed my questions and how I interpreted the views of the participants. Through guidance from my supervisors, who helped with the development of interview guides, and an experienced qualitative researcher, who guided the data analysis process and audit trail, I made a point of reflecting more on my assumptions and ensuring I was more open-minded when collecting and analysing data without compromising the quality of the data. In addition, I ensured that I documented all my thoughts and observations in a reflective journal, which challenged me to be cognisant of my assumptions.

1.8.2 Interpersonal reflexivity

Interpersonal reflexivity relates to how the relationships in the research process influences data collection, the people involved, understanding of the context, and the results (Olmos-Vega et al., 2022). I worked as an occupational therapist in the acute mental health unit where I recruited the informal caregivers and service providers who took part in this study. In other words, some of the service providers who participated in this study were former colleagues that I worked with for a couple of years, and one of the participants was former student whom I had taught and supervised in their clinical blocks. As a result, I had to think carefully around my interactions, and in my reflexive journal capture how these pre-existing relationships could affect my data. I had to be cognisant of the power dynamics and ensure I gave the former student enough autonomy to decide if they wanted to participate in the study. For example, I had to arrange a meeting with this participant prior to data collection to clarify my position in this research and give them an opportunity to read the information sheet (Appendix I) where I emphasised that the choice to participate was voluntary. I also gave this participant an opportunity to accept or decline participation via an email, which gave them an opportunity to make their decision without any pressure that would come with making this decision in my presence.

Being known in the context was useful as I got the necessary help in terms of recruiting participants and sorting out logistical matters such as securing a private space where the research assistants and I could gather data without disturbance. I found the service providers more willing to engage with me on the subject matter, and since they understood my familiarity with the context, they found it easy to relate some of the inherent challenges they encountered in the delivery of caregiver-orientated services. My experience and knowledge about the service delivery models made it easy for me to extend empathy towards the challenges encountered by the service providers and this made them share their experiences honestly. For example, some were able to admit their general neglect of caregiver health and wellbeing in their practice. Having worked in the research context, I had to consider if there may have been pre-existing differences of opinions that could influence my interactions with the participants and the level of engagement during the interviews. To overcome this, I ensured that I gave participants information about the study and gave them the autonomy to choose if they wished to be part of the study.

1.8.3 Methodological reflexivity

This study was conducted from a pragmatism research paradigm, using a mixed methods approach with multiphase design. Pragmatism was deemed useful for this study as it embraces the plurality of methods to answer a research question, thus emphasising that there is not a single way of exploring a phenomena (Brierley, 2017). Going into this study, I had to appreciate the intricate nature of caregiver burden as a concept, that methods used to understand it are nonlinear, and that multiple methods are required to comprehensively explore the phenomena to ensure development of relevant strategies for alleviating it. Using the pragmatic approach, I was able to appreciate that the nature of the experiences and the views the participants had regarding caregiving was largely influenced by the situations and the context in which caregiving took place (Kaushik & Walsh, 2019). This meant employing both positivist (quantitative) and interpretivist (qualitative) approaches as both were needed to answer the research question as intended in this study.

As a researcher, I have been exposed mostly to quantitative methods in both my undergraduate and postgraduate studies, and as a result, my worldview has been that of a positivist. For this reason, one of my core values is the centred belief that each problem has a solution and that for each problem there is a practical way to reach a certain solution. Through this research process, I had to learn to explore the participants' subjective experiences, interpret data through the

participants' voices, and find my voice in the interpretation of data. Using the pragmatic approach made me realise the importance of using both the positivist and interpretivist paradigms in research to ensure the comprehensiveness of data. I learned the value of investigating the participants' unique experiences because I started to see informal caregivers as experts on their own experiences. I recognised the importance of viewing my participants as people capable of suggesting solutions that are relevant for them and their context.

It was therefore necessary that I keep a reflexive journal and receive constant guidance from my supervisors to ensure my assumptions did not compromise the trustworthiness of my findings. The use of a conceptual framework was useful as this helped me keep track of the focus of the study and to affirm the appropriateness of the methods selected in this study. Constant evaluation throughout the research process was necessary to ensure alignment between the paradigm and the conceptual framework when methodological decisions in data generation and analysis were made (Olmos-Vega et al., 2022).

1.8.4 Contextual reflexivity

In order to be contextually reflexive in this study, I needed to understand the uniqueness of Bushbuckridge municipality as a selected study site. Having an understanding of the limited infrastructure and funding for mental health services in Bushbuckridge meant that I needed to take this into consideration when suggesting strategies for alleviating burden. I had to look at the existing limited resources to ensure the suggested strategies are focused on using these to implement caregiver-orientated services to ensure relevance and feasibility to the context.

In order to have an in-depth understanding of the context of caregiving, I conducted the interviews with the caregivers (Objective 2) in the participants' homes. This gave me a clear idea of the distances travelled to get to the hospital; for example, some participants travel as far as 50 kms to get to the hospital on very inaccessible roads where one can drive a maximum speed of 20–40 km/h. Observing this was useful as it affirmed the need to address accessibility of services when recommending the strategies for alleviating caregiver burden.

Being a member of a Bushbuckridge community gave me an added advantage as I can speak the language of the participants, Xitsonga and are familiar with the cultural practices, which created a safe space for participants to fully open up about their subjective experience and it was easy for

me to extend empathy. This also made the logistics of travelling around the community easy as I had an idea of where the various locations are and could approach local community members to locate the participants' households. This contributed to the richness of the data and my ability to interpret some of the humanism concepts, such as Ubuntu, that my participants expressed as I was able to experience this first-hand. In contrast, the fact that I was a local resident made some participants reluctant to participate; this may be because they felt uncomfortable sharing their challenges with a local person and allowing me access to their unfavourable living conditions.

1.9 CONCLUSION

This chapter provided an overview of the context and positionality of this study. The rationale of the study was outlined. The study aim and the objectives of the study were outlined in accordance with the various phases of the study. In addition, the chapter provided a brief overview of the methods used as well as the researcher's reflexivity to reflect her positionality as far as the research processes in this study were concerned. In Chapter 2, the key concepts and the conceptual framework are highlighted.

CHAPTER 2
CONCEPTS AND CONCEPTUAL FRAMEWORK

2.1 INTRODUCTION

This chapter presents the key concepts and conceptual framework that underpinned the study and was used to answer the research question. This chapter provides a description of three key concepts, namely caregiving, caregiver burden, and healthcare access, and also outlines the conceptual framework that was critical to answer the research question.

2.2 OVERVIEW OF THE CONCEPTS

2.2.1 Informal caregiving

The concept of informal caregiving has received attention in healthcare and social sciences research. However, the use of the word 'informal' has been regarded as controversial and criticised for its lack of conceptual clarity, which perpetuates the general neglect of caregivers in healthcare (Castro et al., 2023). Similarly, 'care' has been identified as a multidimensional concept that is constructed from distinct disciplinary, legislative, and political frameworks, thus contributing largely to its ambiguity and controversy (Addati, 2018; Cruz et al., 2023). Recent studies called for the need to formalise 'informal caregiving' as a concept and regarded this as a first step towards ensuring understanding of the unique and diverse needs of informal caregivers and ensuring they are better connected to necessary support networks (Havyer et al., 2017; Castro et al., 2023).

According to the Addati (2018), care can be paid or unpaid and encompasses direct, personal, and relational support activities provided to a person who is in a position of dependency. Additionally, care can include indirect care activities such as organisation, preparation, tidying, and cleaning tasks (Addati, 2018). Family, friends, and community members can provide unpaid care and professionals provide paid care. Informal caregiving is described as unpaid care that is provided by family, friends, neighbours, or relatives who provide support to a person with a declining physical or cognitive condition or a life-limiting chronic illness (International Alliance of Carer Organizations, 2021). Cruz et al. (2023) argue that this perspective emphasises that care is viewed from the relational dimensions of support within a context of illness, disability, and impairment. The social relations of informal care highlight the view of care through circuits. The identified

circuits of care include the view of ‘care as an obligation’ imbedded within the framework of family responsibility, and ‘care as help’, which is based on the reciprocity within a group or community (Cruz et al., 2023).

Most informal caregiving is performed by family and mainly women, which means that the description of this concept is restricted to specific relationships, such as family and household relations (Vicente et al., 2022). In addition, this emphasises the perceptions of caregiving as a gender specific role that most women are expected to fulfil (Penning and Wu, 2016). This negates other spheres of relationships inherent in the provision of care, such as contributions by community members (Larkin et al., 2019; Vicente et al., 2022). The socialisation of informal caregiving as a gender role and the expectation that family should provide care, which makes this role obligatory could be the reason support for informal caregivers is often overlooked (Castro et al., 2023). Having an understanding of the unique contribution and the subsequent challenges encountered in the caregiving role, this thesis focused on exploring the burden of care among the informal caregivers with an aim of developing strategies for supporting them in their role. To ensure the broad exploration of informal caregiving, the study included various informal caregivers, including female and male caregivers, family, friends, neighbours, and community members, who play the role of providing care to a person with SMD.

2.2.2 Caregiver burden

Caregiver burden is an intricate phenomenon to comprehend. This concept first emerged in research during the 1960s in a study by Grad and Sainburg (1966) that described the challenges experienced by caregivers providing home care to people with mental illness (Yıldırım, 2017). These authors first described caregiver burden within the family context and defined it as any cost to the family of which the patient is a member (Grad & Sainsbury, 1966). This description of the concept introduced the idea that occupying the role of caregiving is accompanied by tasks that often introduce an intolerable strain (Chou, 2000; Liu et al., 2020). George and Gwyther (1986: 253) define caregiver burden as encompassing “the physical, psychological, emotional, social and financial stresses that individuals experience due to providing care”. The initial description of this concept carved a way for investigation in research; however, its conceptualisation remained ambiguous as a result of its multifaceted nature (Bastawrous, 2013). There is a lack of agreement on the conceptualisation in the literature, and as a result, caregiver burden is often used

synonymously with ‘caregiver strain’, ‘caregiver stress’, and ‘caretaker role fatigue’, which is difficult for policymakers (Hunt, 2003; Bastawrous, 2013).

Montgomery et al. (1985) clarified the ambiguity of the caregiver burden concept by describing the difference between the subjective and objective burden. Objective burden is described as the burden that is brought about by the tasks performed by the caregiver to fulfil their caregiving role, and subjective burden is described as the characteristics exhibited by the caregiver due to inability to cope with the demands of caregiving (Hoffmann & Mitchell, 1998). Understanding these types of burdens in research is critical as it “gives a full account of what caregiver burden entails and how it can be alleviated” (Bastawrous, 2013: 433). The use of ‘caregiver burden’ has been criticised in the literature as it is thought to negate the positive experiences associated with the role of caregiving. Bastawrous (2013) reminds us that the use of caregiver burden in literature is useful as it enables researchers to capture the negative effects that caregiving has on the health and wellbeing of caregivers. It is for this reason that the focus of this study was caregiver burden with the aim of improving access to support services for caregivers of persons with mental disorders in rural South Africa.

2.2.3 Healthcare access

Healthcare access is considered a strong determinant of health system performance worldwide. Although considered a critical element in healthcare, the conceptualisation of access remains complex due to the variety in description of the concepts across various authors (Levesque et al., 2013). Historically, healthcare access has been described as access to services, a provider, or an institution. Whitehead (1992) describes access as the ease with which healthcare recipients or communities are able to use services when required. This description of access produces a narrow view of this concept as it limits healthcare access to ‘access to places’. Penchansky and Thomas (1981) provide a clear conceptualisation of access as a fit between healthcare services and clients’ needs. In this description, access is viewed as a by-product of interaction between various factors, including a person’s characteristics, household, social and physical environments, and the characteristics of the healthcare system. This view of access emphasises the dynamic nature of this concept and provides an opportunity for broad exploration of access when healthcare services are evaluated (Ricketts & Goldsmith, 2005). Levesque et al. (2013) propose five dimensions of access for consideration in healthcare policy and health service research, namely approachability;

acceptability; availability and accommodation; affordability; and appropriateness. Consideration of these dimensions in mental health research is critical, particularly in the South African context where the distribution of mental health services is multidimensional (South African Department of Health, 2023). Access to mental health services for MHCUs is limited, and as a result, caregivers are faced with challenges when looking after their loved ones with mental disorders (Strümpher et al., 2014; Souza et al., 2017). According to Pillay, (2019) only 27% of those with SMDs receive treatment. This limited access to mental health services means that majority of the MHCUs do not receive the necessary care and rehabilitation that they require to be stable. Consequently, informal caregivers are required to deal with the destructive behaviours that are exhibited by the MHCUs (Brooke-Sumner, Lund and Petersen, 2014). Access to mental health services can be improved if there is an in-depth exploration of the experiences of the informal caregivers and their needs to ensure relevant and accessible support services are planned and developed (Greco, 2018).

2.2.4 Conclusion

The conceptualisation of informal caregiving highlights the obligatory nature and the intolerable strain that arises from occupying this role. It is therefore necessary that the concept of caregiver burden be investigated to ensure that necessary services are planned, developed, and implemented to alleviate caregiver burden and support informal caregivers in their role. Planning and development of strategies for alleviating burden of care should consider the five dimensions of healthcare access to ensure they are approachable, acceptable, available, affordable, and appropriate.

2.3 CONCEPTUAL FRAMEWORK

Figure 2.1 presents the conceptual framework used in this study. Due to the intricate nature of the phenomena caregiver burden, it was difficult to identify one conceptual framework that covered all the key concepts and comprehensively addressed the research question. A decision was taken to merge the caregiver stress conceptual model by Pearlin et al. (1990) and the socioecological conceptual framework by Mcleroy et al. (1988). The conceptual framework is framed within the working assumption that caregiver burden is a complex phenomenon to comprehend (Pearlin et al., 1990; Ahmed et al., 2018). This is to say, caregiver burden arises based on the complex

interplay between a variety of personal and contextual factors, and therefore, strategies used to explore and address caregiver burden are nonlinear (Murthy, 2016; Mulud & McCarthy, 2017).

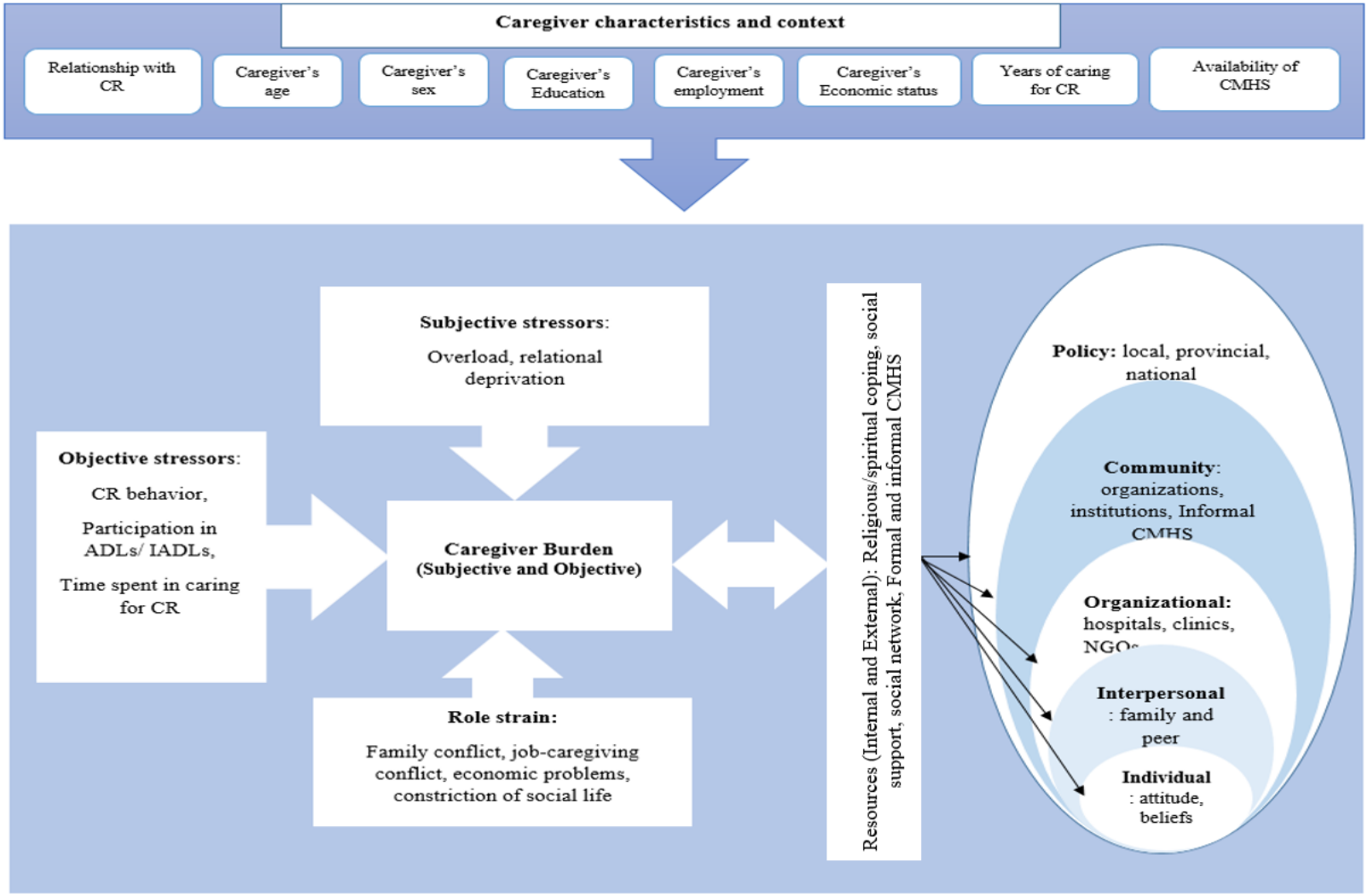


Figure 2.1 Conceptual framework adapted from the caregiver stress conceptual model (Pearlin et al., 1990) and the socioecological conceptual framework (Mcleroy et al., 1988)

The caregiver stress conceptual model by Pearlin is useful for conceptualising the relationship between informal caregiving and stress. Pearlin et al. (1990) emphasise that in the context of informal caregiving, the emergence of serious and prolonged impairment that leads to dependency is likely to produce severe stress. The caregiver stress conceptual model is therefore used to understand the stress arising from the disruption in the informal caregiver's background and context and how these lead to the consequent caregiver burden (Pearlin et al., 1990). There are four components of the conceptual model, namely the background and context of stress, the stressors, mediators of stress, and outcomes or manifestation of stress. The background and context of stress process include the characteristics of the caregivers and the environment where caregiving takes place. According to Pearlin et al. (1990), age, gender, ethnicity, educational level, employment, and economic status serve as predisposing factors for stress encountered in caregiving. This is because these characteristics influence the unequal distribution of rewards, privileges, opportunities, and responsibilities. Contextual factors such as the state of the relationships between the carer and the care recipient as well as the hours spent in caregiving have also been identified as key factors contributing towards the stress experienced by the informal caregivers (Pearlin et al., 1990).

Stressors are described as the core elements of the caregiver stress process. This relates to the primary stressors, including objective stressors like dealing with the problematic behaviours brought on by the care recipient's condition and dealing with dependencies on self-care tasks. Subjective stressors, which relates to the caregivers' feelings of overload and burnout, which arises from occupying the role of caregiving (Pearlin *et al.*, 1990). Subsequently, this leads to sense of relational deprivation brought about by the separation that informal caregivers feel from their loved ones. Mental disorders have a strenuous effect on the caregiver-patient relationships. Consequently, the progression of these disorders may result in a caregiver feeling increasingly separated from parts of their lives that have been supported or shared with the MHCUs (Pearlin *et al.*, 1990). Lastly, secondary stressors include role strain, which entails strain on family, impact on ability to participate in job-related tasks, and restricted social life. If not addressed, the stressors result in outcomes such as caregiver burden, which has serious implications for the physical and mental health and wellbeing of the informal caregiver. As a result, mediating factors, including internal resources such as caregiver coping and external resources such as social support, are required. Lack of these resources is likely to perpetuate the cycle of stress, which in turn increases

the burden of care for the informal caregivers, thus reducing the quality of care received by the MHCUs (Pearlin et al., 1990).

The multilevel approach proposed by Mcleroy et al. (1988) in the socioecological conceptual framework was used together with Pearlin's caregiver stress conceptual model. The theoretical basis of this conceptual framework lies in Bronfenbrenner's (1977) ecological model, which highlights human beings as embedded in large complex social systems where a dynamic interplay exists between people and their environment (Stokols, 1992). The conceptual framework presents five levels, namely individual, interpersonal, organisational, community, and policy levels. The individual level is concerned with intrapersonal factors such as caregiver characteristics, their knowledge, attitudes, behaviour, and skills they possess to fulfil their caregiving role. The interpersonal level includes the formal and informal social networks and support systems available within the informal caregiver's immediate environment, including family, peer/friends, and community. The organisational level includes the formal and informal social and health institutions where informal caregivers access help to enable them to deal with the demands of caregiving. The focus at community level is on resources, the relationships between organisations, institutions, and informal service providers, and the effect this has on the level of support for informal caregivers. Policy level looks at the availability of caregiver-orientated guidelines and policies at the local, state, and national level (Mcleroy et al., 1988).

In this study, the multilevel approach proposed by Mcleroy et al. (1988) in the socioecological conceptual framework was used to understand the internal and external resources available for mediating caregiver burden among the informal caregivers. Internal resources relate to the individual factors possessed by the informal caregiver that facilitate or hinder their ability to cope with their caregiving role (Ahmed et al., 2018). External resources relate to the interpersonal relationships, community resources, and policy level factors affecting the informal caregivers in their caregiving role (Stokols, 1992; Cho et al., 2016). The multidimensional relationship across various levels exists and provides a baseline through which collaborations are formed across stakeholders at each level to develop contextually relevant strategies for alleviating caregiver burden.

CHAPTER 3

PHASE ONE: CONCEPTUALISATION OF BURDEN OF CARE AMONG INFORMAL CAREGIVERS

3.1 INTRODUCTION

This section focuses on an in-depth understanding of burden of care among the informal caregivers in a low-resourced community of Bushbuckridge municipality, Mpumalanga province. Two objectives are presented in the form of articles to describe the extent of the burden and the lived experiences of the informal caregivers in their role of providing care to a person with a SMD.

Ethical approval to conduct these studies was obtained from the University of the Witwatersrand Human Research Ethics Committee (Appendix A). Permission to conduct the studies at the research sites was granted by the Mpumalanga Research Committee (Appendix B and C), the Ehlanzeni district office (Appendix D), the Bushbuckridge sub-district office (Appendix E) and Tinstwalo hospital (Appendix F). The University of the Witwatersrand Faculty of Health Sciences granted approval for the study (Appendix G)

Prior to participating in this study participants were given an information sheet (Appendix H) containing details of the study. Participants who agreed to take part in the study were required to give written consent (Appendix J) for participation and consent for the audio recording of interviews (Appendix K).

Data gathering tools used for Objective 1 included the caregiver demographic questionnaire (Appendix L), the care recipient demographic questionnaire (Appendix M), and the burden measure (Appendix N). Permission to use the burden measure (Appendix O) was obtained from the instrument developers. For Objective 2, an interview guide (Appendix P) was used to guide the interviews with the informal caregivers.

All submitted manuscripts are written according to the journals' author guidelines; however, the reference style has been modified to ensure uniformity across the document.

3.2 OBJECTIVE 1: TO DESCRIBE THE EXTENT OF SUBJECTIVE AND OBJECTIVE BURDEN AMONG THE INFORMAL CAREGIVERS OF PERSONS WITH SEVERE MENTAL DISORDERS

This section is presented as a published article. The article comes from the findings of the first objective that set out to describe the extent of subjective and objective caregiver burden among the informal caregivers of persons with SMDs. Table 3.1 outlines the details of the article.

Table 3.1 Manuscript details

Title	Journal	Author contributions		Key findings	Status
Extent of caregiver burden among informal caregivers of persons with severe mental disorders in rural South Africa	*Rural and Remote Health* DHET accredited Impact factor: 1.759 DOI: 10.22605/RRH7509	Conceptualisation	Silaule, Nkosi & Adams	Higher levels of objective and subjective burdens were established. Burdens experienced by the informal caregivers are associated with age, gender, residence, and daily caregiving.	Published
		Manuscript draft	Silaule		
		Manuscript review and editing	Silaule, Nkosi & Adams		
		Supervision	Nkosi & Adams		

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ORIGINAL RESEARCH

Extent of caregiver burden among informal caregivers of persons with severe mental disorders in rural South Africa

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ABSTRACT:

Introduction: Informal caregivers are the backbone of recovery for people with severe mental disorders in South Africa, particularly in rural areas where access to mental health services is limited. While their unique contribution and the subsequent burden arising from occupying the role of informal caregiver are acknowledged, there is limited evidence on the extent of the subjective and objective burdens among informal caregivers of people with severe mental disorders in rural areas. This article reports on a study that aimed to establish the extent of subjective and objective burdens among informal caregivers of people with severe mental disorders in rural South Africa.

Methods: A descriptive quantitative cross-sectional design was used. Data were gathered through structured interviews with 170 informal caregivers of people with severe mental disorders attending an outpatient clinic at a rural hospital in South Africa. A structured questionnaire guided the interviews and included demographics and caregiving characteristic information. Montgomery, Gonyea and Hooyman's scale was used to assess objective and subjective burdens. Data was analysed descriptively using Stata v15.

Results: The majority of the participants were female informal caregivers (83.5%) between the ages of 45 and 64 years (45.3%),

and parents represented the largest proportion (45.3%) of caregivers. The global burden scores revealed that most informal caregivers reported moderate-to-severe objective burden and mild-to-moderate subjective burden. Significant associations with objective burden were established for age, gender and residence (p=0.025, p=0.034 and p=0.038, respectively), and subjective burden yielded significant associations with daily caregiving (p=0.012).

Conclusion: Caring for people with severe mental disorders is associated with high levels of objective and subjective burdens. The present study highlights the need to integrate the assessment of burdens among informal caregivers of people with severe mental disorders in routine clinical practice. Additionally, the study urgently calls for the development of strategies to support informal caregivers to ensure successful community reintegration among people with severe mental disorders.

Keywords:

caregiver burden, caregiver stress, informal carers, mental disorders, South Africa.

FULL ARTICLE:

Introduction

Severe mental disorders (SMDs) affect 4% of the adult population globally and account for 26.1% of the reported cases of mental disorders in South Africa[1,2]. These disorders include major depressive disorder, bipolar mood disorder, schizophrenia, and other psychotic disorders[3]. Although no official statistics exist on SMDs in rural South Africa, a profile of common causes of mental illnesses in Mpumalanga, a rural province, revealed that most patients were diagnosed with bipolar mood disorder, schizophrenia, major depressive disorder, and substance induced psychosis[4]. People with SMDs experience a decline in function, and their ability to live independently is compromised. This dependency on others results in enormous social and economic burdens on themselves, their informal caregivers, and their communities[5].

Caregiver burden is described as the strain encountered by a person providing care to someone who is chronically ill[6], and can be categorised into objective and subjective burdens[7]. Objective burden relates to the tangible negative effects of caregiving that arise from the demands of the tasks required to care for a person with a mental disorder[8]. This burden is characterised by disruption in family routines, restrictions on families' social and leisure activities, and additional financial costs incurred due to caregiving[6]. Subjective burden relates to the perceived feeling of getting overwhelmed as a result of providing care to a person with a mental disorder[8]. This burden is characterised by negative appraisal of the caregiving circumstances, which results in feelings of loss, guilt, shame, and anger[7].

Studies conducted in Sub-Saharan countries found that the extent of caregiver burden among informal caregivers of people with mental disorders ranges between 60% and 90%[9-11]. Studies conducted in Ethiopia found that 63% of informal caregivers of people with schizophrenia and bipolar mood disorder experience moderate-to-severe caregiver burden[10]. Similarly, a study conducted in Nigeria found that 45% of caregivers of people with major depressive disorder experience a moderate-to-severe subjective burden[12]. In South Africa, 43.4% of caregivers of people with schizophrenia were reported to experience severe caregiver burden[13].

In rural and remote areas where general access to mental health services is limited, the sustained care and management of those with SMDs often becomes the responsibility of informal caregivers. The role of informal caregiving is often filled by family and at times by friends, neighbours, or any compassionate person, who are often unpaid while providing ongoing care to a person with an SMD[14]. Informal caregivers assume responsibility for the day-to-day needs of people with SMDs, manage their behaviour, monitor their mental state, and identify the early signs of illness relapse and deterioration[15]. Additionally, they are expected to supervise compliance with medication, provide emotional support, and help the people with SMDs access mental health services[16-18]. Most informal caregivers within rural and remote areas struggle to access mental health services to support them in providing adequate care to people with SMDs[19-22]. It is important to understand the extent of caregiver burden among informal caregivers because this forms the basis for the development of strategies to support caregivers in their role.

In rural South Africa, there is limited published evidence on the extent of subjective and objective caregiver burden among informal caregivers of people with SMDs. This study therefore aimed to establish the extent of subjective and objective burden experienced by informal caregivers. This forms part of a PhD project aimed at developing strategies for alleviating caregiver burden among informal caregivers of people with SMDs in rural South Africa.

Methods

Context and setting

The study took place in an acute mental health unit situated in Bushbuckridge municipality in the Mpumalanga province of South Africa. Mpumalanga province is a rural province in the north-east of South Africa. The population size of Bushbuckridge municipality is 546 215, and the municipality has an estimated average annual household income of US$850 (~A$1280)[23]. The acute mental health unit is considered the largest in the province, with a bed capacity of 50, and caters for a variety of patients, ranging from acute to chronic and forensic cases. Therefore, all patients with SMDs requiring long-term care are referred to this unit for further management. After discharge, patients with their caregivers attend follow-up visits at the outpatient clinic, which take place once per week at the mental health unit. Depending on the severity of their conditions, patients are required to attend their follow-up visit 1 month after discharge or every 6 months for review. If the patient is deemed stable after the first follow-up visit, they are referred to their local clinic for further management. Due to the limited mental health services in the province, the unit caters for a large catchment area, which was further expanded by the introduction of forensic services in 2014. As a result, there is a shortage of staff to cater for the needs of the patients and their caregivers. Currently, the unit has a multidisciplinary team consisting of a part-time psychiatrist and a medical officer who

work 3 days per week. Nursing staff consist of a psychiatrically trained sister in charge of the unit, a professional nurse, and an auxiliary nurse per 7-day shift. One social worker, a registered counsellor, and two occupational therapists facilitate the rehabilitation programs for both in- and outpatients in the unit. At the local clinics there are nursing staff, and a medical officer who visits the clinic once a month to offer mental health services.

Study design

This study used a quantitative, descriptive cross-sectional design. The data were generated through structured interviews with the participants.

Measures: The demographic and caregiving characteristics were gathered using a questionnaire developed by the first author from existing literature. The burden measure developed by Montgomery, et al[24] was used to measure objective and subjective burdens. This scale was considered appropriate as it is multidimensional, and therefore provides aggregate scores for objective and subjective burdens. This instrument comprises the following 22 items: 9 items on objective burden with a Cronbach alpha of 0.85, and 13 items on subjective burden with a Cronbach's alpha of 0.86. Each subscale item is rated using a five-point Likert scale (Table 1). For objective burden, the global scores range from 9 to 45, with higher scores indicating a higher burden, and the subjective burden global scores range from 13 to 65, with the higher scores indicating a higher burden. Table 2 outlines the five categories representing the levels of severity for both objective and subjective burdens[24].

Permission was received from the instrument developers to use and modify the instrument for the study context. A pilot study was conducted to establish the validity and reliability of the burden measure. Face validity, a subset of content validity, was conducted by inviting six participants who were considered knowledgeable in mental health to give their subjective opinions on whether the instrument measured the objective and subjective burdens as intended[25]. The identified participants rated each subscale item using four categories: relevance, clarity, simplicity, and ambiguity[25]. Items requiring revision were modified for clarity based on the recommendations of the participants. Prior to data collection, the revised scale was sent back to the pilot participants for the finalisation of the items on the instrument. In addition, the inter-rater reliability was conducted to determine the reproducibility of the results when using the burden measure. The researcher and two trained research assistants were required to independently administer the burden measure, with 10 informal caregivers recruited from the research site. These informal caregivers were excluded from the overall sample of the study. A standardised instruction sheet was used to ensure homogeneity in the process followed by the three raters. A weighted kappa was calculated using the *Statistical Package for the Social Sciences v27 (IBM; https://www.ibm.com/products/spss-statistics)* to determine the level of agreement between the raters. Landis and Koch's classification was used to determine the acceptable kappa value, where 0 was regarded as poor agreement, 0.00–0.20 as slight agreement, 0.21–0.40 as fair agreement, 0.41–0.60 as moderate agreement, 0.61–0.80 as substantial agreement, and 0.81–1.00 as almost perfect[26]. The weighted kappa value of 0.69–0.86 was established as indicating a substantial to almost-perfect agreement between the three raters, proving the reproducibility of the results when using the Montgomery, Gonyea, and Hooyman burden measure[26].

Table 1: Objective and subjective burdens subscale score descriptors

Burden subscale score	Descriptor
Objective burden subscale	
5	A lot less (worse)
4	A little less (worse)
3	The same
2	A little more (better)
1	A lot more (better)
Subjective burden subscale	
5	Most of the time
4	Often
3	Sometimes
2	A little of the time
1	Rarely or never
Collapsed objective burden subscale	
3	A little less to a lot less
2	The same
1	A lot more to a little more
Collapsed subjective burden subscale	
3	Often to most of the time
2	Sometimes
1	Rarely/never to a little of the time

Table 2: Objective and subjective burdens severity categories

Severity score	Descriptor
Objective burden severity	
9	No burden
10–18	Minimal burden
19–27	Mild-to-moderate burden
28–36	Moderate-to-severe burden
37–45	Severe burden
Subjective burden severity	
13	No burden
14–26	Minimal burden
27–39	Mild-to-moderate burden
40–52	Moderate-to-severe burden
53–65	Severe burden
Collapsed objective burden severity	
9–18	No burden to minimal burden
19–27	Mild-to-moderate burden
28–45	Moderate-to-severe burden
Collapsed subjective burden severity	
13–26	No burden to minimal burden
27–39	Mild-to-moderate burden
40–65	Moderate-to-severe burden

Data collection: Data were collected using structured interviews conducted by the first author along with two trained research assistants. This process took place over a period of 6 months, starting from March 2021.

Sampling size and method: To estimate the sample size of the informal caregivers, sample size calculations were based on the number of patients attending the outpatient clinic at the research site with an assumption that each patient has one informal caregiver. An estimated number of 353 mental healthcare users were identified as attending the outpatient clinic at the research site per month. Therefore, a sample size of 185 informal caregivers was required when the margins of the error were set at 5% with a confidence interval of 95% on Cochrane's formula[27]. A non-probability convenience sampling method was used to recruit informal caregivers of people with SMDs who accompanied their care recipients to follow-up visits at the outpatient clinic. Participants were approached in the queues as they waited to be seen by the doctor. The purpose of the study was explained to the group of informal caregivers, and those willing to participate were interviewed in a separate room before or after being seen by the doctor, depending on their preference.

Inclusion criteria: A set of inclusion criteria was used to identify suitable participants for the study. The inclusion criteria were (1) informal caregivers included a family member, a relative, a friend, or any person who provided unpaid care to a person with an SMD; (2) the informal caregiver had provided continuous care for the person with an SMD for more than 6 months; (3) the age of the informal caregiver was more than 18 years; and (4) the informal caregiver performed activities associated with caregiving at least once a week (administering medication, assisting with and structuring daily activities). Informal caregivers with physical conditions or chronic illnesses (including mental conditions) were excluded to avoid confounding factors that could arise from difficulty in dissociating the burden resulting from caregiving and the burden caused by their own disability or illness.

Statistical analysis: Stata v15 software was used for the data analysis. Descriptive statistics were used to summarise the demographic and caregiving characteristics of the informal caregivers, the severity of the objective and subjective burdens, and the level of burden projected by each item on the two subscales. To determine the level and severity of objective and subjective burdens, the data were collapsed into three categories and the ratings of each subscale were grouped together. Categories were collapsed to produce summary statistics and enable better data management (Tables 1, 2). In addition, for the purpose of this study, the severity of the burden was identified based on the three revised categories for both objective and subjective burdens (Tables 1, 2). The Pearson χ^2 was computed to test the association between the objective and subjective burdens with demographic and caregiving characteristics.

Ethics approval

Ethics clearance (M200957) was obtained from the University of the Witwatersrand Human Research Ethics Committee. Permission to conduct the study was obtained from the CEO of the research site, and the Mpumalanga Department of Health Research Committee granted final approval (MP_202010_010). All participants were required to sign an informed consent form declaring their willingness to engage in the study. Each participant was allocated a unique participant code to ensure the anonymity of the data.

Results

Demographic characteristics of informal caregivers

The results of the study as outlined in Tables 3 and 4 reveal that most of the informal caregivers were female (83.5%) in middle-to-late adulthood, with the majority (45.3%) in the age range of 45–64 years, followed by those in early-to-middle adulthood with the age range of 34 years and younger (34%). Many informal caregivers reported being single (57.1%) with a high school level of education (53.0%). Participants who were unemployed and dependent on a social grant formed the majority of the sample (39.4%).

Table 3: Associations between the demographic characteristics and levels of objective caregiver burden (*n*=170)

Variable	Participants *n* (%)	No burden to minimal burden *n* (%)	Mild-to-moderate burden *n* (%)	Moderate-to-severe burden *n* (%)	Statistical test
Gender					
Female	142 (83.5)	31 (21.8)	41 (28.9)	70 (49.3)	X^2 (2)=7.39 p=0.025
Male	28 (16.5)	10 (35.7)	12 (42.9)	6 (21.4)	
Age (years)					
≤34	34 (20.0)	14 (41.2)	8 (23.5)	12 (35.3)	X^2 (6)=13.66 p=0.034
35–44	33 (19.4)	5 (15.2)	10 (30.3)	18 (54.6)	
45–65	77 (45.3)	12 (15.6)	29 (37.7)	36 (46.8)	
≥65	26 (15.3)	10 (38.5)	6 (23.1)	10 (38.5)	
Marital status					
Single	97 (57.1)	27 (27.8)	29 (29.9)	41 (42.3)	X^2 (4)=3.33 p=0.503
Married	58 (34.1)	11 (18.9)	21 (36.2)	26 (44.8)	
Separated	15 (8.8)	3 (20.0)	3 (20.0)	9 (60.0)	
Education					
No formal education	22 (12.9)	4 (16.7)	9 (37.5)	11 (45.8)	X^2 (6)=5.19 p=0.519
Primary school	49 (28.8)	9 (18.4)	15 (30.6)	25 (51.0)	
High school	90 (53.0)	27 (30.7)	25 (28.4)	36 (40.9)	
Tertiary level	9 (5.3)	1 (11.1)	4 (44.4)	4 (44.4)	
Employment					
Employed	22 (13.0)	8 (36.4)	5 (22.7)	9 (40.9)	X^2 (6)=8.69 p=0.192
Unemployed (social grant)	67 (39.4)	17 (25.4)	24 (35.8)	26 (38.8)	
Unemployed (no social grant)	64 (37.6)	10 (15.6)	22 (34.4)	32 (50.0)	
Other (self-employed, volunteering, student)	17 (10.0)	6 (35.3)	2 (11.8)	9 (52.9)	

Table 4: Associations between the demographic characteristics and levels of subjective caregiver burden (*n*=170)

Variable	Participants *n* (%)	No burden to minimal burden *n* (%)	Mild-to-moderate burden *n* (%)	Moderate-to-severe burden *n* (%)	Statistical test
Gender					
Female	142 (83.5)	5 (3.5)	82 (57.8)	55 (38.7)	X^2 (2)=3.42 p=0.180
Male	28 (16.5)	2 (7.1)	20 (71.4)	6 (21.4)	
Age (years)					
≤34	34 (20.0)	3 (8.8)	20 (58.8)	11 (32.4)	X^2 (6)=9.78 p=0.134
35–44	33 (19.4)	0 (0.0)	15 (45.5)	18 (54.6)	
45–65	77 (45.3)	3 (3.9)	48 (62.3)	26 (33.8)	
≥65	26 (15.3)	1 (3.9)	19 (73.1)	6 (23.1)	
Marital status					
Single	97 (57.1)	4 (4.1)	58 (59.8)	35 (36.1)	X^2 (4)=0.93 p=0.920
Married	58 (34.1)	3 (5.2)	34 (58.6)	21 (36.2)	
Separated	15 (8.8)	0 (0.0)	10 (66.7)	5 (33.3)	
Education					
No formal education	22 (12.9)	2 (8.3)	13 (54.2)	9 (37.5)	X^2 (6)=3.61 p=0.728
Primary school	49 (28.8)	2 (4.1)	32 (65.3)	15 (30.6)	
High school	90 (53.0)	3 (3.4)	53 (60.2)	32 (36.4)	
Tertiary level	9 (5.3)	0 (0.0)	4 (44.4)	5 (55.6)	
Employment					
Employed	22 (13.0)	0 (0.0)	13 (59.1)	9 (40.9)	X^2 (6)=3.46 p=0.748
Unemployed (social grant)	67 (39.4)	3 (4.5)	44 (65.7)	20 (29.9)	
Unemployed (no social grant)	64 (37.6)	3 (4.7)	37 (57.8)	24 (37.5)	
Other (self-employed, volunteering, student)	17 (10.0)	1 (5.9)	8 (47.1)	8 (47.1)	

Caregiving characteristics of informal caregivers

Most informal caregivers were parents of the care recipient (45.3%), followed by siblings (24.7%), and the majority of caregivers resided at the same residence as their care recipient (81.2%). The majority of the sample (47.0%) had been providing care for the individual for 5 years or less. The hours spent in daily caregiving varied between one and 24 hours, and most of the informal caregivers spent 8 hours or less daily (53.5%), followed by those who spent 19–24 hours daily (28.8%). The care recipients were diagnosed mainly with schizophrenia (52.8%), and those with a psychotic disorder not otherwise specified accounted for 27.1% of those receiving care from informal caregivers. Care recipients with bipolar mood disorder, substance-induced psychosis, and major depressive disorder accounted for 10.6%, 7.1% and 2.4% of care recipients, respectively. Most of the participants (61.8%) spent less than 100 South African rand (~A$8) per month, with some (34.1%) spending up to 500 South African rand (~A$40) per month

for the medical costs of the care recipients (Tables 5, 6).

Table 5: Associations between the caregiving characteristics and levels of objective caregiver burden (*n*=170

Variable	Participants *n* (%)	No burden to minimal burden *n* (%)	Mild-to-moderate burden *n* (%)	Moderate-to-severe burden *n* (%)	Statistical test
Relationships					
Parents	77 (45.3)	13 (16.9)	26 (33.8)	38 (49.4)	X^2 (6)=6.29 p=0.391
Siblings	42 (24.7)	10 (23.8)	14 (33.3)	18 (42.9)	
Spouse	14 (8.2)	4 (28.6)	4 (28.6)	6 (42.9)	
Other (daughter, grandparents, relatives, parents and siblings in-law)	37 (21.8)	14 (37.8)	9 (24.3)	14 (37.8)	
Residence					
Same as care recipient	138 (81.2)	28 (20.3)	47 (34.1)	63 (45.7)	X^2 (6)=6.55 p=0.038
Different to care recipient	32 (18.8)	13 (40.6)	6 (18.8)	13 (40.6)	
Duration of caregiving (years)					
1–5	80 (47.0)	17 (21.3)	27 (33.8)	36 (45.0)	X^2 (4)=1.89 p=0.792
6–10	45 (26.5)	11 (24.4)	15 (33.3)	19 (42.2)	
>10	45 (26.5)	13 (28.9)	11 (24.4)	21 (46.7)	
Daily caregiving (hours)					
1–8	91 (53.5)	24 (26.4)	31 (34.1)	36 (39.6)	X^2 (4)=2.94 p=0.568
9–18	30 (17.7)	8 (26.7)	7 (23.3)	15 (50.0)	
19–24	49 (28.8)	9 (18.4)	15 (30.6)	21 (51.0)	
Diagnosis of care recipient					
Schizophrenia	90 (52.8)	27 (30.0)	26 (28.9)	37 (41.1)	X^2 (8)=9.06 p=0.337
Psychotic disorder not otherwise specified	46 (27.1)	6 (13.0)	17 (25.0)	23 (50.0)	
Bipolar mood disorder	18 (10.6)	3 (16.7)	17 (36.9)	23 (50.0)	
Substance-induced psychosis	12 (7.1)	3 (25.0)	5 (41.7)	4 (33.3)	
Major depressive disorder	4 (2.4)	2 (50.0)	1 (25.0)	1 (25.0)	
Monthly medical costs (South African rand)[1]					
<R100	105 (61.8)	29 (27.6)	34 (32.4)	42 (40.0)	X^2 (4)=4.14 p=0.387
R100–R500	58 (34.1)	11 (18.9)	18 (31.0)	29 (50.0)	
>R500	7 (4.1)	1 (14.3)	1 (14.3)	5 (71.4)	

[1] R100=A$8.

Table 6: Associations between the caregiving characteristics and levels of subjective caregiver burden (n=170)

Variable	Participants *n* (%)	No burden to minimal burden *n* (%)	Mild-to-moderate burden *n* (%)	Moderate-to-severe burden (%)	Statistical test
Relationships					
Parents	77 (45.3)	4 (5.2)	46 (59.7)	27 (35.1)	X^2 (6)=7.41 p=0.284
Siblings	42 (24.7)	1 (2.4)	31 (73.8)	10 (23.8)	
Spouse	14 (8.2)	0 (0.0)	8 (57.1)	6 (42.9)	
Other (daughter grandparent, relatives, in-laws)	37 (21.8)	2 (5.4)	17 (45.9)	18 (48.7)	
Residence					
Same as care recipient	138 (81.2)	5 (3.6)	83 (60.1)	50 (36.2)	X^2 (2)=0.46 p=0.793
Different to care recipient	32 (18.8)	2 (6.3)	19 (59.4)	11 (34.4)	
Duration of caregiving (years)					
1–5	80 (47.0)	2 (2.5)	54 (67.5)	24 (30.0)	X^2 (4)=4.20 p=0.378
6–10	45 (26.5)	3 (6.7)	23 (51.1)	19 (42.2)	
>10	45 (26.5)	2 (4.4)	25 (55.6)	18 (40.0)	
Daily caregiving (hours)					
1–8	91 (53.5)	5 (5.5)	63 (69.2)	23 (25.3)	X^2 (4)=12.84 p=0.012
9–18	30 (17.7)	2 (6.7)	16 (53.3)	12 (40.0)	
19–24	49 (28.8)	0 (0.0)	23 (46.9)	26 (53.1)	
Diagnosis of care recipient					
Schizophrenia	90 (52.8)	4 (4.4)	60 (66.7)	26 (28.9)	X^2 (8)=9.27 p=0.320
Psychotic disorder not otherwise specified	46 (27.1)	3 (6.5)	23 (50.0)	20 (43.5)	
Bipolar mood disorder	18 (10.6)	0 (0.0)	8 (44.4)	10 (55.6)	
Substance-induced psychosis	12 (7.1)	0 (0.0)	9 (75.0)	3 (25.0)	
Major depressive disorder	4 (2.4)	0 (0.0)	2 (50.0)	2 (50.0)	
Monthly medical costs (South African rand)†					
<R100	105 (61.8)	4 (3.8)	66 (62.9)	35 (33.3)	X^2 (4)=3.00 p=0.557
R100–R500	58 (34.1)	2 (3.5)	32 (55.2)	24 (41.4)	
>R500	7 (4.1)	1 (14.3)	4 (57.1)	2 (28.6)	

† R100=A$8.

Associations between caregiver burden and demographic characteristics

The results revealed a significant association between gender and objective burden. Female participants reported a significantly higher burden than males, with most (49.3%) reporting moderate-to-severe objective burden (X^2 (2)=7.39; p=0.025). Similarly, the associations between age and objective burden yielded significant results, with many informal caregivers aged between 45 and 65 years (46.8%) reporting moderate-to-severe burden (X^2 (6)=13.66; p=0.034). Thus, older caregivers reported a higher burden of care. While most participants were unemployed and dependent on a social grant, the findings revealed that the associations between employment status and objective burden were statistically insignificant. The associations between the demographic characteristics and subjective burden were not statistically significant (p>0.05; Tables 3, 4).

Associations between caregiver burden and caregiving characteristics

The informal caregivers who resided with care recipients reported significantly higher objective burden, with most participants (45.7%) reporting moderate-to-severe burden (X^2 (6)=6.55; p=0.038). The associations between objective burden and other caregiving characteristics were not significant (p>0.05). The associations between daily caregiving and subjective burden yielded significant results, with most informal caregivers (53.1%) who provided care for 19–24 hours reporting a moderate-to-severe burden (X^2 (4)=12.84; p=0.012). No associations were established between subjective burden and other caregiving characteristics (p>0.05; Tables 5, 6). While there were no significant associations between care recipients' diagnoses and objective and subjective burdens, it is important to note the levels of these burdens (Tables 5, 6).

Objective and subjective burdens global scores

The global burden scores revealed considerable burden among the informal caregivers. Most informal caregivers (44.7%) reported moderate-to-severe objective burden, followed by those who reported mild-to-moderate burden (31.2%). Those with no burden to minimal objective burden accounted for 24.1% of the sample (Fig1). Similarly, most informal caregivers (60%) reported mild-to-moderate subjective burden, while 35.9% reported moderate-to-severe subjective burden, and the least number of participants (4.1%) reported no burden to minimal subjective burden (Fig2).

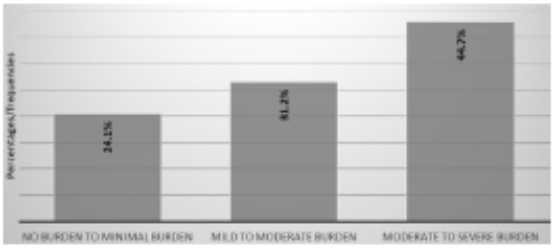


Figure 1: Informal caregiver objective burden global scores (n=170)

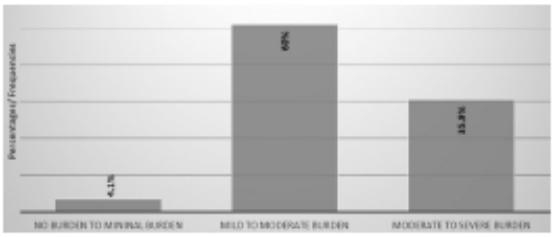


Figure 2: Informal caregiver subjective burden global scores (n=170)

Discussion

The global burden scores for both objective and subjective burdens revealed a higher burden among the informal caregivers in rural South Africa. A majority of the informal caregivers (44.7%) reported moderate-to-severe objective burden, and 35.8% reported moderate-to-severe subjective burden. This indicates that the severity of objective burden was higher than that of subjective burden. The results of this study differ from previous studies conducted in Sweden and Nigeria that reported higher subjective burden among informal caregivers of people with schizophrenia[8,28,29]. Additionally, a study conducted in Nigeria indicated that 45% of informal caregivers of people with major depressive disorder reported moderate-to-severe subjective burden[12].

The higher levels of objective burden can be attributed to various factors, including the gender and age of the informal caregiver. In the present study, most of the informal caregivers were women (83.5%), with significant associations established between gender and the objective burden reported by informal caregivers (p=0.025). This is consistent with previous studies conducted in other developing countries, including South Africa, that identified that most informal caregivers tend to be women[11,13,30-33]. These findings are not surprising as caregiving is considered a traditional role that best fits women in the home and community[13,33].

Female informal caregivers occupy many roles that predispose them to higher burdens than their male counterparts. The roles include being a mother, worker, house maintainer and key emotional supporter[11]. A study conducted in India among informal caregivers of people with bipolar mood disorder highlighted that cultural issues such as restriction of females to household duties, the inability to spend time on leisure activities, and the financial dependency were associated with high burden among informal caregivers[33]. In rural South Africa, women are responsible for overseeing the day-to-day running of households and, as a result, when a responsibility for caregiving arises, their routines are disrupted, resulting in less time for self and socialisation, leading to objective burden[34]. Therefore, the findings in this study highlight that gender can be considered a predictor for objective burden among informal caregivers of those with SMDs[35,36].

The results revealed non-significant associations between objective burden and employment status; however, it is important to note that both employed and unemployed informal caregivers reported higher levels of objective burden. It could be that the informal caregivers struggled to meet the expenses of the household and provide for the needs of the care recipients in spite of their employment status. The results in this study are similar to a study conducted in rural Ethiopia that revealed that caregivers reported higher levels of burden related to financial problems, often due to the cost of treatment[37]. The informal caregivers in this study were expected to meet basic household expenses, and they were required to deal with the additional cost of providing care, which includes covering the transport costs to the hospital for follow-ups. Marimbe et al highlighted that the increased financial burden may be related to the fact that some informal caregivers frequently forego economic opportunities to fulfil their caregiving responsibilities[33]. It is therefore necessary to plan and implement community-based programs that enable caregivers to take up income-generating roles to increase household income[38].

Although no significant associations were established between subjective burden and the demographic characteristics of the informal caregivers, most males (71.4%) and females (57.8%) reported mild-to-moderate subjective burden. This highlights that male caregivers in this study reported the same level of subjective burden as females. These findings differ from previous studies conducted in Sweden and Nigeria that reported that females experienced higher subjective burden than men[29,38]. The findings of the present study are worth noting as they emphasise that research aimed at developing strategies for alleviating subjective burden should focus on the needs of both male and female caregivers.

The majority of the informal caregivers in this study were older adults in middle-to-late adulthood, and many were aged between 45 and 65 years (45.3%), with some aged 65 years or more (15.3%). These findings are consistent with a study conducted in South

Africa that revealed that most caregivers are above the age of 55 years and that 15.8% are above the age of 65 years[13]. The increased age of the informal caregivers in this study yielded a significant association with established levels of objective burden (p=0.034). These results are concerning as old age is associated with poor quality of life and a decline in health caused by comorbidities[13]. Additionally, older caregivers often have decreased energy levels to perform daily activities, reducing their ability to cope with the demands of caregiving[6,36,38,39]. The age of the informal caregivers and the schizophrenia diagnosis of most of the care recipients in this study are concerning facts given the recovery patterns of this mental disorder. Schizophrenia is associated with serious functional and social impairments as well as unpredictable and risky or even hostile behaviours, which demand more time and structure from informal caregivers[40-45]. Considering declining health and energy levels among elderly people, this means that the burden of care becomes the responsibility of those who may be struggling to care for themselves, and this may have serious consequences for continuity of care for the care recipients. In a resource-constrained context like rural South Africa, there is limited access to mental health services, and thus informal caregivers are the backbone of recovery for mental healthcare users. The combination of a resource-constrained healthcare system and the advanced age of caregivers poses a serious threat to the quality of caregiving, which can aggravate relapses in people with SMDs[46]. Therefore, this is likely to perpetuate a cycle of the 'revolving door' phenomenon that is constantly crippling the mental health system in South Africa[47].

Most informal caregivers in early-to-middle adulthood (35–44 years) reported a moderate-to-severe subjective burden (54.6%). Most caregivers at this age are in their productive stage and actively participating in working life[27]. In this study, 22 (13%) informal caregivers reported being in full-time employment. According to Flyckt, et al, employed informal caregivers experience reduced productivity and often struggle to cope with a full-time working week[40]. This is attributed to the fact that the demands of caregiving and work often compete for the same limited resources, such as time, financial, and psychological resources[48]. Consequently, most informal caregivers are likely to experience high levels of stress, which results in reduced mental health and wellbeing, precipitating limited productivity[48]. Some studies conducted in Europe revealed that employed informal caregivers reported high rates of absenteeism compared to non-caregiving employees[49,50]. Additionally, the caregivers were more likely to exit the open labour market prematurely compared to those who did not have caregiving responsibilities[47]. Therefore, it is important that strategies be implemented to support working informal caregivers, to prevent them from losing their incomes.

In the present study, a significantly higher subjective burden was established among informal caregivers who spent prolonged hours in daily caregiving (p=0.012). Those who spent 1–8 hours (69.2%) in daily caregiving reported mild-to-moderate subjective burden, but those spending 19–24 hours (53.1%) reported more severe subjective burden. It is not surprising that increased time spent on daily caregiving leads to an increase in the severity of subjective burden reported by the informal caregivers, considering that most (81.2%) stay in the same residence as the care recipient. Ayalew et al[9] also identified that informal caregivers who spent long hours in daily caregiving expressed feelings of higher burden. With increased time spent on caregiving, the informal caregivers had less time for themselves, which predisposed them to increased burden[51-53] and burnout, manifesting as physical, emotional, and mental exhaustion[54]. Informal caregivers who experience caregiver burnout are likely to express high levels of emotion, including critical comments and emotional hostility toward care recipients[55]. Experiencing criticisms and hostility acts as a stressor, which may be a causative factor leading to a person with SMDs experiencing relapse[56].

Limitations

The limitations of this study include the cross-sectional design and convenience sampling of participants at a single research site, which means these findings may not be able to be generalised to other populations. The omission of care recipient characteristics, such as their age, gender and duration of illness, in this study prevented a comprehensive understanding of the factors associated with caregiver burden. Future studies should therefore investigate the impact of care recipients' characteristics on the burden of care reported by informal caregivers in rural areas. Incorporating a qualitative component could add value in the in-depth exploration of caregiver burden, and this is an area that can be explored in future research.

Conclusion

Caring for individuals with SMDs is associated with considerable levels of objective and subjective burdens for the informal caregivers. The impact of these burdens on the health and wellbeing of the informal caregivers and the spill-over effect of this to the quality of care received by care recipients have been clearly defined in previous studies. The findings in this study highlight the need to integrate the assessment of burdens among informal caregivers of people with SMDs in routine clinical practice. This can be done by ensuring that regular assessments are conducted to determine who is providing care and to determine the mental and physical status of the informal caregiver. It is important that gender stereotypes, such as labelling caregiving as a female-oriented activity, be addressed to ensure that both males and females are equally involved in the role of caregiving. Support strategies such as respite care may be implemented by involving other family members in caregiving activities to ensure the distribution of the caregiving demands. This can be achieved by strengthening community-based mental health services such as setting up day centres where people with SMDs can participate in activities to provide some respite to informal caregivers. To alleviate the financial burden of informal caregivers, it is recommended that governments implement a caregiver grant as an incentive, particularly in low-resource settings where employment opportunities are limited.

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3.3 OBJECTIVE 2: TO EXPLORE THE LIVED EXPERIENCES OF INFORMAL CAREGIVERS OF PERSONS WITH SEVERE MENTAL DISORDERS

This section is presented a published article and two manuscripts all structured according to the journals' author guidelines. The articles are yielded from the findings of the objective that aimed to explore the lived experiences of informal caregivers of persons with SMDs. The findings documented in the three manuscripts are presented below.

3.3.1 Experience of burden of care and support needs of informal caregivers of persons with severe mental disorders in rural South Africa: A qualitative study

Manuscript (a) reports on the experiences of burden and support needs of informal caregivers of persons with SMD. The paper has been submitted to *Hindawi: Mental Illness*. Details of the manuscript are outlined Table 3.2.

Table 3.2 Manuscript (a) details

Title	Journal	Author contributions		Key findings	Status
Experience of burden of care and support needs of informal caregivers of persons with severe mental disorders in rural South Africa: A qualitative study	*Hindawi: Mental Illness* DHET accredited Impact factor: 6.3	Conceptualisation	Silaule, Nkosi & Adams	Caregivers experienced burden in their caregiving role Caregivers expressed support needs in their caregiving role	Post review corrections submitted
		Manuscript draft	Silaule		
		Manuscript review and editing	Silaule, Nkosi & Adams		
		Supervision	Nkosi & Adams		

Hindawi: Mental Illness

Experience of burden of care and support needs of informal caregivers of persons with severe mental disorders in rural South Africa: A qualitative study

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Abstract

Severe mental disorders are chronic and disabling conditions marked by serious functional impairments. As a result, persons with severe mental disorders require long-term care from their family, relatives, or friends. Providing care is accompanied by negative experiences that result in distress for the caregivers, and as such, they require support to cope with their caregiving responsibilities. This study aimed to explore the experiences and support needs of informal caregivers caring for persons with severe mental disorders in rural South Africa. A descriptive qualitative approach was used to explore the experiences and supports needs of the informal caregivers. Ten semi-structured interviews were conducted with 12 informal caregivers who were purposely selected to participate between January and June 2022. Data were analysed using reflexive thematic analysis. The two themes identified during the data analysis were caregivers' experience of burden in the caregiving role and caregivers' expressed support needs. The informal caregivers reported burdens related to dealing with the chronic and disabling nature of severe mental disorders, role and financial strain, and stigmatisation from family and community. Support needs include access to mental health services, and empowerment and social support from family, government, and religious and community organisations. The findings highlight the complexity of caregiver burden experienced by informal caregivers of persons with severe mental disorders, which calls for multisectoral collaboration in the planning and development of support services for informal caregivers, particularly in sub-Saharan Africa where access to community mental health services is limited.

Introduction

Severe mental disorders (SMDs), including schizophrenia spectrum disorders, depressive disorders, bipolar mood disorders, and substance use disorders, are serious public health concerns (Vigo et al., 2016). Globally, SMDs are estimated to affect 4% of the adult population and are counted among the top 20 causes of the global burden of disease, which make them a major contributor to the growth of morbidity and disability (Global Burden of Disease Study 2013 Collaborators, 2015; WHO, 2017a; Charlson et al., 2018). Individuals who are diagnosed with a

SMD often experience serious functional and role impairments and require structure to function within their communities (Kessler et al., 2005; Addo et al., 2018). Schizophrenia spectrum disorders are characterised by psychotic, and at times, violent behaviour as well as cognitive and functional decline that lead to the deterioration of social and occupational functioning (Van Os & Kapur, 2009; Asmal et al., 2014). These disorders manifest in early adulthood and persist throughout life. Consequently, these disorders affect people's ability to earn a livelihood and to form meaningful relationships, resulting in a need for prolonged care and management (Arun et al., 2018). Similarly, depressive disorders are characterised by prolonged feelings of sadness and apathy, which limit engagement in daily living activities, including work-related activities. As a result, individuals affected by depressive disorders struggle to function independently and thus require long-term care (Global Burden of Disease Study 2013 Collaborators, 2015). Individuals who are diagnosed with bipolar mood disorders experience substantial impairments in their mood and daily living activities, and thus struggle to fulfil their responsibilities at work and within their household. These symptoms are likely to persist even when managed with medication. It is reported that 55–70% of adults with bipolar mood disorder have recurring episodes within 2–4 years of initial diagnosis, even when maintained on pharmacotherapy (Miklowitz et al., 2003; Reinares et al., 2016). The rate of recurrences and persistent symptoms frequently lead to functional impairments that place emotional strain on MHCUs and their families (Hubbard et al., 2016; Reinares et al., 2016).

Those with substance use disorders often experience cognitive impairments, including problems with thinking clearly, decline in memory, and difficulty focusing their attention (National Institute on Drug Abuse, 2020). In addition, they exhibit physical aggression and poor social behaviour, which affect their work performance and personal relationships, thus leading to functional impairments with severe influence on the mental healthcare users (MHCUs) and their families (Marcon et al., 2012). The chronic and disabling nature of these mental disorders requires prolonged care and management.

In sub-Saharan Africa where there is limited community-based infrastructure to meet the needs of those with SMDs, their care and management often rely on informal caregivers (Kisa et al., 2016; Molodynski et al., 2017; Addo et al., 2018). Informal caregivers can be a family member, a relative, or any community member who provides care without remuneration (Olagundoye & Alugo, 2018). Caregiving is identified as a stressful responsibility for informal caregivers and is

often accompanied by caregiver burden (Yerriah et al., 2021; Vukeya et al., 2022; Silaule et al., 2023). This is because informal caregivers are often required to fulfil this role without any training, and as such, they lack the knowledge and skills to handle the behaviour of the persons with SMDs (Chadda, 2014). Two types of caregiver burden are well-documented, namely objective and subjective burden. Objective burden refers to the tangible negative effects of caregiving such as prolonged time spend on caregiving, financial costs, and disruptions in household functions and routines. Subjective burden refers to the emotional distress encountered because of the demands of caregiving, and usually manifests in the form of guilt, shame, and feelings of despair (Chadda, 2014; Mokgothu et al., 2015; Paruk & Ramdhial, 2018). Previous studies establish that informal caregivers require support from family, mental health professionals, and their community in order to cope with the demands of their caregiving responsibilities (Ntsayagae et al., 2019; Vukeya et al., 2022). Addo et al. (2018) acknowledge the paucity of research on the burden of care brought on by SMDs and call for more research to inform service planning and policy making in sub-Saharan Africa. The current study therefore aimed to explore the experiences of burden of care and support needs of informal caregivers of persons with SMDs in Bushbuckridge, South Africa. It is important to understand the experiences of informal caregivers as it forms the basis for planning and developing contextually responsive interventions to support them in their role. The research questions addressed in this study were: (1) What are the burdens experienced by informal caregivers of persons with severe mental disorders? (2) What are the support needs of informal caregivers of persons with severe mental disorders in rural South Africa?

Materials and methods

Study design and approach

A qualitative, descriptive research design was used to explore the subjective experiences of informal caregivers and their support needs while occupying the role of providing care to persons with SMDs (Bradshaw et al., 2017). This design was selected as it allowed the researchers to gain an understanding of the informal caregivers' individual experiences within their caregiving context (Doyle et al., 2020). The study forms part of a PhD project that was conducted to establish the extent of burden of care among informal caregivers in rural South Africa (Silaule et al., 2023). The use of a qualitative, descriptive design allowed for an in-depth exploration of caregiving

experiences. For data collection, semi-structured interviews were conducted with the informal caregivers between January and June 2022. In addition, a researcher-developed questionnaire was used to capture the demographic characteristics of both the informal caregivers and the MHCUs. For data analysis, a framework method was used to systematically conduct the data analysis that resulted in the conclusions and recommendations made in this study (Gale et al., 2013).

Setting

This study was conducted in the Bushbuckridge municipality situated in the north-eastern rural part of Mpumalanga province, South Africa. The municipality has a population size of 750 821 and an estimated average annual household income of R16 000.00 (approximately $850) (Statistics South Africa, 2022) . There are two district hospitals and one regional hospital in the Bushbuckridge municipality. Of the three hospitals, only one district hospital has an in-patient mental health unit with a bed capacity of 50, which is by far the largest in the entire Mpumalanga province. As a result, all residents of the Bushbuckridge municipality and surrounding communities requiring in-patient care are admitted to this unit for care and treatment. In addition, the mental health unit offers outpatient services. Persons with SMDs requiring in-patient and outpatient care are often treated at this facility, and some travel distances of up to 50 kms to access the services at this facility. Due to low bed capacity, MHCUs are admitted for a short period, and once their psychotic symptoms are stabilised, they are discharged to the community in the care of their informal caregivers. Discharged persons with SMDs receive follow-up care at their nearest community health clinic where they receive psychotropic medication. However, due to the severity of their symptoms, some persons with SMDs cannot be managed at their local clinics, and as a result, they receive their follow-up care at the hospital.

Sampling frame and study participants

As part of the PhD project, a quantitative study was conducted to measure the level of burden among informal caregivers, and the participants for the current qualitative interview study were identified from those who participated in the quantitative study. Only informal caregivers who presented with a burden were considered for inclusion, and we used a purposive sampling method to select participants who presented with mild, moderate, or severe burden of care. Potential interview participants who indicated interest in participation were recorded and their contact

details were captured. On commencement of the study, the primary investigator (PI), OS contacted those who indicated interest telephonically and invited to participate. Inclusion criteria guided the identification and selection of appropriate participants for the study. Participants were considered if (1) they are informal caregivers of a person with SMDs, including a family member, friend, or any person who provide unpaid care; (2) they are informal caregivers who have provided continuous care for longer than six months; (3) they are at least 18 years old; (4) they perform caregiving duties at least once a week; and (5) they presented a subjective or objective burden (mild, moderate, or severe) in the quantitative study (Silaule et al., 2023). Overall, 12 participants participated in this study between January and June 2022. A sample size of 12 participants were adequate to allow for full exploration of the burdens and support needs and for answering the research question.

Data collection and Management

Prior to data collection, the PI attended a qualitative methodology workshop, which equipped them with skills to conduct semi-structured interviews and qualitative data analysis using an NVivo software. On commencement of data collection, the PI telephonically contacted all potential participants who agreed to take part in the study. A convenient date, time, and place was set in agreement with the participants for the interviews. All participants preferred that the interviews be conducted in their homes, which allowed for flexibility and an in-depth understanding of the caregiving context. Of the 10 interviews conducted, eight were with individual informal caregivers, one was with a parent-couple, and one with a mother and her son who assist with the caregiving duties. Since the main researcher is a local resident of Bushbuckridge municipality, she speaks the local language and is familiar with the culture and values of the community, and this helped connect with the participants. Semi-structured interviews were conducted using an interview guide (Bradshaw et al., 2017). Prior to the interviews, the researcher went through the information sheet detailing the purpose and aim of the study, while highlighting the expected role of the participants. The participants were invited to share their experiences of burdens in providing care to persons with SMDs and their support needs. All interviews were conducted in Xitsonga, the first language of the interviewer and interviewees. The interviews commenced with the following open-ended question: ‘Please can you tell me about your experience of caring for your family member (son/daughter/husband/wife/sibling/granddaughter/mother/father) with a mental

disorder?' This allowed the participants to share their experiences from their own perspectives. This was followed by questions aimed specifically at exploring the burden and support required to alleviate the burden; for example, 'Describe the different burdens you have encountered since you started providing care to your family member/relative with a mental disorder'; 'How have these burdens impacted your life?'; 'What are the sources of burdens related to providing care to your family member/relative?'; 'What resources/support have you obtained/received since you started providing care to your family member/relative?'; and 'What further resources/support do you need to provide better care to your family member/relative'. In addition, a demographic questionnaire was administered to document the demographic characteristics of the informal caregivers and their care recipients (persons with SMDs). The interviews lasted between 30 and 60 minutes, depending on the experiences shared by the participants. Data were collected until saturation was reached i.e. when no new data emerged during the interview process. Informed consent were obtained from the participants before data collection to participate in the study and to record audio during the interviews. To ensure confidentiality, each participant was assigned a participant ID. The audio-recorded interviews were transcribed and translated from Xitsonga to English by a language specialist working as a researcher at a research facility in the Bushbuckridge municipality. The University of the Witwatersrand Human Research Ethics Committee (M200957) granted ethical approval for the study, and the Mpumalanga Department of Health Research Committee (MP_202010_010) provided approval for conducting research within the Bushbuckridge municipality.

Data analysis

Data were analysed systematically using NVivo 12 software. The analysis followed the six-phase reflexive thematic inductive approach proposed by Braun and Clarke (2021). Following a framework method allowed for the identification, description, and interpretation of patterns inherent in the data, thus allowing for the generation of themes within the phenomena of interest (Goldsmith, 2021), which in this case was the experiences of the caregivers and their support needs. Firstly, the PI conducted data immersion by repeatedly listening to the audio recordings while reading the transcripts. Emerging patterns and meanings from the data set were recorded by writing detailed familiarisation notes for each participant, which were used to guide the initial coding process. Segments of data were assessed, and those deemed to meaningfully address the

phenomena of interest were used to generate codes. Next, systematic coding was done by going through each data item where many codes were coded for as many potential themes. Each code was assigned a description to ensure consistency throughout the coding process. At this stage, notes were recorded to guide reflection on codes requiring further clarity and the identification of potential themes. Following the systematic coding, the PI sorted the codes to generate initial themes. At this stage, relationships were identified, duplicates were removed, and codes requiring further clarity were defined. A codebook was generated to ensure consistency, and relationships were identified based on the descriptions allocated to the codes. The fourth steps was to develop and review the themes by generating a map using NVivo software to give a comprehensive visual representation of the initial themes. This allowed for the review of the themes, and at this stage, some of the codes became themes while additional codes that did not fall under a specific theme were identified and grouped for further analysis in the next stage. Next, PI read the coded data extracts for each theme to guide the refining and renaming of themes. This process was done to ensure the coded extracts merged coherently to form a pattern for a specific theme. The dataset and familiarisation notes were read again to ensure validity of the themes and ensure codes were not missed. Lastly, the findings, recommendations, and conclusions are presented in this study.

Trustworthiness in the analysis process was ensured by conducting an audit trail with an experienced qualitative researcher who reviewed the analysis process and gave feedback to the researcher. Following this process, recommendations for changes to the themes were made and all themes were revised as recommended. The findings were presented to the two research supervisors who, in turn, critically reviewed the analysis process, codes and theme, and revisions were made as recommended by the supervisors. Additionally, peer briefings were conducted with colleagues who are experienced in qualitative research to ensure the refinement of the emerging themes, as well as to promote the quality and truthfulness of the findings. The main researcher kept a journal to document her thoughts and observations from the interviews and analysis process, which allowed for reflexivity.

Results

Table 1 presents the demographics of the informal caregivers of SMDs. Most informal caregivers are female (75%) and over the age of 65 (47.1%), followed by those who are between the ages of 40 and 65 (33.3%). The number of years spent providing care to a person with a SMD ranged

between 5 and 20 years. Many caregivers (50%) spend 1–8 hours a day on caregiving, followed by those who spend 19–24 hrs (41.7%) on caregiving duties.

Table 1 Demographic characteristics of informal caregivers of persons with SMDs (n = 12)

Characteristic	Frequency	Percentage (%)
Age		
20–39	3	25.0
40–65	4	33.3
+ 65	5	41.7
Gender		
Female	9	75.0
Male	3	25.0
Marital status		
Single	2	16.7
Married	7	58.3
Divorced	2	16.7
Widower	1	8.3
Education		
Primary school level	2	16.7
Secondary school level	4	33.3
Tertiary level	2	16.7
Uneducated	4	33.3
Employment status		
Employed	1	8.3
Unemployed	4	33.3
Pensioner	6	50
Self-employed	1	8.3
Relationships		
Mother	6	50
Father	2	16.7
Sibling	4	33.3
Number of care recipients		
1	10	83.3
2	2	16.7
Duration of caregiving		
5–10 yrs.	5	41.7
11–20 yrs.	7	58.3
Daily caregiving (in hours)		
1–8 hrs.	6	50
9–18 hrs.	1	8.3
19–24 hrs.	5	41.7
Monthly household income (ZAR)		
≤ 1 000	1	8.3

Characteristic	Frequency	Percentage (%)
1 100–5 000	10	83.3
≥ 5 000	1	8.3
Monthly medical costs (ZAR)		
≤ 100	1	8.3
101–500	11	91.7
Residence		
Same as care recipient	8	66.7
Different from care recipient	4	33.3

Table 2 presents the demographic characteristics of the MHCUs. Most MHCUs (66.7%) are males between the ages of 30 and 39 years (41.7%) and are unmarried (75.0%). Many (75.0%) have a secondary level education and are unemployed on the disability grant (58.7%). The care recipients are considered relatively stable (83.3%), and many are diagnosed with schizophrenia (58.3%).

Table 2 Demographic characteristics of the MHCUs with SMDs (n = 12)

Characteristics	Frequency	Percentage (%)
Age		
18- 29	3	25
30 - 39	5	41.7
40 - 49	2	16.6
≥ 50	2	16.6
Sex		
Female	4	33.3
Male	8	66.7
Marital status		
Single	9	75
Married	0	0
Divorced	2	16.7
Widower	1	8.3
Education		
Primary school level	3	25
Secondary school level	9	75
Employment status		
Unemployed (without social grant)	4	33.3
Unemployed (with social grant)	7	58.3
Pensioner	1	8.3

Diagnosis		
Schizophrenia	7	58.3
Psychotic disorder Not Otherwise Specified	2	16.7
Substance use disorder	2	16.7
Major depressive disorder	1	8.3
Disease status		
Relatively stable	10	83.3
Unstable	2	16.7
Number of hospitalisations in the previous year		
None	10	83.3
1–2 times	2	16.7
Number of family members living in the household		
1–5 people	8	66.7
6–10 people	4	33.3

Two themes emerged from the data during the inductive analysis, namely caregivers' experience of burden in caregiving, and caregivers' expressed support needs. Each theme has a sub-themes that provide a comprehensive representation of the findings.

Theme 1: Caregivers' experience of burden in caregiving role

This theme relates to the burdens experienced by the informal caregivers, such as the difficulty and strain the caregivers attribute to their caregiving role. This theme is divided into five sub-themes, namely dealing with the chronic nature of a SMD, experience of MHCU's disruptive behaviour, experience of financial strain, experience of stigmatisation, and role of strain of caregiving.

Dealing with the chronic nature of a severe mental disorder

The informal caregivers expressed the burden of dealing with the chronic nature of a SMD and the related symptomology. They stated that it is difficult because the MHCUs isolate themselves, are uncooperative, and need constant supervision. Some of the MHCUs disappear from home for several days without informing their caregivers, which means that in addition to taking care of the daily needs of the MHCUs, caregivers also have to keep a close eye on the MHCUs. One of the participants explained that "when we are living with her as a mentally ill person, it is challenging because we have to always keep an eye on her, especially because she does not like staying at home. She is always disappearing" (TBM 56). The chronic nature of SMDs means that some MHCUs have very short-lived recoveries. One informal caregiver expressed that the MHCUs she

cares for are only stable for a short period after his discharge from the hospital. She said, “I cannot lie and say that there was a time where it was easier to care for him because he was only fine for a short time when he comes back from the hospital, and after that it was a different story” (TBM 06).

Experience of mental healthcare users’ disruptive behaviour

The MHCUs exhibit disruptive behaviours towards their caregivers, and the participants stated that they deal with violent behaviour such as vandalism of household property, physical attacks, and insults from the MHCUs, and this makes fulfilling their caregiving role difficult. Their struggles are captured in the following comments:

> *“He broke my bedroom windows …. He was using the broken windows in my bedroom as his entrance when he wants to come to my room and insult me.” (TBM 04)*
>
> *“When he is at his worst moments, he smashes the window glasses, and he beats us up. That is when it was most difficult for us.” (TBM 98)*

The participants stated that dealing with uncooperative and aggressive behaviour is a concern, and they also reported neglect of personal hygiene and refusal to take medication. When their conditions worsen, MHCUs can become so aggressive that they have to ask for help from the police or local community who will restrain the MHCU to take them to hospital. One caregiver said the following:

> *“It was very difficult for me because in the beginning she was refusing to bath. She did not want to go to the hospital …. She refused for the lights to be switched on in her room. She was very aggressive, to such an extent that whenever we had to take her to hospital, either we had to call the police to come and help us or we tie her with ropes ourselves so that we can be able to take her to the hospital.” (TBM 08)*

MHCUs’ lack of insight also sometimes result in substance abuse, which worsens their conditions and leads to disruptions within their household. One caregiver said, “He would go to the taverns and smoke whatever it is that they are smoking and drink alcohol. When he does that, his condition gets even worse” (TBM 04).

Experience of financial strain

The informal caregivers said they have financial difficulties and struggle to provide for the needs of the MHCUs. Without a state issued disability grant, some struggled to provide for basic needs

of the MHCUs, including buying toiletries, self-care products, and food. One participant explained that "it is very difficult, especially because he is not receiving the disability grant. There are many things that he needs from soap, lotion, food, and everything" (TBM 98).

Some MHCUs' conditions are too severe to be managed at the local clinic, and as a result, the caregivers must cover transport costs to get them to hospital. In the following comment the participant explained that they have to pay what equates to a quarter of the monthly disability grant for just one trip to the hospital because they must hire special private transport, which adds to their financial strain:

> *"We pay R500 for a car hire from here to Acornhoek [hospital]. They are unable to help him in our local clinic, that is why we go to Acornhoek, and when we get there they give him injections to stabilise him. I have to make means to get money so that we can take him to the hospital." (TBM 125)*

Some of the participants struggle to make ends meet even with the disability grant, which means they sometimes have difficulty providing food for the MHCUs. The disability grant (received monthly) is considered insufficient to cover household running costs, and as a result, they must make sacrifices to provide for the MHCUs, as explained in the following comment:

> *"It's just that I don't know how I can explain it to you, but for me the main challenge is food because that R1 890 ($101) that they are getting is not enough, and I sometimes use my children's grant money and buy them what they are lacking." (TBM102)*

The caregivers suggested that the governmental social support should include food as the grant is not enough to provide food for the whole month:

> *"I understand that they are receiving the disability grant, but the food parcels would help as well. Even if they can give them, the food parcels every three months because the money that they are getting does not cover for everything that they need." (TBM 56)*

Experience of stigmatisation

The stigma attached to the MHCUs and their caregivers is an ongoing challenge within the community. The informal caregivers identified stigmatisation from their local community and family as a factor that contribute to their burden because the family and community members ridicule the MHCUs using derogatory words. These behaviours sadden the caregivers as they

regard families and community members as their primary source of support. One participant expressed her feelings as follows:

> *"Now he has become a laughing stock in the community. People are saying, 'He is mad and he has dropped out of school'. Even his father says that. He uses him as an example and refers to him as a mad person. But what can I do about it? They laugh at him and say that he is mad and it is sad when people do that to a mentally ill person." (TBM 87)*
>
> *"I wish people would give me support instead of laughing at me. Some people find pleasure in laughing at people with situations like this. They laugh at how my child is and that breaks me a lot but it would be better if they were giving me any kind of support; even if it is just a prayer for my child, so they are not doing all of that; instead they just laugh at the situation."(TBM 25)*

The caregivers expressed concerns regarding the exploitation of the MHCU's by the community members who sent them to do odd jobs without proper payment. This is captured in the following comment:

> *"People here in the village used to give him odd jobs like fetching wood in the bushes and they would pay only R10 for that or they give him a jar of traditional beer as the payment for fetching the wood. A mentally ill person does not know the worth of the work he has done; he just accepts anything."(TBM79)*

Experience of role strain

Having a person with a mental disorder within the household affects the functioning of the entire family unit. The disruptive behaviour of the MHCU impacts other family members, and therefore, caregivers must deal with the additional strain of worrying about the wellbeing of the entire family. This is captured in the following comment:

> *"My last-born child is not okay due to what she has endured from her brother. She is always angry, and when I talk to her, she is aggressive. Last year she went to further her studies at a college and she failed. To tell you the truth, I understand why she failed because even when I look at myself and this situation that we have been facing for the past nine years, it has been a difficult time for all of us." (TBM04)*

The chronic nature of SMDs and MHCUs' constant need for supervision result in role restrictions for the caregivers as some had to forego economic opportunities, such as securing employment. This is because all the choices they make revolve around the MHCUs. One caregiver said, "I do want a job, but I am scared that if I get a job, I will have to leave him alone, and they will have a problem" (TBM 125). The fact that some of the MHCUs are unable to fulfil their roles and

responsibilities as expected has a spillover effect on their caregivers. Some caregivers experienced role shift as they made adjustments to their routines to assume additional responsibilities within the family. A sibling caregiver said the following:

> *"It affects me because he is older than I am, and he has roles that he should be playing in the family but he cannot do that. So, as his younger brother, I have to step in his shoes and perform the duties of an older brother. It means now I have two roles to play because of his condition. I have to see that everything here at home and ensure the children are in order." (TBM73)*

Theme 2: Caregivers' expressed support needs

In this theme, the informal caregivers described the support they require to enable them to cope with the demands of providing care. The theme is divided in to three sub-themes, namely access to mental health services, caregiver empowerment, and social support.

Access to community-based mental health services

The interviews revealed that the current available mental health services are insufficient to meet the needs of the informal caregivers and MHCUs. Subsequently, the informal caregivers expressed the need for placement and training facilities for the MHCUs to help them attain the skills they require to lead independent lives. Some caregivers were optimistic that having access to these facilities would enable the MHCUs to attain higher levels of education to enable them to secure a job. This indicates that the informal caregivers lack information because such expectations are unrealistic considering the chronic nature of SMDs like schizophrenia that are characterised by progressive functional decline. One participant expressed their hopes as follows:

> *"Now, my biggest prayer and hope is that one day the government can get him an institution where he will stay and maybe complete his studies. It would make me the happiest person alive if I were to hear that [xxx] has found a job, even if it is not a fancy job, it would be fine. Any job where he can come home on weekends. That is what I am praying for right now, and I know that God will answer my prayers one day." (TBM 08)*

The informal caregivers also said they need support from mental health professionals, including social workers and psychologists, in the form of home visits, counselling, and tracking the MHCUs' progress. A participant explained what they need, saying, "The social workers should visit these people to see how they are doing because the more there are those visits there will counselling sessions and they would be able to see that this person is making some progress"

(TBM 73). Another caregiver said that psychologists can equip them with the necessary skills to manage and handle the MHCUs better: "Maybe there are some words that we use when we are talking with him that we should not be using, and maybe there are things that we should not be doing to him … the psychologists will know because they are well trained" (TBM 06).

Need for caregiver empowerment

This sub-theme highlights the need for empowerment as expressed by the informal caregivers. The informal caregivers want to be better prepared for the future as they do not want to be caught off-guard if the condition of the MHCU they care for worsens. A caregiver expressed the need for information on necessary skills to handle the MHCUs as follows:

> *"It would help to have someone who gives me advices on what I should do when things are like this and that. Life is going on. I do not know if maybe one day their conditions will be worse, and if it that happens, I would not know what to do." (TBM 102)*

The caregivers also expressed the need for autonomy to make decisions to benefit the MHCUs. Specifically, they mentioned flexible admission policies, particularly for substance abuse rehabilitation, as they felt the MHCUs lack the control and capacity to make informed decisions to benefit their own health. These views were expressed in the following comments:

> *"It is a very stressful for a caregiver like to go to a certain seeking help and be told that they cannot help because the mentally ill person has not agreed to what he should do to get help. In my understanding, a mentally ill person cannot agree to anything because he does what he wants his own way and he does not have control over the things he does." (TBM 87)*

> *"I think would be helpful is for rehabilitation centres to change their policies that say they must admit mentally ill people against their will. If keeping them in the rehab centre is something that will benefit them, they should admit and keep them there whether it is voluntary or not." (TBM 04)*

Need for social support

Informal caregivers highlighted their need for emotional and tangible support from the family, religious and community organisations, and the government. Some participants said they need emotional support from the family and that they would cope better with their responsibilities if their family checked in with them from time to time. Considering the stigmatisation they experience from their families and community, it could be that caregivers experienced isolation

and loneliness in their caregiving role, and hence, they feel that companionship will help them cope with their responsibilities. A caregiver said it as follows:

> *"It would be much better if she [participant's sister] were calling every now and then to check how things are going here at home; but she never does that. It would be of great help, if I can have someone to check up on us every month or every year to find out how we are doing and how I am coping." (TBM102)*

Most of the caregivers in this study are religious and use religion as a coping strategy to help navigate the challenges of caregiving, and therefore, they expressed the need for religious social support. One informal caregiver expressed a need for prayers and counselling from religious organisations such as the church: "We need support, even if it is from the church where they can give counselling and offer prayers" (TBM 125).

Most informal caregivers expressed the need for more government support in the form of grants and food parcels to ease their financial burden. The caregivers need the disability grant for the MHCU to help cover their daily needs and travel costs to hospital. This also highlighted that some of the informal caregivers lacked information on available services as some caregivers within the same community had already accessed the disability grant for their MHCU. One caregiver said, "It would help if he were getting the disability grant because I would use that money to buy him food, clothes, and use that money to travel to the hospital for his medications" (TBM 98).

The informal caregivers also hoped that community organisations, such as community development forums, could help by prioritising the needs of people with disabilities when allocating community resources. In particular, they mentioned the need for housing as the caregivers find it difficult to share the same house with the MHCUs because they neglect their chores and felt that if the MHCUs had their own space, they would become more responsible and independent. One participant suggested access to an RDP house (Reconstruction and Development Programme house or government subsidised houses) in the following comment:

> *"We have the CDF [community development forums] and it should be responsible for checking if some people qualify to get the RDP house or not. People with mental illness need their own place to stay. You cannot stay in one place with a person who is mentally ill because there are some house chores that they cannot do because they are staying with you. But once they are in their place, they will know that they have to clean the house and anything else." (TBM 56)*

Discussion

The findings in this study gave several insights into the experiences and support needs of informal caregivers who are caring for persons with SMDs in rural South Africa. The findings revealed the informal caregivers' experience of burden, which was attributed to various problems such as dealing with the chronic and disabling nature of SMDs; dealing with the behavioural problems of the MHCUs; financial difficulties; role strain encountered because of restrictions placed on caregivers' participation in tasks; disruptions in family function; lack of family support; and stigmatisation from family and the community. Owing to the burden they experience in their caregiving role, the informal caregivers indicated their need for support. These needs include access to appropriate mental health services for the MHCUs, including access to long-term placement and training facilities; caregiver support from mental health professionals; and caregiver empowerment through enforcing autonomy and caregiver education to help upskill caregivers to handle the MHCUs. Additionally, informal caregivers identified their need for social support, including emotional support from family and religious organisations, as well as tangible support from the government and community organisations.

The experience of burden expressed by the informal caregivers in this study is consistent with previous studies that indicate that caring for a person with a SMD results in objective and subjective burdens (Flyckt et al., 2015; Caqueo-Urízar et al., 2016; Silaule et al., 2023). The experiences of the informal caregivers indicate the presence of objective burden as they raised concerns about the tangible demands of providing care (Chadda, 2014), including the difficulty of dealing with the symptoms of the SMDs, such as MHCUs isolating themselves from family or disappearing from home without informing the caregiver. Subsequently, caregivers provide constant supervision, which increases the amount of time spent on caregiving. As evident in this study, some of the caregivers (41.7%) spend long hours (19–24 hours per day) on caregiving. This prevents the caregivers from participating in other tasks, which compromises their freedom to select and engage in activities of their choice, subsequently leading to role strain. In this study, 33.3% of the informal caregivers are unemployed, and the caregivers reported that while they wanted to get a job, they often cannot get one because they have to take care of the MHCU. These findings are similar to those reported in other studies that reveal that informal caregivers often have to leave their jobs or forego economic opportunities to provide full-time care to MHCUs

(Marimbe et al., 2016; Yerriah et al., 2021). The inability to engage in economic activities means that some of the caregivers are unable to earn a living to support their families and meet the needs of the MHCUs. As a result, the informal caregivers rely on the MHCUs' disability grant to cover all household expenses and cater for the needs of the MHCU, including food and travel costs to the hospital, which leads to financial strain. The informal caregivers reported that the disability grant is insufficient to cover all household expenses, and that they often struggle to purchase enough food for a month. This finding is consistent with the current situation in Bushbuckridge municipality where there are few economic opportunities, and as such, two out of nine people depend on a disability grant, and for many this is the only source of income within the family (Wright, 2015). Wright (2015) reveals that the families of those receiving a disability grant depend on this money to cover all household expenses, including food, clothes, and electricity, and many expressed concern that their food do not last a month. The fact that caregivers expressed having difficulty providing food raises a serious concern about food security among the caregivers and persons with SMDs. Studies conducted in rural Ethiopia reveal that one-third of households who have a person with a SMD are affected by food insecurity. Limited access to disability payments, discrimination, and low annual household income precipitate this problem (Tirfessa et al., 2019, 2020). In the current study, some caregivers expressed having limited access to the disability grant, and those who receive the disability grant indicated that it is not enough to cover the household running costs, thus exposing them to food insecurity. It can be assumed that the threat to food security expressed by the informal caregivers has serious implications for the health and wellbeing of the caregivers and the MHCUs, and this is likely to exacerbate the burden experienced by the informal caregivers. It is therefore important that strategies be put in place to increase financial support for caregivers and people with SMDs in order to uphold Sustainable Development Goal 2, which aims to end hunger by increasing access to enough good quality food to lead to a healthy life (Guterres, 2020).

The functional limitations of the MHCUs mean that some are unable to fulfil their roles and responsibilities as expected. As a result, the informal caregivers expressed experiencing a role shift because they have to adjust their routines to ensure they take up additional responsibilities within the household. These findings are consistent with Ntsayagae et al.'s (2019) finding that informal caregivers often experience a role shift as they shift their responsibilities to ensure they balance their everyday roles while fulfilling their caregiving duties.

The poor insight from the MHCUs in relation to their own illness affect the caregivers as some engage in substance abuse despite being diagnosed with a mental disorder. Previous studies highlight substance abuse as a contributing factor to burden among caregivers of those with SMDs (Tekin Uludağ & Güleç, 2016), and there is a high co-occurrence reported between substance abuse and SMDs such as schizophrenia and bipolar mood disorders (Torrens et al., 2011; Pettinati et al., 2013). Higher alcohol, cannabis, nicotine, and cocaine use are reported among those with schizophrenia than in the general population (Lubman et al., 2010), and this leads to high relapse rates (Soyka, 2000). The caregivers in the current study also reported that MHCUs who abuse substances get worse and often cause disruptions within their households.

The informal caregivers said they have difficulty dealing with the disruptive and uncooperative behaviour of the MHCUs, such as vandalism of property, enduring physical attacks, verbal insults, poor personal hygiene, and aggressive behaviour because they refuse to take their medication. Such behaviours threaten the safety of the informal caregivers, who expressed distress at having to deal with these behaviours. This finding supports the findings of studies that highlight a strong link between MHCUs' violent behaviour and caregiver burden (Hanzawa et al., 2013; Onwumere et al., 2018; Vukeya et al., 2022). The behavioural implications of SMDs on the family unit reported in this study are important because the disruptive behaviour of the MHCUs disrupts the health and wellbeing of other family members, thus affecting family functioning. As a result, the informal caregivers have to worry about the wellbeing of the entire family, which add to their caregiving burden. Previous studies highlight that stressful family environments lead to physical and psychological distress in the families of MHCUs (Thunyadee et al., 2015; Ellersgaard et al., 2018; Fekadu et al., 2019).

Understanding the sources of burden as well as the needs of the informal caregivers are important for the development of intervention programmes to improve patient outcomes and ensure caregivers' wellbeing (Chen et al., 2019). The informal caregivers in this study expressed various support needs, including the need for access to community-based mental healthcare services, caregiver empowerment, and social support. Chan (2011) reveals that access to services, resources, and support for MHCUs and their caregivers is important to alleviate burden of care. The expressed need for training facilities for MHCUs calls for strengthening and diversifying community mental health services, including ensuring the availability of residential facilities and day centres (Robertson & Szabo, 2017). The WHO (2014a) states that community mental health services are

accessible and effective in promoting quality of life for both MHCUs and their families, and therefore, having such facilities ensure proper rehabilitation for MHCUs and enable them to gain the necessary functional skills to be more independent. This eliminates role strain for informal caregivers and allows them time to engage in activities of their choice, including income-generating activities to reduce their financial burdens. Tirfessa et al. (2020) found that food insecurity in households of persons with SMDs can be reduced by improving access to mental health services, which supports the current study's finding. It can be concluded that if community mental health services are available, it will decrease the threat of food insecurity expressed by the informal caregivers, and therefore, it is urgent to redirect mental health resources towards strengthening and improving accessibility of community mental health services (Tsui & Tsang, 2017).

The informal caregivers also expressed a need for support from mental health professionals who can provide information on handling MHCUs, counselling, and home visits. Previous studies report that home visits are valuable because they create opportunities to build therapeutic relationships, facilitate treatment continuity, and reduce readmissions among MHCUs (Bowman et al., 2014; Chang & Chou, 2015). Similarly, psychoeducation is effective in increasing caregivers' knowledge about mental disorders, which enables them to cope effectively with their caregiving duties, thus improving their wellbeing (Sin & Norman, 2013; Soo et al., 2018). There is a healthcare worker shortage in Mpumalanga province, including mental health professionals, and as a result, it may not be feasible to meet the informal caregivers' expressed needs (Lefafa, 2023). It is therefore necessary to implement task shifting by training lay health workers to help support informal caregivers within the community (Kemp et al., 2019).

The need for caregiver empowerment expressed by the informal caregivers in this study indicates their desire to be active participants in the care of the MHCUs and the delivery of mental health services. The informal caregivers indicated their need for skills to be better equipped to handle any behavioural changes in the MHCUs' conditions. In addition, they called for flexible admission policies to give them the power to make informed decisions in the management of the MHCUs. Chiu et al. (2013) highlight that caregiver empowerment is important as it facilitates the active contribution of caregivers in the recovery of MHCUs and enhances caregivers' self-efficacy. Ntsayagae et al. (2019) reveal that caregivers who feel empowered experience satisfaction and positive feelings in their caregiving. Access to appropriate mental health services; knowledge

about the relevant SMD and available services; support; and reinforcement of caregiver coping strategies empower caregivers (Chiu et al., 2013; Jessy & Kalaimathi, 2014). It is therefore important to ensure caregivers are trained to care and manage MHCUs. Additionally, policy makers should consult caregivers when planning and developing services to ensure the appropriate distribution of resources to meet the needs of both the MHCUs and their caregivers.

The informal caregivers expressed the need for emotional support from family and religious organisations, as well as tangible support from the government and community organisations. The need for emotional support from the family members confirm the findings of previous studies that informal caregivers lack support from their family members. Consequently, they are forced to endure the burden of caregiving and fulfil other responsibilities without the necessary support (Ebrahimi et al., 2018; Vukeya et al., 2022). Most of the informal caregivers in the current study are religious, and as a result, they expressed a need for religious support in terms of prayer and counselling. These findings support the findings of a study conducted in rural Uganda that prayer gives informal caregivers hope, which helps them cope with caregiver burden (Ae-Ngibise et al., 2015). The informal caregivers mentioned the need for tangible support in the form of money, food parcels, and housing from the government and community organisations. The findings in the current study revealed the complexities of providing care to persons with SMDs. The informal caregivers highlighted multiple factors that contribute to their experience of burden in their caregiving, including the nature of the MHCUs' conditions; limited access to economic opportunities; limited access to community mental health services; food insecurity; stigmatisation by family and the community; lack of relevant policies and procedures to empower caregivers; and lack of support from family, the community, and the government. This therefore supports the belief that caregiver burden is multidimensional (Fekadu et al., 2019) and requires multisectoral collaboration to address the needs of MHCUs and their caregivers.

This study established the experience of burden among informal caregivers of persons with SMDs in rural South Africa. The need for support expressed by the informal caregivers clearly shows the difficulties they face in coping with the demands of their caregiving roles. This calls for urgent action to develop and strengthen strategies for supporting informal caregivers of persons with SMDs.

The main limitation of the study was that it only included participants from the first quantitative study that was conducted at a single research site. This eliminates the views of other informal caregivers who may experience burden in their caregiving duties but who were not included in the first study. While informal caregivers preferred for the interviews to be conducted in their homes, which gave the interviewer an in-depth understanding of the caregiving context, there was limited space for privacy for some caregivers, which affected their ability to freely share their experiences. Only three male caregivers were interviewed in this study. This limits the views of the male caregivers and their experiences in the care of the MHCUs. The limited exploration of the male caregivers' experience is likely to limit the development and implementation of intervention strategies aimed directly at male caregivers. Consequently, the support needs of these caregivers are likely to be neglected, which then predisposes them to higher levels of burden and subsequent negative effects on their health and well-being.

Conclusions

The present study offers several crucial contributions. On the methodological level, the study follows the quantitative study that was conducted to establish the extent of burden among the informal caregivers in rural South Africa (Silaule et al., 2023), and the experience of burden reported by the informal caregivers in the current study affirms caregiver burden as a multidimensional concept that requires multiple methods to investigate. The burdens reported by the informal caregivers are mainly related to the tangible effects of caregiving, which indicates that the caregivers experience objective burden. These findings supports those of the first quantitative study (Silaule et al., 2023) that there is high levels of objective burden among this population. In addition, these findings provide an in-depth understanding of the factors contributing to caregiver burden from the caregivers' perspectives, which is necessary for planning and developing appropriate support strategies for alleviating the burden among the informal caregivers.

On practice level, the findings show an urgent need to integrate caregiver interventions in routine clinical practice. These interventions should aim to improve caregivers' knowledge about and skills to handle MHCUs, empower caregivers to take an active role in the planning and delivery of mental health services, and strengthen caregiver coping strategies to promote their health and wellbeing. Family interventions should be encouraged to develop insight among MHCUs so they

understand the implications of their behaviour on their caregivers. The experience of role restrictions, which predisposes informal caregivers and their families to food insecurity, is a serious public health concern. Mental health professionals, including occupational therapists, have a critical role to play in this regard, particularly in terms of offering interventions to enable informal caregivers to balance their caregiving duties with other responsibilities without compromising their health. Additionally, occupational therapists can work with informal caregivers and MHCUs to explore economic opportunities to help alleviate their financial burdens.

On the policy level, the findings call for policy makers to ensure they include informal caregivers as key stakeholders in the planning and development of mental health services, particularly in low-resourced settings like rural South Africa where caregivers are the primary source of support for MHCUs. Policies aimed at directing mental health service delivery should prioritise services targeted at improving the health and wellbeing of informal caregivers to direct the distribution of resources that will meet the needs of both MHCUs and their caregivers. There is a need for placement facilities and day centres for MHCUs within the community because this will allow informal caregivers respite and time to engage in other tasks as required in their environment. As evident from the findings of this study, caregiver burden is multidimensional, and as a result, interventions targeted at alleviating burden require multisectoral collaboration between health, social development, local government, and community organisations.

Data availability

Data used to support findings are already included in the article, and therefore, data sharing is not applicable to this article.

Conflicts of interest

The authors have no conflict of interest to declare.

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3.3.2 Health effects of caregiving and coping with severe mental disorders: A caregivers' experience

Manuscript (b) is presented as a published article, which reports on the health effects of caregiving and the coping strategies used by the informal caregivers of persons with SMDs. Table 3.4.outlines the details of the article

Table 3.3 Manuscript (b) details

Title	Journal	Author contributions		Key findings	Status
Health effects of caregiving and coping with severe mental disorders: A caregivers' experience	*South African Journal of Psychiatry* DHET accredited Impact factor: 1.7 DOI: 10.4102/ sajpsychiatry.v 30i0.2144	Conceptualisation	Silaule, Nkosi & Adams	Caregivers experience of physical, emotional, and mental consequences. Caregivers experience of using internal and external coping strategies	Published
		Manuscript draft	Silaule		
		Manuscript review and editing	Silaule, Nkosi & Adams		
		Supervision	Nkosi & Adams		

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Health effects of caregiving and coping with severe mental disorders: A caregivers' experience

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Background: Informal caregivers are an essential health resource in the care of persons with severe mental disorders, particularly in South Africa where access to mental healthcare services is limited.

Aim: The study aimed to explore and describe the coping strategies used by informal caregivers and the specific health impacts they face in the context of severe mental disorders in South Africa.

Setting: The study was conducted in Bushbuckridge municipality situated in the northeastern parts of Mpumalanga province, South Africa.

Methods: A descriptive qualitative methodology was used to conduct semi-structured interviews with 12 purposefully selected participants. Audio-recorded interviews were translated, transcribed and analysed inductively on NVivo12 using reflexive thematic analysis.

Results: The themes identified were caregivers' experience of consequences of caregiving and caregivers' experience of coping with their caregiving role. Participants experienced negative consequences on their emotional, mental and physical health. The participants use internal and external resources to cope with the challenges they face, and many highlighted using emotion-focused coping strategies.

Conclusion: The findings revealed an urgent need to develop support strategies to strengthen informal caregivers' coping and promote good health particularly in rural South Africa where informal caregivers play a crucial role in the management of severe mental disorders.

Contribution: The finding demands that policymakers and healthcare providers prioritise the health and well-being of the informal caregivers. There should be policies targeted specifically at developing and implementing caregiver-orientated healthcare services.

Keywords: informal caregiver; informal carer; caregiving; positive coping mechanisms; negative coping mechanisms; caregiver health; caregiver well-being; mental disorder; severe mental disorder.

Introduction

Mental disorders are a leading cause of disability and significant contributor to the global disease burden.[1] In lower- and middle-income countries (LMICs), mental disorders account for 5% of the total disease burden and 19% to the years lived with disability (YLDs).[2] Severe mental disorders (SMDs) including schizophrenia, bipolar disorders, and depressive disorders are among the top 10 leading causes of disability within LMICs.[3] In South Africa (SA), schizophrenia contributes approximately 2.1% to the overall disease burden,[4] and bipolar mood disorders have been identified as affecting 4 million people, indicating that 1% of the population suffers from these disorders.[5] A lifetime prevalence of depressive disorders is estimated at 9.8% and a 12-month prevalence at 4.9% making it a major contributor to the disease burden in the country.[6]

The growing burden of mental disorders in LMICs is exacerbated further by the limited access to mental health services.[7] Limited funding, poor policy implementation, a lack of infrastructure, limited institutional support and staff shortages have been identified as leading factors contributing to the limited access to mental health services in LMICs.[7,8] The treatment gap between those who need and those who receive treatment is estimated to be at 90% within LMICs.[9] It is estimated that only 15% – 25% of people with mental disorders receive treatment in LMICs.[10] In SA, only 27% of persons with SMDs receive adequate treatment.[11] The limited access to mental health services calls for informal caregivers including the families, friends and relatives

to become key role players in the care and management of SMDs.[12]

The role of informal caregivers in severe mental disorders

The limited access to proper care, treatment and rehabilitation for people with SMDs requires informal caregivers (family, friends, or any person providing care without remuneration) to become a vital healthcare resource in LMICs including SA. The chronic nature of severe mental disorders often results in serious functional limitations that compromise their ability to independently fulfil roles as friend, family member or a worker.[13] Subsequently, informal caregivers take charge of the physical, emotional, medical, and financial needs of care recipients with a SMD.[14] The inherent tasks fulfilled by the informal caregivers in their role include taking care of the day-to-day needs of the care recipients including supervising participation in self-care activities, providing meals and safety for the mental healthcare user (MHCU), seeking help for the MHCU, early identification of relapse, supervising medications, and looking after their financial needs.[12,15] In addition, informal caregivers are required to meet the emotional needs of the MHCUs and deal with the unpredictable, hostile, or risky behavioural disturbances exhibited by the MHCUs.[16] Consequently, fulfilling the role of caregiving tends to be demanding and often introduces an intolerable strain.[17]

Negative consequences for caregivers

The role of informal caregiving is a mammoth task and many are thrust into this role without preparation, knowledge or support.[14] Studies conducted in LMICs revealed a general neglect of the informal caregivers' health status.[14,18] This is because most of the attention is directed towards the health and well-being of the MHCUs.[19] Informal caregivers are often excluded from the decision-making processes regarding the mental disorder and treatment, and their needs are not taken into consideration; as a result, these caregivers do not have a chance to express their concerns and needs.[18] Without preparation, knowledge or support, informal caregivers of persons with SMDs often experience changes in their life.[14] Caregiving is associated with several negative experiences including physical, mental, and social consequences,[18,20,21,22] which subsequently impact their quality of life.[23] Previous studies conducted in LMICs reveal that caregivers experience negative emotions such as irritability, frustration, guilt, shame, and helplessness, which predispose them to mental health problems such as depression, anxiety, stress, and burnout.[14,22,24,25,26] In addition, caregivers experience deterioration in their physical health, including developing physical conditions such as diabetes, high blood pressure, and body aches.[14,26,27] Research evidence emphasises the importance of caregivers in the well-being and relapse prevention of persons with SMDs,[28,29] and thus, any negative consequences on the caregivers' health threaten the well-being of their care recipients.

Coping mechanisms

Literature highlights that different informal caregivers utilise various coping mechanisms when caring for the MHCUs.[30,31] Coping mechanisms relate to any cognitive and behavioural efforts made by any person to prevent, manage, or control emotional distress and protect them from the effects of a stressful life event.[32] Lazarus and Folkman[32] classify coping mechanisms into problem-focused and emotion-focused coping mechanisms. Problem-focused coping mechanisms use problem-solving skills to deal directly with a stressful situation, and emotion-focused coping mechanisms relate to efforts made to change one's view about a stressful life event.[32] These mechanisms can be positive or negative. Positive mechanisms include cognitive and behavioural responses such as positive thinking, information seeking, problem solving, and action-orientated pursuits, and social coping mechanisms include social support from family, friends, and religious organisations, access to community resources, and professional support.[33,34] Some of the positive coping mechanisms used by informal caregivers are accessing and using available services, spending time on self-care related activities, sharing experiences with others, accessing information on mental disorders, building resilience, participating in religious activities, and relying on social support from family and friends.[26,33,34] In their study, Ong et al.[30] established that informal caregivers of persons with schizophrenia who utilised positive mechanisms such as social support, spirituality or religious coping, active coping, acceptance and positive reframing experienced lower levels of distress.

In contrast, negative coping mechanisms include avoidance behaviour,[33] disregarding the care recipient, exhibiting resentment towards the care recipient, isolation, denial, and using medication to numb themselves.[25,34] Negative coping mechanisms among the informal caregivers of MHCUs have been associated with high levels of distress.[30] A study by Ata and Doğan[35] revealed that informal caregivers of persons with schizophrenia were likely to use negative coping strategies including crying, denial of the MHCUs' condition, self-blame, social withdrawal and diplaying aggressive behaviour towards the MHCU. The type of coping mechanism used has been linked with the informal caregivers' level of education. In their study, Parks et al.[31] established that informal caregivers who utilised positive mechanisms such as active coping and seeking information of the condition of the MHCU had higher levels of education, while negative mechanisms such as avoidant behaviour were common among those with lower levels of education.

Research gap and study objective

Understanding the implications of caregiving on informal caregivers and the coping mechanisms they use are important to develop support to promote their health and well-being, which will in turn enable them to provide quality care to

persons with SMDs.[34] Previous studies conducted in LMICs, including South Africa, focused on the generic experiences of caregiving, and many other studies focused on the caregivers of persons with schizophrenia. Therefore, there is a paucity of evidence on the effects of caregiving on caregivers' health and the coping mechanisms they use when caring for persons with SMDs. To address this gap, the study aimed to explore and describe the coping strategies used by informal caregivers and the specific health impacts they face in the context of severe mental disorders in South Africa.

Research methods and design

Study design

A qualitative descriptive research approach was used to conduct semi-structured interviews with informal caregivers of persons with SMDs between January 2022 and June 2022.

Study setting

The participants were recruited from the first quantitative study that took place in the acute mental health unit in a district hospital in Bushbuckridge municipality, Mpumalanga province, South Africa. The mental health unit has a 50-bed capacity, which is the largest in the Mpumalanga province. This unit has a large catchment area as it offers both in- and outpatient mental health services to the residents of Bushbuckridge municipality and surrounding communities, and thus, covers a population of more than 546215.[26] Services provided include child, adolescent, and adult mental health services ranging from acute to chronic and forensic cases. Persons with SMDs are often treated and followed-up in this facility.

Study population

Participants were purposely selected from the first quantitative study that aimed to establish the extent of caregiver burden among the informal caregivers of persons with SMDs.[37] During the first study, potential participants who expressed interest were recorded. Once this study commenced, participants were contacted telephonically and invited to participate. A sample size of 12 participants was adequate to allow for full exploration of caregiving experiences and answering the research question. Data were considered saturated as no additional information were identified.

The primary inclusion criterion was that participants had to be an adult (+18 years) informal caregiver providing continuous unpaid care to a person with a SMD for longer than 6 months. Participants had to perform caregiving duties at least once a week. Only participants who presented with a subjective or objective burden (mild, moderate, or severe) in the first study were considered for participation.

Data collection

Potential participants were contacted telephonically. The main researcher and the participants agreed on a date, time, and convenient place to conduct the interviews. All participants preferred for the interviews to be conducted in their homes, which provided adequate privacy and allowed for a rich exploration of experiences within the caregiving context. The main researcher is a local resident of Bushbuckridge municipality, and this made it easier to relate to the participants. Prior to the interviews, the researcher went through the information sheet detailing the purpose of the study. Informed consents, one for participation and another for audio recording, were gathered from the participants. Demographic characteristics of the informal caregivers were documented using a demographic questionnaire. An interview guide was used for the semi-structured interviews.[38] To enable participants to share their experience from their own perspective, an open-ended question asked the participants to describe their experience of caregiving. Following this, the researcher asked questions aimed at exploring the burden of care among the informal caregivers. Participants were asked to describe the following: (1) the burdens encountered in their caregiving; (2) the impact of these burdens on their lives; (3) the sources of the burdens experienced; and (4) the resources and support they require in their caregiving role. The interviews lasted between 30 min and 60 min, depending on the experiences shared by the participants. All interviews were conducted in Xitsonga, the first language of both the participants and the researcher.

Data analysis

All interviews were audio recorded. A language specialist working in a research facility in Bushbuckridge municipality transcribed and translated the interviews into English. Transcriptions were entered into NVivo 12 software and reflexive thematic inductive analysis was performed following the six-phase approach proposed by Braun and Clarke.[39] Data familiarisation was carried out by listening to the recordings, and reading and re-reading the transcripts. Notes were taken that guided the generation of ideas for coding. Initial codes were assigned using inductive coding and each code was assigned a description to ensure consistency in the coding process. The codes were then grouped and initial themes were generated. Themes were developed and reviewed by generating maps on NVivo, which were printed and displayed to allow for comprehensive visual representation of the initial themes. At this stage, some codes became themes and additional codes were grouped for further analysis. The refining and renaming of themes were performed by reading coded extracts to ensure they merged coherently to form a pattern for a specific theme. This was followed by re-reading the dataset and familiarisation with the notes to ensure that no codes were missed and that the themes were valid. Trustworthiness was ensured by conducting an audit trail of the analysis process with an experienced qualitative researcher. The findings were then presented to research supervisors who reviewed the analysis process and by conducting peer briefings. This process allowed for reviewing, refining, and naming the themes as well as promoting the quality and truthfulness of the findings.

The main researcher kept a reflexive journal to document all the thoughts and observations made during the study.

Ethical considerations

The Human Research Ethics Committee of the University of the Witwatersrand (M200957) approved this study. Permission was also sought from the Mpumalanga Department of Health Research Committee (MP_202010_010). Informed consent was obtained from the participants before data collection to participate in the study and to record audio during the interviews. To ensure confidentiality, each participant was assigned a participant ID.

Results

A summary of the informal caregivers' demographic and caregiving characteristics is presented in Table 1. Most participants are the mothers (50.0%) of the mental healthcare users (MHCUs) and are above the age of 65 (41.7%). The majority (66.7%) live in the same residence as the care recipient and have been providing care for 11–20 years (58.3%). Most caregivers spend between 1 h and 8 h a day on caregiving (50.0%) and others spend 19 h – 24 h per day (41.7%).

The participants were asked to describe their lived experience of providing care to a person with a SMD, and two themes were identified from the data during the inductive analysis, namely caregivers' experience of consequences of caregiving, and caregivers' experience of coping with their caregiving role. Each theme has sub-themes that describe the expressed experiences in more detail.

TABLE 1: Demographic characteristics of informal caregivers of persons with severe mental disorders ($N = 12$).

Characteristic	Frequency	Percentage
Age		
20–39	3	25.0
40–65	4	33.3
>65	5	41.7
Gender		
Female	9	75.0
Male	3	25.0
Marital status		
Single	2	16.7
Married	7	58.3
Divorced	2	16.7
Widowed	1	8.3
Education		
Primary school level	2	16.7
Secondary school level	4	33.3
Tertiary level	2	16.7
Uneducated	4	33.3
Employment status		
Employed	1	8.3
Unemployed	4	33.3
Pensioner	6	50
Self-employed	1	8.3
Relationships		
Mother	6	50
Father	2	16.7
Sibling	4	33.3
Number of care recipients		
1	10	83.3
2	2	16.7
Duration of caregiving		
5–10 years	5	41.7
11–20 years	7	58.3
Daily caregiving		
1–8 h	6	50
9–18 h	1	8.3
19–24 h	5	41.7
Monthly household income (ZAR)		
≤ 1000	1	8.3
1100–5000	10	83.3
≥ 5000	1	8.3
Monthly medical costs (ZAR)		
≤ 100	1	8.3
101–500	11	91.7
Residence		
Same as care recipient	8	66.7
Different as care recipient	4	33.3

ZAR, South African Rand.

Caregivers' experience of the consequences of caregiving

When describing their experiences of the consequences of caregiving, the participants highlighted these sub-themes: emotional consequences of caregiving, walking on eggshells, mental consequences of caregiving, and physical consequences of caregiving.

Emotional consequences of caregiving

The participants expressed living in a constant state of vigilance because of the MHCUs' previous violent behaviour and unpredictability caused by their mental conditions. Despite the MHCUs being on treatment, the caregivers feared they will relapse and exhibit the same behaviours as displayed prior to treatment. One caregiver said:

> 'Even when I am with him, I am very cautious because I am scared that at any time he can change and be that person he used to be before he started taking the treatment.' (TBM79, Mother, age 73)

The participants grieved the loss of potential for their care recipients to lead independent lives, which leads them to subsequently lose hope and experience feelings of anguish. One participant explained it as follows:

> 'When I was raising my children, I had hope that one day they will be able to look after themselves so that I can also have a break. So, instead things are just getting worse, and it makes me realise that I will never have a break until I die.' (TBM04, Mother, age 65)

Walking on eggshells

The participants explained that they feel they must tread gently around the MHCUs as they fear that any disagreement with the MHCUs will trigger their illness. As a result, the participants follow the MHCUs' lead to avoid triggering their illness, for example:

> 'If he does not want to talk and you insist on talking to him, it triggers him, and sometimes you may even have to take him to the hospital. So, as a caregiver I have to be always gentle with him in everything.' (TBM48, Father, age 73)

Some participants fear the MHCUs they are taking care of and give in to their demands to maintain harmony within their homes. One participant explained that 'it is easier when I agree with him because if I do not, he gets angry and bad things happen when he is angry.' (TBM06, Father, age 64)

Mental consequences of caregiving

The participants reported insomnia, a depressed mood, and memory problems. The stress of caregiving triggers sleep disturbances and forgetfulness as the participants are preoccupied with caregiving responsibilities, and as a result, their mental health is compromised. This was captured in the following comments:

> 'There are days where I do not sleep at all at night, and I cry a lot.' (TBM79, Mother, age 73)

> 'Since I have been caring for him, I am very forgetful.' (TBM 04, Mother, age 65)

Some of the participants also relive past traumas because of their caregiving. One participant had a recollection of painful past events:

> 'I have been living a very difficult life for many years because even when I was married my husband abused me. I decided to separate from him and come back home with my children. I was hoping that life will be better, but it doesn't get any better. The whole situation changed for the worst.' (TBM04, Mother, age 65)

Physical consequences of caregiving

Some participants reported that they have developed medical conditions and others reported that their pre-existing medical conditions have worsened because of the stress of providing care. Most participants reported being diagnosed with hypertension since providing care; for example: 'I was always stressed and crying to a point where I was diagnosed with hypertension, and I have been put on treatment because of that' (TBM125, Mother, age 45). A participant who suffered a stroke said:

> 'I was told that my blood pressure was very high and I was at a high risk of a stroke. Even now, there is a part of my body, which is not yet fine. It is not functioning well, and I get tired very easily because of it.' (TBM48, Mother, age 68)

Other participants reported weight loss that they attribute to their caregiving role. One caregiver said, 'This is not my normal weight. I have lost weight due to all the problems that I have faced.' (TBM79, Mother, age 73)

Caregivers' experience of coping with their caregiving role

The participants reported various coping strategies they use in their caregiving role that are described in the sub-themes: internal resources for coping and external resources for coping.

Internal resources for coping

The participants rely on their resourcefulness and resilience to help them cope with caregiving. Some of the strategies used include acceptance of their situation, perseverance, being patient, exercising self-control, loving the MHCU, and socialising with others. Accepting their responsibility as a caregiver allows the participants to show unconditional love to the MHCUs, which enables them to develop tolerance for their disruptive behaviour. One participant explained:

> 'Providing care for a mentally ill person is very difficult, but for as long as that love for him is still there, we survive, and that is why when we do not see him around, we make sure that we go around and look for him to bring him home.' (TBM79, Brother, age 42)

Most participants use religion to cope and reported accepting their situation as something God destined for them. One participant explained that she resorts to prayer as she has found it helps improve the MHCUs' condition: 'My support comes from prayer because when he starts, I just pray and he gets better.' (TBM48, Mother, age 68)

Having a sense of a collective experience in caregiving is another coping strategy the participants identified. They said that seeing other informal caregivers at the hospital during the MHCUs' follow-up visits gives them a sense of comfort and universality as they realise they are not alone in their situation. One participant explained that 'the only way to deal with this is to understand that other people are going through the same situation, and it is difficult for them.' (TBM102, Mother, age 77)

External resources for coping

Having access to medical and social support helps some participants cope with their caregiving. Participants who access medication and hospitalisation for the MHCUs indicated that this helped stabilise the MHCUs, thus making it more manageable to provide care: 'The hospital has helped as well. He stayed in hospital, and he was given injections and other treatment until he was better.' (TBM79, Brother, age 42). Other participants indicated that access to social worker services within the community helps them to cope. The social workers conduct home visits and arrange rehabilitation for the MHCUs with substance abuse problems, which make the participants feel supported, as one participant explained:

> 'The social workers were visiting us from time to time. They suggested that he should be taken to a rehab centre hoping that maybe he will forget about the things that he smokes. That shows that I had the support I needed in caring for him.' (TBM04, Mother, age 65)

Some participants receive social support from family, the community, and religious organisations. They indicated

that they received financial and emotional support from their families, which gave them encouragement. One caregiver said:

> 'I am getting support from my mother and my siblings. They always call to check how we are doing and to encourage me. They also sometimes give me money to help me care for him, and pay for the cars that we hire to take him to the hospital.' (TBM98, Sister, age 38)

Other participants said their families help with caregiving duties, which gives them time to attend to other tasks: 'That girl who just came in helps if I have to go somewhere. She is the one who looks after her and remind her to take her medications and bath.' (TBM102, Mother, age 77)

Some participants also receive help from community members who prevent the MHCUs from engaging in disruptive activities such as substance abuse, reinforce medication compliance, and take the MHCUs to the hospital. One participant said, 'People used to help me to hold him down and tie him so that we can take him to the hospital for the medications' (TBM04, Mother, age 65). Participants also reported receiving support from the church through prayer and words of encouragement, which enables them to accept their caregiving situation. One participant said:

> 'They pray with me and for us. After praying, there is a change, and I come home feeling free and calm and be able to accept whatever situation that may come.' (TBM102, Mother, age 77)

Discussion

The study highlighted the health effects that caring for persons with a SMD has on informal caregivers in rural South African and the coping strategies they use. This study's findings revealed that caring for a person with a SMD has negative consequences on informal caregivers' emotional, mental, and physical health. This finding is similar to that of Phillips et al.[40] that caring for a person with a SMD negatively impacts the physical and mental health of caregivers. According to Ntsayagae et al.,[25] caregivers of persons with SMDs experience negative emotions, such as feelings of hopelessness, emotional pain because of the level of care required by MHCUs, and helplessness as the SMD progresses. The participants' experiences in this study are consistent with this and highlighted the impact of caregiving on caregivers' emotional health. The participants also had varying experiences that compromise their emotional health; for example, they reported living in a constant state of vigilance because of the MHCUs' previous violent behaviour and the unpredictability of their mental conditions. Their sense of helplessness and hopelessness was attributed to grieving the MHCUs' loss of potential to achieve independence, subsequently resulting in emotional pain. Ntsayagae et al.[25] highlight that helplessness and fear often go hand in hand. The participants in this study live in a constant state of fear as they are cautious of their actions to avoid triggering a relapse in the MHCUs. Subsequently, they adopt avoidant coping strategies such as agreeing with the MHCUs to maintain peace in their homes, which is similar to what is reported in previous studies.[41,42]

Brain et al.[43] notice that 85% of caregivers of persons with treatment-resistant schizophrenia reported a negative impact on their mental health. Gupta et al.[26] reveal that those caring for persons with schizophrenia experience sleep difficulties and insomnia. The findings in this study are consistent with these results, and also revealed that the caregivers experience memory problems, which could be attributed to preoccupation with caregiving responsibilities and the stress of caregiving.[44] These findings highlighted that informal caregivers are at risk of developing anxiety and depression, emphasising the need to integrate health screening for caregivers into routine clinical care.[45] The experience of reliving past traumas expressed by the participants can be seen as a predisposing factor to psychiatric conditions such as post-traumatic stress disorders. These findings are similar to those reported by Nuwara et al.,[46] who establish that the stress of caring for persons with schizophrenia and bipolar affective disorders places caregivers at risk of post-traumatic stress disorders. Similar to the findings of previous studies,[24,47] the stress of caregiving encountered by the participants in this study manifests as physical illnesses, with some reporting weight loss, high blood pressure, and cardiovascular conditions such as stroke. The effects of caregiving on emotional, mental, and physical health highlight the urgent need for routine health screening among the caregivers because it will facilitate early interventions to promote caregivers' health and well-being, thus enabling them to provide quality care to MHCUs.

Most participants use emotion-focused coping strategies such as positive skills and emotions such as love, patience, self-control, acceptance, and perseverance to help them develop a sense of resourcefulness and resilience to adapt to the stress of their caregiving role. This finding is consistent with the benefit-finding theories for stress adaptation and coping, which indicate exhibiting positive emotions is crucial for fostering a variety of adaptive and durable personal resources important for developing resilience.[48] The use of religious coping expressed by participants in this study is similar to the finding by Modise et al.[49] that caregivers of MHCUs use prayer as a coping mechanism as they believe this helps with their challenges. In contrast to other studies, the participants in this study found hope in being part of a collective of caregivers who share similar experiences in their caregiving. This emphasises the need for caregiver support groups to create opportunities for sharing and facilitating the universality for caregivers to realise they are not alone in their stressful circumstances.[50] The findings also revealed that some participants use problem-focused coping strategies to seek and use medical and social support. Access to medication, social worker services, and social support from family, the community, and religious organisations are external resources that help the participants cope. Previous studies reveal that problem-focused coping strategies

are more effective at reducing distress and improved patient outcomes compared to emotion-focused coping strategies[18,51,52] because problem-focused coping strategies deal directly with the root cause of the stressful situation, and thus, encourage the use of both internal and external resources to cope.[51,53] In contrast, emotion-focused coping strategies use internal resources to cope.[53] While some participants in this study have access to medical and social support, it is important to notice that these services are not readily available for all participants. Therefore, most participants rely on their internal resources to cope, predisposing them to negative health consequences. Evidence suggests that the coping strategies used by the caregiver impact MHCUs' health, relapses, and readmissions.[54] It is therefore important to focus on building internal and external resources to facilitate coping and promote the health and well-being of informal caregivers and MHCUs.

As a qualitative study that used purposive sampling, the findings of this study cannot be generalised as they may not be representative of the experiences of all informal caregivers in Bushbuckridge municipality. In addition, participants for this study were selected from the first quantitative study, thus excluding those who did not participate in this study. The strength of the study is that it explored the full range of caregiving experiences, allowing for reporting on the positive aspects of caregiving, which is different from previous studies that mostly report on the negative coping strategies used by caregivers.

Conclusion

The study provides insights into the impact of caregiving on the emotional, mental, and physical health of informal caregivers and the coping strategies they use. The findings revealed that caregivers use their internal resources to appraise their caregiving experience; however, this was insufficient because informal caregivers were still susceptible to negative health consequences. The findings demand that policymakers and healthcare providers prioritise the health and well-being of the informal caregivers. Routine health screenings should be implemented in clinical practice to ensure early detection of health conditions, which will also facilitate early interventions. Policies in mental health should clearly outline specific caregiver-orientated services to ensure the planning and implementation of such services. Future research should conduct in-depth explorations of the coping mechanisms used by informal caregivers of persons with SMDs and the opportunities to strengthen these coping mechanisms to promote good health among informal caregivers.

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Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

Authors' contributions

O.S. conceived the parent study under the guidance of F.A. and N.G.N. O.S. conducted the interviews and wrote the first manuscript draft with contributions thereafter from F.A. and N.G.N.

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Data availability

The data supporting this study's findings are available from the corresponding author, O.S. upon reasonable request.

Disclaimer

The views and opinions expressed in this article are those of the authors and do not necessarily reflect the official policy or position of any affiliated agency of the authors.

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3.3.3 What if I die? Existential crises when caring for persons with severe mental disorders in rural South Africa

Manuscript (c) reports on the experience of existential crisis among the informal caregivers of persons with SMDs. The paper has been submitted to the *PLoS Global Public Health*. Details of the manuscript are outlined in Table 3.5.

Table 3.4 Manuscript (c) details

Title	Journal	Author contributions		Key findings	Status
What if I die? Existential crises when caring for persons with severe mental disorders in rural South Africa	*PLoS Global Public Health* DHET accredited	Conceptualisation	Silaule, Nkosi & Adams	Caregivers' experience of existential responsibility towards MHCUs' health and wellbeing, physical needs and activities of daily living. Caregivers' experience of existential anxiety driven by the fear of what will happen in the future should a caregiver die and fear over the future of the MHCU.	Post review corrections submitted
		Manuscript draft	Silaule		
		Manuscript review and editing	Silaule, Nkosi & Adams		
		Supervision	Nkosi & Adams		

PLoS Global Public Health

What if I die? Existential crises when caring for persons with severe mental disorders in rural South Africa

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Abstract

The role of informal caregiving is associated with various crises and psychological distress that triggers the caregiver's fear of death and dying. A vast amount of evidence exists on the burden of care related to the psychological distress faced by the informal caregivers in mental health. However, there is paucity of evidence on the existential crises faced by informal caregivers of persons with severe mental disorders. Understanding the existential concerns affecting informal caregivers in mental health is important for developing strategies to support the health and psychological wellbeing of these caregivers. A descriptive qualitative approach was used to explore the lived experiences of informal caregivers of persons with severe mental disorders in rural South Africa. Semi-structured interviews were conducted with 12 participants who were informal caregivers who were purposely selected to participate in the study between January and June 2022. Only participants who gave written consents for interviews and audio recording were considered for participation. To ensure confidentiality each participant was assigned a participant ID. Audio-recorded interviews were translated, transcribed, and analysed inductively on NVivo12 using thematic analysis. Two themes were identified, sense of responsibility, and caregivers' experiences of existential death anxiety. The informal caregivers experienced a sense of responsibility and accountability towards meeting the health and physical needs of their care recipients. Fear over the continuity of care in the event of caregivers' death was described as the main contributor to the existential death anxiety experienced by the informal caregivers.This experience poses a serious risk to the psychological wellbeing of informal caregivers, and threatens the future wellbeing of the mental healthcare users who depend on their caregivers to function within their community. Therefore, succession planning in the care of mental healthcare users is necessary, and care should be a shared responsibility between primary caregivers, their families, and communities. Future studies should focus on developing and implementing stigma reduction programmes and caregiver support strategies to facilitate recovery and independency of persons with severe mental disorders in communities.

Key words: caregiver, developing country, existential distress, severe mental disorder

Introduction

Severe mental disorders including depressive disorders, schizophrenia and bipolar mood disorders, are chronic and counted among the top 20 disabling disorders (Vos *et al.*, 2015; James *et al.*, 2018). Due to a gap in the treatment of mental disorders in lower middle-income countries(LMICs), the burden of these disorders is estimated to be four times greater than in high income countries (Charlson *et al.*, 2018). Depressive disorders affect 5% of the population globally and 80% of those affected resides in LMICs, with 16% in Africa(Herman *et al.*, 2009; Seedat *et al.*, 2009).Similarly, schizophrenia affects about 24 million people in the world, indicating that 1% of the population suffers from schizophrenia(World Health Organization, 2022). Bipolar mood disorder(BMD) is estimated to affect 45 million people worldwide, with a lifetime prevalence of 2.4% in developed countries(Merikangas *et al.*, 2011; James *et al.*, 2018). In South Africa, 4 million people are estimated to suffer from BMD, indicating that 3–4 % of the population are affected(South African Depression and Anxiety Group, 2019).

Globally, the growing burden of mental disorders has been overcome by persistent challenges, and one prominent challenge is the treatment gap between the need and provision of mental health services(Thornicroft and Semrau, 2019). In high-income countries, about a third of the people with mental disorders receive treatment, but in LMICs, less than 5% of people with mental disorders receive treatment(Thornicroft *et al.*, 2017; Alonso *et al.*, 2018). In African countries, including South Africa, limited funding, poor policy implementation, lack of infrastructure, limited institutional support, and staff shortages exacerbate the treatment gap(Monteiro, 2015). In a deinstitutionalised mental health system, the inadequate access to mental health services calls for informal caregivers to become key role players in the recovery of persons with mental disorders, particularly for those with SMDs who often require long-term care and management(Ndikuno *et al.*, 2016; Paruk and Ramdhial, 2018). The role of being an informal caregiver is often occupied by family, friends, neighbours, or a good Samaritan, who are often not remunerated for providing care, who provide continuous care to a person with a SMD(Roth, Fredman and Haley, 2015; Akbari *et al.*, 2018).

The limited access to mental healthcare for people with SMDs has dire consequences for patients and their caregivers, such as recurrent relapses (Moges *et al.*, 2021), homelessness (Smartt *et al.*, 2019), stigma and discrimination (Nxumalo and Mchunu, 2017), caregiver burden (Silaule, Nkosi

and Adams, 2023), poor quality of life (Gupta *et al.*, 2015), and poor psychological wellbeing (Yerriah, Tomita and Paruk, 2021). In the absence of a functional mental health system informal caregivers are expected to assume responsibility for the health and wellbeing of the person with a SMD (Chadda, 2014). The responsibilities include providing for their daily needs, including financial support; providing emotional support; dealing with disruptive behaviour; monitoring their mental state; supervising medication; and identifying early warning signs of relapse and deterioration (Chadda, 2014; Gharavi *et al.*, 2018; Paruk and Ramdhial, 2018).

Dealing with the caregiving responsibilities has been linked to severe psychological distress and existential concerns among the informal caregivers(Schulz and Sherwood, 2008). Previous studies conducted in high-income countries and low and middle-income countries established that caring persons with chronic conditions such as SMDs is a formidable task that has been linked with increased financial, emotional and physical burdens(Semenova and Stadtlander, 2016; Akbari *et al.*, 2018). Various factors have been identified to contribute to these burdens and this includes the caregivers' anticipation of negative health outcomes, grief over lost potential of the care recipient, emotional distress from watching their loved ones suffer from their conditions, feelings of resentment, disappointment and guilt over inability to change course of events(Marimbe *et al.*, 2016; Semenova and Stadtlander, 2016; Addo, Agyemang and Tozan, 2018). The experience of burden along with watching the care recipients go through the pain of dealing with their mental disorders is likely to awaken existential death anxiety which is brought about by the caregiver's own fear of death and dying(Semenova and Stadtlander, 2016).

A study by Thakkar (Thakkar, 2018) reveal that parents of adult children with high and complex needs often face the question of what will happen to their children when they are dead. The concerns relate to whether their adult children would receive adequate care when they are no longer there to care and advocate for them (Thakkar, 2018). Dealing with this question is worrisome (Thakkar, 2018) as caregivers are confronted with the existential reality of their death and mortality. This has been shown to lead to increased levels of depression, hopelessness, powerlessness, and anxiety, which threatens the physical, emotional, and psychological wellbeing of caregivers (P D Jönsson *et al.*, 2011; Applebaum *et al.*, 2016; Semenova and Stadtlander, 2016; Larsson *et al.*, 2022).

There is numerous studies reporting on existential distress among the informal caregivers of persons with brain tumors (Henoch and Danielson, 2009; Ford *et al.*, 2012; Applebaum *et al.*, 2016). The studies identified existential distress as a significant component of burden among the informal caregivers and associated this with feelings of hopelessness, demoralization, loss of meaning in their lives and decrease will to live(Applebaum *et al.*, 2016). In contrast to the factors identified to cause burden among the informal caregivers in mental health; the burden of care among the informal caregivers of persons with brain tumours has been associated with the experience of isolation and change in identity(Ford *et al.*, 2012). Additionally, existential distress has been liked with the fear of dealing with the imminent death of the patients and need to continue after the death of the patient(Kanter *et al.*, 2014).The health and wellbeing of informal caregivers are important as it determines the quality of care provided to the person with a SMD(Akbari *et al.*, 2018). Understanding the existential concerns is important for developing strategies for supporting the health and wellbeing of the informal caregivers of persons with SMDs. Currently, limited studies report on the existential concerns such as death anxiety affecting informal caregivers in mental health. This study aims to address this gap by reporting on the existential crises experienced by informal caregivers of persons with SMDs in rural South Africa.

Study methodology

Study context

The study took place in Bushbuckridge municipality in Mpumalanga province, South Africa. Bushbuckridge municipality lies in the north-eastern rural part of Mpumalanga and has a population of 546 215 (Statistics South Africa, 2018). The province is mostly rural, which makes it hard to attract skilled mental health professionals. Currently there is no specialised psychiatric hospital in the province. There are two provincial hospitals and one district hospital that offer in-patient mental health services within the province. The two provincial hospitals has a bed capacity of 26 and 17, respectively. The district hospital has the largest mental health unit in the entire province with a bed capacity of 50. As the largest mental health unit in the province, the unit caters for a large catchment area, including other parts of the province beyond the Bushbuckridge municipality, which was expanded by the introduction of forensic services since 2014. This mental

health unit caters for both in- and outpatients with a variety of mental disorders, ranging from acute to chronic and forensic cases. Mental healthcare users (MHCUs) with SMDs within Bushbuckridge municipality are often treated at this district hospital. Once discharged, MHCUs with SMDs and their caregivers are referred to collect their psychotropic medication from their closest community health clinic, which varies in distance depending on where they live.

Study design

A descriptive, qualitative design was used in this study. A qualitative approach allowed for an inductive analysis of reality as perceived by the individual participants, their life outlook, and their subjective experiences as informal caregivers of persons with SMDs (Kivunja & Kuyini, 2017). Data collected in this descriptive study were analysed systematically using a six-phase reflexive thematic inductive analysis approach proposed by Braun and Clarke (2021).

Study participants

This study is part of a larger PhD study investigating strategies for alleviating caregiver burden among informal caregivers of persons with SMDs in Bushbuckridge municipality, Mpumalanga province. The inclusion criteria for this part of the study were that participants (1) must be informal caregivers of a person with SMDs, including a family member, a friend, or any person for whom they provide unpaid care; (2) must be informal caregivers who have provided continuous care for longer than six months; (3) must be at least 18 years old; (4) must be performing caregiving duties at least once a week; and (5) must have presented with a subjective or objective burden (mild, moderate, or severe) in the first study (Silaule et al., 2023). In total, 12 participants were recruited for the study between January and June 2022.

Sampling methods and procedure

Potential participants were identified from the first study that aimed to establish the extent of burden among the informal caregivers of MHCUs (Silaule et al., 2023). In total, 170 informal caregivers took part in the first study, of which 120 gave consent to be contacted for the consecutive PhD studies. Participants who presented with mild, moderate, or severe levels of subjective and objective burdens were purposely selected. During the first study, participants were informed of the second study, and their intention to participate was recorded. Potential participants

were contacted telephonically, informed of the purpose of the study, and invited to participate. A convenient date and time were identified for the interviews, which took a maximum of one hour.

Data collection method and procedures

The Primary Investigator (PI) telephonically contacted all potential participants who agreed to take part in the study. All participants contacted were available and willing to engage in the study. Interviews were conducted with 12 participants in their homes as preferred, which allowed flexibility to accommodate participants' availability in their natural settings where caregiving duties are mostly performed. The interviews were individual with the exception of two interviews conducted with a parent-couple and the mother and sibling of a care recipient. The duration of the interviews was between 30 min – 1hour and on the average, the interviews took 45 minutes to conduct.A demographic questionnaire was used to capture the characteristics of both the caregivers and the MHCUs receiving care. During the semi-structured interviews, participants were invited to share their views on their experience of caregiver burden and the resources and support needed to address caregiver burden. The following open-ended question was used to start the conversation: Please can you tell me about your experience of caring for your family member (son/daughter/husband/wife/sibling/granddaughter/mother/father) with a mental disorder. This was followed by questions aimed specifically at exploring the distress among the informal caregivers; for example, 'Describe the different burdens you have encountered since you started providing care to your family member/relative with a mental disorder'; 'How have these burdens impacted your life?'; 'What are the sources of burdens related to providing care to your family member/relative?'. Data were collected until saturation was reached i.e. when no new data emerged during the interview process. Two written informed consents were obtained from the participants prior to data collection: one for participating in the study, and the other for audio recording. Participant identities were used to preserve the confidentiality of the participants. The interviews were conducted in Xitsonga, the participants' mother tongue. The interviews were audio recorded, transcribed, and translated to English by a language specialist who works as a researcher at a research entity situated in Bushbuckridge municipality.

Data analysis

NVivo 12 software was used in this study to analyse the data. To capture the experiences of the informal caregivers in their caregiving role, a six-phase reflexive thematic inductive analysis approach, proposed by Braun and Clarke (2021), was used for systematic data analysis. The following steps were followed: (1) Data familiarisation and writing familiarisation notes, (2) systematic data coding, (3) generating initial themes from coded and collated data, (4) developing and reviewing themes, (5) refining, defining, and naming themes, and (6) reporting (Braun & Clarke, 2021). For data immersion, the main researcher repeatedly listened to the audio recording from each interview. This process was done concurrently with reading the transcripts to ensure the transcribed data reflected what the participants reported in the interviews. Familiarisation notes were made for each participant to demonstrate the patterns and meanings emerging from the data set. Codes were generated systematically by identifying segments of data that the researcher assessed to be meaningful in relation to the phenomenon of interest, namely caregivers' experiences in each data item. The researchers coded as many codes for as many potential themes, and descriptions for each code were added to ensure consistency in the coding process. Notes were kept to help the researchers reflect on some of the generated codes that needed further clarity and to help the researchers think of potential themes. Duplicates were identified and codes that needed clarity were identified as the grouping took place. This process enabled the researchers to identify relationships in the generated initial codes. A codebook was generated to enable consistency and ensure that information was not missed. In addition, the codebook was used to identify relationships between the codes as guided by the allocated description. At this stage, some of the initial codes became themes. Additional codes, such as those that could not be grouped in to a theme, were identified and grouped together for further analysis in the next phase. Themes were refined by reading the coded data extracts for each theme, which ensured that these merged to form a coherent pattern that informed the specific theme. The researcher then read the dataset and notes again to ensure validity of the themes and to identify other codes that may have been missed. To ensure trustworthiness, an experienced qualitative researcher conducted an audit trail of the data analysis process. Trustworthiness was further ensured by presenting the analysis process and findings to the research supervisors and peers, which helped promote the quality and truthfulness of the findings. Member checking was conducted by sharing the research findings with the participants, who confirmed that the findings reflect their caregiving experience as intended in the

study. In keeping with reflexive practice, the main researcher kept a journal that allowed her to document thoughts and observations on the experiences of caregivers during the interviews and analysis process.

Ethical considerations

The University of the Witwatersrand Human Research Ethics Committee (M200957) and the Mpumalanga Department of Health Research Committee (MP_202010_010) provided ethical approval. The methods followed in this study were in accordance with the relevant ethical principles for medical research involving human subjects (The World Medical Association Inc., 2008). Prior to data collection, all participants were given an information sheet, which informed them about the aim of the study, confidentiality and anonymity. To ensure confidentiality each participant was assigned a participant ID. Informed written consent was obtained from all participants to grant permission to participate and audio recording of the interviews.

Results

Twelve informal caregivers between the ages of 34 and 76 years participated in this study, and the majority (41.7%) are in late adulthood, followed by those in middle adulthood (33.3%). The informal caregivers are mainly female (75.0%), and many are mothers (50.0%) and siblings (33.3%) of the MHCUs. Most informal caregivers are married (58.3%). Four (33.3%) of the informal caregivers have a secondary level education and 33.3% is uneducated, but most informal caregivers are pensioners (50%) and unemployed (33.3%). All informal caregivers (83.3%) with the exception of two informal caregivers (16.7%) are responsible for one care recipient. The duration of caregiving ranges between 5 and 20 years, and most of the informal caregivers (58.3%) have occupied the role of caregiving for 11 to 20 years. Most caregivers (50.0%) spend between one and eight hours a day on their caregiving duties, and some (41.7%) spend 19–24 hours daily on caregiving. The average household income range between ZAR1 100 ($61) and ZAR5 000 ($271), and many (91.7%) spend between ZAR101 ($6) and ZAR500 ($28) on medical costs for the care recipient monthly. Most (66.7%) informal caregivers stay in the same residence as their care recipient. This information is summarised in Table 4.

Table 3 Demographic characteristics of informal caregivers of persons with SMDs (n = 12)

Characteristic	Frequency	Percentage
Age		
20–39	3	25.0
40–65	4	33.3
+ 65	5	41.7
Gender		
Female	9	75.0
Male	3	25.0
Marital status		
Single	2	16.7
Married	7	58.3
Divorced	2	16.7
Widower	1	8.3
Education		
Primary school level	2	16.7
Secondary school level	4	33.3
Tertiary level	2	16.7
Uneducated	4	33.3
Employment status		
Employed	1	8.3
Unemployed	4	33.3
Pensioner	6	50
Self-employed	1	8.3
Relationships		
Mother	6	50
Father	2	16.7
Sibling	4	33.3
Number of care recipients		
1	10	83.3
2	2	16.7
Duration of caregiving		
5–10 yrs.	5	41.7
11–20 yrs.	7	58.3
Daily caregiving		
1–8 hrs.	6	50
9–18 hrs.	1	8.3
19–24 hrs.	5	41.7
Monthly household income (ZAR)		
≤ 1 000	1	8.3
1 100–5 000	10	83.3
≥ 5 000	1	8.3
Monthly medical costs (ZAR)		

Characteristic	Frequency	Percentage
≤ 100	1	8.3
101–500	11	91.7
Residence		
Same as care recipient	8	66.7
Different as care recipient	4	33.3

The demographic characteristics of the MHCUs (Table 5) revealed that most are male (66.7%) between the ages of 18 and 35 years (58.7%). Most of the MHCUs (75.0%) are single with a secondary level education (75.0%). The majority (58.5%) are unemployed with a disability grant as their main source of income. MHCUs who are diagnosed with schizophrenia formed the majority of the care recipients (58.3%) and were considered relatively stable (83.3%) at the time of data collection. Many of the MHCUs (66.7%) reside in a household with 1–5 family members.

Table 4 Demographic characteristics of the MHCUs with SMDs (n = 12)

Characteristics	Frequency	Percentage
Age		
20–39	8	66.7
40–65	4	33.3
Gender		
Female	4	33.3
Male	8	66.7
Marital status		
Single	9	75
Married	0	0
Divorced	2	16.7
Widower	1	8.3
Education		
Primary school level	3	25
Secondary school level	9	75
Employment status		
Unemployed (without social grant)	4	33.3
Unemployed (with social grant)	7	58.3
Pensioner	1	8.3
Diagnosis		
Schizophrenia	7	58.3
Psychotic disorder not otherwise specified	2	16.7
Substance use disorder	2	16.7
Major depressive disorder	1	8.3
Disease status		

Characteristics	Frequency	Percentage
Relatively stable(without active psychotic symptoms)	10	83.3
Unstable	2	16.7
Number of hospitalisations in the previous year		
None	10	83.3
1–2 times	2	16.7
Number of family members living in the household		
1–5 people	8	66.7
6–10 people	4	33.3

Following inductive analysis of the interviews, the following themes were identified: Caregivers' experience of sense of responsibility, and caregivers' experience of existential anxiety. Each theme comprises sub-themes that provide a multifaceted and detailed breakdown of the findings.

Caregivers' experience of sense of responsibility

When asked about their caregiving experience in caring for the MHCUs, the participants expressed experiencing sense of responsibility. In this theme, the informal caregivers described their sense of responsibility and accountability towards meeting the needs of MHCUs. This experience is highlighted in the following sub-themes: (1) Sense of responsibility towards the health and wellbeing of MHCUs; (2) sense of responsibility towards meeting the physical needs of MHCUs; and (3) sense of responsibility towards enabling participation in daily occupations. These sub-themes emphasise the demands of caregiving and nature of responsibility that informal caregivers have when caring for a person with a SMD.

Sense of responsibility towards the health and wellbeing of mental healthcare users

Participants indicated having a sense of responsibility towards supporting the health and wellbeing of MHCUs. Various responsibilities connected to supporting the health of the MHCUs were identified, including supporting MHCUs in seeking help for their condition, visiting them while in a hospital, and managing their medication following discharge from the hospital. Because most people diagnosed with a SMD require assistance managing and maintaining their health, the informal caregivers felt it is necessary for them to fulfil this role to ensure the MHCU remain stable, as expressed by the following participant:

> *"Sometimes when he was walking around the yard, I would ask him what is wrong and he would say, 'I cannot sit down; I have to keep walking because they are telling*

me to walk'. When I ask him whom are those people telling him to walk, he would not tell me. When his father came back from work, I would tell him everything that happened during the day, and he would suggest that we take him to the hospital. When we get to the hospital, they would give him an injection, and that is when he would sit down." (Mother, age 70)

Participants expressed a sense of responsibility to ensure the wellbeing of not only the MHCU but also the other members of the family. To fulfil this responsibility, they must be accountable in their caregiving duties and play a protective role by becoming a shield for other members of the family. Protecting other family members becomes an obligatory role as their sense of responsibility and fears force them to take up this role. The lack of choice led to some informal caregivers seeing themselves as the only person suitable to provide care and ensure the MHCU's wellbeing. As a result, they self-sacrifice to ensure the other members of the family remain protected. A participant in the following comment explained this:

"I was sad. Our mother is alive, but I fear that he might find an object and beat her with it, and that is the reason why I took him with me. What can I say … he is my brother, and there is nothing I can do because I am the eldest; I have to care for him. I cannot give him to someone else to care for him and as I have said that I fear that he might hurt our mother if he can go and stay with her. He was staying with my mother but we were afraid that he might hurt her because there are times where he is uncontrollable." (Sister, age 37)

In an attempt to ensure the health and wellbeing of MHCUs, informal caregivers also play the role of mediator between MHCUs and the community. Because of the nature of their mental conditions, some MHCUs get into conflicts with members of the community, and as a result, the community members approach the informal caregiver to express their complaints regarding the conduct of their care recipients. This adds to the demands of caregiving as the informal caregiver assume the responsibility of mediating the conflicts and paying for any damages incurred by the MHCU, as explained in the following comment:

"When he has had fights with people, they come to me and complain about what he has done to them. They cannot complain to him because they know that he is not okay. I have to deal with those situations. If I have to pay for whatever damage he has done, I pay. If I have to talk to those people in a polite manner, I do it as well and make them understand that he is mentally ill." (Sister, age 37)

Sense of responsibility towards meeting the physical needs of mental healthcare users

The caregivers expressed a sense of feeling responsible to fulfil the physical needs of the MHCUs. The various tasks connected to fulfilling this responsibility include providing financial support, providing food, managing the disability grant with accountability to ensure the needs of the MHCU are met, and providing for the needs of the MHCUs to ensure they are not exploited by the community. Due to the disabling nature of SMDs, most MHCUs are unable to obtain and retain employment, and as a result, they tend to depend on their caregivers for financial support. In this study, most MHCUs (58.5%) are unemployed and receive a disability grant, and most informal caregivers (50%) are pensioners and others (33.3%) are unemployed with a household income of less than ZAR5 000 ($274) per month. It is therefore not surprising that a participant said it is a financial strain to meet the daily needs of the MHCU:

> *"We are all living on that little money I get from the government, and you can see that it is very challenging. As grown-up as he is, I still take care of him, and when I receive the pension money, I have to make sure that I buy him everything that he has to use at his house. I buy from maize meal, meat, and toiletries. When he does not have the washing powder, the bath soap, or the deodorant … I have to buy all of those things. Whatever it is that I eat here, he should have them as well at his house, and they are never enough. When we do not have food, I just go to the tuck shop around here and ask for food on credit so that I can give him. So … aaah!" (Mother, age 62)*

In spite of the financial strain expressed by the informal caregivers, some had to make sacrifices to meet the financial demands of the MHCUs to protect them from being exploited by the members of the community. Due to limited autonomy, some MHCUs are taken advantage of by community members who send them to do odd jobs, such as woodcutting or running errands, without proper payment. The informal caregivers feel helpless to preserve the dignity of their care recipients. They feel a sense of responsibility to protect MHCUs from exploitation, which further add to the financial strain faced by informal caregivers who must provide the money the MHCU need to prevent them from seeking work outside the house. The participants explained it as follows:

> *"Yes, they always looked for him. And we would always fight with those people and tell them that this person is not mentally okay for them to be sending him around. He is the person who always wants money, and he wants it almost every day. And because he is in that condition and we have to ensure that we meet him halfway with whatever he wants because if we do not do that, it will trigger something in his head. We are making sure that we give him what he wants because we don't want him to*

think of doing petty jobs like chopping woods for people in return for money." (Brother, age 42)

"People here in the village used to give him odd jobs like fetching wood in the bushes, and they would pay only R10 ($0.54) for that, or they give him a jar of traditional beer as the payment for fetching the wood. A mentally ill person does not know the worth of the work he has done; he just accepts anything." (Mother, age 66)

Sense of responsibility towards enabling participation in daily occupations

The participants expressed feeling responsible for ensuring the MHCUs' participation in daily activities, which is linked to performing daily tasks for MHCUs, providing constant supervision, and structuring daily tasks for MHCUs. The caregivers expressed a sense of responsibility for performing daily activities for the MHCUs, including cleaning, cooking, and washing. In addition, the caregivers said they perform activities to prevent MHCUs from harming themselves. One participant explained it as follows:

"My responsibility as a caregiver is to make sure that he eats proper food, take the medications. I wash his laundry so that he can be neat around other people and he does not look different to other people. I do that to make sure that he is well cared for and he takes his medications on time. He is able to do many things on his own, but I cannot trust him with cooking because I fear that he might attempt to cook on the stove he gets burned, so I cook for him. I also clean his room because he leaves it untidy most of the time." (Sister, age 37)

The participants also explained that they must structure the MHCUs' daily activities and provide constant supervision. Most MHCUs (58.3%) in this study have been diagnosed with schizophrenia, and because of the disabling nature of this SMD, it is expected that some MHCUs require external structure to participate in daily occupations as they struggle to develop and maintain their own routines. In the absence of such structure, the MHCUs often fail to participate in their daily occupations as expected, and thus, caregivers must provide them with structure. A participants explained it as follows:

"I am taking care of him, and I have to make sure that I remind him to do things such as bathing; remind him that he did not bath yet and he has to do it. So, it is difficult because I always have to look after him like a little child. He bathes by himself, and he also does his own laundry when I tell him to. If I do not tell him, he does not do it. Yes, I always have to give instruction so that he can do what he should do. If maybe, I have to go somewhere and I leave without telling him what to do, he does not do anything." (Mother, age 42)

Caregivers' experience of existential anxiety

The informal caregivers said they experience existential anxiety in their caregiving role. This theme describes their fear and anxiety over the future of their care recipients when they die, and is divided into two sub-themes, namely (1) experiencing fear regarding what will happen to the MHCU in the event of a caregiver's death; and (2) experiencing fear for the MHCUs' future because of the unpredictability of their mental disorder and ability to earn a living in the future. These sub-themes highlight the intense emotions that the informal caregivers deal with because of the uncertain future of the functioning and continuity of care for MHCUs.

Experiencing fear regarding what will happen to a mental healthcare user in the event of their caregiver's death

Participants are anxious about what would happen to the MHCUs they are caring for in the event of their death. These fears are connected to existential death anxiety, continuity of care, and concerns over whether the MHCUs would be able to access the help they need if their caregiver died. Existential death anxiety is caused by the fear that care for the MHCUs would cease in the event of the caregivers' death. Because of the level of dependency and many responsibilities attached to the caregiver role, the caregivers feel distressed and helpless because they fear other members of the family will struggle to cope with the demands of caregiving. One participant expressed his fears as follows:

> *"We all know that we are not here to live forever, and my worry is that if we die there will be no one to look or care for him. I do not think his brothers and sisters would be able to care for him because they would be married and they will not be able to take care of an older person like him. That thought does not give me peace of mind because I know that one day we will die. That is the most challenging for me, and I do not know what to do about it." (Father, age 72)*

The caregivers feared that the MHCUs will not receive the same level of care that they provide as primary caregivers, and that in their absence MHCUs will struggle to access the medical care they require to remain stable. The caregivers' preoccupation with their death and continuity of care for the MHCUs is mainly attributed to the lack of independence of the MHCUs, their constant need for supervision, and idea that other family members are less equipped to cope with the demands of caregiving, as expressed in the following comment:

"Another thing is that when I am caring for him, I always wonder how he will live if I die because he does not know when he has to go to the hospital. Sometimes I wonder if my closest family will be able to take over and care for him when I am no longer around. I always ask myself these questions. There is definitely no one who will be able to care for him the way I do. I am just wondering if that particular person who takes over will be able to be patient enough to make those trips to the hospital or not. I am just asking myself that question." (Mother, age 42)

While some participants expressed being content with their ability to fulfil their responsibilities to provide for the daily needs of the MHCUs, but they were anxious over whether these needs would be met in the event of their death. One participant explained as follows that they are constantly worried and under pressure to ensure they provide the best care possible to make up for their absence in the future:

"My biggest worry is that he will have no one to care for him when I am no more. Now that I am still alive, I am able to care for him, and there is no day that he goes to bed hungry. When he goes out, I make sure that I know where he is and if he has eaten something. It affects me a lot because I do not know how long I will live, and I do not know who will help him when I am no more." (Mother, age 70)

The informal caregivers said that managing MHCUs' disability grant gave them a sense of responsibility for the MHCUs. The fact that most caregivers are solely responsible for the MHCU and managing their money concerned the participants who were apprehensive and anxious over the anticipated mismanagement of this grant in their absence and the implications for the nature of care the MHCUs will receive if the money is misused. This demonstrates the sense of ownership that caregivers feel towards their caregiving duties, which can be seen as an act of selflessness or sense of mistrust towards the other family members in fulfilling this role. A participant explained her apprehension as follows:

"Whatever it is that they do, I have to see it including the mistakes that they make because my sister cannot always come home just to see how they are doing. I am the one responsible for them because I am the one who is receiving their disability grant. My worry is that if I die, they will have no one to manage their money well because people are not the same even if they are siblings. You may find that the person who would take over would not be as

responsible as I am with their money. Someone can take over from me as their caregiver but they may not be able to care for them the way that I do." (Sister, age 37)

Experiencing fear about the mental healthcare users' future

The participants highlighted their fears around the unpredictability of the MHCUs' conditions, anticipated future relapses, and the MHCUs' ability to earn a living in the future. While most of the caregivers (83.3%) reported that the MHCUs they care for are relatively stable, they live in a state of constant fear over relapses in the future. Given the unpredictability of SMDs and the caregivers' past experiences dealing with these conditions, the caregivers expressed a lot of doubt and mistrust about the mental state of the MHCUs even when they are relatively stable on medication. In addition, the caregivers felt hopeless because they do not believe the destructive behaviours of the MHCUs will change, which is attributed to the chronic nature of SMDs and makes MHCUs prone to multiple relapses. One participant expressed her fear as follows:

"He was a normal person and he was working. He was able to buy whatever he wanted, but he has destroyed everything that he bought while he was working. Now, I do not even have the courage to buy him a cheaper bed because when I think about it, I think that maybe he will destroy it. So, I am very discouraged to buy him things that he needs because I am scared that he can destroy [it] in a blink of an eye." (Mother, age 62)

The caregivers are also concerned about the MHCUs' ability to earn a living in the future because most MHCUs (66.7%) in this study are between the ages of 20 and 40 years, and are at an age where they are expected to earn a living. However, because the informal caregivers are often the sole providers of care and because of the MHCUs' dependence on their caregivers, the caregivers are worried that their care recipients will suffer when they die. One participant described her hope that her care recipient will find a job to secure an income as follows:

"I have accepted everything, but my worry is that he will suffer if I die. It would make me the happiest person alive if I were to hear that he has found a job. Even if it is not a fancy job, it would be fine. Any job where he can come home on weekends. It will help me because even if I die, I will know that he has something to do for a living." (Mother, age 71)

Discussion

This study aimed to explore the lived experiences of informal caregivers of persons with SMDs. The findings revealed two main themes, namely the informal caregivers' experience of sense of responsibility and their experience of existential anxiety while occupying the caregiving role. The experience of sense of responsibility theme had three sub-themes that highlighted the sense of responsibility and accountability the informal caregivers have towards ensuring the MHCUs' health and wellbeing, meeting their physical needs, and enabling their participation in daily occupations. The two sub-themes of experience of existential death anxiety were fear for the MHCUs' future if the caregiver died, and the unpredictability of the mental conditions and MHCUs' ability to earn a living in the future. In these themes and sub-themes, the experiences of informal caregivers were centred in the fear, constant state of worry, despair, and powerlessness they feel because of the realisation of their own mortality while dealing with the demands of caregiving, their sense of ownership towards the MHCUs, and the need to protect their care recipients.

Most informal caregivers (41.7%) in this study are in their late adulthood, while many others are in middle adulthood (33.3%), and many are the parents of the MHCUs (66.7%), which could be predisposing factors to their experience of distress related to the sense of responsibility. The informal caregivers' perceived their sense of responsibility and accountability towards meeting the needs of the MHCUs, which seems to be driven by their fear, the need to be protective of the wellbeing of their care recipients, and their powerlessness brought on by their existential death anxiety. Erikson's (1950) human development theory classifies middle adulthood as a stage of generativity versus stagnation that is characterised by the need to give to and assume responsibility for others. For parents, generativity is achieved by successfully nurturing their children's growth and development to help them become capable and contributing members of the society. Successfully achieving generativity is therefore linked with life satisfaction and psychological wellbeing (Homan et al., 2020). Parents of MHCUs are the primary source of care and support for their children despite their age, and as a result, active parenting does not end even when the MHCUs reach adulthood. Subsequently, the prolonged care required by the MHCUs is often accompanied by strain that threatens the caregivers' psychological wellbeing (Seltzer et al., 2011). In this study, most MHCUs (66.7%) are in early adulthood and some (33.3%) are in middle

adulthood. While many were considered relatively stable i.e. not showing any positive psychiatric symptoms they still displayed dependency towards their informal caregivers. As a result, the informal caregivers feel a sense of responsibility to ensure the MHCUs' health and wellbeing and to meet their needs. Consequently, fulfilling these responsibilities result in distress due to the sense of responsibility arising from the caregivers' knowledge of the functional limitations of the MHCUs, which leads to fear, worry, and feelings of powerlessness when they face their own mortality. According to Erikson (1950), generativity is characterised by the psychological "need to be needed", and therefore, the role of caregiving can be related to higher perceptions of generativity (Grossman & Gruenewald, 2017).

The caregivers in this study expressed a sense of responsibility towards the MHCUs, and they often identified themselves as the sole person suitable for fulfilling the role of caregiving. While assuming ownership of their caregiving duties can result in satisfaction for caregivers and promote the wellbeing of the MHCUs (van Nistelrooy, 2014), it can also be detrimental to caregivers' psychological wellbeing. For some caregivers in this study, fulfilling the role of caregiving is obligatory, and means dealing with financial strain and protecting both the MHCU and other members of the family, which eventually leads to self-sacrifice. This self-sacrifice leads informal caregivers to sacrifice the little money they have to meet the financial needs of the MHCUs to protect them from exploitation by the community. According to Van Nistelrooy (2014), the act of self-sacrifice tends to be inherent in the caregiving role because caregivers are faced with a constant need to sacrifice their time, finances, relationships, and at times, employment to help improve and protect the wellbeing of their care recipients (Yerriah et al., 2021). The limited autonomy in caregiving subsequently leads caregivers to become objects merely acted up on by their environment rather than subjects that can act in and on the environment (Boudioni et al., 2015). Consequently, occupying the caregiving role predisposes participants to a state of powerlessness, which likely leads to feelings of stagnation. These findings are similar to those of Jönsson et al. (2011), who found that caregivers of those with mental disorders experience worry and powerlessness while fulfilling their caregiving responsibilities.

The experience of existential death anxiety expressed by the informal caregivers in this study is expected because many (41.7%) are in late adulthood. Existential death anxiety is characterised by feelings of hopelessness, despair, and demoralisation accompanied by loss of personal meaning and dignity, and feelings of burden up on realising one's mortality (Applebaum et al., 2016). Late

adulthood is the last stage of life, and individuals in this stage are confronted with the reality of death and their mortality. Erikson (1950) identifies late adulthood as a stage of ego integrity versus despair (Maree, 2021). Despair surfaces when older individuals are confronted with stressful life situations (van der Kaap-Deder et al., 2021). The demands of caregiving, such as being the sole provider of care for their adult children, dealing with financial strain, dealing with the functional limitations of their care recipients, and the unpredictability of SMDs, trigger a state of despair among caregivers. Consequently, caregivers experience an existential crisis brought on by their concerns that the MHCUs will suffer when the caregivers' care ceases in the event of their death. Most care recipients (58.3%) in this study developed schizophrenia in early adulthood and are unmarried. In spite of them being in their productive stages of development, these MHCUs remain dependent on the care and structure their caregivers give to function in their environment. This is because schizophrenia is a chronic mental disorder characterised by psychosis and unpredictable, hostile, or risky behaviour with long-term functional limitations (Shamsaei et al., 2015; Yazıcı et al., 2016). It is therefore fitting that the informal caregivers in this study expressed fear over the unpredictability of the MHCUs' condition, anticipate future relapses despite the MHCUs being stable on treatment, and expressed fear over the MHCUs' ability to earn a living in the future. Given the chronic nature of schizophrenia, those diagnosed tend to be susceptible to relapses even while on treatment (Moges et al., 2021). In fact, the relapse rate of schizophrenia is estimated to range between 50% and 92% globally (Csernansky & Schuchart, 2002). It is therefore a serious concern that care for these MHCUs relies on the elderly who are considered a vulnerable population group, and in addition to dealing with the decline in their own health, are required to bear the stressful demands of caregiving, which threatens their psychological wellbeing (Yerriah et al., 2021). As evident in this study, stress among the elderly population becomes a predisposing and precipitating factor for despair (van der Kaap-Deder et al., 2021), which can be attributed to the existential crisis experienced by the caregivers.

Most of the informal caregivers in this study are the sole providers of care for the MHCUs, and their fears about the continuity of care for their care recipients in the event of their death raise concerns over succession planning for the care of the MHCUs in rural South Africa. A study by Thakkar (2018) on succession planning for adult children with disabilities reveal that caregivers often avoid future planning for their care recipients because they find this topic overwhelming because they are forced to deal with the inevitability of their own mortality and deal with the

anxieties of relinquishing their responsibilities to others, which may mean an end to their caregiving role (Taggart et al., 2012; Thakkar, 2018). The caregivers in this study identified themselves as 'the only person fit to provide quality care', highlighting a lack of confidence in the other family members' ability to provide quality care for the MHCUs. In addition, they anticipate that other family members will not be able to cope with the demands of caregiving, and as a result, they predicted that care would cease in their absence. Nonetheless, the dire effects of the lack of a succession plan cannot be ignored. In the event that the primary caregiver dies or ceases to provide care, the absence of a succession plan can lead to crises and emotional trauma for everyone involved, and cause unexpected dilemmas for other members of the family who may be ill-equipped to occupy this role (Heller & Arnold, 2010). In rural South Africa where there is a limited institutional care for MHCUs (Rural Mental Health Campaign, 2015; Vergunst, 2018), the death of a primary caregiver may pose a serious risk for recurrent relapses and even homelessness. A study by Moyo et al. (2015) conducted in South Africa reports that the death of a parent is a risk factor for homelessness among mentally ill persons. Succession planning with clear action steps is necessary to ensure continuity of care for MHCUs in the future.

The continued stigma surrounding mental illness in communities remains a serious problem with substantial consequences for MHCUs and their caregivers (Nxumalo & Mchunu, 2017). As highlighted in the findings of this study, conflicts with and exploitation by members of the community were reported to contribute to the strain of caregiving. These findings are similar to those of previous studies conducted in rural South Africa and rural Canada that report that exploiting MHCUs is common in rural and remote areas (Pachkowski, 2017; Nxumalo & Mchunu, 2017). The families of MHCUs are often blamed for the behaviour of their family members with a mental illness and endure exploitation from community members who demand payment for damages caused by MHCUs (Pachkowski, 2017; Nxumalo & Mchunu, 2017). It can be concluded that the ill-treatment that the caregivers witness their care recipients experience from the community warrants their preoccupation with concerns over the wellbeing of the MHCUs in the event of their death.

This study identified the need to explore the effects of providing care to persons with SMDs on the health and wellbeing of the elderly, particularly in rural areas where care relies on this vulnerable population. This study highlighted that strategies are required to ensure the distribution of caregiving responsibilities between primary caregivers, their families, and communities.

This study was qualitative with purposive sampling, and therefore, the findings may not be representative of all the informal caregivers of persons with SMDs within Bushbuckridge municipality since these findings cannot be generalised. However, as part of a bigger PhD project, this study follows a quantitative study that investigated the extent of burden among the same population (Silaule et al., 2023). Therefore, our aim was not to generalise but rather to get an in-depth understanding of the experiences of the informal caregivers.

Limitations of the study

This study was qualitative with a small homogenous sample therefore the findings cannot be generalised to the population of informal caregivers of persons with SMDs within Bushbuckridge municipality. As part of a bigger PhD project, this study follows a quantitative study that investigated the extent of burden among the same population therefore only participants who presented with caregiver burden were selected. This creates a selection bias since the views of caregivers who did not present with a burden were excluded from the study.

Conclusion

The findings of this study highlights the presence of existential crises among the informal caregivers as evident in the distress and existential death anxiety established in this study. This requires an immediate attention; strategies for care and support of the informal caregivers should be developed and implemented to enable informal caregivers to cope with the demands of caregiving. These strategies should equip informal caregivers with knowledge and skills for handling the MHCUs and structuring activities for them to facilitate their independence. In addition, strategies should empower caregivers to take an active role in the planning and delivery of mental health services to ensure appropriateness, and strengthen caregiver coping strategies to promote their health and wellbeing.

On the policy level, the findings call for policy makers to ensure they include informal caregivers as key stakeholders in the planning and development of mental health services, particularly in low-resourced settings like rural South Africa where caregivers are the primary source of support for MHCUs. Policies aimed at directing mental health service delivery should prioritise services targeted at improving the health and wellbeing of informal caregivers to direct the distribution of resources that will meet the needs of both

MHCUs and their caregivers. There is a need for placement facilities and day centres for MHCUs within the community because this will allow informal caregivers respite and time to engage in other tasks as required in their environment. There is an urgent need to adopt task shifting particularly in low-resourced settings; lay health workers such as community health workers should be equipped with knowledge and skills necessary to support informal caregivers within the community. As evident in the findings of this study, the challenges experienced by informal caregivers of persons with SMDs are multidimensional, and as a result, interventions targeted at alleviating burden requires multisectoral collaboration between health, social development, local government, and community organisations.

Future studies should include a bigger sample to allow for generalisation of the findings. Studies should investigate succession planning and the role this plays in ensuring continuity of care following the death of the primary caregiver in mental health. Focus should also be directed towards investigating stigma reduction programmes to help reduce stigma towards the MHCUs and their caregivers.

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Author contribution

OS conceived the parent study under the guidance of FA and NN. OS conducted the interviews and wrote the first manuscript draft with contributions thereafter from FA and NN.

3.4 SUMMARY OF FINDINGS IN THE PHASE

Phase 1 aimed to conceptualise the burden of care among the informal caregivers of persons with SMDs in a low-resourced setting. The findings revealed that most informal caregivers experience high levels of caregiver burden with 44.7% informal caregivers reporting severe-to-moderate objective burdens and 35.8% reporting moderate-to-mild subjective burdens. The established levels of caregiver burden were further emphasised by the findings of the qualitative study that revealed that informal caregivers are susceptible to health consequences, which negatively affect

their emotional, mental and physical health. The subsequent negative consequences result in existential responsibility and existential anxiety brought about by the fear of what would happen to the MHCUs in the event of the informal caregivers' death. The caregivers expressed their need for emotional and tangible support, including the need for skills to handle MHCUs, financial support, counselling, home visits, and empowerment to enable them to cope with the burdens of caregiving. To cope with the demands of caregiving, some informal caregivers expressed using internal resources such as resilience and resourcefulness, and external resources, including access to medication, social worker services, and social support family, the community and religious organisations.

The next phase of the study explores the strategies for alleviating burden among the informal caregivers in the low-resourced community of Bushbuckridge municipality, Mpumalanga province.

CHAPTER 4

PHASE 2: EXPLORATION OF STRATEGIES FOR ALLEVIATING CAREGIVER BURDEN AMONG THE INFORMAL CAREGIVERS

4.1 INTRODUCTION

This section focuses on the exploration of the strategies for alleviating burden among the informal caregivers in the low-resourced community of Bushbuckridge municipality, Mpumalanga province. Chapter 4 presents the findings of Objective 3 in the form of a manuscript that describes the strategies for alleviating caregiver burden among the informal caregivers based on existing literature.

4.2 OBJECTIVE 3: TO DESCRIBE EXISTING STRATEGIES FOR ALLEVIATING CAREGIVER BURDEN IN DEVELOPING COUNTRIES THROUGH A SCOPING REVIEW

This section is presented as a published article. The article is yielded from the findings of the objective that aimed to describe existing strategies for alleviating caregiver burden in developing countries through a scoping review. The findings documented in the manuscript are presented next.

4.2.1 Strategies to alleviate the burden experienced by informal caregivers of persons with severe mental disorders in developing countries: A scoping review

The article reports on the strategies to alleviate the burden experienced by informal caregivers of persons with SMDs in developing countries. The paper was published in the *Interactive Journal of Medical Research*. Details of the article are outlined in Table 4.1.

Table 4.1 Manuscript details

Title	Journal	Author contributions		Key findings	Status
Strategies to alleviate the burden experienced by informal caregivers of persons with severe mental disorders in developing countries: A scoping review	*Interactive Journal of Medical Research* DHET accredited Impact factor: 2.0 DOI:10.2196/48587	Conceptualisation	Silaule, Casteleijn, Nkosi & Adams	The included studies were from 16 developing countries situated in Asia, Africa, Europe, and South and North America. Most studies were randomised controlled trials (47.7%) conducted in Asian countries. Psychoeducation and support group interventions were identified as the common strategies for alleviating burden of care.	Published
		Manuscript draft	Silaule & Casteleijn		
		Manuscript review and editing	Silaule, Casteleijn, Nkosi & Adams		
		Supervision	Nkosi & Adams		

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Review

Strategies to Alleviate the Burden Experienced by Informal Caregivers of Persons With Severe Mental Disorders in Low- and Middle-Income Countries: Scoping Review

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Abstract

Background: There is considerable evidence of the burden of care encountered by informal caregivers of persons with severe and enduring mental health conditions in low- and middle-income countries. Previous studies have highlighted the need to support these informal caregivers as key players in the care of these patients. To date, limited evidence exists on the extent and types of strategies for supporting these informal caregivers in low- and middle-income countries.

Objective: This scoping review aims to identify and describe the extent and type of evidence on the existing strategies for alleviating the burden of care among informal caregivers of persons with severe and enduring mental health conditions in low- and middle-income countries.

Methods: A systematic literature search was completed following the Joanna Briggs Institute methodology for scoping reviews. The participants, concept, and context framework was used to guide the search for literature sources across 5 databases: PubMed, MEDLINE, CINAHL, and PsycINFO for published literature and ProQuest for unpublished literature. This review included studies that reported on strategies for alleviating the burden of care among informal caregivers of persons with severe and enduring mental health conditions, with a focus on studies that evaluated or recommended caregiver interventions and support strategies in low- and middle-income countries. The search was limited to studies conducted between 2001 and 2021, and only papers written in English were considered for inclusion. Using the Covidence software (Veritas Health Innovation), 2 reviewers independently screened the papers, applied the inclusion and exclusion criteria, and met biweekly to discuss and resolve conflicts. The relevant studies and reported outcomes were summarized, organized, and analyzed descriptively using numeric summary analysis and deductive content analysis.

Results: Of the 18,342 studies identified, 44 (0.24%) met the inclusion criteria. The included studies were from 16 low- and middle-income countries in Asia, Africa, Europe, and South and North America. Most studies (21/44, 48%) were randomized controlled trials conducted in Asian countries. The identified strategies were grouped into 2 categories: implemented and recommended intervention strategies. Identified strategies included community-based interventions, psychoeducation interventions, support groups, cognitive behavioral therapy, spirituality-based interventions, and smartphone-based interventions. In addition, mindfulness and empowerment, collaborative interventions, standard care, financial and social support, counseling, occupation-based interventions, policy and legislature, and access to mental health care were identified. Psychoeducation and support group interventions were identified as common strategies for alleviating the burden of care among informal caregivers of persons with severe and enduring mental health conditions.

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Conclusions: This review provides evidence on the types of implemented and recommended strategies for alleviating the burden of care among informal caregivers in low- and middle-income countries. Although psychoeducational interventions were the most preferred strategy for alleviating burden, their benefits were short-lived when compared with peer-led support groups.

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KEYWORDS

severe mental disorders; informal caregivers; caregiver stress; caregiver support; low- and middle-income country; mobile phone

Introduction

Background Functional Implications of Severe and Enduring Mental Health Conditions

People with severe and enduring mental health conditions are unable to cope with the demands of everyday life and need care after being discharged from a health facility. Serious functional limitations frequently interfere with the ability of people with severe and enduring mental health conditions to perform essential roles such as being a worker, family member, or friend [1]. The lack of independence among people with severe and enduring mental health conditions in daily living activities and, in some cases, behavioral problems result in poor quality of life. Psychosis, bipolar mood, major depressive, anxiety, eating, and personality disorders are often classified as severe and enduring mental health conditions [2]. The amount of care needed varies greatly depending on the diagnosis, severity of symptoms, and level of independent functioning. As such, assistance is needed in areas of basic self-care, healthy eating, following daily routines, medication management and compliance, engagement in meaningful activities, and community integration. Therefore, informal caregivers are essential to fulfill the care needs of people with severe and enduring mental health conditions. This task becomes draining, and the caregiver burden should not be underestimated [3,4].

Informal Caregivers in Mental Health

Informal caregivers are people who deliver care without remuneration to persons with a chronic condition. The caregivers of persons with severe and enduring mental health conditions are most often family members or neighbors who assist with the care of the person with a mental health condition [5]. Dixon et al [6] noted that, often, the caregiver of a person with a severe and enduring mental health condition does not have a choice in being the caregiver, which is an additional burden of care for the carer. Informal caregivers' roles include monitoring medication, being the contact person between the health provider and family, early identification of signs of relapse, taking care of daily tasks such as self-care, providing meals, and ensuring the safety of the person [7,8]. Informal caregivers provide emotional support when needed and deal with the challenging behavior of the person with a severe and enduring mental health condition, which may lead to police involvement [9]. Involving informal caregivers in the routine care and management of persons with severe and enduring mental health conditions has shown a positive influence on the course of the illness but only if the caregivers' needs are addressed and they are supported in one way or another [5,6,10].

Caregiver Burden and Need for Support

The burden of care experienced by caregivers is classified into objective and subjective burden. Objective burden refers to the tangible impact of the demands of caring tasks and encompasses the practical and concrete aspects of caregiving that can be quantified or assessed externally [11,12]. Subjective burden refers to the emotional and psychological experiences, feelings, and perceptions of caregivers related to their caregiving role [8,13]. It focuses on how caregivers perceive the impact of their responsibilities on their well-being and mental health.

In low- and middle-income countries, objective burden can easily overshadow subjective burden, such as a lack of community mental health care services and clinics that are out of stock of medication for people with severe and enduring mental health conditions, causing relapse and often readmission [11]. Other concrete aspects of objective burden, such as long hours of being available to the care recipient, time lost from daily activities, and not being able to earn an income, have serious consequences for caregivers as they are unable to pursue their own goals in life and, accordingly, experience a lower quality of life [9,12]. Cultural beliefs about being cursed by ancestors [14] and stigma from health care professionals [15] further aggravate the caring duties of caregivers, precipitating objective burden. The objective burden of care is less reported in the literature than subjective feelings of burden. Many studies have reported the subjective burden of care, which highlights emotional distress and feelings of anxiety, depression, and sadness related to the challenges of caregiving and witnessing the struggles of their family member. Loss of freedom and autonomy has also been reported owing to the demand of caregiving [16]. Feelings of shame and social isolation stem from the stigma of mental illness and cultural beliefs about being cursed by ancestors. Caregivers can also experience role strain as they have to juggle responsibilities at home, which can cause fatigue and overall dissatisfaction in life [17]. Both dimensions of burden are crucial for understanding the challenges faced by family caregivers of individuals with severe and enduring mental health conditions and play a vital role in informing support strategies and interventions.

There is overwhelming evidence in the literature for the need to support caregivers, and several studies from high-income and low- and middle-income countries have indicated successful strategies for alleviating caregiver burden. Studies on informal caregivers of people with severe and enduring mental health conditions in low- and middle-income countries have also increased over the past 10 years, and the burden of caregivers has been well described [18-21]. Yerriah et al [16] reported on the extent of the burden of caregivers of persons with

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schizophrenia in rural South Africa and found that this sample has a higher burden of care. A recommendation from this study was to develop strategies to support caregivers with the aim of improving their quality of life.

Support Strategies for Caregivers

To date, a number of strategies to support caregivers have been investigated with varying results. In Turkey, family-to-family support programs have shown a positive impact on the burden of care [22]. A meta-analysis by Chen et al [23] showed some support for nonpharmacological interventions (mostly psychoeducation) for caregivers of persons with schizophrenia, but the authors reported a potential bias in the results because of the small sample size. In contrast, the systematic review and meta-analysis by Sin et al [24] did not support psychoeducation to improve compliance with treatment and prevent relapse in persons with psychosis, and they reported a lack of available data; thus, no meta-regressions could be conducted. Ewertzon and Hanson [18] conducted a narrative review and identified provision of knowledge, problem-solving, stress management, mutual support groups, and individual-support interventions as successful support interventions for caregivers. Finally, a systematic review by Napa et al [25] revealed that there is insufficient evidence of interventions for psychological distress and expressed emotions in families of persons who experienced first-episode psychosis.

There is limited evidence of web-based health care services and digital health technologies for supporting informal caregivers of individuals with severe and enduring mental health conditions [26]. Sin et al [27] developed an eHealth intervention called Carers for People with Psychosis e-support, but its effectiveness has not yet been investigated. Ploeg et al [28] conducted a rapid review of web-based interventions to improve general caregiver outcomes. More than half of the 17 included studies showed a positive outcome for decreased depressive symptoms, stress, and anxiety among caregivers. If virtual strategies can support caregivers in rural areas, they may be a feasible method to reach people in remote areas who have poor access to health care.

Informal caregivers in rural or remote areas face additional objective burdens such as poor access to services, lack of integration of mental health into community health services [29], and poor intersectoral collaboration. They often have to wait long hours before any support arrives, and in many cases, they have to deal with challenges with the limited resources they have available.

If the types of intervention strategies that could be relevant for low- and middle-income countries, how they were implemented, and the outcome that was achieved were mapped, it could guide health care workers to support informal caregivers on various levels and with various strategies. The availability of virtual support strategies could add another dimension of support to caregivers, which may lead to additional positive outcomes such as immediate support, available information, and contact with support groups. People with severe and enduring mental health conditions benefit as they are most likely to receive optimal care, and their relapse rate may decrease, which means less need for readmission in overextended mental health care wards or hospitals. In addition, people with severe and enduring mental health conditions may also experience a better quality of life if their carers are supported. Thus, it is essential to understand the strategies to alleviate informal caregiver burden and how these strategies should be implemented.

This scoping review aimed to map the strategies to alleviate the objective and subjective burden of informal caregivers of persons with severe and enduring mental health conditions in low- and middle-income countries. The objectives of this scoping review were to (1) identify the types of existing strategies (virtual and face-to-face) for alleviating the objective or subjective burden of care, (2) describe the characteristics of the identified strategies, and (3) list the positive outcomes that were achieved using the identified strategies.

Methods

Review Methodology

This scoping review followed the Joanna Briggs Institute methodology specific to scoping reviews [30]. An a priori protocol for this review has been published [31].

Review Question

The scoping review addressed two research questions related to the strategies for alleviating the burden of care among informal caregivers of persons with severe and enduring mental health conditions:

1. Which existing strategies are reported in the literature for alleviating the burden of informal caregivers of persons with severe and enduring mental health conditions in low- and middle-income countries?
2. What are the outcomes reported by the authors of the strategies for alleviating burden among informal caregivers?

Eligibility Criteria

Participants

Studies were included if participants were informal caregivers of persons with severe and enduring mental health conditions in low- and middle-income countries. Studies that focused on informal caregivers of patients diagnosed with Alzheimer disease and dementia were excluded. This included family, friends, neighbors, and community members who voluntarily provided care without any remuneration. Studies that included both informal caregivers and patients as participants were considered for inclusion, whereas those that reported only on patients were excluded.

Concept

Caregiver burden was defined as the physical, psychological, emotional, social, and financial stresses of providing care to a person with severe and enduring mental health conditions [32]. Severe and enduring mental health conditions in this scoping review included the schizophrenia spectrum and other psychotic disorders, bipolar and related disorders, mood or depressive disorders, and personality disorders. Studies that investigated strategies for alleviating caregiver burden were considered for inclusion. This also included studies that investigated the synonyms used to describe the burden of care among informal caregivers, such as *caregiver strain*, *stress*, and *role fatigue*.

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Studies that reported on the burden of care without suggesting strategies for alleviating it were excluded.

Context

Studies from low- and middle-income countries, including countries in Africa, Asia, Latin America, and the Caribbean, were considered for inclusion. In addition, the inclusion criteria comprised studies from lower-middle-income countries using the World Bank classification of the economic status of a country at the time the study was conducted. The term *developing country* was included as it is similar to *lower-middle-income country*, and thus, countries in Africa, Asia, and Latin America (including the Caribbean) were eligible for inclusion.

Types of Sources

This review included published qualitative, quantitative, and mixed methods studies with all types of designs as well as unpublished studies, including dissertations and theses. Over the last decade, there has been a growing body of knowledge from studies outlining strategies for alleviating burden among informal caregivers in low- and middle-income countries. As a result, this review was only restricted to studies conducted between 2011 and 2021. Only papers written in English were included in this review.

Search Strategy

A 3-step search strategy process was used to identify relevant studies. The search strategy commenced with an initial limited search of PubMed, MEDLINE, CINAHL, and PsycINFO for published studies between 2011 and 2021. The keywords were as follows: "[informal caregiver/s OR caregiver/s] AND [caregiver burden OR caregiver stress] AND [support strategy/ies OR intervention/s] AND [severe mental disorder/s OR mental illness] AND [developing country/ies]."

The second search was refined with the assistance of the librarian at the University of the Witwatersrand, and additional terms were added: "[Carers or 'Informal Carers' or 'Male Caregiver' or Women Caregiver' or 'Family Caregivers'] AND [Caregiver* strain' or 'Caregiver *Exhaustion' or 'Caregiver* burnout' or 'Carer* burden'] AND ['underserved' or 'deprived' or 'middle-income' or low income country]." On advice from the librarian, gray literature such as conference presentations and unpublished studies was searched on ProQuest Dissertations and Theses Global and public health and conference databases. Finally, 2 reviewers (OS and DC) screened the reference lists of the included articles for additional studies. Textbox 1 presents the final list of search terms used to search published and unpublished studies across all the selected databases in this review. The identified references were imported into the Mendeley reference manager (Elsevier) for screening.

Textbox 1. Search terms used in the databases.

'Informal caregiver*' or Caregiver* or Carers or 'Informal Carers' or 'Male Caregiver' or 'Women Caregiver' or 'Family Caregivers' or 'Unpaid Caregiver' or 'Spouse Caregiver' or 'Caretaker' or 'Older Caregiver'

AND

'Caregiver* burden' or 'Caregiver* stress' or 'Caregiver* strain' or 'Caregiver *Exhaustion' or 'Caregiver* burnout' or 'Carer* burden' or 'Carer* stress' or 'Caretaker* role fatigue' or 'Burden of Caregiver*' or 'Caretaker* burden' or 'Caretaker* load' or 'Caregiver* Psychology'

AND

'Strategy' or 'Strategies' or 'Intervention' or 'Procedure' or 'Programme*' or 'Management' or 'Protocol* Guidelines' or 'Guide' or 'Policy' or 'Policies'

AND

'Mental disorders' or 'Mental illness' or 'schizophrenia' or 'bipolar mood disorder' or 'Major depressive disorder' or 'Psychotic disorder' or 'Personality disorder' or 'Bipolar affective disorder'

AND

(developing OR (less* N1 developed) OR "under developed" OR underdeveloped OR "under served" OR underserved OR deprived OR poor* OR "middle income" OR (low* N1 income)) N1 (countr* OR nation* OR population* OR world)) OR ((developing OR (less* N1 developed) OR "under developed" OR underdeveloped OR "under served" OR underserved OR deprived OR poor* OR "middle income" OR (low* N1 income)) N1 (countr* OR nation* or population* OR world)) OR ((developing OR (less* N1 developed) OR "under developed" OR underdeveloped

Source of Evidence Selection

Following the search, all identified citations were exported to the Mendeley reference manager and thereafter to a web-based software, Covidence (Veritas Health Innovation), for primary screening and data extraction from the selected articles. Duplicates were removed, and 2 reviewers (OS and DC) independently conducted the screening for titles, abstracts, and full texts using the inclusion and exclusion criteria. To enhance the reliability of the review results, the first 5 abstracts were screened, and the 2 reviewers compared the screening results and clarified conflicts. Following this, the criteria were revised to ensure a detailed description of the various types of burden. The remaining abstracts were screened, and comparisons were made after 10 screenings to manage conflicts. The 2 reviewers (OS and DC) proceeded to screen texts and extract data from the selected articles. Any disagreements regarding the inclusion of the studies were resolved through discussion between the 2 reviewers.

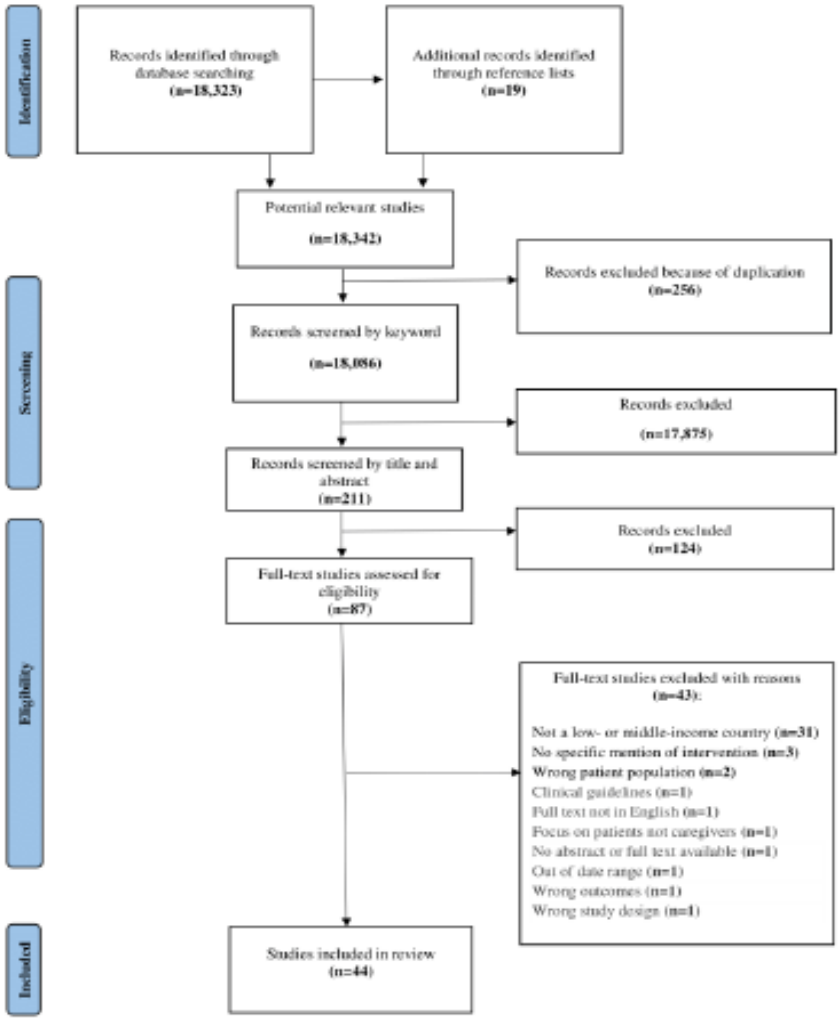
Data Extraction

The Covidence software has templates for data extraction. These templates were modified using the data extraction tables proposed by Peters et al [30]. To ensure the extraction of

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relevant data to answer the review question, these templates were piloted by the reviewers before use. In total, 2 separate data extraction templates (Multimedia Appendix 1) were used to extract data from studies that implemented an intervention and from studies that recommended interventions and strategies for alleviating caregiver burden. Data related to the characteristics of the studies were extracted, including study title; study aims; citation details; population of interest; concept of interest; context of the study, including the country and type of setting; type of evidence sources; study approach and designs; and participant characteristics, such as age, gender, and diagnosis of the care recipients. In addition, information on the characteristics of the interventions was extracted. This included the intervention content (ie, type of intervention, intervention developer and deliverer, and type of burden targeted by the intervention). The intervention description included the duration of the intervention, number of sessions, and location for the intervention. The templates for extracting the data are available in Multimedia Appendix 1. The reviewers extracted the data independently. Web-based meetings were held biweekly to discuss and resolve any discrepancies in the extracted data. Regular comparisons were easy and quick to conduct and improved the consistency of the extracted data. After completing the data extraction, the 2 reviewers scanned the references of the included articles to ensure that no articles were missed. Included and excluded studies were reported in a PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) flow diagram (Figure 1).

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram.



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Data Analysis and Presentation

To increase consistency in the data, this review followed a 3-step analysis process as proposed by Levac et al [33]. This included analyzing the data, reporting the results, and applying meaning to the results [33]. The first step was reviewing the extracted data and identifying the type of data to be analyzed, which were then grouped according to the objectives of the review. This was followed by identifying the type of analysis appropriate for the specific type of data and then analyzing the extracted data. A descriptive quantitative analysis was conducted in a Microsoft Excel (Microsoft Corp) spreadsheet to describe the characteristics of the studies. This included the overall number of studies, types of study design, years of publication, characteristics of the study populations, countries where the studies were conducted, and types of interventions. In addition, descriptive content analysis was conducted deductively using the NVivo software (Lumivero) to code the characteristics of the extracted data into overall categories [34]. Data were categorized into types of strategies—implemented and recommended intervention strategies—and the outcomes of the strategies aimed at alleviating the burden of informal caregivers as reported by the authors. To enhance the clarity of the emerging findings, the data were summarized and presented in graphs and tables.

Results

Study Inclusion

A total of 18,323 studies were identified from the databases using the keywords. In total, 19 additional studies were identified from the reference lists of the included studies, thereby bringing the total number of potentially relevant studies to 18,342. Subsequently, of the 18,342 studies, 256 (1.4%) duplicates were removed, thereby leaving 18,086 (98.6%) studies deemed relevant to the review based on the keywords. A total of 98.83% (17,875/18,086) of these studies were then excluded; this exclusion of numerous studies occurred because of their incongruence with the predefined inclusion criteria, such as instances in which the study did not pertain to a low- or middle-income country context or in which the primary emphasis lay on the patient rather than the caregiver. Therefore, 1.17% (211/18,086) of the studies were screened by title and abstract based on set inclusion and exclusion criteria. This led to the exclusion of 58.8% (124/211) of these studies from the review. A total of 41.2% (87/211) of the studies were then retrieved as full texts based on eligibility by screening their titles and abstracts. Of these 87 studies, 43 (49%) were excluded for various reasons: 31 (72%) were not from low- or middle-income countries; 3 (7%) did not specify the intervention strategy; 2 (5%) focused on the wrong patient population; and another 7 (16%) were excluded for being a clinical guideline, focusing on patients rather than caregivers, having misaligned outcomes and a study design within the exclusion criteria (eg, review articles), being out of the date range of this review, the full text being in a language other than English, and a lack of an abstract and full text. Finally, 44 studies were included in this scoping review. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram was used to present the selection of the studies (Figure 1). It took approximately 8 months, from September 2021 to June 2022, to carry out the study from conception to completion of the project.

Characteristics of the Eligible Studies

Summary of Studies and Evidence Type

The included studies were published between 2011 and 2021. Most studies (31/44, 70%) were published between 2016 and 2021, and 30% (13/44) were published between 2011 and 2016. The types of studies included peer-reviewed journal articles (40/44, 91%), research reports or theses (2/44, 5%), and opinion pieces (2/44, 5%). Of the 44 included studies, 29 (66%) reported on a specific implemented intervention strategy, and 15 (34%) outlined recommended intervention strategies aimed at alleviating the burden of informal caregivers of people with severe and enduring mental health conditions in low- and middle-income countries. The study designs included randomized controlled trials (21/44, 48%), quantitative studies (15/44, 34%), qualitative studies (3/44, 7%), mixed methods studies (3/44, 7%), and gray literature (2/44, 5%; Table 1).

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Table 1. Characteristics of the included studies (N=44).

Characteristic	Studies, n (%)
Summary of studies	
Implemented strategy studies	29 (66)
Recommended strategy studies	15 (34)
Type of evidence	
Journal articles	40 (91)
Research reports or theses	2 (5)
Opinion pieces	2 (5)
Year of publication	
2011-2015	13 (30)
2016-2021	31 (70)
Study design	
Randomized controlled trial	21 (48)
Quantitative design	15 (34)
Qualitative design	3 (7)
Mixed methods	3 (7)
Gray literature	2 (5)

Context of the Studies

A total of 44 studies identified from 16 low- and middle-income countries in Asia, Africa, Europe, and South and North America (Mexico) were included. The countries included China (12/44, 27%); Iran (10/44, 23%); India (5/44, 11%); Brazil (3/44, 7%); Greece (2/44, 5%); Ghana (2/44, 5%); and Thailand, Nepal, South Korea, Indonesia, Jordan, Mexico, Ethiopia, Turkey, Botswana, and mixed countries (including Brazil, Iran, Colombia and Mexico 1/44, 2% of the studies each). As shown in Table 2, majority of the studies with implemented strategies (24/29, 83%) and those with recommended strategies (9/15, 60%) were from Asian countries. Overall, 7% (2/29) of the studies each from Europe, South America, and North America implemented the strategies for alleviating burden and 13% (2/15) of the studies from South and North America recommended the strategies. Only 3% (1/29) of the studies conducted in Africa implemented the strategies and 20% (3/15) of the studies recommended the strategies. A study (1/15, 7%) from mixed countries recommended the strategies for alleviating burden.

Table 2. Continents of the recommended and implemented strategies (N=44).

Continent	Implemented strategies, n (%)	Recommended strategies, n (%)
Asia	24 (83)	9 (60)
Africa	1 (3)	3 (20)
Europe	2 (7)	0 (0)
South and North America	2 (7)	2 (13)
Mixed countries	0 (0)	1 (7)

Characteristics of the Study Populations

The targeted populations in the included studies were mainly family caregivers (38/44, 86%), 7% (3/44) of the studies targeted informal carers, and some studies (3/44, 7%) did not specify their targeted population but rather identified them as caregivers. Most studies (33/44, 75%) included both male and female caregivers, and 25% (11/44) did not specify the sex of their sample. Similarly, most studies (24/44, 55%) included both male and female care recipients, only 2% (1/44) of the studies focused only on male care recipients, and 43% (19/44) did not specify the gender of the care recipients included in the studies. The diagnoses of the care recipients in the included studies were grouped into 6 categories: schizophrenia (17/44, 39%), mood disorders (4/44, 9%), multiple diagnoses including schizophrenia and mood disorders (5/44, 11%), mixed severe and enduring mental health conditions (5/44, 11%), other psychotic and chronic conditions (6/44, 14%), and unspecified mental disorders (7/44, 16%; Table 3).

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Table 3. Characteristics of the study populations in the included studies (N=44).

Characteristic	Studies, n (%)
Population of interest	
Family caregiver or caregivers	38 (86)
Informal carer or carers	3 (7)
Caregiver or caregivers	2 (5)
Carer or carers	1 (2)
Concept of interest	
Caregiver burden	18 (41)
Family burden	16 (36)
Caregiver stress	9 (20)
Caregiver strain	1 (2)
Sex of caregivers	
Mixed-gender groups (male and female)	33 (75)
Not specified	11 (25)
Gender of care recipients	
Mixed-gender groups (male and female)	24 (55)
Male	1 (2)
Not specified	19 (43)
Diagnosis of care recipients	
Schizophrenia	17 (39)
Mood disorders	4 (9)
Schizophrenia and mood disorders	5 (11)
Mixed diagnoses of severe mental disorders	5 (11)
Unspecified mental disorders	7 (16)
Other (drug dependency, psychotic disorders, and chronic conditions)	6 (14)

Concept of Interest

The concepts of interest reported in the studies included caregiver burden (18/44, 41%), family burden (16/44, 36%), caregiver stress (9/44, 20%), and caregiver strain (1/44, 2%; Table 3).

Review Findings

This section outlines the findings of the scoping review and includes the types of intervention strategies, characteristics of the intervention strategies, and author-reported outcomes from the included studies.

Types of Intervention Strategies

The various strategies for alleviating caregiver burden were grouped into 2 categories: implemented and recommended intervention strategies. The implemented intervention strategies emerged from studies that investigated the effects of a specific intervention to alleviate the burden of informal caregivers. The recommended interventions were identified from studies that investigated caregiver burden and outlined recommended intervention strategies to be used to alleviate the burden of informal caregivers of persons with severe and enduring mental health conditions. Most studies (29/44, 66%) reported on an implemented intervention strategy, and 34% (15/44) of the studies recommended strategies to alleviate caregiver burden.

Most of the studies and articles (33/44, 75%) originated in Asia, with 55% (24/44) implemented and 20% (9/44) recommended intervention strategies reported on, followed by Africa with 2% (1/44) implemented and 7% (3/44) recommended intervention strategies, South and North America with 5% (2/44) implemented and 5% (2/44) recommended intervention strategies, and Europe with 5% (2/44) implemented intervention strategies (Table 2). A study from mixed countries only reported recommended intervention strategies. The identified strategies were grouped into the following categories: community-based interventions, psychoeducation interventions, support groups, cognitive behavioral therapy (CBT), spirituality-based interventions, smartphone-based interventions, mindfulness and empowerment, collaborative interventions, standard care, financial and social support, counseling, occupation-based interventions, policy and legislature, and access to mental health care (Table 4 and Textbox 2). These categories are discussed in the following subsections.

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Table 4. Description of the identified evaluated strategies for alleviating informal caregiver burden.

Type of strategy	Evaluated interventions	Author-reported outcomes
Community-based interventions	• CoMHIP[a] • RESHAPE[b]	• Positive outcomes (positive effects on family caregivers)
Psychoeducation interventions	• Psychoeducation program • Group psychoeducation • FLEP[c] • Peer-assisted education	• Improved coping skills • Enhanced recovery • Improved QoL[d] • Knowledge and skill acquisition • Reduced burden of care • Reduced anxiety and stress • Reduced psychological strain • Enhanced family functioning • Relapse prevention • Reduced prolonged admissions • Negative outcomes (no efficacy on burden of care, QoL, or self-esteem among BMD[e] caregivers)
Support groups	• FPGP[f] • Family-led mutual support program	• Knowledge and skill acquisition • Enhance help seeking • Alleviation of guilt • Improved family and patient functioning • Decreased demand on mental health services • Improved psychosocial health • Improved QoL
Cognitive behavioral therapy	• Emotional regulation training	• Reduced burden of care • Reduced anxiety and stress • Increased resilience
Spirituality-based intervention	• Spirituality-based program	• Reduced anxiety and stress
Guided self-help interventions	• Manual-guided PBSP[g] • The Good Mood Guide	• Strengthened positive caregiving experience • Reduced negative caregiving experience • Increased access to support
Smartphone-based interventions	• MHapps[h]	• None
Mindfulness and empowerment interventions	• IEP[i] • MBSR[j] program	• Caregiver empowerment • Improved QoL • Decreased depressive symptoms • Increased self-efficacy
Collaborative interventions	• Participatory care model	• Reduced burden of care • Increased resilience
Standard care	• Multimodal intervention (general medicine, psychiatry, psychology, family therapy, neuropsychological rehabilitation, and occupational therapy)	• Reduced burden of care • Increased social support

[a]CoMHIP: community mental health early intervention project.
[b]RESHAPE: Reducing Stigma Among Healthcare Providers.
[c]FLEP: Family Link Education Programme.
[d]QoL: quality of life.
[e]BMD: bipolar mood disorder.
[f]FPGP: Family-led Peer Support Group Program.
[g]PBSP: problem-solving–based self-learning program.
[h]MHapps: mental health apps.
[i]IEP: integrated empowerment program.
[j]MBSR: mindfulness-based stress reduction.

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Textbox 2. Description of the identified recommended strategies for alleviating informal caregiver burden.

Community-based interventions

- Strengthening existing primary health care system
- Establishment of day nursing or care
- Respite care
- Vocational training for patients
- Single-family caregiver organization
- Supported employment for patients
- Home visits

Psychoeducation interventions

- Group psychoeducation
- Family education
- Continuing education programs for effective practice
- Educational lectures
- Psychoeducation program

Support groups

- Nongovernmental mental health–related support groups
- Family caregiver assistance programs

Cognitive behavioral therapy

- Family therapy groups

Spirituality-based intervention

- Turning to traditional healers and spiritual leaders

Smartphone-based interventions

- Mental health apps

Mindfulness and empowerment interventions

- Stress management training

Collaborative interventions

- Caregiver involvement in all program elements
- Pluralistic and ecological approach to service delivery

Standard care

- Telepsychiatry
- Availability of emergency teams

Financial support

- Disability grant
- Fee-free mental health services
- Medical insurance and free medication

Social support

- Medical care social security
- Social resources

Counseling

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- Basic counseling
- Supportive psychotherapy

Occupation-based interventions

- Physical and leisure activities

Policy and legislature

- National health insurance schemes
- Advocacy for a strong mental health policy
- Integration of caregiver actions and interventions into national mental health care plans
- Fee-free mental health services

Access to mental health care

- Caregiver care inclusion in daily treatment facilities
- Access to therapeutic tools
- Availability of mental health units or departments
- Periodic health checks for caregivers (every 6 months on average)
- Improvement in institutional mental health care

Psychoeducational Interventions

The first strategy was psychoeducational interventions, which was identified as the most common strategy implemented and recommended to alleviate caregiver burden. A total of 27% (12/44) of the studies implemented 4 different psychoeducational interventions, including 58% (7/12) of these studies using a psychoeducation program [35-40], 17% (2/12) using group psychoeducation [41,42], 17% (2/12) using the Family Link Education Programme [43,44], and 8% (1/12) of the studies implementing peer-assisted education [45] (Table 4). Similarly to the implemented intervention strategies, the recommended psychoeducational interventions identified included psychoeducational programs, group psychoeducation, family psychoeducation, continuing education programs for effective practice, and educational lectures [7,46] (Textbox 2).

Support Group Interventions

The second strategy was support groups. In total, 7% (3/44) of the studies implemented support group strategies, including the Family-led Peer Support Group Program, family-led mutual support programs, and nongovernmental mental health–related support groups [47-49] (Table 4). The recommended support group strategies identified in this review included nongovernmental mental health–related support groups and family caregiver support programs [50-54] (Textbox 2).

Community-Based Interventions

Community-based interventions were identified as a third strategy to alleviate caregiver burden, and 5% (2/44) of the included studies reported on implementing a community mental health early intervention project and Reducing Stigma Among Healthcare Providers [55,56] as community-based interventions (Table 4). The recommended community-based interventions included strengthening existing primary health care systems, establishing day nursing or care for the care recipients, respite care, vocational rehabilitation training for patients, single-family caregiver organizations, supported employment for patients, and home visits [46,52,53,57] (Textbox 2).

Guided Self-Help Interventions

A total of 5% (2/44) of the studies implemented guided self-help interventions, namely, a manual-guided problem-solving–based self-learning program [58] and the Good Mood Guide [59] (Table 4). No recommended guided self-help interventions were identified in this review.

Mindfulness and Empowerment Interventions

Mindfulness and empowerment interventions were implemented in 5% (2/44) of the studies, and the programs implemented were a mindfulness-based stress reduction program and an integrated empowerment program [60,61] (Table 4). Stress management training was identified as a recommended mindfulness and empowerment intervention strategy in this review [7] (Textbox 2).

CBT Interventions

Emotional regulation training was the only implemented CBT strategy identified in 5% (2/44) of the included studies [62,63] (Table 4). The recommended cognitive behavioral strategy identified in this review was family therapy groups [64] (Textbox 2).

Spirituality-Based Interventions

In total, 2% (1/44) of the studies implemented a spirituality-based program for informal caregivers in which the comparison intervention was 2 standard group training sessions related to general mental disorders [65] (Table 4). Turning to traditional healers and spiritual leaders was identified as a recommended spirituality-based intervention for alleviating informal caregiver burden [52] (Textbox 2).

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Participatory Care Model

In total, 2% (1/44) of the studies implemented a participatory care model as a collaborative intervention strategy [66] (Table 4). The recommended collaborative interventions were caregiver involvement in all program elements and a pluralistic and ecological approach to service delivery [56,67] (Textbox 2).

Standard Care

The implemented standard care interventions were multimodal interventions that encompassed general medicine, psychiatry, psychology, family therapy, neuropsychological rehabilitation, and occupational therapy with no comparison intervention [68] (Table 4). The recommended standard care interventions were telepsychiatry and ensuring the availability of emergency teams [53] (Textbox 2).

Smartphone-Based Interventions

Only 2% (1/44) of the studies implemented smartphone-based interventions using mental health apps to alleviate the burden of informal caregivers with no comparison intervention [67] (Table 4). Although the study indicated the use of the mental health apps with care recipients and their caregivers, the specific intervention offered was not described. No recommended smartphone-based interventions were identified in this review.

Additional Strategies Recommended for Alleviating Caregiver Burden

The additional recommended intervention strategies were financial support, including the provision of a disability grant, fee-free mental health services, medical insurance, and free medication for care recipients [7,57,68]. The recommended social support comprised medical care social security and social resources [52,54,56,57,69]. Recommended counseling interventions comprised basic counseling and supportive psychotherapy [64,69]. Occupation-based interventions included participation in physical and leisure activities [64]. Policy and legislature recommended interventions comprised the implementation of national health insurance schemes, advocacy for a strong mental health policy, integration of caregiver actions and interventions into national mental health care plans, and fee-free mental health services [53,62,68]. Finally, other recommended interventions were access to mental health care, which considers caregiver care inclusion in daily treatment facilities; access to therapeutic tools; availability of mental health units or departments; periodic health checks for caregivers (every 6 months on average); and improved institutional mental health care [35,52,54,67] (Textbox 2).

Characteristics of the Implemented Intervention Strategies

Most of the implemented intervention strategies (18/29, 62%) were targeted at alleviating both objective and subjective burden, and 38% (11/29) were exclusively aimed at alleviating subjective burden. The intervention developers were reported as being researchers based on evidence (13/29, 45%) and researchers with expert input (5/29, 17%). In total, 28% (8/29) were existing interventions implemented without any adaptations, and 10% (3/29) of the interventions did not specify the intervention developer. The intervention deliverers identified in the studies included trained peer facilitators (7/29, 24%), researchers (7/29, 24%), psychiatrists and nurses (5/29, 17%), multiple health care professionals (4/29, 14%), and psychologists (3/29, 10%), and 10% (3/29) of the interventions did not specify who delivered them.

The number of sessions offered in the implemented intervention strategies was between 6 and 8 sessions (13/29, 45%), ≤5 sessions (8/29, 28%), and ≥11 sessions (5/29, 17%), and 10% (3/44) of the interventions did not specify the number of sessions. The duration of the implemented interventions in the studies was 6 to 15 weeks (10/29, 34%), ≤5 weeks (7/29, 24%), and ≥16 weeks (4/29, 14%), and 28% (8/29) of the interventions did not specify the duration. Most interventions (9/29, 31%) were delivered once per week, some were offered twice a week (8/29, 28%), and some of the interventions (12/29, 41%) did not specify the frequency of their sessions. The length of the sessions in the implemented interventions ranged between 2 and 2.5 hours (8/29, 28%), 1 to 1.5 hours (6/29, 21%), and ≤1 hour (1/29, 3%), and 48% (14/29) of the interventions did not specify the length of their sessions (Table 5).

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Table 5. Characteristics of the implemented strategies for alleviating informal caregiver burden (N=29).

Study	Year of publication	Type of intervention	Type of burden targeted by the intervention	Intervention developer	Intervention deliverer	Number of sessions	Duration of intervention	Frequency of sessions per week	Length of the sessions
Ng et al [56]	2018	CoMHIP[a]	Subjective and objective	Not specified	The Integrated Community Centre for Mental Wellness	Not specified	Not specified	Not specified	Not specified
Rai et al [55]	2018	RESHAPE[b]	Subjective and objective burden	Developed as part of WHO[c] mhGAP[d] and PRIME[e]	TPO[f] Nepal, a Nepali nongovernmental organization	5 sessions	4 days	Not specified	Not specified
Rajai et al [45]	2021	Peer- assisted education	Subjective and objective burden	Researchers and approved by 3 faculty members of the Army College of Medical Sciences	Trained peer facilitators	6 sessions	3 weeks	Twice weekly	1 hour
Zhou et al [44]	2020	FLEP[g]	Subjective and objective burden	FLEP: peer-led psychoeducation program developed from the stress and coping model by Pearlin et al [70]	Group facilitators who were peer specialists of experienced caregivers	8 sessions	8 weeks	Once weekly	2 hours
Dewi et al [37]	2019	Family psychoeducation and care decision without pasung	Subjective and objective burden	Researchers	Researchers	3 sessions	3 weeks	Not specified	35-40 minutes
Tabelešo et al [36]	2018	Psychoeducation	Subjective and objective burden	Not specified	10 psychologists	6 sessions	Not specified	Not specified	Not specified
Ntsayagae [40]	2017	Psychoeducation	Subjective and objective burden	Researcher based on existing literature	Researcher	2 sessions	Not specified	Not specified	Not specified
De Souza et al [39]	2016	Psychoeducation	Subjective and objective burden	Psychoeducational intervention for patients with BD[h] by Colom et al [71] translated and adapted by Dell-Aglio et al [72]	Psychiatrist responsible for specific case	6 sessions	6 to 8 weeks	Twice weekly	Not specified
Kolostoumpis et al [38]	2015	Psychoeducation	Subjective burden	Adapted from the treatment protocol developed by Reinares et al [73] in the Barcelona Bipolar Disorders Program in Spain	Psychiatrist and psychologist	7 sessions	Not specified	Not specified	Not specified
Jessy and Kalaimathy [35]	2014	Psychoeducation	Subjective and objective burden	Researcher based on WHO guidelines for educational interventions and existing literature. Manual translated into Tamil.	Researcher	5 modules	10 weeks	Twice weekly	1 hour

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Study	Year of publication	Type of intervention	Type of burden targeted by the intervention	Intervention developer	Intervention deliverer	Number of sessions	Duration of intervention	Frequency of sessions per week	Length of the sessions
Fallahi Khoshknab et al [41]	2014	Group psychoeducation	Subjective and objective burden	Researchers based on educational program of psychiatric nursing and psychiatric textbooks	Organized based on educational program of psychiatric nursing and psychiatric textbooks (Campbell [74]) and converted to understandable text for patients and families	4 sessions	4 weeks	Once weekly	2 hours
Navidian et al [42]	2012	Psychoeducation	Subjective burden	Researchers based on the families' needs and the existing literature	Psychiatrist and mental health nurse	4 sessions	4 weeks	Once weekly	2 hours
Sharif et al [75]	2012	Psychoeducation	Subjective and objective burden	Psychiatrist and psychiatric nurse based on the literature and needs of the families	Psychiatrist, nurse, and guest speakers	10 sessions	5 weeks	Not specified	1.5 hours
Chiu et al [43]	2011	FLEP	Subjective burden	Task force consisting of a mental health social worker, a recovered patient with editorial experience, and a caregiver based on available related local educational materials and the NAMI[i] Family-to-Family program	Trainers who were themselves family members of people with SMI[j]. They received training and a trainer manual.	8 sessions	Not specified	Once weekly	Not specified
Chien et al [48]	2018	Family-led support program	Subjective and objective burden	Family-led mutual support group—contents were based on similar program protocols and the researcher-developed family mutual support groups for psychotic disorders	Family-led mutual support group—co-led by 2 peer family caregivers along with a researcher and rehabilitation nurse	16 sessions	36 weeks	Twice weekly	2 hours
Mentis et al [49]	2015	Support group intervention	Subjective burden	Nongovernmental mental health organization (NGOMH[k])	Not mentioned	Not specified	Not specified	Not specified	Not specified
Chien et al [48]	2018	Family-led mutual support program	Subjective burden	6 experts on psychiatric rehabilitation (including psychiatrists, clinical psychologists, and nurse specialists)	Peer leader who received training from the researchers and worked closely with a group leader who was a trained psychiatric nurse	14 sessions	39 weeks	Twice weekly	2 hours

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Study	Year of publication	Type of intervention	Type of burden targeted by the intervention	Intervention developer	Intervention deliverer	Number of sessions	Duration of intervention	Frequency of sessions per week	Length of the sessions
Chien and Chan [47]	2013	FPGP[j]	Subjective and objective burden	Content and format were based on previous programs conducted by Li and Arthur [76] in mainland China. Appropriateness of the content was rated by 7 experts, including psychiatrists, psychologists, and nursing specialists.	Peer support—peer leader supported by principal researcher	14 group sessions	39 weeks	Twice weekly	2 hours
Behrouian et al [62]	2021	Emotional regulation	Subjective burden	On the basis of the Dialectical Behavior Therapy Skills Workbook and CBT[m] principles	Clinical psychologist	8 sessions	8 weeks	Once weekly	Not specified
Behrouian et al [63]	2020	Emotion regulation training	Subjective and objective burden	Sessions were based on previous studies (Gratz and Gunderson [77]). Trainings were based on the Dialectical Behavior Therapy Skills Workbook (McKay et al [78]).	Clinical psychologist	8 sessions	Not specified	Not specified	Not specified
Faghih and Pahlavanzadeh [79]	2019	CBT	Subjective burden	Researchers based on existing literature	Researcher	16 sessions	8 weeks	Twice weekly	1.5 hours
Khosravi et al [65]	2021	Spirituality-based program	Subjective burden	Researcher	Researcher	6 sessions	8 weeks	Twice weekly	1 hour
Chien et al [58]	2020	Manual-guided PBSP[n]	Subjective and objective burden	Developed by McCann et al [80] in Australia, and its Chinese translated version was validated and refined by the research team.	Psychiatric nurse	5 modules	21 weeks	Not specified	Not specified
McCann et al [59]	2015	Guided self-help manual	Subjective and objective burden	The Good Mood Guide developed by Lifeline South Coast NSW[o], Australia	Researcher via telephone	8 modules	8 weeks	Once weekly	Not specified
Deb et al [67]	2018	Smartphone-based interventions (MHapps[p])	Subjective and objective burden	Researcher	Psychiatrist	Not specified	Not specified	Not specified	Not specified

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Study	Year of publication	Type of intervention	Type of burden targeted by the intervention	Intervention developer	Intervention deliverer	Number of sessions	Duration of intervention	Frequency of sessions per week	Length of the sessions
Hyun et al [61]	2018	IEP[h]	Subjective burden	Developed by Hyun et al [61] for community-living PMIs[i] based on the empowerment theories of Kanter [81] and McLean [82]	Mental health professionals who received training with a written structured intervention protocol from the research team	4 sessions	4 weeks	Once weekly	2 hours
Hou et al [60]	2014	MBSR[a] program	Subjective burden	Not stated but assumed that the researchers modeled the program on the original MBSR by Kabat-Zinn [83]	3 trained instructors with >3 years of experience in MBSR	8 sessions	8 weeks	Once weekly	2 hours, with a CD of 30-45 minutes for home practice
Zoladl et al [56]	2020	Participatory care model	Subjective burden	Researchers	Researchers and staff at the research site	8 sessions	12 weeks	Once weekly	1.5 hours
Ramirez et al [68]	2017	Standard care—included care from general medicine, psychiatry, psychology, family therapy, neuropsychological rehabilitation, and occupational therapy	Subjective and objective burden	Not stated	Medical officer, psychiatrist, psychologist, and occupational therapist	12-18 sessions	10 weeks	Not specified	Not specified

[a]CoMHIP: community mental health early intervention project.
[b]RESHAPE: Reducing Stigma Among Health Care Providers.
[c]WHO: World Health Organization.
[d]mhGAP: Mental Health Gap Action Programme.
[e]PRIME: Programme for Improving Mental Health Care.
[f]TPO: Transcultural Psychosocial Organization.
[g]FLEP: Family Link Education Programme.
[h]BD: bipolar disorder.
[i]NAMI: National Alliance on Mental Illness.
[j]SMI: severe mental illness.
[k]NGOMH: nongovernmental mental health.
[l]FPGP: Family-led Peer Support Group Program.
[m]CBT: cognitive behavioral therapy.
[n]PBSP: problem-solving–based self-learning program.
[o]NSW: New South Wales.
[p]MHapps: mental health apps.
[q]IEP: integrated empowerment program.
[r]PMI: person with mental illness.
[s]MBSR: mindfulness-based stress reduction.

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Perceived Effectiveness of the Implemented Intervention Strategies

This review outlines the effectiveness of the implemented intervention strategies as reported by the authors who conducted the studies (Table 4). It should be noted that this scoping review included both published and gray literature, and therefore, no critical appraisal of the studies or meta-analyses were conducted. Therefore, care should be taken as these interpretations may be clouded by author bias [84].

The authors expressed the effectiveness of the implemented intervention strategies by highlighting whether the strategy resulted in a positive or negative outcome for the informal caregivers or their care recipients. Overall, the implemented strategies were reported to be effective in reducing the burden of care and improving the quality of life of informal caregivers. Psychoeducation intervention strategy outcomes included improved coping skills, improved quality of life, reduced anxiety and stress, reduced burden of care, reduced psychological strain, improved knowledge and skills in caregiving, enhanced family functioning, enhanced recovery, relapse prevention, and reduced prolonged admissions. Support group outcomes included alleviation of guilt, enhanced help-seeking behavior, improved quality of life, improved knowledge and skills in caregiving, improved psychosocial health, improved family and patient functioning, and decreased demand for mental health services. CBT outcomes included reduction in burden of care, anxiety, and stress and increased resilience of informal caregivers. Guided self-help outcomes included strengthened positive caregiving experiences, reduced negative caregiving experiences, and increased access to support. The reported outcomes for mindfulness and empowerment interventions included empowerment of caregivers, increased self-efficacy, improved quality of life, and decreased depressive symptoms. Collaborative intervention outcomes included reduced burden of care and increased resilience. The standard care outcomes reported included positive outcomes in caregiving, reduction in the burden of care, and increase in social support for caregivers.

Negative outcomes were only reported for the psychoeducation and mindfulness and empowerment intervention strategies. The reported negative outcomes of psychoeducation interventions were no improvement in the burden of care, quality of life, or self-esteem. The reported negative outcomes of mindfulness and empowerment interventions included short-lived improvement in anxiety, and the authors highlighted no improvement after 3 months of follow-up with the participants and no effect on perceived stress, quality of life, and self-compassion, indicating that the effects of the interventions were not sustainable.

Discussion

Principal Findings

This scoping review set out to map the literature on strategies for alleviating the burden of informal caregivers of persons with severe and enduring mental health conditions in low- and middle-income countries. The review identified types of strategies, strategy characteristics, and outcomes of the strategies as reported by the authors. The types of strategies identified were categorized as implemented and recommended intervention strategies and included community-based interventions, psychoeducational interventions, support groups, CBT, spirituality-based interventions, guided self-help, smartphone-based interventions, mindfulness and empowerment, collaborative interventions, standard care, financial and social support, counseling, occupation-based interventions, policy and legislature, and access to mental health.

Most of the implemented and recommended intervention studies (33/44, 75%) were conducted in Asian countries and targeted both subjective and objective burdens, and some studies (18/29, 62%) focused exclusively on subjective burden. This shows an increasing research interest in caregiver interventions in mental health research in Asian countries over the last decade. In contrast, the small number of studies from other low- and middle-income countries possibly confirms the limited research on support strategies for alleviating caregiver burden in mental health. Despite consensus on the high levels of burden of informal caregivers of persons with severe and enduring mental health conditions in these countries [56,85-87] and the importance of supporting caregivers, few studies (44/18,086, 0.24%) implemented and recommended intervention strategies for alleviating caregiver burden. This evidence gap raises significant concerns considering the scarcity of mental health care professionals and limited access to quality mental health services in many low- and middle-income countries. As a result, informal caregivers assume a vital role in the support and care of persons with severe and enduring mental health conditions in these regions [88,89]. Having limited strategies for alleviating the burden of informal caregivers may have dire consequences for the management of persons with severe and enduring mental health conditions in these countries.

The implemented and recommended intervention strategies were mainly focused on both male and female family caregivers. These findings are consistent with the literature as families have long been acknowledged as key stakeholders in the care and management of mental disorders [90-93]. Therefore, it is important to ensure that the strategies for alleviating caregiver burden are targeted specifically to this population, particularly in low- and middle-income countries, where occupying this role is often obligatory [94]. The fact that most implemented intervention strategies were aimed at both male and female caregivers is important to note. Although caregiving is identified as a female-oriented role, there is evidence that men also occupy the primary caregiver role and are also likely to experience high levels of caregiver burden [20,94]. This emphasizes the need to ensure that, where strategies for alleviating caregiver burden are implemented, they focus on all caregivers irrespective of their gender. The care recipients in these studies were mostly diagnosed with schizophrenia and mood disorders. This is consistent with the literature highlighting that depressive disorders, schizophrenia, and bipolar disorders are among the top 10 leading causes of disability in low- and middle-income countries [95].

The findings of this scoping review emphasize the need for evidence-based intervention strategies aimed at alleviating the

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burden of informal caregivers in low- and middle-income countries. Most implemented intervention strategies were informed by evidence, in which researchers consulted existing literature and sought expert input to develop their interventions. Trained peer facilitators delivered most of the implemented interventions and were informal caregivers themselves. This is important to note as it aligns with task shifting, which is focused on transferring skills and responsibilities to local people with the aim of increasing access to mental health services in low- and middle-income countries where there is a shortage of human resources [96,97]. In addition, the findings of this review reveal that researchers, nurses, and psychiatrists offered some of the interventions, which may not be sustainable in low- and middle-income countries given the shortage of mental health professionals [95]. Most studies (13/29, 45%) offered 6 to 8 sessions over 6 to 8 weeks, and the sessions were facilitated once or twice a week for 1 to 2 and a half hours. Given the number and frequency of sessions, it may be useful to use peer facilitators to offer these interventions as most are already in the community, which will ensure sustainability in resource-constrained contexts in low- and middle-income countries.

Overall, the implemented intervention strategies were reported to have a positive effect on alleviating the burden of informal caregivers of people with severe and enduring mental health conditions in low- and middle-income countries. In some studies, these effects were reported for both informal caregivers and their care recipients. The authors reported the effectiveness of the strategies in their studies in terms of the help, benefit, and effect that a specific implemented intervention strategy had on the informal caregivers. Some compared their interventions mainly with standard psychiatric care and psychoeducation, which focused on providing caregivers with information on specific or general mental disorders. Psychoeducational interventions were frequently implemented intervention strategies and were identified as helpful, beneficial, and effective in reducing caregiver burden [35,38,42,75]. This type of intervention was reported to improve caregiver knowledge and skills to enable them to cope with the demands of caregiving. In addition, psychoeducational interventions were linked with positive patient outcomes as they were reported to enhance patient recovery, which subsequently reduced relapses and prolonged admissions. These interventions were commended for being simple, feasible, and cost-effective, making them the most preferred form of intervention strategy to address the burden of informal caregivers.

Similarly, implemented intervention strategies such as support groups, community-based interventions, guided self-help, mindfulness and empowerment, and CBT were reported to have a positive effect on the burden of informal caregivers in low- and middle-income countries. It is important to note that the family-led mutual support program, a peer-facilitated intervention, was reported to have long-term desirable benefits on the psychosocial health of both caregivers and their care recipients compared with the psychoeducational program and standard care offered by psychiatrists, clinical psychologists, and nursing specialists. Similarly, the manual-guided problem-solving–based self-learning program, a guided self-help intervention, was reported to have a superior treatment effect on caregiver burden, care recipients' symptom severity, and the duration of rehospitalizations at the 6-month follow-up compared with a well-accepted family psychoeducation group program. This implies that support groups and guided self-help, although not frequently implemented, should be considered beneficial strategies for alleviating caregiver burden. In addition, as self-directed and peer-evaluated interventions, these intervention strategies may be considered cost-effective in extending the services to informal caregivers, especially in low- and middle-income countries where a shortage of human resources affects the delivery and quality of mental health services.

Although not frequently implemented, intervention strategies such as spirituality-based, collaborative, and standard care interventions were also reported to reduce caregiver burden. Spirituality-based interventions were identified as an inexpensive and readily available resource for alleviating the burden of informal caregivers. Similarly, the participatory care model was reported to be an efficient and low-cost method for reducing caregiver burden and increasing caregiver resilience. Therefore, it is necessary to further explore the use of these interventions with informal caregivers of people with severe and enduring mental health conditions in low- and middle-income countries.

Despite their potential, the use of virtual interventions or telehealth strategies for informal caregivers remains underrepresented in the literature. This may be attributed to the relatively slow adoption of telehealth among informal caregivers. Notably, only 1 smartphone app was identified in this scoping review. However, telehealth holds promise as a viable approach for disseminating psychoeducational information, providing real-time support, and facilitating participation in virtual caregiver support groups, particularly in remote areas. The increasing proliferation of smartphones and internet access in Africa further emphasizes opportunities for the development of telehealth programs tailored to caregivers of individuals with severe and enduring mental health conditions. Although most of the implemented intervention strategies reported positive effects on caregiver burden, there were negative outcomes reported for some interventions. Hou et al [60] reported that the mindfulness-based stress reduction program led to a short-lived improvement in the stress and anxiety of the informal caregivers but that no improvement was noted after the 3-month follow-up. In addition, this intervention did not demonstrate a sustained effect on health-related quality of life, perceived stress, or self-compassion. These outcomes were attributed to the loss to follow-up and the fact that the measurement instruments could have been less sensitive to changes in quality of life and stress. Similarly, the 6-session individual psychoeducation intervention for informal caregivers of persons with bipolar mood disorder showed no effect on burden, quality of life, or self-esteem. This was attributed to the reduction in the number of sessions from 21 in the original instruction [71] to 6 in this study [35]. Another reason was that the sessions were conducted individually, whereas the literature highlights that multifamily intervention groups are effective [71,73,98].

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Implications for Practice and Policy

The findings of this review provide evidence for the reported evaluated and recommended interventions having benefits in reducing the burden of care among informal caregivers in low- and middle-income countries. Previous studies conducted in low- and middle-income countries have since emphasized the urgent need to strengthen informal caregiver support regarding mental health. The need for information and skills in handling mental health care users, as well as the need for emotional and tangible support, has been highlighted in previous studies [42,99]. The findings of this review revealed that psychoeducation and support groups were highly used strategies for improving knowledge and skills as well as building support for informal caregivers in low- and middle-income countries. Furthermore, these strategies were reported to be beneficial and cost-effective, thereby making them a viable option for implementation in low- and middle-income countries, where limited access to mental health resources prevails [100]. The need to ensure that these strategies are offered on a continuous basis was highlighted in many studies, indicating the need for 6 to 10 sessions over a period of 6 to 10 weeks [7]. To ensure sustainability, training of peer facilitators to deliver these interventions may be realistic as this aligns with a task-shifting approach, which has long been advocated for as a cost-effective strategy for increasing access to mental health services in low- and middle-income countries [101]. It is interesting to note that peer support groups and guided self-help were reported to have long-term benefits on caregiver burden compared with psychoeducation; this highlights that using self-directed interventions is considered a practical option for alleviating informal caregiver burden. In low- and middle-income countries where a shortage of human resources prevails, it is important to consider such interventions as they empower informal caregivers to build support and take ownership of their health and well-being [35]. Spiritual-based interventions, although not frequently implemented, are important to note in the context of low- and middle-income countries as most informal caregivers have been identified as relying on spiritual and religious coping [102,103]. Recommended strategies such as the provision of financial and social support as well as policy and legislature strategies call for an urgent need for policies in mental health to shift focus toward integrating caregiver-oriented services into practice. In addition, these findings highlight the need to adopt an intersectoral approach [104] in which various sectors such as religious and spiritual organizations provide mental health services to extend their accessibility to informal caregivers.

Limitations

In alignment with Arksey and O'Malley, this review did not include a critical appraisal to ascertain the quality of the studies as the purpose of this scoping review was to map existing strategies for alleviating caregiver burden and report on the outcomes as stated by the authors. In their study, Woo et al [105] cautioned that the exclusion of critical appraisals in scoping reviews means that the review cannot ascertain the research gaps that it aims to address if the included studies are of poor methodological quality. Although this scoping review provides evidence on the existing strategies for alleviating caregiver burden, it is important that the suggested strategies be evaluated in the specific context to ensure their effectiveness before implementation in clinical practice. This step was omitted as the purpose of this review was to map the available intervention strategies and the outcomes reported by the authors in alleviating burden among informal caregivers in low- and middle-income countries. This review only included studies conducted in low- and middle-income countries, and only papers written in English were considered, thus reducing the extent and scope of the evidence on the strategies for alleviating burden among informal caregivers regarding mental health.

Conclusions

The findings of this scoping review provided the authors with categories they can use to develop semistructured interview guides to use when exploring the existing formal and informal community mental health services to alleviate the burden of informal caregivers in rural South Africa. The categories outline the different types of strategies that can be used to alleviate caregiver burden, in particular the types of strategies offered to informal caregivers and the intervention developers and deliverers in and outside the mental health care system. Although most of the included studies (29/44, 66%) implemented these strategies, a few studies conducted in other low- and middle-income countries (15/44, 34%) recommended the use of these interventions to alleviate caregiver burden. Future studies from low- and middle-income countries in other continents, including Africa and South and North America, should address this gap in the research by evaluating these intervention strategies to alleviate the burden of informal caregivers.

Critical appraisal, which is used to ascertain the quality of the studies, was omitted as the purpose of this scoping review was to map existing strategies for alleviating caregiver burden and report on the outcomes as stated by the authors. Future studies should conduct quality appraisals to establish the effectiveness of these strategies in alleviating the burden of informal caregivers. Peer-facilitated support group interventions, although not frequently implemented, were identified as having long-term benefits compared with frequently implemented interventions such as psychoeducation. It is recommended that future research be directed at implementing and evaluating these interventions to alleviate burden in low- and middle-income countries.

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Data Availability

All data generated or analyzed during this study are included in this published paper.

Authors' Contributions

OS completed the literature search. OS and DC completed the screening of titles, abstracts, and full texts of the identified studies. In addition, they extracted data from all the included studies and completed the draft of the manuscript. FA and NGN reviewed the manuscript draft. OS incorporated the feedback from the authors for publication.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Data extraction templates.
[DOCX File , 23 KB-Multimedia Appendix 1]

Multimedia Appendix 2

PRISMA-ScR Checklist.
[PDF File (Adobe PDF File), 156 KB-Multimedia Appendix 2]

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Abbreviations

CBT: cognitive behavioral therapy
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews

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CHAPTER 5

PHASE 2: EXPLORATION OF STRATEGIES FOR ALLEVIATING CAREGIVER BURDEN AMONG THE INFORMAL CAREGIVERS

5.1 INTRODUCTION

Chapter 5 presents the findings of Objective 4 in the form of manuscripts to describe the service providers' perspectives on the formal and informal CMHS for alleviating burden.

Data gathering instruments used in this study included a demographic questionnaire (Appendix Q), the interview guide used for the focus groups with the CHWs (Appendix R) and with the primary health care supervisors (Appendix S). The invitation letter for the focus groups directed to the sub-district primary health care coordinator is in Appendix T.

5.2 OBJECTIVE 4: TO DESCRIBE SERVICE PROVIDERS' PERSPECTIVES ON THE FORMAL AND INFORMAL COMMUNITY MENTAL HEALTH SERVICES FOR ALLEVIATING CAREGIVER BURDEN AMONG THE INFORMAL CAREGIVERS WITHIN A LOW-RESOURCED COMMUNITY IN MPUMALANGA PROVINCE, SOUTH AFRICA

This section is presented as two manuscripts structured according to the selected journals' author guidelines. The articles are yielded from the findings of the objective that aimed to describe the service perspectives on the formal and informal CMHS for alleviating caregiver burden among the informal caregivers. The findings documented in the two manuscripts are presented in the following subsections.

5.2.1 Service providers' perspective on caregivers' experiences and the availability of support services for alleviating informal caregiver burden rural in South Africa: A descriptive study

Manuscript (a) reports on the service providers' perspective on caregivers' experiences and the availability of mental health services for alleviating caregiver burden. The paper has been submitted to *PLoS ONE*. Details of the manuscript are outlined in Table 5.1.

Table 5.1 Manuscript (a) details

Title	Journal	Author contributions		Key findings	Status
Service providers' perspectives on the challenges of informal caregiving and the need for caregiver-orientated mental health services in rural South Africa: A descriptive study	*PLoS ONE* DHET accredited Impact factor: 3.752	Conceptualisation	Silaule, Nkosi & Adams	Service providers' acknowledgement of burdens experienced by informal caregivers There are minors who are providing care to parents with a SMD. Mental health services are insufficient to address caregiver needs Various factors affect delivery of caregiver-orientated services.	Post review corrections submitted
		Manuscript draft	Silaule		
		Manuscript review and editing	Silaule, Nkosi & Adams		
		Supervision	Nkosi & Adams		

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Service providers' perspective on caregivers' experiences and the availability of support services for alleviating informal caregiver burden rural in South Africa: A descriptive study

Short title: Caregiving experiences and support services for informal caregiver burden in rural South Africa: A service providers' perspective

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Abstract

Informal caregivers of persons with mental disorders encounter various challenges in their role of caregiving. As such, they require support to enable them to cope with the demands of their

caregiving. There is comprehensive evidence on the experiences of burden among informal caregivers in mental health; however, few studies report the mental health services to support informal caregivers in their role. To address this gap, this study aimed to explore the perspectives of the service providers regarding the challenges encountered by informal caregivers and the mental health services available to support these caregivers.

Semi-structured interviews were conducted with mental health coordinators at provincial, district, and sub-district level and mental health professionals from a district hospital. Focus group discussions were conducted with primary healthcare supervisors and community health workers in Bushbuckridge municipality, South Africa, at participants' workplaces and sub-district offices. Semi-structured interviews and focus group guides with semi-structured questions were used to direct data collection in August 2022–January 2023. All interviews were audio recorded and transcribed verbatim. Reflexive thematic inductive analysis was conducted using NVivo 12 software.

Three themes were identified, namely perceived caregiving consequences and related factors, current state of mental health services, and factors affecting delivery of informal caregiver mental health services. The service providers acknowledged the various challenges encountered by the informal caregivers as well as the subsequent burdens. The current state of formal and informal community mental health services was described and considered inadequate to meet informal caregivers' needs. Various personal, health system, and contextual factors influencing the provision of caregiver-orientated services were identified.

The findings revealed the need for intersectoral collaborations between hospital-based and community-based mental health service providers, and community stakeholders to ensure the provision of user-friendly and accessible mental health services for informal caregivers.

Key words: informal caregivers, mental health professionals, caregiver support services, community mental health services.

Introduction

Globally, mental disorders are highly prevalent and ranked as the fifth highest contributor to overall disease burden (WHO, 2017b). It is estimated that more than 80% of people with mental disorders reside in low- and middle-income countries (LMICs) (WHO, 2008c). Severe mental

disorders (SMDs), including depressive disorders, schizophrenia, bipolar mood disorders, and substance use disorders, are reported to be among the top 10 causes of disability in LMICs, accounting for 19.1% of all disabilities and health related conditions (WHO, 2008c). The growing burden of mental disorders is a continuous challenge in LMICs because mental health remains a neglected priority, especially in rural areas (WHO, 2017b; Vergunst, 2018). A mental health treatment gap of 75–85% persists between the need and provision of treatment in LMICs compared to the 30–50% gap in high-income countries (WHO, 2017b; Rössler et al., 2019). It is estimated that only 10.4% of persons with SMDs in Nigeria and 11.1% in China receive treatment (Wang et al., 2007). In South Africa, only 27% of persons with SMDs are reported to receive treatment,

which is concerning as 52% of the South African population reside in rural areas, and it can be assumed that most persons with SMDs who live in rural communities have limited mental health resources (Reid, 2006; Pillay, 2019). Various factors have been identified to influence provision of mental health services in LMICs like South Africa, such as infrastructural problems, shortage of mental health professionals, limited available health budget, affordability and accessibility of mental health services, public and personal stigma, and mental healthcare users' (MHCUs) low perceived need for treatment (Sibeko et al., 2018; Vergunst, 2018). In LMICs, help-seeking and access to mental health services are further influenced by cultural and religious factors because many people are likely to seek help from complementary mental health service providers such as traditional, faith, and spiritual healers (Rathod et al., 2017). It is for this reason that calls have been made to integrate collaborative care in mental healthcare, particularly in resource-constrained contexts, and to ensure user-friendly services to improve outcomes for persons with mental disorders (Cauce et al., 2002; Ae-Ngibise et al., 2010).

In resource-constrained countries like South Africa, it is recommended that efforts be directed towards strengthening community-based mental health services to increase access (Burgess, 2017). Community mental health services are divided into formal and informal mental healthcare. Formal community mental health services are provided by primary healthcare workers in health and social welfare (WHO, 2008d), including care in day centres, rehabilitation facilities, community centres, home help, and outpatient services at primary healthcare facilities (WHO, 2008d). Informal community mental health services are non-specialised services provided by sectors other than health and/or social development services, including care from families, friends, traditional healers, religious organisations, village workers, lay community workers, and non-

governmental organisations (WHO, 2008b; Mugisha et al., 2017). Informal community mental health services are deemed essential in the management of SMDs as they provide cost-effective mental healthcare, reduce relapses for MHCUs, and increase support for caregivers (WHO, 2008b). Despite continuous advocacy to strengthen community mental health services in LMICs, these services remain underdeveloped (Robertson & Szabo, 2017). In South Africa, community mental health services remain under-funded and under-resourced as the limited mental health funds are directed towards hospital-based care (South African Department of Health, 2012; Robertson et al., 2018). It should be acknowledged that the mental health system, provided by the Department of Health in South Africa, fails to meet the diverse needs of MHCUs (Pillay, 2019). These unmet needs have a spillover effect on informal caregivers, including families, friends, and community members, who provide care to MHCUs without remuneration and with limited support in their role (Olagundoye & Alugo, 2018).

The National Mental Health Strategy of Ethiopia (Federal Democratic Republic of Ethiopia Ministry of Health, 2015) recognises the support that MHCUs and their family or caregivers requires, but not much has been achieved in this regard in South Africa (South African Department of Health, 2012). Given the current state of mental health services in South Africa, informal caregivers are a vital resource in the care and management of persons with mental disorders (Ndikuno et al., 2016). Informal caregivers are expected to deal with patient behaviour, structure their routines, and monitor treatment without any access to resources for support (Chadda, 2014; Mokgothu et al., 2015; Paruk & Ramdhial, 2018). For example, Vigo et al. (2016) highlight lack of psychoeducation, communication, involvement in treatment planning, and community social services as precipitating factors of caregiver burden.

Previous studies conducted in rural South Africa reveal high levels of burden among informal caregivers of persons with SMDs (Mhaule & Ntswana-Lebang, 2009; Yerriah et al., 2021; Vukeya et al., 2022; Silaule et al., 2023). Identified burdens include emotional and physical burdens, economic burdens, disrupted family routines, and relationship burdens (Mhaule & Ntswana-Lebang, 2009; Nxumalo & Mchunu, 2017; Yerriah et al., 2021; Silaule et al., 2023). Therefore, informal caregivers must be supported to ensure the care and recovery of MHCUs within communities (Scazufca, 2002). In addition, Adelman et al. (2014) suggest that services aimed at caregivers should incorporate psychoeducation, communication, and emotional support. While previous studies reported on the challenges of caregiving in mental health, very limited studies

report on these challenges from the service providers' perspectives. In addition, there is limited studies reporting on the mental health services aimed at supporting informal caregivers in their role. Understanding the perspectives of the service providers regarding the challenges of informal caregiving is fundamental for the development and implementation of caregiver-orientated mental health services. It is for this reason that this study focused on exploring the perspectives of the service providers regarding the challenges of informal caregiving and the availability of mental health services for supporting the informal caregivers in rural South Africa.

Materials and Methods

A qualitative descriptive research design was adopted in this study. Semi-structured interviews were conducted with mental health coordinators at provincial, district, and sub-district level and mental health professionals from a district hospital in Bushbuckridge municipality in South Africa (Colorafi & Evans, 2016). Focus group discussions were also conducted with primary healthcare supervisors and community health workers (CHWs) based in the local communities of Bushbuckridge municipality (Colorafi & Evans, 2016). Data were collected sequentially according to the various levels of healthcare where the participants worked, namely the province, district, and sub-district level. This article adhered to the Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007).

Setting

This study took place in Bushbuckridge municipality situated in Ehlanzeni district in the north-eastern rural part of Mpumalanga province, South Africa. This municipality has a population size of 750 821 (Statistics South Africa, 2022). There is one regional hospital, two district hospitals, and 34 primary health clinics situated within Bushbuckridge municipality. Currently, the regional hospital and one district hospital offer 72-hour observation services, and the other district hospital has a mental health unit, which is the largest in the entire Mpumalanga province with a 50-bed capacity. This mental health unit offers in- and outpatient services to MHCUs with a variety of mental disorders, ranging from acute to chronic and forensic cases. Therefore, all persons with SMDs requiring long-term and/or in-patient care are referred to this facility for further management. Once discharged to the care of their families, MHCUs are referred to primary health clinics to collect their psychotropic medications. The primary health clinics are organised into

clusters with five clinics per area. A cluster refers to a group of clinics supervised by the same primary healthcare supervisor (Naidoo et al., 2017). The clinics are nursed-led.

Participants

Twenty-nine mental health service providers were purposively selected to participate in this study. To be selected for this study, participants needed to be over 18 years of age and be employed in their current position for longer than six months.

Data collection

Once all relevant consent and permissions were obtained, data were gathered between August 2022 and January 2023 using semi-structured interviews and focus groups. Conducting individual semi-structured interviews and focus groups was necessary for capturing the perspectives of multiple service providers across the various levels of care. In particular, a focus group was considered a convenient and cost-effective way of gathering data from the service providers. This allowed for in-depth exploration of the challenges experienced by the informal caregivers at the community level and the current mental health services for supporting informal caregivers.

The first author (OS) who served as the primary investigator conducted semi-structured interviews under the guidance of two research supervisors (FA and NGN). Prior to data collection, the PI attended a qualitative methodology workshop, which equipped them with skills to conduct semi-structured interviews and qualitative data analysis using an NVivo software. Up on commencement of data collection, the primary investigator contacted all potential participants telephonically, informed them of the purpose of the study, and invited them to participate. All approached participants agreed to engage in the study. A convenient date, time and place were identified for the interviews; the interviews ran for a maximum of one hour. All participants preferred that the interviews be conducted in their workplace, which allowed for flexibility and an in-depth understanding of the context. Interviews were conducted in a private space to give the participants an opportunity to freely express themselves.

Prior to the interviews, the researcher went through the information sheet detailing the purpose of the study. Three semi-structured interviews were conducted with four mental health coordinators at the provincial, district and sub-district level. This was followed by four semi-structured

interviews that were conducted with the mental health professionals including a medical officer, nursing manager, a social worker and two occupational therapists. Of the seven interviews conducted, one was conducted with two mental health coordinators and another was conducted with two occupational therapists. These interviews were conducted together for the convenience of the participants.

Data were collected until saturation was reached i.e. when no new data emerged during the interview process. An interview guide and demographic questionnaire were used. The development of the demographic questionnaire and interview guide was informed by literature (Bradshaw et al., 2017). Participants were invited to share their views on the challenges of informal caregiving and the mental health services for supporting the informal caregivers in their role. The first open-ended question aimed to capture the generic perspectives of the service providers on the observations they have made about the people who are taking care of people with mental disorders within the community. This was followed by questions aimed specifically at exploring the service providers' perspectives regarding the burden of care and the formal and informal community mental health services for supporting informal caregivers of persons with SMDs.

For convenience to the participants, two focus group discussions were conducted concurrently, thus requiring two separate teams to facilitate. The first team comprised of the primary investigator and the minute taker, and the second team had a skilled focus group facilitator and a minute taker. The primary investigator arranged for the focus groups through the Bushbuckridge sub-district coordinator. The focus groups were planned to coincide with the primary healthcare supervisors' monthly meeting. Two focus groups were conducted with the primary healthcare supervisors and CHWs. The primary investigator facilitated a focus group with the CHWs and an identified skilled moderator facilitated the focus group with the primary healthcare supervisors. To ensure uniformity, the two focus group facilitators had meetings prior to data collection to discuss the processes that were to be to be followed during the discussions. A semi-structured focus group guide was developed to ensure consistency in the facilitation of the focus groups and to guide the exploration of the perspectives of the participants regarding the challenges of informal caregiving and the mental health services for supporting informal caregivers. To ensure validity of the questions the focus group guide was reviewed by four experts, which includes two lecturers, a staff nurse and an occupational therapist who are experienced in mental health. . The discussions started with an open-ended question aimed to capture perspectives of the participants on the

observations they have made about the people who are taking care of people with mental disorders within the community. This was followed by questions aimed specifically at exploring the service providers' perspectives regarding the burden of care and the formal and informal community mental health services for supporting informal caregivers of persons with SMDs. The sessions ran concurrently in separate venues within the Bushbuckridge sub-district offices. Data collection ceased after 1.5 hours when data saturation was reached i.e. when there was limited new information emerging from the discussion in the group. Debriefing was done between the two teams who conducted the focus groups and field notes were captured to add to the details of the interviews. Prior to data collection, written informed consent was obtained from all participants to grant permission for participation and audio recording of the interviews and focus groups. The interviews and one focus group were conducted in English. The CHWs' focus group was conducted in Xitsonga, which is the first language of the participants and interviewer. All interviews were audio-recorded, transcribed, and translated to English by a language specialist who works as a researcher at a research entity situated in Bushbuckridge municipality. In preparation for data analysis, the primary investigator listened to the audio recording while concurrently reading the transcripts. Where necessary corrections and omissions were addressed to ensure accuracy in data translation.

Data analysis

Transcriptions were uploaded onto NVivo 12 software for analysis. A six-phase reflexive thematic inductive approach proposed by Braun and Clarke (2021) was used to systematically analyse the data. This enabled the researchers to find meanings and patterns within the data (Braun & Clarke, 2021). The primary investigator (OS) conducted data familiarisation by reading and re-reading the transcripts while concurrently listening to the recordings. Familiarisation notes were made, and these provided guidance for generating ideas for codes. The PI conducted systematic coding inductively, and each code was assigned a description to ensure consistency. The PI then grouped the generated codes to form patterns that led to the generation of initial sub-themes and themes. The refining and renaming of themes were done by reading the coded extracts to ensure they merged coherently into a pattern to form a specific theme. Additionally, the data set and familiarisation notes were read to ensure no codes were missed and to check the validity of the themes. To ensure trustworthiness, an audit trail of the analysis process was conducted by an

experienced qualitative researcher. To promote the quality and truthfulness of findings, peer briefings and presentation of findings were done with the two research supervisors (FA and NGN). Member checking was conducted by sharing the transcripts with the participants who were then given an opportunity to comment and add any information that they feel may have been omitted. Keeping a reflexive journal enabled the primary investigator to capture all the field notes outlining the thoughts and observations that guided the analysis process.

Ethical considerations

The Human Research Ethics Committee of the University of the Witwatersrand (M200957) approved this study. Permission was also sought from the Mpumalanga Department of Health Research Committee (MP_202010_010). The methods followed in this study were in accordance with the relevant ethical principles for medical research involving human subjects (World Medical Association, 2008). Prior to data collection, all participants were given an information sheet that informed them about the aim of the study, confidentiality, and anonymity. Informed written consent was obtained from all participants to grant permission to participate and audio record the interviews.

Results

Participant characteristics

The participant characteristics are presented in Table 6. Overall, 28 participants participated in this study, including three mental health coordinators at the provincial, district, and sub-district level; five mental health professionals at the mental health unit of a district hospital situated within Bushbuckridge municipality; five primary healthcare supervisors; and 15 CHWs. The participants' years of experience ranged between 2 and 34 years.

Table 5 Participant characteristics

Identity of participant	Format of data collection	Setting of data collection	Number
Mental health coordinators (MHCs)			
Provincial	SSI	Workplace	2
District	SSI	Workplace	1

Sub-district	SSI	Online	1
Mental health professionals (MHPs)			
Medical officer	SSI	Workplace	1
Nursing manager	SSI	Workplace	1
Social worker	SSI	Workplace	1
Occupational therapist	SSI	Workplace	2
Community-based service providers			
Primary healthcare supervisors (PHCSs)	FG	Sub-district offices	5
CHWs	FG	Sub-district offices	15
Total			29

Abbreviations: SSI = semi-structured interviews; FG = focus groups

The study aimed to explore the perspectives of the service providers regarding the challenges of informal caregiving and mental health services available for supporting informal caregivers of persons with SMDs in rural South Africa. The analysis of the semi-structured interviews and focus groups led to the identification of the following three themes, which are set out in Table 7:

- Theme 1: Perceived caregiving consequences and related factors, which outlines service providers' perspectives on the demands encountered by informal caregivers and contributing factors.
- Theme 2: Current state of mental health services, which outlines the formal and informal mental health services currently offered at the study site and the suitability of these services to alleviate burden of care among informal caregivers.
- Theme 3: Factors affecting the delivery of caregiver mental health services, which outlines factors currently hindering the provision of mental health services for alleviating burden among informal caregivers at the study site.

The voices of the participants are reflected in this paper by using direct quotes.

Table 6 Themes and sub-themes representing service providers' perspectives on informal caregiving

Themes	Sub-themes
Perceive caregiving consequences and related factors	Consequences of caregiving
	Caregiver-related factors impacting caregiving experiences

Themes	Sub-themes
	Contextual factors impacting caregiving
	Health system factors impacting caregiving
	Intersectoral factors impacting caregiving
Current state of mental health services	Current community-based mental health services
	Current institution-based mental health services
Factors impacting delivery of caregiver mental health services	Caregiver-related factors impacting delivery of caregiver mental health services
	Mental health professional factors impacting delivery of caregiver mental health services
	Contextual factors impacting delivery of caregiver mental health services

Theme 1: Perceived caregiving consequences and related factors

The service providers expressed that informal caregivers of persons with SMDs encounter challenges in their role. The informal caregivers are perceived encounter negative caregiving consequences. Various factors were identified to affect the informal caregivers in their role, including caregiver, contextual, health system, and intersectoral factors.

Consequences of caregiving

The service providers reported that informal caregivers encountered negative consequences in their caregiving. Identified burdens were attributed to the uncooperative and violent behaviours exhibited by the MHCUs. Some MHCUs were identified to abuse substances and often refuse medications. Subsequently, MHCUs relapse and start displaying aggressive and violent behaviours towards their caregivers, making it difficult for them to provide care. This was captured in quotes like the following:

> *"The biggest challenge is smoking, and there are many substances that they smoke." (MHP)*

> *"I had a client who presented psychosis; the caregiver couldn't take what was happening. They were being beaten by the relative with mental illness, and they struggled to bring him for consultation as he was not adhering to medication." (Mental health coordinator)*

Service providers expressed that some informal caregivers encountered stigma in the community, which leads to conflict. Community members require informal caregivers to account for the behaviour of the MHCUs and pay for damages caused by the MHCU. For example, one participant

said: “Another challenge is that they have conflicts with the community because the mentally ill person may go out and destroy people’s things, and the community will come to the caregiver to report that their person has destroyed their things, and the caregiver will have to pay” (PHCS). The stigma in the community means that some informal caregivers are likely to be lonely and isolated. A participant explained that “caregivers can feel very alone and even isolated within their families, and people don’t want to visit when there is someone with mental health issues in the house” (MHP).

Some MHCUs require full-time care, and as a result, the informal caregivers are restricted in terms of the activities they can do. Service providers indicated that some informal caregivers are forced to leave school or jobs to provide full-time care to a person with a mental disorder. The loss of income perpetuates the cycle of financial strain experienced by informal caregivers. For example, a participant said, “Her daughter is good with her [mother]. The problem is that she had to drop out of school because she wanted to take care of her mother” (CHW).

The burden encountered by informal caregivers result in negative consequences that influence their emotional, mental, and physical wellbeing. The disruptive behaviours displayed by MHCUs cause informal caregivers to live in a constant state of fear for their safety, and consequently, they experience negative emotions such as frustration, anger, and stress due to their caregiving role. A service provider said: “They don’t feel free; they feel they are at high risk of getting killed by these MHCUs. The burden is quite high on the caregivers, and many times you observe that the caregivers are very stressed all year around. They are frustrated and angry” (MHP).

The service providers perceived that the stress of caregiving compromises the mental health of informal caregivers. Some service providers reported that informal caregivers often present with mental conditions, including depression, anxiety and adjustment disorders, and one participant explained that “we are having these caregivers that are coming to consult mostly for depression and anxiety” (MHC). Some informal caregivers have also developed physical conditions due to the demands of caregiving. One service provider said, “The mother of the patient got sick and was diagnosed with high blood pressure and heart disease” (CHW).

Caregiver-related personal factors affecting caregiving

According to the service providers, some informal caregivers lack the information and skills to handle the MHCUs, and as a result, they struggle to cope with the demands of caregiving. In addition, informal caregivers struggle to accept the conditions of MHCUs, which results in the exclusion and isolation of the MHCUs. One participant explained the problem as follows:

> *"The problem is lack of information; they don't know how to take care of the mentally ill patient. They do not know how to handle them; they do not know how to talk to them; and that is the problem. They are afraid of them, and as long as they are mentally ill, they don't treat them the same as others. They exclude them, they isolate them from all activities." (MHC)*

Lack of information leads some informal caregivers to delay seeking help for the MHCUs. The service providers reported that some caregivers sought help only when they are threatened by the MHCUs' violent behaviour. This could be related to the fact that caregivers lack knowledge and understanding of the symptoms to look for that could indicate a decline or beginning of a psychotic episode, and thus, they only seek help when their lives are endangered. It was explained as follows: "You only see them when the patient is causing problems at home, or they call us and when we ask how we can assist them, they tell us that this guy [MHCU] is threatening us, breaking windows" (MHC).

The service providers also stated that to cope with the demands of caregiving, some informal caregivers adopt avoidant coping strategies. Due to the violent behaviours MHCUs displayed prior to hospitalisation, some caregivers avoid visiting them during hospitalisation as they fear the early discharge of the MHCUs. One participant said, "Caregivers are saying that they are violent and that is why they want them to be cared for in the hospital. They feel frustrated to take them home. Sometimes they end up not visiting the patient because they are scared that the healthcare workers will give them the patients to take them home" (MHP).

Contextual factors impacting on caregiving

The service providers identified the challenges encountered by informal caregivers to be related to the shortage of rehabilitative activities for MHCUs within the community. Service providers highlighted that hospitals play a key role in stabilising psychiatric conditions; however, there are very limited resources to rehabilitate MHCUs within their communities, and this poses a challenge

as some requires full-time care from their caregivers. For example, one participant said the following:

> *"There are no support groups in the communities, and if they were there, maybe they would have activities like soccer or any other games to be involved in … so there is nothing for them. We just give them the treatment, and they go back home until we see them again when they relapse, and this means that there is nothing for these patients when they are in the community." (MHP)*

The lack of support from family and the community were identified as a limitation in the context, affecting the informal caregivers. Although some communities hold community dialogues to discuss the care of people with mental disorders, none of these discussions are aimed specifically at creating support for the caregivers; for example, "the community dialogues are happening for the patients, but not to support the caregivers" (PHCS).

Health system factors impacting on caregiving

The limited access to caregiver-orientated mental health services was identified as a factor that influences informal caregivers' ability to cope with their caregiving. The service providers highlighted a general neglect of mental health services within the community. In spite of acknowledging the importance of caregiver support, none of the community clinics facilitated mental health support groups aimed at supporting the informal caregivers: "We are not doing the support groups in our facilities, and this field [mental health] is usually neglected" (PHCS).

Some participants expressed that services are targeted specifically at the MHCUs and that less focus is directed at meeting the caregivers' needs. Lack of caregiver empowerment services was identified as a factor that compromises caregivers' coping mechanisms. The service providers indicated that having patient-orientated services neglected the needs of the informal caregivers, and as a result, they lack information on handling MHCUs and are often perceived as less proactive and more passive because they accept the behaviours exhibited by the MHCU even at the detriment of their health. The following comments by participants highlight this:

> *"The services are only targeting the patient; the family don't get these services." (MHC)*
>
> *"I think they become quite passive, and they just accept it as it is, and they are not proactive and they are not empowered at all to change the circumstances." (MHP)*

Intersectoral factors impacting on caregiving

The service providers acknowledged that the provision of comprehensive mental health services requires collaboration between sectors such as health and social welfare, and as such, they identified some of the intersectoral factors they perceived as influencing informal caregivers. The service providers identified lack of long-term placements and day-care centres as a factor that increases caregiving demands because it means that caregivers do not have time away from the MHCUs. Caregivers are obligated to provide care even when their coping is compromised, and this increases their stress levels. One participant explained, "I think what is really hard is that we don't have any options for places for the patients to go when caregivers are not coping anymore or a long-term placement, and that causes extra stress" (MHP).

Information regarding available support is not readily available for informal caregivers, and some informal caregivers complained about the lack information on social grants and welfare support available to alleviate their financial strain. A participant explained their experience by saying, "I don't think they are aware that they should also be getting the grants. Those who are aware, are the ones who are looking after the elderly people. They are getting the supplement grant or grant in aid. But, the caregivers of people with mental disorders, they don't know about it" (PHCS).

Theme 2: Current state of mental health services

Understanding the current state of mental health services was important to determine the level of support accessible to informal caregivers within their communities. Service providers described formal and informal community mental health services offered at the community and institution-based levels and their suitability to meet the needs of informal caregivers.

Community-based mental health services

Due to lack of physicians and psychiatrists, formal mental health services at primary healthcare clinics rely mostly on psychiatric nurses. The nurses are responsible for administrating psychotropic medications, referring MHCUs from the clinic to the district hospital for further management, and issuing referrals to social welfare for social grants. Additionally, psychiatric nurses arrange awareness campaigns on generic health related topics, and mental health is included

in these as a sub-topic. All services are structured to address the needs of the MHCUs, with less focus on caregivers. The following comments give a clearer picture of the current situation:

> *"Most of them are the psychiatric trained nurses; those who have a qualification in psychiatry. We do not have the psychiatrists in our clinics; it is only the psychiatric nurses." (MHC)*
>
> *"Awareness campaigns are more comprehensive. It is where everything is included, HIV/AIDS, mental health, TB [tuberculosis]." (PHCS)*

Some primary health clinics have CHWs to help extend services within the local community. CHWs work in collaboration with ward-based outreach teams and home-based carers to identify MHCUs within the community, monitor treatment compliance, and issue referrals to local clinics in cases where MHCUs are non-compliant. These services are focused on the MHCUs, with emphasis on monitoring treatment compliance. One participant explained, "Community health workers with the community ward-based outreach team are able to identify the mental healthcare users in the community, and they also monitor if they are complying with the treatment or not, and they refer them to the facility if they are not" (PHCS).

School health services were identified as additional services within the community. These services are comprehensive and include mental health services. Nurses often conduct visits to schools within designated areas and render mental health services, including identification of learners who reside in the same house as MHCUs to offer them support and refer them where necessary. A participant said, "Some of the learners you find that there is a family member who is mentally ill, and it affects them because the community or other learners mock them at school. The nurses are able to identify those learners as a way of trying to find out what could be the problem" (PHCS).

Service providers identified informal mental health services within the community and highlighted a lack of collaboration between informal and formal mental health service providers. Caregivers were reported to use informal services from traditional healers, churches, prophets, and pastors; for example, "We have the traditional healers and the people with mental health disorders are taken to them. We also have churches, prophets, pastors and the *sangomas* [traditional healers]" (PHCS).

The service providers identified stakeholders within the community who support MHCUs and their caregivers. The stakeholders include the South African Police Services, who help caregivers take aggressive MHCUs to the hospital for treatment, and the South African Social Security Agency,

who helps with the MHCUs' disability grant. The following comments give more information on the stakeholders:

> *"The SAPS [South African Police Services] they assist us with the aggressive patients. If they are aggressive, they are the ones that take the user to the nearby health facility." (MHC)*
>
> *"We also refer to the SASSA [South African Social Security Agency] department because the patients should also apply for the grant." (PHCS)*

Community leaders, including ward councillors and civic members, were also identified as stakeholders who help families get MHCUs to the hospital when they struggle, as the following comment explains:

> *"The community leaders like the civic members and the councillors are assisting. Like now we have a patient who has been brought by the councillor. Some of the community councillors are assisting in bringing the patients to us and to show support to the family, but this happens after the family has asked for assistance from them." (MHP)*

Institution-based mental health services

The service providers identified three referral hospitals offering mental health services within the Bushbuckridge community. Of the three hospitals, two offer 72-hour observation services and one offers in- and outpatient mental health services but only short-term care. Caregiver services include health talks, which are facilitated weekly during the outpatient clinic and focus mainly on improving the caregivers' knowledge of mental conditions, the importance of treatment and compliance, monitoring the warning signs of relapses, and the importance of engaging MHCUs in daily occupations. The following comments expand on these services:

> *"The other facilities, which are [name of hospital] and [name of hospital], are offering 72-hour assessments, and that's it. At least [name of hospital] is designated to keep them but not for a longest time; they keep them for a short time." (MHP)*
>
> *"We have a health talk with the caregiver and the patients when they come, and that generally focuses on the importance of taking their medication, warning signs of relapse, and also the importance of having a balanced daily occupational life at home." (MHP)*

Individual caregiver services are only offered on a referral basis. Referrals to a social worker, counsellor, or occupational therapists are issued if a caregiver expresses having difficulty caring for the MHCU; for example, "if the doctor sees that caregiver is really struggling, she would refer

to us, and we would refer the caregiver to a social worker, OT [occupational therapist], or psychology" (MHP).

Interventions, such as a family therapy, that focuses on educating caregivers on mental disorders and the importance of treatment compliance are offered only when MHCUs are discharged from the hospital, and often occur with the person who fetches the MHCU from the hospital. One participant explained, "Family therapy happens only when the patient is admitted in the hospital and they are getting the psychological service on referral when they are getting discharged. Not all family members are involved. The service is only given to the person who is there to fetch the patient home" (MHP).

Theme 3: Factors impacting delivery of caregiver mental health services

The service providers acknowledged that the current mental health services are inadequate to address the needs of informal caregivers. Various factors were identified as influencing the provision of caregiver-orientated mental health services, including personal, health system, and contextual factors.

Caregiver-related factors impacting the delivery of caregiver mental health services

The service providers indicated that informal caregivers are not always available. Despite their willingness to collaborate with informal caregivers in caring for MHCUs, service providers struggle as MHCUs often come for follow-up appointments on their own. One participant explained, "It is more important for us to collaborate with the caregivers, but we have found that sometimes the mental healthcare users comes to the appointment alone and caregiver does not come with them. That also has been a challenge" (MHP).

Some informal caregivers reject help as they often hide the MHCUs from the CHWs when they conduct home visits to offer support. The participants indicated that CHWs are residents of the same community they serve, and given the stigma informal caregivers experience within their communities, it can be difficult to receive help from members of the same community. One participants said, "The community health workers are not accepted in some of the families. If the community health workers visit them in order to give them support, the families hide their patients" (PHCS).

Caregivers' cultural beliefs were identified as another factor influencing the provision of caregiver services. Some informal caregivers seek help from traditional healers and religious organisations, which results in relapses among MHCUs as they stop taking their treatment, making their management challenging. One participants explained this challenge as follows:

> *"You want to help the client but the family has other beliefs. They do not bring the client back, and if they come back, they present with severe psychotic features, and this could be prevented if the person adhered to medication. So, culture is the challenge, and we have to look at how best do we bridge this gap and for us to be able to bridge it. We also a great team." (MHC)*

Health system factors impacting the delivery mental health services to the caregiver

The service providers acknowledged that services focus on addressing physical conditions rather than mental disorders. Support groups are regularly facilitated for those with HIV, tuberculosis, and diabetes, but none of the support groups focus on those with mental disorders. A participant admitted this, saying, "I can see that the mental health issue is being overlooked, and I am saying this because we do have the diabetic support groups, HIV and tuberculosis support groups, and also the disability support group" (PHCS). As a result, caregivers of MHCUs only receive support upon request, which is concerning considering that most informal caregivers lack knowledge and often delay seeking help for the MHCUs. One participant explained the situation by saying, "The support is only given if the caregiver goes to the clinic and report a case that she needs help with, and the home-based outreach attends to that case or the OTTs [occupational therapy technicians]. This happens only if the caregiver comes to ask for assistance. We don't have people going out to ask caregivers if they are coping" (PHCS). The stigma and limited knowledge among some of the lay health workers, including CHWs and home-based carers, cause some to be afraid of MHCUs, and therefore, reluctant to assist caregivers as they perceive the MHCUs to be violent and dangerous. One participants explained that "the community-based workers are usually afraid of these patients. It is the stigma. They feel that these people are very dangerous" (MHP).

The service providers also indicated a lack of referral pathways between the hospital and community-based services. Some of the service providers are not always aware of the lay health workers in the community, and there are no established referral pathways to enable them to refer both the MHCUs and their caregivers. This breakdown in communication influences the continuity of care from hospital to the community. A participant said, "We do not have a system of referring

directly, and that would be useful because we are good at giving referrals to the clinics, and we might use the home-based carers, but we do not know where the active home-based carers are and that information would be useful as well" (MHP).

The service providers indicated that budget constraints in mental health is an ongoing problem that affects the provision of mental health services. Limited access to physical resources, such as transport to conduct home visits, was identified as a factor that influences service providers' ability to support informal caregivers. A participant explained it as follows: "We have transport problem, but if we had transport, we would be able to visit the families to check if the user is taking the treatment and to check the relationship between the user and the family" (MHC).

Contextual factors impacting the delivery of caregiver mental health services

While the service providers acknowledged the important role played by stakeholders such as the South African Police Services to help them support caregivers, they also indicated that lack of training among the police limits their ability to handle the MHCUs appropriately. One participant explained that "another thing as far as SAPS [South African Police Services] is concerned, you find that some of the police are not empowered on how to handle the mental healthcare users cases" (MHP).

The distance travelled to the hospital was identified as a problem. The fact that only one hospital has a mental health unit within Bushbuckridge means that some informal caregivers need to travel long distances to access the services they require. This poses a challenge as some informal caregiver's experiences financial strain, and one participant said, "The hospital is the one that is challenging because they need money to travel to the hospital" (MHP).

The rurality of Bushbuckridge municipality makes it difficult to attract skilled mental health professionals like psychologists, psychiatrists, and social workers, and this reduces access to these services within the community. One participant explained the challenge as follows: "Our challenge is that we have posts that are funded for clinical psychologists, but we don't have people who can come and fill them. This is because these areas are rural, and we have young people that are coming from the universities. They wouldn't opt to go to such places" (MHC).

Discussion

The study aimed to explore the perspectives of service providers regarding the experiences of informal caregivers of persons with SMDs and the mental health services available for supporting these caregivers in their role. Three themes were identified, namely perceived caregiving consequences and related factors, current state of mental health services, and factors affecting delivery of mental health services to the caregiver. Understanding the service providers' perspectives on the challenges that are encountered by the informal caregivers in their caregiving was useful for establishing their awareness and their understanding of the need for caregiver-orientated mental health services. Additionally, this helped establish a more comprehensive view of the burden of care among informal caregivers, which is vital for planning and developing contextually responsive strategies for alleviating informal caregiver burden.

Factors impacting on caregiving

The service providers in this study indicated that informal caregivers of persons with SMDs encountered challenges in their caregiving role, which led to stress and burden. These challenges were attributed to the MHCUs functional limitations, aggressive and violent behaviours, and substance abuse. Due to their functional limitations, some MHCUs require full-time care, and as a result, informal caregivers had to leave their jobs, which led to financial strain that predisposes informal caregivers to economic burdens. These findings are consistent with previous studies conducted on informal caregiver experiences in sub-Saharan Africa that reveal that the caregivers' employment status and the severity of the MHCUs' condition are associated with the economic burden experienced by the caregivers (Addo et al., 2018; Vukeya et al., 2022). The fact that some caregivers are minors who had to leave school to look after their parents with a SMD raises a serious concern regarding the wellbeing and future of these minor caregivers. Leahy (2015) highlights that children whose parents are diagnosed with SMDs must undertake inappropriate levels of responsibility as they are often expected to care for themselves, their siblings, as well as look after the household in addition to caring for their mentally ill parents. Consequently, these children are at risk of developing psychological, social, and academic problems (Leahy, 2015). Leaving school early reduces the chances of entering the open labour market, particularly in resource-constrained areas like rural South Africa where fewer economic opportunities exist

(Niyimbanira, 2016). It can therefore be concluded that occupying this role plunges these minor caregivers further into the cycle of poverty (South African Department of Health, 2012).

The service providers highlighted substance abuse as a common problem among the MHCUs, which is related to high relapse rates that subsequently lead to aggressive and violent behaviours, making it difficult for informal caregivers to provide care. The findings are similar to that of previous studies that reveal that high relapse rates among persons with SMDs are mainly related to substance abuse and that this contributes largely to the high levels of caregiver burden (Tekin Uludağ & Güleç, 2016; Yerriah et al., 2021).

In agreement with the concerns raised by informal caregivers in previous studies conducted in rural South Africa and Zimbabwe, the service providers identified stigma as a contributing factor to caregiver burden (Marimbe et al., 2016; Vukeya et al., 2022). Similar to previous studies conducted in rural South Africa, the service providers expressed that caregivers are susceptible to exploitation by community members who expect them to cover costs for damages caused by MHCUs in their psychotic states (Nxumalo & Mchunu, 2017). The experience of stigma exposes caregivers to feelings of loneliness and isolation, subsequently leading to negative consequences for the caregivers' emotional, mental, and physical health. Some informal caregivers were reported to have consulted mental health professionals for depression, anxiety, and adjustment disorders. In addition, others reported having developed physical conditions, such as high blood pressure, which is consistent with the findings highlighted by informal caregivers in previous studies (Marimbe et al., 2016; Sinha Deb et al., 2018; Walke et al., 2018).

Various factors are related to the burdens and negative consequences experienced by informal caregivers in their role. Caregiver-related factors, including caregivers' lack of knowledge and skills in handling MHCUs, were attributed to burdens expressed in this study. These results are supported by Ntsayagae et al. (2019) and Marimbe et al. (2016), who reveal that informal caregivers reported lack of knowledge on mental conditions and practical skills required to assist MHCUs, and as a result, they struggle to cope as they feel powerless in their caregiving roles. Similarly, the service providers in this study reported that informal caregivers lack information on mental conditions, which compromises their ability to cope as they struggle to handle the behaviours exhibited by the MHCUs. The service providers perceived that lack of knowledge of mental disorders leads informal caregivers to delay help-seeking as they often wait until the

MHCUs are aggressive and violent to seek help. Lack of knowledge on mental disorders is considered a common problem that influences help-seeking behaviour in LMICs (Bakar & Moshi, 2022; Ambikile & Iseselo, 2023). This is because the approach to decentralise mental health services was adopted without the proper development of community-based mental health services, and as such, there is limited awareness of mental disorders that prevail within communities (Pillay, 2017). A study conducted in rural South Africa reveals that lack of knowledge about mental illness is a factor that influences help-seeking behaviour among MHCUs and their caregivers, and recommends psychoeducation for caregivers as a way of addressing this problem (Bila & Carbonatto, 2022). Chadda (2014) highlights that in order for psychoeducation to be effective, sessions must be held weekly for a period of three months to one year and should include basic information on a mental disorders, common symptoms, available treatments, side effects, and warning signs of relapses. In addition, these interventions should include practical strategies for the day-to-day handling of MHCUs, as well as stress management and coping skills for the caregivers.

Contextual and intersectoral factors such as limited access to community resources, including long-term facilities and day centres to rehabilitate MHCUs, were highlighted as contributing factors to the burdens and consequences encountered by informal caregivers. Service providers expressed that MHCUs receive hospital treatment that stabilises their conditions but that there is no continuity of treatment to rehabilitate them within their communities. According to Saha et al. (2020), rehabilitation of MHCUs is critical for facilitating the development of the functional, social, and intellectual skills they require to lead independent lives within their communities. Additionally, the WHO commends community-based psychiatric rehabilitation as a core element in improving quality of life and facilitating inclusion and participation among MHCUs within communities (WHO, 2015). The limited access to rehabilitation services compromises MHCUs' ability to gain the necessary skills for independent living. It is therefore not surprising that in this study, informal caregivers were reported to provide full-time care to their care recipients with SMDs, which predisposes them to economic burdens.

Current state of mental health services

In spite of acknowledging the burdens faced by informal caregivers and the negative consequences of caregiving on the emotional, mental, and physical health of caregivers, the current mental health

services do not address the needs of caregivers. While service providers identified some institution-based caregiver services, such as health talks, psychoeducation, and family therapy, these services were reported to be made available on interim basis and mainly directed at improving the MHCUs wellbeing, with less focus on caregiver health and wellness. Additionally, these services are targeted specifically at caregivers who already presented with a problem, highlighting that the services follow the biomedical approach and place less emphasis on prevention and health promotion among informal caregivers. Referrals to mental health professionals, including social workers, counsellors, and occupational therapists, are only done in cases where caregivers express difficulty coping with their duties. This raises serious concerns because informal caregivers often lack information about the services available for them. These findings are consistent with those reported by Akbari et al. (2018), who reveal that the health status of caregivers is often not prioritised in mental healthcare. The lack of prioritisation of caregivers' health means that their unique needs are not considered, which perpetuates their burdens and health risks (Akbari et al., 2018).

The service providers identified non-specialists health workers, including CHWs and home-based carers, as key role players in the management of mental disorders within the community. A study conducted in five LMICs, namely Ethiopia, India, Nepal, South Africa, and Uganda, reveal that using non-specialist health workers is an acceptable and feasible way to improve access to mental health services in low-resourced communities (Mendenhall et al., 2014). The availability of non-specialist health workers within the study context is an opportunity to extend community mental health services to help alleviate burdens among informal caregivers of persons with SMDs.

The service providers in this study identified informal mental health service providers within the community, including traditional healers, herbalists, and religious organisations, but highlighted a lack of collaboration between these service providers and the formal mental health service providers within the community. Sorsdahl et al. (2009) identify alternative practitioners, such as traditional healers, as key role players in the delivery of mental health services. This emphasises the need for collaboration between mental health workers and alternative service providers such as traditional healers and religious practitioners, particularly in low-resourced settings where informal caregivers have been reported to rely on their religious practices to help cope with the demands of caregiving (Ae-Ngibise et al., 2010; Gureje et al., 2015; Modise et al., 2021).

Community-based stakeholders, including the police and community leaders, including ward councillors and civic members, were identified as a valuable resource that helps families of persons with mental disorders during mental health emergencies. These stakeholders were identified to be helpful in assisting families to get aggressive MHCUs to the hospital when needed. These findings are consistent with those reported by Modise et al. (2021) in rural South Africa where families of MHCUs identified police intervention as a critical resource that help them cope in emergency situations where MHCUs are uncontrollable.

Factors affecting the delivery of caregiver mental health services

Service providers acknowledged that the current institution-based and community mental health services are inadequate to address the burdens experienced by informal caregivers of persons with SMDs. The unavailability of caregivers, rejection of help from the CHWs, and caregivers' cultural beliefs were identified as caregiver-related factors influencing the delivery of caregiver mental health services. Some of the institution-based service providers expressed their interest in working collaboratively with informal caregivers to support them in their caregiving role; however, they encounter a challenge as informal caregivers are often unavailable during follow-up visits. The unavailability of informal caregivers could be attributed to the transport costs incurred in accessing institution-based mental health services. In addition, this could be because informal caregivers occupy other roles and have responsibilities outside of their caregiving duties, which make it difficult for them to attend follow-up visits with the MHCUs. The fact that only one hospital has a mental health unit that offers in- and outpatient services means that some need to travel long distances to access services for themselves and the MHCUs. Previous studies conducted in rural South Africa reveal high levels of financial burdens (Mhaule & Ntswana-Lebang, 2009; Yerriah et al., 2021; Vukeya et al., 2022; Silaule et al., 2023). Given that the services are tailored to meet the needs of the MHCUs with less focus on the caregivers' health and wellbeing, it can be assumed that once the informal caregivers perceive the MHCUs to be stable enough to attend follow-up visits, they stop accompanying them in an attempt to cut the travelling costs. Ntsayagae et al. (2019) reveal that informal caregivers are required to combine their caregiving duties with other roles and responsibilities, such as executing daily chores and taking care of themselves and other family members. To ensure successful collaboration with informal caregivers in the care of MHCUs, service providers should direct services towards assisting informal caregivers to obtain

balance in their activities. The rejection of help from CHWs could be related to the stigma that informal caregivers encounter within the community. The CHWs usually render services to the same community in which they reside (Bhutta et al., 2010), and therefore, it could be that informal caregivers are reluctant to receive help from members of the same community that blame them for the behaviours exhibited by the MHCUs. It is therefore important to ensure mental health education to orientate informal caregivers to mental health services that are available and their purpose in alleviating their burdens. In addition, stigma reduction programs are required to address the exploitation of informal caregivers by the community (Ambikile & Iseselo, 2023).

The cultural beliefs of the informal caregivers were identified as a caregiver-related factor that hinders delivery of support to informal caregivers. Service providers indicated that some informal caregivers prefers services from traditional healers and religious organisations, which impedes caregiver support and MHCUs' recovery. According to Cauce et al. (2002), cultural beliefs have a substantial influence on help-seeking and choice of treatment providers. Even though the informal caregivers in this study seek medical help, they still consult traditional healers, who stop MHCUs' from taking medication, which worsens their condition. This highlights the importance of adopting a collaborative care model where mental health professional and complementary service providers like traditional healers ensure the recovery of MHCUs and build support for informal caregivers (Ae-Ngibise et al., 2010; Gureje et al., 2020; Ambikile & Iseselo, 2023).

Health system factors, including limited prioritisation of mental health services, limited knowledge and stigma from lay health workers, lack of referral pathways between institution-based and community-based mental health service providers, and funding constraints in mental health, were identified as influencing the provision of caregiver-orientated mental health services. The service providers acknowledged that mental health, particularly that of caregivers, is not prioritised within the community. In addition, they highlighted continuous budget constraints from the Department of Health in South Africa, which hinder outreach mental health services in the community. Matlala et al. (2018) state that while mental health is considered a critical component of health, there is a general neglect of mental health services evident in LMICs. It is for this reason that even with the high prevalence of mental disorders, these countries are reported to spend less than 3% of their budget on mental healthcare (WHO, 2014b). It is therefore not surprising that budget constraints were highlighted as influencing the provision of caregiver services in this study. Rathod et al. (2017) highlight the need for prioritising mental health services and emphasise that this can only

be achieved with political will, improved legislation, equitable resource distribution, and collaborations between MHCUs, caregivers, and formal and informal health providers. While service providers highlighted caregivers' rejection of services from CHWs, they also highlighted that lay health workers, including CHWs and home-based carers, often avoid providing services because of the stigma that MHCUs are violent. According to Sibeko et al. (2018), CHWs received basic training on chronic conditions such as HIV, hypertension, and diabetes but no standard training on mental health. It can therefore be concluded that the attitudes displayed by lay health workers in this study context can be attributed to the limited knowledge related to lack of training on mental health. Contextual factors, such as limited knowledge from stakeholders such as the South African Police Service, highlight the need for training to ensure better handling of MHCUs and support to caregivers (Modise et al., 2021). Distances travelled to hospital and rurality of the study context were reported as contextual factors influencing the delivery of caregiver interventions. Service providers indicated that the provision of institution-based mental health services pose a challenge since informal caregivers have to travel long distances and struggle because of financial constraints. The fact that the study context is in a rural area makes it difficult to attract skilled mental health practitioners (Parliamentary Monitoring Group, 2017). The contextual factors highlight the importance of strengthening community-based mental health services to ensure access of services to informal caregivers. The gap in mental health professionals can be bridged by integrating mental health into the training of CHWs and home-based carers (Deimling Johns et al., 2018; Sibeko et al., 2018).

Limitations

The study only focused on investigating caregiver mental health services within the Bushbuckridge municipality, and while there may be similarities of the study context to allow for replication of findings in other contexts, the findings cannot be generalised to all rural areas of South Africa. Very few mental health professionals were interviewed in this study because the participants were recruited from the one hospital with a mental health unit, excluding service providers from the other two hospitals offering 72-hour observation mental health services within Bushbuckridge municipality. While conducting interviews in the participants' workplace was useful for understanding their work context, it also meant many interruptions during the interviews, which could have influenced the depth of information shared by the participants. In cases where there

were interruptions, the interviewer requested an additional time for the interview to allow the participants enough time to share their views. Member checking was also conducted to ensure that participants had an opportunity to review their transcripts and add any relevant information that the participants wished to share. In one of the interviews, it was mentioned that minor children are caregivers; however, this was reported by the service providers who could not trace the information back to where these children are in order to provide proper support. The lack of convergent systemic and culturally competent evidence evincing the likelihood ratios of SMDs might have contributed towards potential interviewer and responder bias.

Conclusions

The results revealed that service providers acknowledged the challenges encountered by informal caregivers of persons with SMDs in their caregiving role. The challenges encountered by informal caregivers result in negative consequences that influence caregivers' emotional, mental, and physical wellbeing. In spite of the service providers' awareness of the challenges encountered by informal caregivers and the subsequent burdens, they struggle to provide caregiver-orientated mental health services because of personal, health system, and contextual factors. Given the continuous challenges facing the provision of mental health services in low-resourced contexts, it is necessary to explore strategies to facilitate the efficient use of existing resources. The findings in this study calls for the development and strengthening of community-based rehabilitation of MHCUs to improve their function within the community and reduce their dependency on their informal caregivers. Strategies such as task shifting can be adopted to train lay health workers, including CHWs and home-based carers, to extend rehabilitation services within the community. Training lay health workers should also include knowledge and skills on the delivery of caregiver-orientated services to improve support for informal caregivers. Informal caregivers should be educated on available services to improve their help-seeking and acceptance of help from lay health workers in the community. Future studies should focus on investigating collaborations between formal and informal mental health service providers and stakeholders within the community to ensure the provision of user-friendly and accessible mental health services for informal caregivers.

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5.2.2 Service providers' perspectives on strategies for alleviating burden of care among informal caregivers of persons with mental disorders in rural South Africa: A descriptive study

Manuscript (b) reports on the service providers' perspectives on strategies for alleviating burden of care among informal caregivers. The manuscript is in a submissible format because will be submitted to *BMC Psychiatry*. Details of the manuscript are outlined in Table 5.2.

Table 5.2 Manuscript (b) details

Title	Targeted Journal	Author contributions		Key findings	Status
Service providers' perspectives on strategies for alleviating burden of care among informal caregivers of persons with mental disorders in rural South Africa: A descriptive study	*BMC Psychiatry* DHET accredited Impact factor: 4.144	Conceptualisation	Silaule, Nkosi & Adams	Service providers identified various strategies for alleviating caregiver burden, including caregiver-driven, health worker-driven, community-based, intersectoral, and policy and legislature strategies. Findings call for an urgent need to fast track the adoption of task shifting in the planning, development, and implementation of caregiver-orientated services in mental health, particularly in low-resourced contexts	To be submitted to a journal
		Manuscript draft	Silaule		
		Manuscript review and editing	Silaule, Nkosi & Adams		
		Supervision	Nkosi & Adams		

Targeted journal: *BMC Psychiatry*

Service providers' perspectives on strategies for alleviating burden of care among informal caregivers of persons with mental disorders in rural South Africa: A descriptive study

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Abstract

Background: Caregiver burden is a public health problem affecting the emotional, physical, and mental health of informal caregivers of persons with severe mental disorders worldwide. A burdened informal caregiver is unlikely to provide quality care to a person with a severe mental disorder. There is overwhelming evidence highlighting the need for strategies for alleviating burden of care among informal caregivers but there is very limited evidence on these strategies, particularly in sub-Saharan Africa. This study aimed to address this gap by exploring the service providers' perspectives on the formal and informal mental health services for alleviating burden of care among informal caregivers of persons with severe mental disorders in rural South Africa.

Methods: Semi-structured interviews were conducted with mental health coordinators at the provincial, district, and sub-district level and mental health professionals from a district hospital. Focus group were conducted with primary healthcare supervisors and community health workers in Bushbuckridge municipality. Data were collected in the participants' workplace and the Bushbuckridge sub-district offices as preferred by the participants. Interview and focus group guides were used for data collection conducted between August 2022 and January 2023. All interviews were audio recorded and transcribed verbatim. Reflexive thematic analysis was conducted using NVivo 12 software.

Results: Twenty-eight mental health service providers participated in this study. The service providers highlighted their awareness of the need for caregiver-orientated mental health services and identified various strategies they considered useful in alleviating burden of care among the informal caregivers. Identified strategies include caregiver-driven, health worker-driven, community-based, intersectoral, and policy and legislature strategies.

Conclusions: Most of the suggested strategies are consistent with those highlighted in existing literature, indicating that strategies aimed at alleviating caregiver burden could be similar despite context. The findings revealed the need to fast track the adoption of task shifting in the planning, development, and implementation of caregiver-orientated services in mental health, particularly in low-resourced contexts. The strategies suggested by the service providers in this study form the basis for the development and implementation of caregiver-orientated services in rural South Africa, and as such, future studies should investigate interventions aligned to the proposed strategies.

Key words: caregiver burden, caregiver strain, mental health professionals, mental health workers, lay health workers, caregiver support, low-resourced setting, developing country.

Introduction

It is estimated that globally 450 million people suffer from some form of a mental disorder, and severe mental disorders (SMDs), including schizophrenia, bipolar mood disorders, depression, and substance use disorders are a leading cause of disability (GBD 2016 Disease and Injury Incidence and Prevalence Collaborators, 2017; Charlson et al., 2018; Uddin et al., 2019). With a growing number of mental disorders, mental healthcare is shifting from hospital to families and communities (Sharpe et al., 2005). Informal caregivers, including family, friends, neighbours or any member of the community providing care without remuneration, are key role players in the delivery of long-term care for persons with SMDs (Kisa et al., 2016; Molodynski et al., 2017). However, studies conducted in high income countries(HICs) and low-middle-income countries(LMICs) report that most informal caregivers experience high levels of burden in providing care to a person with a SMD (Adeosun, 2013; Ae-Ngibise et al., 2015; Morrison & Stomski, 2019). Caregiving has thus become a major public health issue affecting the quality of life of millions of individuals worldwide (Talley & Crews, 2007).

Caregiver burden is described as any emotional, physical, and financial demands encountered by the family, friends, or other individuals providing care to a person who because of an illness or disorder have lost the ability to carry out respective activities on their own (Dillehay & Sandys, 1990). There are various types of caregiver burden, and objective burden results from the tangible effects of caregiving including disrupted family routines, restrictions on family's social and leisure

activities, and additional financial costs incurred due to caring for MHCUs with mental disorders (Chadda, 2014). Subjective burden relates to the caregivers' negative appraisal of the circumstances that results in feelings of loss, guilt, shame, and anger (Chadda, 2014). Caregiver burden also includes environmental burden, which arises due to the public stigma and isolation of informal caregivers by their families and communities (Alexander et al., 2015; Sharif et al., 2020). Studies conducted in rural South Africa reveal that informal caregivers of persons with SMDs experienced high levels of subjective and objective burdens (Mhaule & Ntswana-Lebang, 2009; Yerriah et al., 2021; Silaule et al., 2023). The factors attributed to these burdens encountered include financial strain, dealing with the care recipients' poor self-care, non-compliance with treatment, dealing with psychotic symptoms, disruptions in family routines, and stigmatisation from family and community (Mhaule & Ntswana-Lebang, 2009; Nxumalo & Mchunu, 2017; Yerriah et al., 2021). Caregiver burden has a negative impact on caregivers' mental, physical, and emotional health as well as their quality of life. In addition, it also have negative consequences for the recovery outcomes of the person with a SMD (Ntsayagae et al., 2019; Phillips et al., 2023).

To date, a number of strategies aimed at alleviating caregiver burden have been explored and proposed. The American Psychiatric Association (Lehman et al., 2004) and National Institute for Health and Care Excellence (2014) guidelines for schizophrenia recommend family-based interventions for informal caregivers of persons with mental disorders. All family-based interventions recommended in the guidelines consist of psychoeducation and psychosocial support (Chien, 2008). Previous studies conducted in HICs like the USA and United Kingdom UK (Reinares et al., 2010; Berk et al., 2011) and LMICs like India, Brazil, Nigeria, and Botswana (Jessy & Kalaimathi, 2014; Ntsayagae, 2017; Tabeleão et al., 2018; Iyidobi et al., 2022) found psychoeducation to be effective in reducing caregiver burden among caregivers of persons with mental disorders.

Individual and group psychoeducation interventions are the most recommended and evaluated interventions (Chien & Chan, 2013; Chien & Thompson, 2013; Ntsayagae, 2017; Worrall et al., 2018). These interventions include a brief introduction to a mental disorder, symptoms of a mental disorder, early warning signs of relapses, information on medication, including their efficacy and side effects, and basic stress management and coping skills (Chadda, 2014). Similarly, support groups have been identified as a common intervention for addressing burden among the families of persons with mental disorders. Mutual support groups are peer-led groups established to meet

the needs of caregivers and mental healthcare users (MHCUs) whose needs are not met by the formal/traditional health services (Chien, 2008). These groups are organised and facilitated by caregivers of people with mental disorders or volunteers with first-hand experience dealing with mental disorders (Worrall et al., 2018). Through participation in mutual support groups, informal caregivers has a safe space to share their challenges with others who are encountering similar difficulties as well as gain information about mental disorders (Chien, 2008). Previous studies reveal that attending mutual support groups is associated with increased support for the caregivers, promoted acceptance of the caregiving role, improved knowledge on mental disorders and adoption of effective coping skills, led to caregiver empowerment, and improved psychosocial functioning (Chien, 2008; Chien & Chan, 2013; Chien & Thompson, 2013).

While several studies conducted in HICs and LMICs demonstrate evidence on strategies for alleviating burden of care among caregivers of persons with mental disorder, very limited studies report on the service providers' perspectives as key role players in the planning and delivery of such strategies in mental health. In South Africa, there are limited studies reporting on the strategies for alleviating caregiver burden among the informal caregiver of persons with SMDs. Given the fact that mental health service providers are required to provide mental health services to caregivers and MHCUs, it is important to establish their awareness and understand their perspectives on the mental health services that are required for alleviating informal caregiver burden. The perspectives of the service providers combined with those of the informal caregivers are useful for providing a comprehensive understanding of the factors that contribute to caregiver burden. In addition, the views of the service providers and the informal caregivers are important for facilitating the development and implementation of contextually responsive and sustainable caregiver-orientated mental health services that promote caregivers' quality of life. This study aimed to explore the formal and informal mental health services for alleviating burden among the informal caregivers of persons with SMDs in rural South Africa from a service providers' perspective.

Methods

Type of research

This study used a qualitative descriptive research design. Data were gathered using semi-structured key-informant interviews with service providers at different levels of healthcare, including mental health coordinators (MHCs) at the provincial, district, and sub-district level and mental health professionals (MHPs) based at the mental health unit at the district hospital within Bushbuckridge municipality (Colorafi & Evans, 2016). The semi-structured key-informant interviews were conducted between August 2022 and January 2023. In addition, one focus group (FG) was conducted with primary healthcare supervisors (PHCSs) and another with the community health workers (CHWs) who were based at the local community of Bushbuckridge municipality and these were facilitated in January 2023 (Colorafi & Evans, 2016).

Study setting

This study took place in Bushbuckridge municipality in the Ehlanzeni district in the north-eastern rural part of Mpumalanga province, South Africa. This municipality has a population size of 750 821 (Statistics South Africa, 2022). There is one regional hospital, two district hospitals, and 34 primary health clinics situated within Bushbuckridge municipality. Currently, the regional hospital and one district hospital offer 72-hour observation, and one district hospital has a mental health unit with a bed capacity of 50, which is the largest in the entire Mpumalanga province. This mental health unit offers in- and outpatient services to MHCUs with variety of mental disorders, ranging from acute to chronic and forensic cases. Therefore, all persons with SMDs requiring long-term and/or in-patient care are referred to this facility for further management. Once discharged into the care of their families, MHCUs are referred to the primary health clinics to collect their psychotropic medications. The primary health clinics are nurse-led and organised into clusters with five clinics per area. A cluster refers to a group of clinics supervised by the same PHCS (Naidoo et al., 2017).

Study population

This study targeted a sample of mental healthcare service providers at various levels of healthcare. The inclusion criteria for this study were (i) participants over ages of 18; (ii) participants who were

employed by the Mpumalanga Department of Health and offering services within the Bushbuckridge municipality; and (iii) participants employed in their current positions for longer than six months.

Mode of data collection

The first author who served as a primary investigator (PI) for the study conducted semi-structured interviews with the mental health service providers. The PI contacted all potential participants telephonically, informed of them of the purpose of the study, and invited them to participate. A convenient date, time, and place were identified for the interviews. These interviews ran for a maximum of one hour. In total, seven semi-structured interviews were conducted with the MHCs and MHPs. Individual interviews were conducted with the participants, except for two interviews, which at the participants' convenience, were conducted with two MHCs and two occupational therapists. A demographic questionnaire and an interview guide developed from existing literature by the PI (with guidance from research supervisors) were used for data collection (Bradshaw et al., 2017).

FGs were conducted by two separate teams. Team one comprised the PI and a minutes taker, and the other team consisted of a skilled FG moderator and a minute taker. The PI contacted the Bushbuckridge sub-district coordinator and arrangements were made for the FGs to conveniently coincide with the PHCSs' monthly meeting. Two FGs were conducted, one with the PHCSs and another with CHWs. The PI facilitated the FG with the CHWs and the skilled moderator facilitated the FG with the PHCSs. To ensure consistency in the facilitation, the two FG facilitators had meetings to go through the semi-structured FG guide and the processes to be followed during the FGs were discussed and clarified. The sessions ran concurrently in separate venues within the Bushbuckridge sub-district offices and lasted for 1.5 hours (until there was limited new information emerging from the discussions). At the end of the sessions, a debriefing was conducted with the two teams and field notes were captured to document any information that may have been missed. All interviews were audio recorded and transcribed verbatim in preparation for data analysis.

Method of analysis

All transcripts were uploaded on NVivo 12 software for analysis. Data were analysed systematically following a six-phase reflexive thematic inductive approach proposed by Braun and Clarke (2021), which enabled the researchers to find meanings and patterns within the data. For data familiarisation, the PI read the transcripts continuously while concurrently listening to the recordings. Familiarisation notes were made and served as a guide for generating ideas for codes. Coding was done systematically and inductively with each code assigned a specific description to ensure uniformity in the coding process. Following this, codes were grouped together to form patterns and generate initial sub-themes and themes. Themes were refined and renamed through reading the coded extracts. This was done to ensure that identified codes merged coherently into a pattern to form a specific theme. The data set and familiarisation notes were read to ascertain that no codes were missed and to check the validity of the themes. Trustworthiness was ensured by inviting an experienced qualitative researcher to conduct an audit trail on the analysis process. This was further ensured by conducting peer briefings and presenting the findings to the research supervisors. The PI practiced reflexivity by keeping a journal where all thoughts and observations used to guide the analysis process were documented.

Ethical considerations

Each participant was given an information sheet that outlined the purpose of the study along with details on confidentiality and anonymity to be reinforced during the study. Two separate consents were obtained from the participants, one for participation and the other for audio recording of interviews. Ethical approval was obtained from the Human Research Ethics Committee of the University of the Witwatersrand (M200957) on 21 January 2021. In addition, permission was obtained from the Mpumalanga Department of Health Research Committee (MP_202010_010). Anonymity was ensured by allocating a participant code to identify each participant.

Results

Twenty-eight mental health service providers were recruited to participate in the study; three were MHCs at the provincial, district, and sub-district level, and five were MHPs, including a medical officer, nursing manager, social worker, and two occupational therapists, at a mental health unit

in a local district hospital. In addition, five PHCSs and 15 CHWs based in the local community of Bushbuckridge municipality were invited to participate. The participants had diverse working experience that ranged from 2 to 34 years in their current positions. The participant details are shown in Table 8.

Table 7 Participant details

Identity of participant	Format of data collection	Setting of data collection	Number
MHCs			
Provincial	Semi-structured interview	Workplace	1
District	Semi-structured interview	Workplace	1
Sub-district	Semi-structured interview	Online	1
MHP			
Medical officer	Semi-structured interview	Workplace	1
Nursing manager	Semi-structured interview	Workplace	1
Social worker	Semi-structured interview	Workplace	1
Occupational therapist	Semi-structured interview	Workplace	2
Community-based service providers			
PHCSs	FG	Sub-district offices	5
CHWs	FG	Sub-district offices	15
Total			28

The study aimed to explore the service providers' perspectives of the formal and informal mental health services for alleviating the burden of care among informal caregivers in rural South Africa. When asked about their perspectives regarding the mental health services for alleviating burden of care among the informal caregivers, the service providers identified various strategies, including caregiver-driven, health worker driven, community-based, intersectoral, and policy and legislature strategies.

Caregiver-driven strategies

The services providers identified informal caregivers as active role players in the implementation of strategies for alleviating their own burden of care. Caregiver empowerment was identified as a key strategy for supporting and enabling informal caregivers to cope with their caregiving responsibilities. Service providers indicated the need to create opportunities for informal caregivers to empower themselves with skills to accept and manage the conditions of the MHCUs, and one MHC said, "They need to be empowered to change their circumstances". Training informal caregivers to become peer facilitators of caregiver support groups was identified as a

strategy to encourage informal caregivers to build social networks and support for each other. One MHP explained it as follows:

> *"The caregiver could run the support group. I heard of them where I was getting training. We observed that where there are support groups in the community; there are facilitators responsible for these support groups. Then, the health care worker can go there to give support in that particular support group". (MHP)*

Health worker-driven strategies

The service providers identified caregiver psychoeducation as a predominant strategy for alleviating burden among the informal caregivers. They highlighted that MHPs should provide education with basic information on the causes of mental disorders, medication management, including monitoring side effects, and warning signs of relapses to ensure they seek timeous help for the MHCUs. One MHP explained it as follows:

> *"With the psychoeducation I think it is just the basics about the mental illness, like for example, the causes… and also medication management … like explaining how the patient must take the medication and also explaining the side effects and that it is important to bring them to see the doctor …, and the symptoms that they might see like the warning signs of relapse so that the caregiver will know when to bring the user back to the hospital." (MHP)*

Support groups were identified as a strategy for alleviating burden among the informal caregivers. Service providers indicated that support groups can create a safe space for informal caregivers to express the challenges and get support from others who are going through similar experiences. One MHP said, "The support groups would really help as the caregivers would come together for support, they can come to the hospital without the patient so that there is a safe space to discuss their challenges and support each other in that way".

Service providers highlighted the need for the entire family to be involved in caregiving, and as such, they identified family therapy as a strategy to help build support for the primary caregivers. A PHCS explained that "family therapy, where not only the caregiver gets it but the rest of the family for them to support the person who is looking after the mental healthcare user. The rest of the family needs to be involved and family therapy will assist".

Facilitating the development of skills for handling MHCUs and structuring their engagement in activities was identified as a strategy for alleviating burden among the informal caregivers.

Occupational therapists were identified as suitable professionals for facilitating skills training among the informal caregivers, as shown in the following comment:

> *"I think they need to be skilled, given information on how to manage these people in their homes. I think that is the job of the OT [occupational therapist]. I think that is the best because the patients may have time when they are home to do something with their hands and the OTs]can assist". (MHP)*

Lastly, some service providers identified building a good rapport with the informal caregivers as a strategy for creating a safe space for them to express their challenges. For example, a CHW said, "As CHWs we should build rapport with the caregivers so that they can be able to open up to us about their problems".

Community-based strategies

The service providers identified community-based strategies alleviating burden among the informal caregivers. Service providers expressed that support groups and counselling services should be community-based to ensure accessibility to all informal caregivers and to give them an opportunity to share their challenges and gain appropriate coping skills and stress and conflict management skill so they can handle the MHCUs appropriately. An MHP explained it as follows:

> *"In terms of the support groups where it is clearly their platform for them to discuss the challenges, and I guess it is probably more about education where they are educated on the coping skills, stress management, conflict management, or communication skills. This is just to equip them so that they can be able to deal better with the mental health care user at home". (MHP)*

The use of existing community resources, including community dialogues and community radio stations, to raise awareness on mental disorders was highlighted as a strategy for addressing stigmatization and building support for the informal caregivers within the community, as shown in the following comments:

> *"We should also have the community dialogues where community members can be invited and they can raise their myths, their understanding of the MHCU's behaviour, and they can be educated on their behaviour and how to deal with them in a positive way". (PHCS)*

> *"Another point I have here is the radio slot where they can discuss about this matter and others can call including those who are mentally ill and if they are listening they may be able to understand that they are not alone". (PHCS)*

Some service providers highlighted a need for recreational facilities to enable caregivers to engage in recreational activities to allow them some time away from their caregiving duties and time for relaxation and enjoyment: “The recreational facilities are also needed because they may give the caregiver some relief to relax while they are out to entertain themselves” (MHP).

The service providers identified the need for community-based facilities including day centres, sheltered employment, and respite care facilities. Facilities such as day centres and sheltered employment were regarded as useful in facilitating the development of skills for independent living among the MHCUs to reduce their dependence on caregivers. Respite facilities were identified as a resource for short-term relief of caregivers when they struggle to cope. The following comments are examples of the suggestions that were made:

> *“Identifying places for patients to go during the day in the communities. It could be used to have quality interventions or up skilling the patient”. (MHP)*
>
> *“For the mental health care users there is this thing called the sheltered employment”. (MHC)*
>
> *“What I know is that if the caregiver is no longer coping, we need to relieve them and the institutions would serve the purpose of relieving the caregiver”. (MHP)*

Intersectoral strategies

Intersectoral collaboration between health and other government sectors was identified as a strategy for alleviating informal caregiver burden. Service providers indicated that platforms such as case flow can be used to build support for informal caregivers. Case flow was described as a platform where service providers from health and other government sectors, including municipalities, South African Police Services, forensics, Department of Home Affairs, and the Department of Social Development, come together to discuss ways of supporting the MHCUs and their families within the community. One MHP said, “In this case flow there was Department of Home Affairs, Social services, South African Police Services, municipality, the forensics, Justice … all the departments were coming together and discussing the cases. It was simpler and very helpful”.

In addition, service providers identified the need for intersectoral collaborations between the Departments of Health, Social Development, and Education to share budgets to increase the number of lay health workers in the community to help strengthen the mental health services for MHCUs and their caregivers:

"DSD [Department of Social Development] must come with a category. Education must have their category, and when they come together …, they can make a huge category. All of them should collaborate, and we are assisted with funds, we can appoint more CHWs". (MHC)

Collaborations between health and community stakeholders were identified as a way of strengthening community support for informal caregivers. Identified stakeholders included religious organisations like churches, informal mental health service providers like traditional healers, municipality ward councillors, and traditional leaders within the community. One PHCS explained it as follows:

"I have included the churches, traditional healers, and the community involvement by the stakeholders such as the ward committees, the Indunas *[traditional leader] and all those that are part of the leadership in the community. They can discuss the issue of caregivers, share ideas, and discuss this with the community during their* Imbizos *[community gatherings]". (PHCS)*

Policy and legislature strategies

The service providers identified policy and legislature strategies for alleviating burden among the informal caregivers. They highlighted the need for policies and guidelines aimed at caregiver-orientated services to strengthen the support for the informal caregivers and that policies must be aligned with the available financial resources to ensure implementation. The participants explained it as follows:

"I think the mental health … maybe the provincial can come up something uniform whether some guidelines because I think the caregivers need support". (MHP)

"What we need to have is to develop policies and put them in line with the finance but also now to presume straight to implementations so that we move forward. The policies should be in place to address this problem". (MHC)

In addition, service providers indicated that policies aimed at addressing caregiver burden should be easy to implement with practical action points. The action points should specifically outline the resources required, resource availability, and responsible persons to drive the implementation process. One MHP explained this as follows:

"I am interested in policies if there is interest in implementing them. I am interested in knowing if there is a respite centre or that there are health care workers trained and if there is anyone who is being allocated in every ward or clinic to run a support group. The first step would be piloting with the mental champion at the clinic". (MHP)

The need for quality assurance was highlighted as a critical step in implementing policies for improving access to caregiver-orientated services in mental health: “It needs to be allocated to a specific person with a name and be checked on and note if things are happening or not” (MHP).

Training of MHPs and lay health workers was identified as a strategy for increasing access to community mental health services, and it was suggested that these services be expanded to include caregiver-orientated services. Access to refresher training courses was identified as a need for mental health professions, including nurses: “I think if we can have the refresher courses for mental health for the nurses that could perhaps revive us” (PHCS).

The service providers identified that policy strategies should be targeted at improving training within the communities. This training should focus on capacitating lay health workers such as CHWs and lay health counsellors to offer caregiver-orientated. A MHC suggested that “another strategy can be training in communities like the lay health counsellors; in terms of mental health … it would help as they would assist with screening”.

CHWs expressed that such training strategies should be directed at developing their identities and raising awareness of their services for the community to accept their services. They expressed that they struggled to provide services as the community cannot identify them as health workers and suggested that nametags may address this problem. One CHW claimed that “the clinics they are failing to give us the nametags. When we are doing fieldwork, people are chasing us away. Some people say that they do not know us because we do not have anything to identify us”.

Discussion

The study aimed to explore the service providers’ perspectives on formal and informal mental health services for alleviating the burden of care among informal caregivers of persons with SMDs in rural South Africa. Various strategies were identified for alleviating burden of care among the informal caregivers, namely caregiver-driven, health worker-driven, community-based, intersectoral, and policy and legislature strategies.

In the findings of this study, the service providers identified informal caregivers as active partners/participants in implementation of strategies aimed at alleviating their burden. As such, caregiver empowerment was identified as a core caregiver-driven strategy for alleviating burden among the informal caregivers. Jessy and Kalaimathi (2014) describe empowerment as a process

through which individuals gain control and mastery over their lives and identified empowerment practices as a viable approach when working with informal caregivers of persons with mental disorders. Correspondingly, Perlick et al. (2013) identify empowerment as an effective way of reducing physical and mental burdens among family caregivers by building self-efficacy and acquiring ongoing social support. Thus, informal caregivers can help themselves to accept and cope with their caregiving responsibilities to enable them to take ownership of their role through increased feelings and perceptions of empowerment by acquiring knowledge and skills for handling the MHCUs, having information on available services, and gaining skills for managing their stress and for facilitating support groups.

MHPs like occupational therapists were identified as suitable for training informal caregivers to develop skills necessary for handling the MHCUs and structuring their engagement in activities. This is not surprising considering that occupational therapists have a unique understanding of the functional limitations exhibited by persons with SMDs and are equipped to facilitate participation in daily activities to promote good health (Valverde-Bolivar et al., 2022). Using their knowledge and skills, occupational therapists can support both the MHCUs and their caregivers and promote their participation in activities of daily living, including household tasks, meal preparation, managing medical appointments and medication, shopping, financial management, and personal care (Howes & Ellison, 2022; Valverde-Bolivar et al., 2022).

Similar to previous studies (Chien & Norman, 2009; Chien et al., 2018), the service providers in this study highlighted peer support groups as a strategy for building social support networks for caregivers. In addition, the service providers identified support groups as vital in facilitating development and sharing skills for managing caregiving duties, creating a safe space for sharing and promoting effective coping skills and stress and conflict management among informal caregivers. Previous studies commended support groups for being cost-effective and beneficial in reducing caregiver burden among caregivers of persons with mental disorders (Schulze Mönking, 1994; Chien & Chan, 2013; Worrall et al., 2018). Chien and Chan (2013) report that peer-led support groups are effective as they provide informal caregivers with a platform to share and re-examine their caregiving challenges with the help of their peers who are going through similar experiences. Peer-led support groups are useful in improving emotions and empathy and facilitating effective communication between caregivers and their care recipients (Chien & Norman, 2009; Chien et al., 2018). Additionally, some studies identified support groups as

effective in fostering hope among informal caregivers, creating an opportunity for mutual learning, building coping strategies, reducing isolation by increasing social networks, creating an opportunity for caregivers to express their repressed emotions, and building autonomy in caregiving (Worrall et al., 2018; Bernabéu-Álvarez et al., 2022). While support groups are beneficial in addressing burden of care among caregivers, some challenges can influence their effectiveness and successful implementation, including irregular attendances, having dominant members who exert negative pressure on group members, and overexpression of negative feelings. To overcome these challenges, Worrall et al. (2018) recommend training of professional workers, peer facilitators, and volunteer group leaders to ensure effective facilitation.

The service providers identified psychoeducation as a predominant health worker driven strategy for alleviating caregiver burden. This strategy is supported by a systematic review by Soo et al. (2018), which reveal that group and family psychoeducation increase caregiver knowledge and improve skills and caregiver wellbeing, subsequently reducing burden of care among caregivers of persons with bipolar mood disorders. Similarly, studies conducted in low- and middle-income countries, including Nigeria (Iyidobi et al., 2022) and Iran (Navidian et al., 2012), reveal that psychoeducation is effective in reducing caregiver burden among family caregivers of persons with schizophrenia and mood disorders. To be effective, psychoeducation should go beyond knowledge translation to incorporate skills development. Psychoeducation should facilitate the development of skills for communicating with and handling of MHCUs, facilitate help-seeking through enabling identification and use of available resources such as welfare services, and build skills for self-employment and management of day-to-day activities (De Souza et al., 2016; Zhou et al., 2020).

Family therapy is another strategy identified as relevant for building support and enabling informal caregivers to cope with the demands of their caregiving. According to Caqueo-Urízar et al. (2016), family therapies are specialised psychological counselling interventions that encompass various forms, including psychoeducation, stress reduction, emotional processing, and structured problem-solving, and their delivery is always dependent on the MHPs. Previous studies establish that family therapy is linked to a reduction in family stress by promoting a positive environment and improving quality of life for the MHCUs and their families (Okpokoro & Sampson, 2014; Caqueo-Urízar et al., 2015). Petersen et al. (2014) reveal that counselling is useful for enabling families to cope with MHCUs' condition and to deal with the effects of experienced and internalised stigma.

While family therapies have been proven beneficial for both the caregivers and their care recipients, their implementation may not be feasible in low-resourced settings like rural South Africa where there is a shortage of healthcare professionals (Lefafa, 2023).

Previous studies conducted in low- and middle-income countries highlight the feasibility and acceptability of using task shifting by training CHWs to deliver counselling (Padmanathan & De Silva, 2013; Petersen et al., 2014). In South Africa, the use of CHWs to deliver basic mental health counselling has been endorsed as a viable option for extending counselling services from primary healthcare facilities to the community (South African Department of Health, 2023). Zegwaard et al. (2017) reveal that building trusting relationships between caregivers and MHPs is crucial for fostering the effectiveness of caregiver-centred counselling. In the findings of the current study, community-based counselling was identified as a useful strategy for creating a safe space for caregivers to share their caregiving challenges. Therefore, it can be concluded that the use of community-based counselling as a strategy for alleviating burden is feasible in the current study site and CHWs should be trained to provide these services. Training provided should capacitate CHWs to build good relationships with informal caregivers to create a safe space for sharing challenges encountered in caregiving.

Capacitating lay health workers such as CHWs and lay counsellors through training is a critical step for implementing the task shifting approach, which has been identified as crucial in addressing the mental health treatment gap in low-resourced settings like rural South Africa (Ojha & Pant, 2018; Sibeko et al., 2018). Previous studies highlight the need for regular supervision, availability of resources, and access to quality training as prerequisites for ensuring successful implementation of task shifting (Yaya Bocoum et al., 2013; Agyapong et al., 2016). The CHWs in the current study are responsible for bringing services closer to the local community through home visits, and they are able to extend access of mental health services. It can be assumed that the provision of adequate education and training would enable them to offer accessible caregiver-orientated services for alleviating burden among the informal caregivers within the community.

The need for strengthening community support was identified as a strategy for alleviating burden among the informal caregivers. Service providers identified tangible and emotional support from family in the form of help-seeking and emotional check-ins as useful for informal caregivers to cope. The findings in this study are consistent to those of Ong et al. (2018), who revealed that

social support is beneficial for building resilience and mediating caregiver burden among informal caregivers. In agreement with the *National Mental Health Policy Framework and Strategic Plan 2023–2030* and some previous studies conducted in South Africa (Lund & Flisher, 2009; Robertson & Szabo, 2017; South African Department of Health, 2023), the findings in this study highlighted the need for community-based facilities such as day centres, sheltered employment, and respite care facilities to reduce burden among the informal caregivers. Having access to community-based facilities or services such as day-care, in-home respite, and institutional respite services has been endorsed as a strategy for caregiver support and reducing caregiver burden in HICs

like the USA, the UK, and Australia (Organisation for Economic Co-operation and Development, 2011). In spite of advocacy for these services and their usefulness in alleviating caregiver burden, their implementation has proven to be challenging as they are considered costly and their financing remains problematic across various LMICs (Organisation for Economic Co-operation and Development, 2011). Therefore, any attempt to implement such services in low-resourced settings like South Africa should consider cost-effective strategies such as the adoption of community-based rehabilitation where collaborations are formed with multiple stakeholders, including health, other governmental sectors, community leaders, caregivers, and MHCUs to ensure the delivery of such services (Chatterjee et al., 2009, 2014).

To strengthen caregiver support within the community, collaboration is necessary between the MHPs and service providers in other government departments such as the South African Police Services. These findings are consistent with *National Mental Health Policy Framework and Strategic Plan 2023–2030*, which highlights the need to develop intersectoral collaborations between a various governmental sectors and NGOs to support mental health (South African Department of Health, 2023). In support of the findings, previous studies conducted in rural South Africa reveal that collaborations within the community are a promising strategy for increasing access to mental health services that are culturally appropriate and addressing stigma within the community (Petersen et al., 2012, 2019).

The findings in this study support those of previous studies that collaboration is necessary between MHPs and complementary and alternative care providers, including traditional healers and religious organisations (Laher, 2014; van der Watt et al., 2017; Gureje et al., 2020). While mental

health policies and researchers have called for intersectoral collaborations to increase access to contextually responsive mental health services, evidence suggests that the implementation of this strategy has proven to be a challenge (Lund et al., 2015; Gureje et al., 2020). Therefore, to ensure implementation of this strategy in building caregiver support, a clear referral systems must be established that acknowledges alternative care providers as members of the multidisciplinary team (Truter, 2023).

The service providers in this study identified the need for caregiver-orientated policies that are practical with clear actionable points specific to building support for informal caregivers. Correspondingly, Beach et al. (2022) reveal the need for caregiver-orientated policies and emphasise that such policies should go beyond relieving burden to building sustainable support for the caregivers to attain positive emotions, engage in activities of their choice, and build meaningful relationships. Caregiver-orientated policies should provide practical solutions for addressing the needs of the informal caregivers, including the provision of grants to cover caregiving costs, addressing the need for broader supportive resources by increasing access to community support, mental health, and social services, and providing practical resources to facilitate caregiver educational support (Beach et al., 2022).

Limitations

The study focused on service providers who were identified as offering outpatient and community-based mental health services to MHCUs and informal caregivers. As a result, the study excluded health professionals from the two hospitals that offer 72-hour mental health services and this limited the extent of the evidence gathered. Conducting interviews in the participants' workplace was ideal; however, the interviews were constantly interrupted as some needed to be paused to allow the participants to attend to their work, which interrupted the flow and depth of information shared by the participants.

Conclusion

The study outlines suggested strategies for alleviating burden of care among informal caregivers in rural South Africa. Given the paucity of evidence in this area, the study adds to the body of knowledge on contextually responsive strategies for supporting informal caregivers in rural areas. The strategies suggested by the service providers in this study form the basis for the development

and implementation of caregiver-orientated services in rural South Africa. The findings of this study revealed that the mental health service providers are aware of the strategies required to alleviate burden among the informal caregivers of persons with SMDs. Most of the suggested strategies are consistent with those highlighted in existing literature, indicating that strategies aimed at alleviating caregiver burden can be similar despite the context. The findings revealed the need to fast track the adoption of task shifting in the planning, development, and implementation of caregiver-orientated services in mental health, particularly in low-resourced contexts. In addition, the suggested strategies outlined by the service providers emphasise the complexity of delivering comprehensive mental health services and calls for intersectoral collaborations to extend caregiver-orientated services within the community. The service providers called for policies with practical solutions to the current challenges facing the delivery of caregiver-orientated services within the community. Efforts should therefore be made to ensure strategies aimed at alleviating caregiver burden are clearly outlined within policy documents and that the roles of the people responsible for rendering such services are clearly identified and allocated. While the service providers highlighted feasible strategies for alleviating burden within a rural context, some of the highly specialised strategies, such as family therapy, may not be feasible considering the recurring financial and human resource challenges facing the delivery of services in these areas. Future studies should focus on developing and implementing caregiver-driven, health worker-driven, community-based, intersectoral, and policy and legislature interventions for alleviating informal caregiver burden.

5.3 SUMMARY OF FINDINGS IN PHASE 2

Phase 2 aimed to conceptualise the burden of care among the informal caregivers of persons with SMDs in a low-resourced setting. The findings of the scoping review included studies from 16 LMICs, many from Asia countries. Identified strategies for alleviating caregiver burden from the existing literature include community-based interventions, psychoeducation interventions, support groups, cognitive behavioural therapy, spirituality-based interventions, smart phone-based interventions, mindfulness and empowerment, collaborative interventions, standard care, financial and social support, counselling, occupation-based interventions, policy and legislature, and access to mental health. The service providers revealed their awareness of the burdens experienced by the informal caregivers and highlighted the insufficiency of the current formal and informal mental

health services to alleviate the burden of care among the informal caregivers. Proposed strategies for alleviating burden based on the service providers perspectives included caregiver-driven, health worker-driven, community-based, intersectoral, and policy and legislature strategies.

The next phase of study focused on triangulating data collected in Phases 1 and 2 to develop strategies for alleviating burden among the informal caregivers in the low-resourced community of Bushbuckridge municipality, Mpumalanga province.

CHAPTER 6

PHASE 3: DEVELOPMENT OF STRATEGIES FOR ALLEVIATING CAREGIVER BURDEN AMONG THE INFORMAL CAREGIVERS

6.1 INTRODUCTION

This section focuses on reporting on the development of strategies for alleviating burden among the informal caregivers in the low-resourced community of Bushbuckridge municipality, Mpumalanga province. The findings from Phases 1 and 2 were triangulated to inform the development of strategies for alleviating burden among the informal caregivers of persons with SMDs.

6.2 OBJECTIVE 5: TO IDENTIFY INDIVIDUAL, ORGANISATIONAL, AND POLICY STRATEGIES FOR ALLEVIATING CAREGIVER BURDEN AMONG INFORMAL CAREGIVERS OF PERSONS WITH SEVERE MENTAL DISORDERS IN BUSHBUCKRIDGE, MPUMALANGA PROVINCE

6.2.1 Introduction

This section describes the steps followed in the development of the strategies for alleviating caregiver burden in a low-resourced setting. The process was guided by triangulating the findings of the studies conducted in Phases 1 and 2 of this study. The panel, which consisted of a group of experts, including me as the primary investigator, a research expert with extensive experience in public and private mental health systems, and the two PhD supervisors, consolidated the findings and identified the strategies. An international academic professor who is experienced in mental health intervention was consulted to review the strategies and provide an expert opinion on the proposed strategies.

6.2.2 Data triangulation

Data triangulation is the stage in which the researcher combined the data generated from multiple sources to answer the research question (Rugg, 2010; Heale & Forbes, 2013). A four-step approach was followed to direct the development of strategies for alleviating caregiver burden in a low-resourced setting. This was done to respond to the study's research question: How can strategies

for alleviating burden among informal caregivers of persons with SMDs in Bushbuckridge, Mpumalanga province be developed? The four steps were summarising key findings from the studies conducted in Phases 1 and 2; using a conceptual framework to consolidate the findings and generate ideas for strategies; identify strategies for alleviating caregiver burden using findings from the quantitative and qualitative studies and existing literature; and integrate proposed strategies for alleviating caregiver burden in a low-resourced setting. Figure 6.1. presents an outline of the steps followed to develop the strategies.

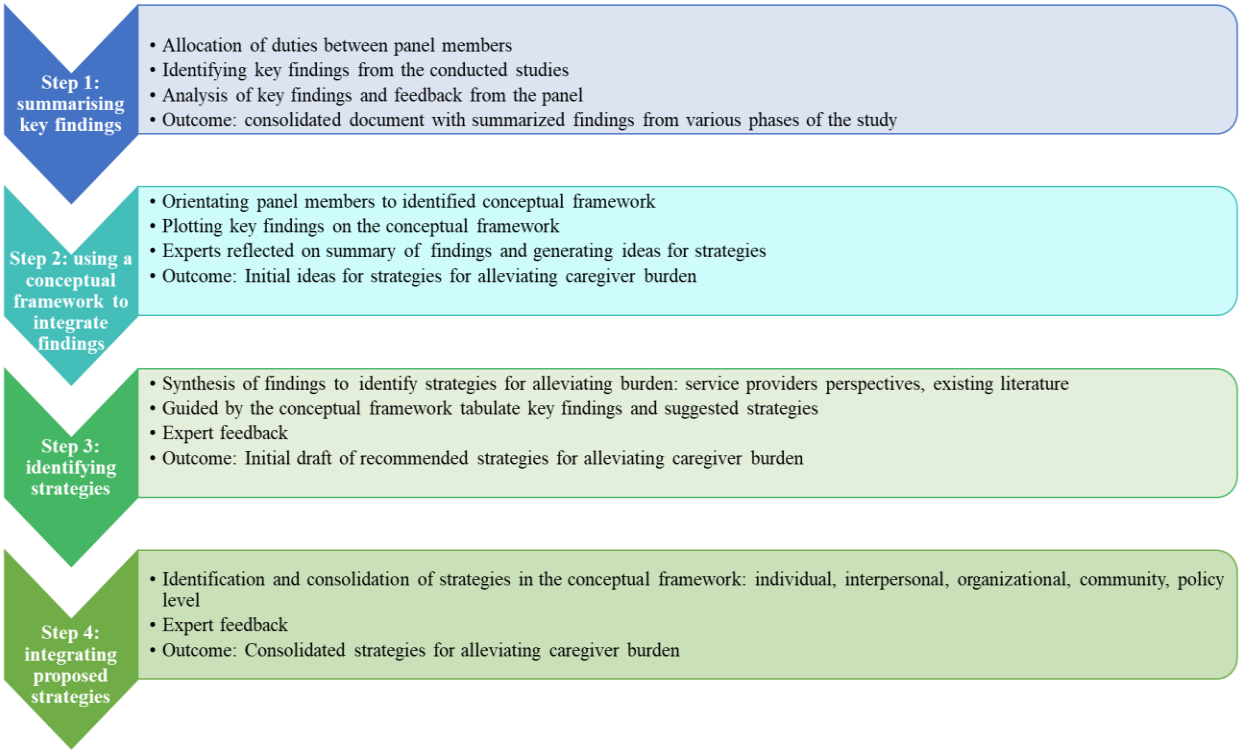


Figure 6.1 Steps followed to develop the strategies for alleviating informal caregiver burden

6.2.2.1 Step 1: Summary of key findings

This step entailed summarising the findings generated from the quantitative study, the scoping review, the semi-structured interviews, and focus groups conducted in Phases 1 and 2 of this study. In this step, the findings were summarised by the experts who consisted of the primary investigator (me), the research expert, and two PhD supervisors. The research expert was responsible for facilitating this step. The research question, aim, and study objectives guided the synthesis of key findings from each study phase. Since all the results were written in article format, each panel

member was assigned an article from which to compile a summary of key findings. The key findings were outlined as per the objective of the study and plotted on charts, which were displayed visually. Each member was required to present the key findings based on their summaries while the other members went through the articles to ensure no information was missed. Where necessary, additional notes were added to ensure key findings were captured comprehensively. Once all the key findings were plotted and presented, the experts discussed the key findings and all points that required clarity were addressed to ensure consensus among the members of the panel. Table 6.1 presents the summarised findings from the various phases. Links between the key findings in various studies were established and documented to guide the identification of the strategies.

Table 6.1 Summary of findings from studies conducted in Phases 1 and 2

<table>
<tr><th>Quantitative</th><th colspan="3">Qualitative</th></tr>
<tr><td colspan="4">PHASE 1</td></tr>
<tr><td rowspan="2">Objective 1: To describe the extent of subjective and objective caregiver burden among the informal caregivers of persons with SMDs.
Higher levels of objective and subjective burdens
Most caregivers are in their old age
Caregivers are mostly female with higher levels of objective burden due to disruptions in routines
Low levels of education among caregivers: Most have secondary level of education and primary school level, and some have no education
Share the same residence with care recipients
The care recipients have a diagnosis of schizophrenia, which means poor recovery</td><td colspan="3">Objective 2: To describe the lived experiences of informal caregivers of persons with SMDs (analysis of caregiver burden to identify needs of the caregivers)</td></tr>
<tr><td><u>Perception of burden and support needs of caregivers</u>
Experience of burden:
Dealing with the chronic nature of mental disorders
Experience of the MHCUs’ disruptive behaviour
Experience of financial strain
Experience of role strain
Experience of stigma: family and public
Needs:
Access to community-based mental healthcare services
Caregiver empowerment
Social support:
Family
Religious and community organisations
Emotional support</td><td><u>Existential crisis in caregiving</u>
Demographics:
Old age 40+
Education: lower levels
Economic status: financial strain
19–24 hours spent in caregiving
Most care recipients are schizophrenic
Caregivers share the same residence with recipients
Existential responsibility:
Responsibility towards MHCU: Health and wellbeing, physical needs, activities of daily living.
Existential anxiety:
Fear of what will happen if caregiver dies</td><td><u>Health effects of caregiving and coping with SMDs</u>
Consequences of caregiving:
Emotional consequences
Walking on egg shells
Mental consequences
Physical consequences
Coping strategies:
Internal resources
Resourcefulness and resilience
Religious coping
Sense of collective experience
External resources
Access to medical support
Access to social worker services
Social support: family, community, and religious organisations</td></tr>
</table>

<table>
<tr><th>Quantitative</th><th colspan="3">Qualitative</th></tr>
<tr><td>• No rehabilitation centres or homes for the MHCUs
• Outcome: Need for objective screening</td><td></td><td>• Fear over the future of the MHCU</td><td></td></tr>
<tr><td colspan="4">PHASE 2</td></tr>
<tr><td rowspan="2">Objective 3: To describe existing strategies for alleviating caregiver burden in developing countries through a scoping review
Community-based interventions:
• Reduced stigma
• Early intervention
Psychoeducation:
• Group- and peer-led/ assisted
Support groups:
• Family-led and Non-governmental mental health organizations NGOM
Cognitive behavioural therapy:
• Emotional regulation
Spiritual-based intervention:
• Traditional and spiritual healers
Guided self-help intervention:
• Problem-solving
• The Good Mood Guide
Smart phone intervention:
• Mindfulness and empowerment intervention
Collaborative intervention:
• Caregiver input in programmes
Standard care:
• Psychiatry, nursing, psychology, and rehabilitation
• Financial support in the form of grants
• Social support</td><td colspan="3">Objective 4: To describe stakeholders' perceptions of the formal and informal CMHS for alleviating caregiver burden among the informal caregivers within a low-resourced community in Mpumalanga province, South Africa</td></tr>
<tr><td><u>Perspectives on caregiver experiences and availability of mental healthcare services for alleviating burden</u>
Factors impacting caregiver burden:
• MHCU-related factors
• Behaviour and functional limitations
• Caregiver-related factors
• Minor caregivers providing care
• Lack of information and handling skills
• Cultural and spiritual beliefs
• Avoidant coping strategies
• Contextual factors
• Community stigma
• Lack of support
• Health system factors
• Lack of caregiver care
• Lack of caregiver empowerment
• Intersectoral factors
• Lack of placement facilities for MHCUs (placements and day-care facilities)
• Lack of awareness of grants
Current state of mental health services:
• Lack of caregiver-orientated services at institutional and community levels
• Caregiver support available on request
• Community-based mental health services
• Lack of specialised services</td><td><u>Perspectives on strategies for alleviating caregiver burden</u>
Caregiver-driven strategies:
• Handling skills for MHCUs
• Psychoeducation
• Peer-led support
• Caregiver empowerment
Healthcare worker-guided strategies:
• Training to improve attitude towards mental health
• Integrating caregiver care into routine practice
Community-based strategies:
• Strengthening of primary healthcare services
• Integrated services
• Training of mid-level and lay health workers
• Task shifting: CHWs and home-based carers to offer caregiver services
• Support groups
• Building family support
• Community education
• Dialogues
• Awareness through radio stations
• Availability of placement and rehabilitation services
• Day centres, sheltered employment, and respite care
• Skills training for MHCUs
• Use of school health services
• Support for caregivers who are minors
Intersectoral strategies:
• Stakeholder collaborations
• Case flow
• Health, Department of Social Development, informal service providers, and traditional and community leaders</td></tr>
</table>

Quantitative	Qualitative	
• Counselling • Occupation-based intervention • Physical and leisure activities *Policy and legislature*: • National Health Insurance, advocacy • Access to mental healthcare		*Policy and legislature strategies:* • Guidelines and flexible policies • Training for mental health professionals and lay health workers • Support for mental health professionals to provide services • Increasing access to mental health services

6.2.2.2 Step 2: Using the conceptual framework to integrate findings

a) Description of the conceptual framework

The initial conceptual framework was revised to include new concepts that emerged from the findings of the study. As outlined in Figure 6.2, the revised conceptual framework was created by adapting and merging the two conceptual frameworks of the caregiver stress model by Pearlin et al. (1990) and the socioecological framework by Mcleroy et al. (1988), as described in section 2.3. The revision of the conceptual framework was necessary to ensure emerging concepts applicable to the study context were captured to ensure the strategies developed are relevant to the context. The study aimed to explore the burden of care among the informal caregivers of persons with SMDs to inform the development of strategies for alleviating burden among informal caregivers of persons with SMDs in Bushbuckridge, Mpumalanga province. As outlined by Pearlin et al. (1990), understanding the background and context of caregiving is important to identify mediating factors to alleviate such stressors. In the caregiver stress model, Pearlin et al. (1990) propose that understanding the caregiver characteristics, including their age, gender, education, and employment status, is important to understand factors contributing to caregiver burden. In addition, understanding the caregiving context was highlighted, including identifying years of caring, the state of the relationships with the care recipients, and exploring the availability of services for addressing the stress encountered by the caregivers (Pearlin et al., 1990).

Previous literature on caregiver burden report links caregiver characteristics and caregiver burden (Möller-Leimkü Hler & Wiesheu, 2012; Ribé et al., 2018; Hsiao et al., 2020); however, the qualitative findings of the current study revealed that in order to fully understand caregiver burden,

the caregivers' cultural and religious beliefs should be considered. In addition, this study revealed that understanding the care recipients' characteristics is essential. The findings of the current study revealed that the care recipients' age, gender, education, employment, marital status, diagnosis, disease status, and previous hospitalisations contribute to the stressors experienced by their caregivers. Based on the findings, the conceptual framework was revised to expand on the caregiver characteristics to include their cultural and religious beliefs. Additionally, the conceptual framework was expanded to include the characteristics of the care recipients. In addition to the contextual factors proposed by Pearlin et al. (1990), the findings of the current study revealed contextual factors that should be considered to understand burden of care among the informal caregivers, including establishing the place of residence of both the caregiver and the care recipient, and number of care recipients for whom the caregiver is responsible. The findings also contributed to the understanding of social and attitudinal factors affecting caregiving. Identified social factors include availability of tangible and emotional support for the caregivers; and attitudinal factors include stigma in the family and community. In addition, the findings revealed that access to caregiver orientated mental health services should include availability, affordability and appropriateness. Based on these findings the conceptual framework was revised to ensure appropriateness to the study context. Therefore, I propose a revised conceptual framework that highlights that understanding intrapersonal factors, such as the caregivers' and care recipients' characteristics, and contextual factors are crucial for the in-depth exploration of factors that contribute to the burden of care among the informal caregivers. Separating the intrapersonal and contextual factors is recommended to ensure a comprehensive exploration of these factors and the role they play in the burden of care among the informal caregivers.

The multilevel approach as outlined in the socioecological framework by Mcleroy et al. (1988) was used to guide the identification of internal and external resources for alleviating burden among the informal caregivers. In the current study, individual factors relate to the intrapersonal factors, including caregiver and care recipient demographic characteristics that contribute to the burdens encountered by informal caregivers of persons with SMDs in their caregiving role. In addition, these factors include the needs, adaptability, stress response, and coping skills used by the informal caregivers to handle the demands of their caregiving. Contextual factors relate to a range of factors influencing the caregiving experience within the informal caregivers' immediate surroundings at the interpersonal and community level. Interpersonal factors relate to social networks, including

family and peers in the informal caregivers' immediate context. Community relates to the societal and attitudinal factors affecting the caregiving experience, as well as the access to CMHS and resources for alleviating their burden. Organisational factors relate to any factors thought to influence delivery of caregiver-orientated services at the institutional level. Lastly, policy factors relate to the national and local policy factors that impact on the caregiving experiences and availability of caregiver-orientated services. Figure 6.2. presents the proposed conceptual framework for identifying strategies for alleviating caregiver burden in low-resourced settings.

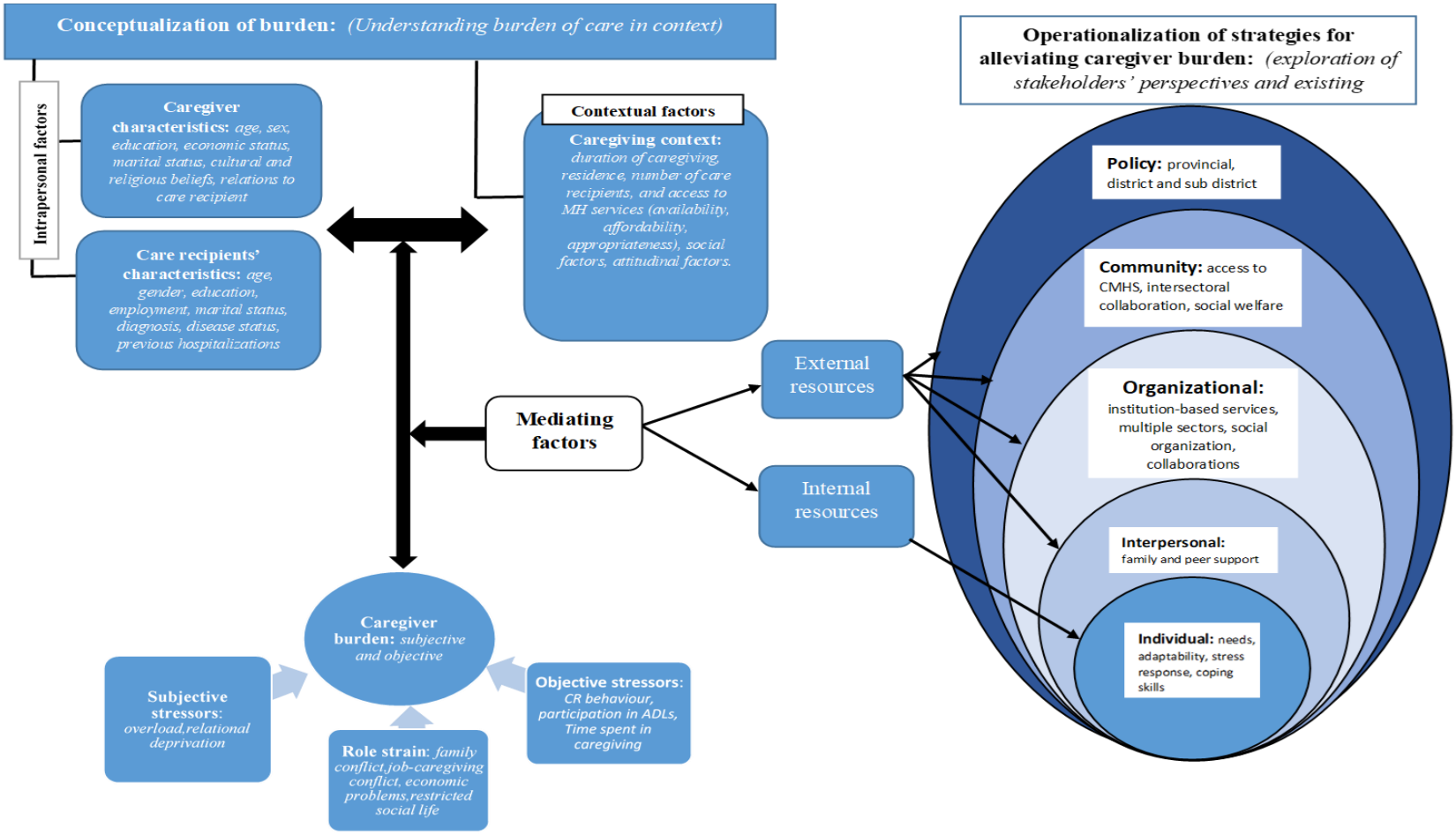


Figure 6.2 Proposed conceptual framework for identifying strategies for alleviating caregiver burden in low-resourced settings

a) Application of the conceptual framework

The conceptual framework for identifying strategies for alleviating caregiver burden in low-resourced settings (Figure 6.2) was used to guide the development of the strategies. This enabled an in-depth synthesis of the findings to establish links and provide the structure for arranging the proposed strategies. I plotted the findings summarised in Step 2 in the conceptual framework. Keeping the research question in mind, each objective corresponding to the specific findings were populated on the conceptual framework (Figure 6.3). The experts synthesised the key findings and generated ideas for strategies to alleviate burden. At this stage, general ideas for strategies were identified and discussed in detail by all experts. The existing knowledge and previous experience of the experts informed the discussion and identification of strategies. To ensure credibility, the experts kept referring to the results of the study to ensure the identified strategies are appropriate for this population. The findings of the study are documented with corresponding strategies in Table 6.2.

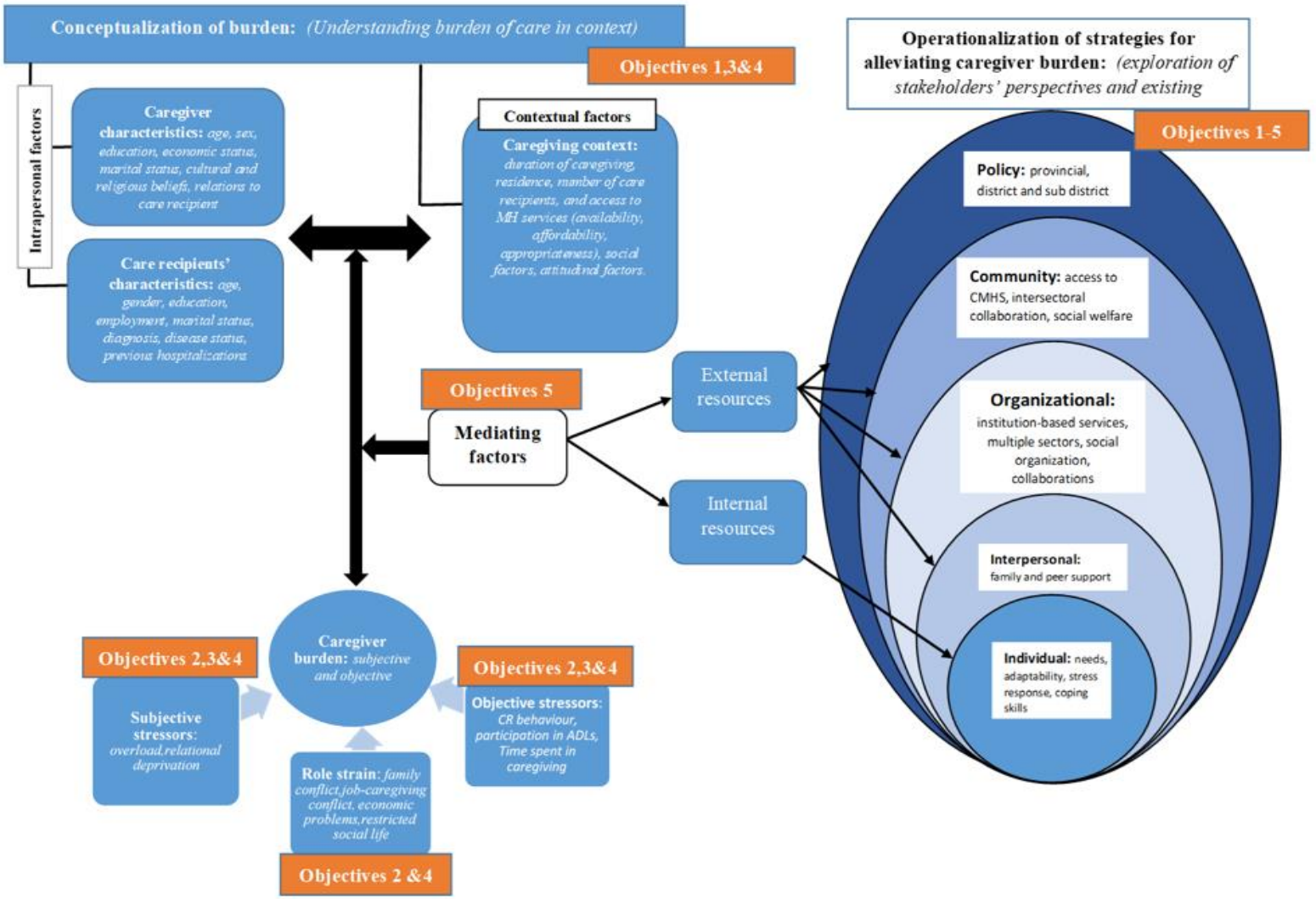


Figure 6.3 Proposed conceptual framework for identifying strategies for alleviating caregiver burden in low-resourced settings with populated objectives

6.2.2.3 Step 3: Identifying the strategies for alleviating caregiver burden

I followed the strategy to tabulate the framework components, summary of findings, and the identified strategies for alleviating burden (Table 6.2). In this step, content of the strategies were established and the possible mode of delivery was highlighted. The formulation and selection of strategies were based on what was considered contextually relevant as recommended by the participants in the findings and the existing literature. Informed by the conceptual framework, the categorised strategies were arranged into individual, interpersonal, organisational, community, and policy level strategies. This was done by labelling and colour-coding the identified strategies. Once all information was tabulated, the document was shared electronically with all the experts who provided feedback. I revised the strategies based on suggestions. The revision of the strategies were done by adding suggested strategies, rephrasing strategies for grammar and to ensure fit to the local context, removal of repetitions, and where necessary, generating new strategies. Once revisions were done, I shared the document with the experts for review. I added the complete table as Appendix U because of the length of the document.

Table 6.2 gives an overview of the data triangulation process followed to synthesize the findings from different studies according to different conceptual framework components to inform the development of the strategies for alleviating caregiver burden.

Table 6.2 Data triangulation

Framework components	**Summary of findings**		**Proposed strategies** ***(Informed by findings from the scoping review, and service providers' interviews and focus groups)***
Individual factors	*Intrapersonal factors including caregiver and care recipient demographic characteristics that contribute to the burdens encountered by informal caregivers of persons with* SMDs *in their caregiving role.*		
Caregiver characteristics	*Relates to caregiver demographic characteristics that predisposes them to burden in their role of caregiving*		
Age	Objective 2	Minor caregivers providing care to a parent with a mental disorder and having to drop out from school to provide care	**Community level: Community-based strategy** School health services: • Conduct screening to identify minor caregivers **Organisational level: Intersectoral strategy** Social services:

Framework components	Summary of findings		Proposed strategies *(Informed by findings from the scoping review, and service providers' interviews and focus groups)*
			• Family therapy to strengthen support for minor caregivers. • Assist with social grant application.
	Objectives 3 and 4	Caregivers in their Early adulthood to middle age leaving work to fulfil caregiving duties	**Individual level: Caregiver-driven strategy** • Caregiver empowerment • Skills for structuring engagement in Activities of Daily Living(ADLs) and Instrumental Activities of Daily Living(IADLs), including washing/bathing, making a simple meal, basic home management and maintenance skills, i.e. assisting with chores around the household like cleaning the house. **Interpersonal level: Community-based strategy** Family support: • Distribution of caregiving duties **Organisational level: Community-based strategy** • Placement facilities for MHCUs • Proper rehabilitation for MHCUs to facilitate independence • Day-care facilities • Skills development for MHCUs to facilitate independence

6.2.2.4 Step 4: Using the conceptual framework to integrate proposed strategies

The final step entailed identifying and consolidating the strategies for individual, interpersonal, organisational, community, and policy level as guided by the conceptual framework. At this stage, the strategies were summarised and synthesised without losing meaning. Following this, the strategies were plotted on the conceptual framework across the various levels of the conceptual framework, namely individual, interpersonal, organisational, community, and policy levels. The plotted strategies were shared with the experts, and they each provided feedback for revisions. Revisions were shared this with the panel for finalisation.

6.3 CONCLUSION

This chapter aimed to describe the steps followed to develop strategies for alleviating caregiver burden among informal caregivers in a low-resourced setting. The strategies were developed by following rigorous steps and a contextually relevant conceptual framework, which was adapted using the qualitative findings of this study (Mcleroy et al., 1988; Pearlin et al., 1990). According to Ravitch and Carl (2021), a conceptual framework serves as an integrating ecosystem that guides researchers to intentionally integrate the various aspects of their study together. The use of a conceptual framework in this chapter enabled me to create a comprehensive synthesis of findings. The structure provided by the conceptual framework kept the researchers focused on the key findings and enabled the integration of findings in an organised manner. Connections and overlaps were established in the data to ensure the identification of relevant strategies that are responsive to the context and the phenomena of interest, namely caregiver burden (Ravitch & Carl, 2021). The conceptual framework facilitated the comprehensive selection of strategies across the various levels (i.e. individual, interpersonal, organisational, community, and policy levels). The proposed strategies for alleviating caregiver burden among the informal caregivers of persons with SMDs in a low-resourced setting are discussed in detail in the integrative narrative discussion in the next chapter.

CHAPTER 7
INTEGRATIVE DISCUSSION

7.1 INTRODUCTION

This chapter outlines the integrative discussion based on the synthesis of the findings generated in the current study that aimed to explore the burden of care to inform the development of strategies for alleviating burden among informal caregivers of persons with SMDs in Bushbuckridge, Mpumalanga province. Data were collected from the acute mental health unit of a district hospital and the local community of Bushbuckridge municipality in the Mpumalanga province. In this chapter, the discussion of main findings is compared and contrasted with the existing literature. The socioecological framework (Mcleroy et al., 1988; Scarneo et al., 2019) are used to guide the discussion of the findings in this study. Figure 7.1 outlines the studies conducted to address the research aim in this study.

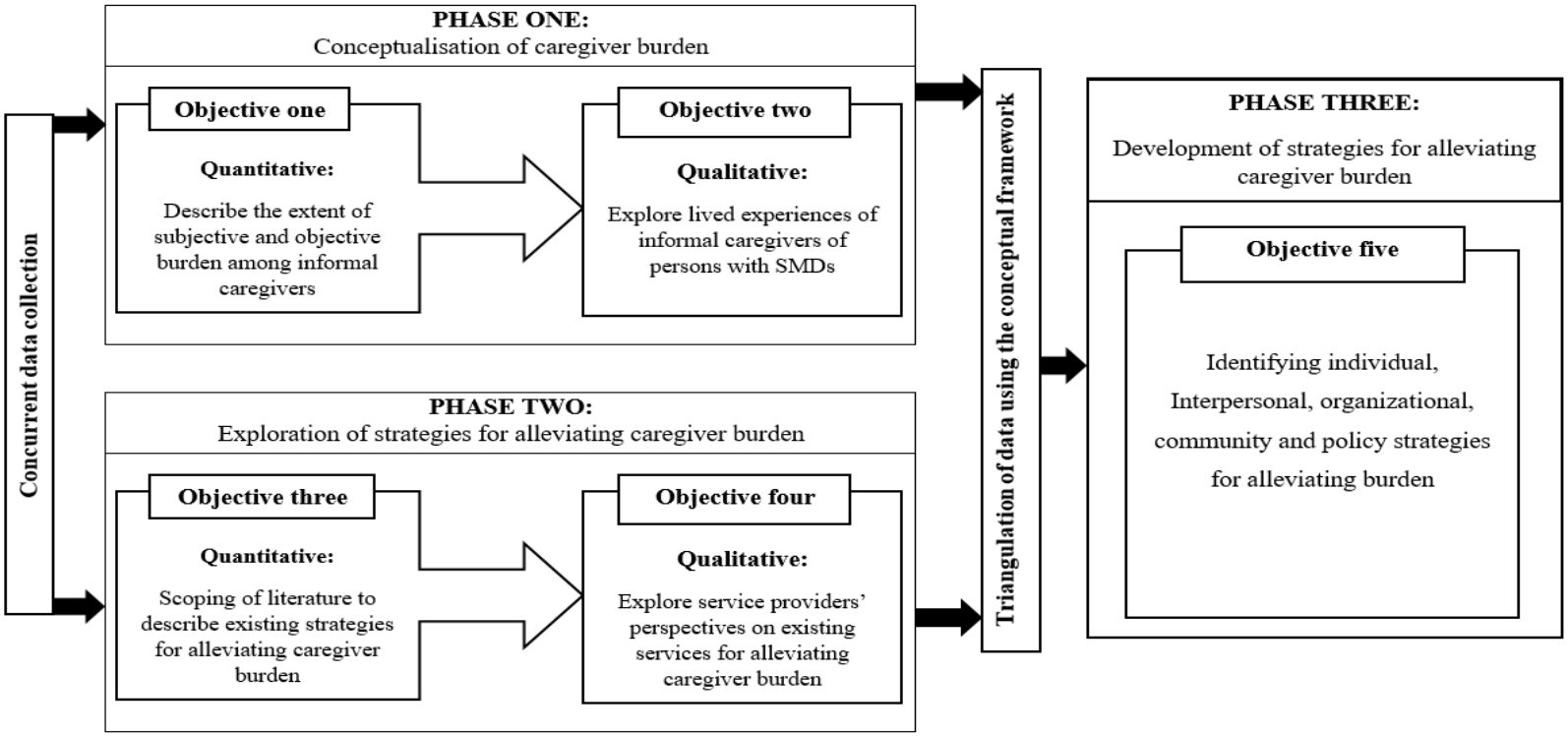


Figure 7.1 Schematic diagram of the studies conducted

To address the study aim, the burden of care among the informal caregivers was conceptualised by measuring subjective and objective burdens to establish the extent of burden among the informal caregivers of persons with SMDs (Objective 1). The lived experiences of the informal caregivers were explored to allow for an in-depth analysis of the burden and capture the needs of the informal caregivers (Objective 2). To explore the strategies for alleviating the burden of care among the informal caregivers, a scoping review of literature was conducted to identify existing strategies for alleviating caregiver burden among the informal caregivers (Objective 3). The perspectives of the service providers on the experiences encountered by the informal caregivers in their role and the available mental health services were explored to analyse the burden and identify strategies for alleviating the burden among the informal caregivers (Objective 4). Data triangulation was conducted using the conceptual framework to identify strategies for alleviating caregiver burden in a low-resourced setting (Heale & Forbes, 2013). Data triangulation allowed the findings from different data sources, namely the measurement of burden (Objective 1), interviews (Objectives 2 & 4) and existing literature (Objective 3), to be corroborated to propose valid and reliable strategies for alleviating burden of care among informal caregivers (Rugg, 2010; Heale & Forbes, 2013).

7.2 SUMMARY OF KEY FINDINGS

This section highlights the key findings of the studies conducted for the current PhD study as outlined in Figure 7.1. For an integrated summary of findings generated in this study, please refer to Table 6.1.

The current study made the following key findings:

a. The burden of care is highly prevalent among the informal caregivers of persons with SMDs. Moderate-to-severe objective burden and mild-to-moderate subjective burdens were established among the informal caregivers. Most caregivers were identified to be elderly females who are mothers of the care recipients. These burdens were significantly associated with caregiver individual factors, including their age and gender, as well as some contextual factors, such as sharing the same residence as the care recipient and the hours spent on caregiving daily.

b. Exploring the lived experiences of the informal caregivers revealed that informal caregivers experience burden and their need for emotional and tangible support. The burdens experienced by the informal caregivers lead to them being in a constant state of fear, worry, and powerlessness, which result in existential anxiety and responsibility. In addition, the role of caregiving was revealed to have a negative consequence on the emotional, physical, and mental health of caregivers, which compromise their quality of life.

   To cope with the demands of caregiving, informal caregivers use internal resources such as resourcefulness and resilience, while others use maladaptive strategies such as avoidance and self-sacrifice. External resources used for coping include family, community, and religious support. Needs identified by the informal caregivers include access to CMHS, empowerment, and emotional and tangible support from family, religious organisations, and the government.

c. The scoping review of existing literature led to the identification of evaluated and recommended strategies for alleviating burden among the informal caregivers. The identified strategies include community-based interventions, psychoeducation interventions, support groups, cognitive behavioural therapy, spirituality-based interventions, smart phone-based interventions, mindfulness and empowerment, collaborative interventions, standard care, financial and social support, counselling, occupation-based interventions, policy and legislature, and access to mental health. Psychoeducation and support group interventions were identified as common and highly effective strategies for alleviating the burden of care among informal caregivers.

d. Exploration of the service providers' perspectives revealed their awareness of the burdens experienced by the informal caregivers and highlighted the involvement of minors in caregiving roles within mental health. The findings also highlighted that the current mental health services are insufficient for addressing the burdens experienced by the informal caregivers, and various factors, including caregiver-related such as cultural beliefs of the informal caregivers, mental health worker-related, and contextual factors such as the community stigma, were identified as influencing the delivery of caregiver-orientated services.

e. Service providers identified various strategies for alleviating burden of care among the informal caregivers, including caregiver-driven, health worker-driven, community-based, intersectoral, and policy and legislature strategies.

7.3 DISCUSSION OF FINDINGS

The socioecological framework (section 2.3) provides a multilevel conceptualisation of health and understands health to be affected by the interaction between individual, interpersonal, organisational, community, and policy factors (Mcleroy et al., 1988; Scarneo et al., 2019). The findings in this study revealed that caregiver burden is a complex phenomenon to comprehend and its effects on caregiver health require multiple methods to understand (Objectives 1–4). In this study, various factors, including individual, interpersonal, organisational, community, and policy level factors, were identified as impacting the burden of care experienced by the informal caregivers of persons with SMDs. As such, multilevel strategies are proposed to alleviate caregiver burden. In this section, the socioecological framework is used to frame the discussion of findings and describe the proposed strategies for alleviating the burden of care among the informal caregivers of persons with SMDs. The findings of this PhD informed the development of the multilevel strategies for alleviating burden of care among the informal caregivers of persons with SMDs in a low-resourced setting, and these are presented in Figure 7.2.

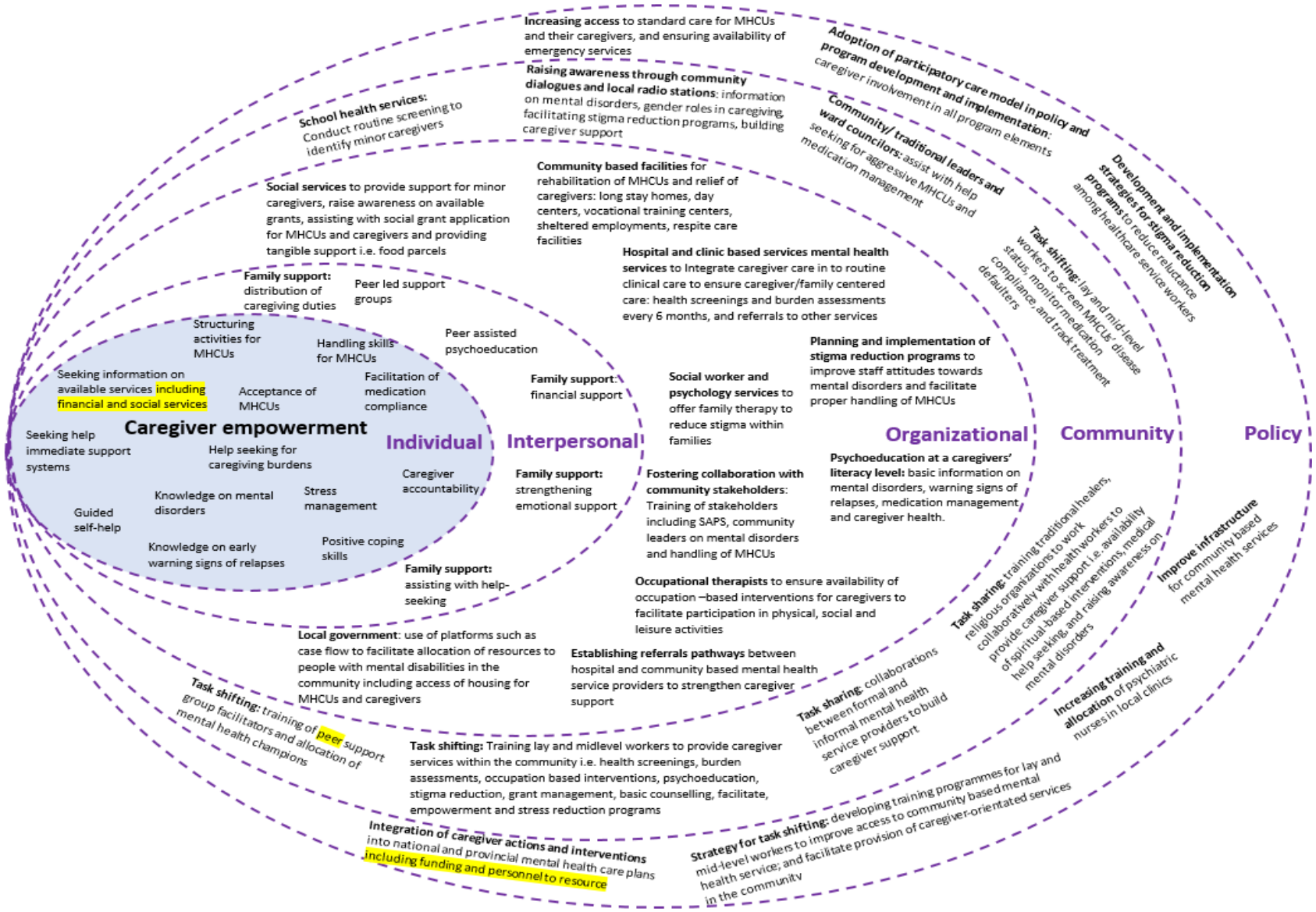


Figure 7.2 Conceptual framework of strategies for alleviating informal caregiver burden

7.3.1 Individual level

The studies on the extent of burden (Objective 1), exploration of lived experiences of informal caregivers (Objective 2), and the service providers' perspectives (Objective 4) revealed that informal caregivers experience burden in their caregiving role. The higher levels of objective burden established in this study were associated with the age of the informal caregivers. The findings in this study revealed that most informal caregivers are older than 65 years and present with mild-to-severe levels of objective and subjective burdens. The findings are consistent with those of studies conducted in Brazil (Souza et al., 2017), Iran (Shamsaei et al., 2015), and Nigeria (Adeosun, 2013), which reveal that being an elderly caregiver is associated with higher levels of burden.

Entrusting the role of caregiving to the elderly raises concerns because many deal with a decline in their emotional, physical, and emotional health while navigating the demands of providing care to younger males, mostly diagnosed with schizophrenia. Schizophrenia is described as a chronic mental disorder that is characterised by psychotic and violent behaviours and cognitive and functional decline (Asmal et al., 2014). Due to severe and debilitating nature of schizophrenia, those diagnosed tend to exhibit poor functional and recovery outcomes, and as a result, require prolonged hours of caregiving (Asmal et al., 2014; Shamsaei et al., 2015; Yazıcı et al., 2016). Across the various studies conducted in this study (Objectives 2 & 4), the experiences of burden among the informal caregivers were often attributed to the violent behaviours exhibited by the MHCUs, which include physical attacks, verbal insults, aggression, and vandalism. These findings affirm those established in previous studies that reported a strong link between the MHCUs' violent behaviours and higher levels of caregiver burden among their informal caregivers (Hanzawa et al., 2013; Onwumere et al., 2018; Vukeya et al., 2022). Some of the violent and uncooperative behaviours displayed by the MHCUs in this study are attributed to their short-lived recovery. The increase in caregiver burden could be due to the frailty experienced by the informal caregivers due to old age and the anxiety experienced in anticipation of the attacks from the MHCUs.

A study conducted in Bushbuckridge municipality revealed that some of the MHCUs relapsed six weeks post-discharge, and the decline was related to the fact that MHCUs were discharged from the hospital without insight to their conditions, which subsequently led to poor treatment

compliance (Silaule & Casteleijn, 2021). As established in Objectives 2 and 4, organisational level factors such as limited access to institutional and community-based mental health services within the study context perpetuate the levels of burdens experienced by the informal caregivers in this study. Currently, Bushbuckridge has one mental health unit with a bed capacity of 50 for a population size of more than 750 821 (Statistics South Africa, 2022). Subsequently, the management of MHCUs tend to be directed towards stabilising the psychotic symptoms rather than proper rehabilitation to facilitate the development of skills for independent living required for recovery and reintegration at community level (Silaule & Casteleijn, 2021). Rehabilitation of persons with schizophrenia has been identified to reduce disability, increase quality of life and productivity, and promote the development of skills required for independent living, which reduces community stigma towards the MHCUs (Mueser et al., 2013; Thara & Kamath, 2015). In a deinstitutionalised mental health system, it should be noted that limited access to proper rehabilitation at the hospital and community-based level has dire effects, particularly in communities like Bushbuckridge municipality where such care fall on the elderly who face a decline in their own health and wellbeing (Yerriah et al., 2021). The findings in this study (Objectives 2 & 4) revealed that limited access to proper rehabilitation among the MHCUs compromises their functioning, subsequently leading to short-lived recovery, which perpetuates the cycle of violence exhibited by the MHCUs towards their informal caregivers. It is therefore important that rehabilitation for MHCUs be strengthened at both the institutional and community-based level. In agreement with the findings in this study, the *National Mental Health Policy Framework and Strategic Plan 2023–2030* (South African Department of Health, 2023) calls for the adoption of community-based models of care in low-resourced settings. A group community-based rehabilitation model proposed by Chatterjee et al. (2014) has been identified as effective in reducing hospitalisations and increasing satisfaction among the MHCUs with SMDs, including schizophrenia, their families, and healthcare workers. In a resource-constrained context like Bushbuckridge municipality where there is a shortage of healthcare workers (Lefafa, 2023), lay and mid-level workers, including CHWs, home-based carers, and occupational therapy technicians, become key role players in the delivery of services. Further in-service training is therefore required for these community-based workers to support the MHCUs and informal caregivers. Opportunities should be explored to train more CHWs to become multi-skilled community rehabilitation workers to specifically increase access to rehabilitation for MHCUs and

build support for informal caregivers within the community (Ned et al., 2020). Intersectoral collaboration between the health sector and other non-governmental organisations should be formed to improve access to psychosocial rehabilitation for MHCUs at the community level where they reside (Brooke-Sumner et al., 2016; South African Department of Health, 2023).

The findings on the service providers' perspectives (Objective 4) revealed that some minors are caring for their parents with a SMD. This is concerning as these minors were pushed to undertake this enormous responsibility without any opportunity to develop their internal resources, such as resilience and resourcefulness, to cope with the demands of caregiving (Zauszniewski et al., 2015). Identified interpersonal level factors (Objectives 1, 2, & 4), such as limited access to family and community support, in the study context meant that some minor carers had to leave school to assume and fulfil their caregiving duty, which is a concern as it threatens the minors' current and future wellbeing. In spite of the threat that caregiving has on these minors, very limited studies in mental health reports on the role of minors in a caregiving, which may be because the role of caregiving is often considered an adult role often occupied by older females (Yerriah et al., 2021). The findings in this study shows an urgent need to investigate the issue of child-headed households with a focus on minors affected by mental disorders. This is especially important because in South Africa, approximately 122 000 children are considered to live in child-headed households overcome by poverty, and 66% of these children live with both parents, while 80% have a mother (Meintjes et al., 2009). Previous studies highlight concerns that the solitary focus on HIV as the main source of child-headed household prevents the identification of other contributing factors and that this risks the development of non-responsive policies, programmes, and interventions (Meintjes et al., 2009; Chidziva & Heeralal, 2016). In agreement with the *National Mental Health Policy Framework and Strategic Plan 2023–2030*, the findings in this study highlighted the need for collaborations between the health and education sector to extend mental health services within the community (South African Department of Health, 2023). Through these collaborations, school health services should be strengthened to facilitate early detection and intervention among minors who occupy the role of caregiving in mental health. In addition, collaborations should be formed with social services to identify and support these minors with emotional and financial support, including grant applications to ensure they meet household needs.

Significant associations were established between the gender and higher levels of objective burdens established within this study (Objective 1). Most informal caregivers in this study are

women and mothers of the care recipients. Zarzycki et al. (2022) identify cultural duty and obligation as an overriding motivation thought to influence the willingness to assume and continue with caregiving. Gendered cultural expectations, a sub-component of cultural duty and obligation, is a community level factor that has been linked strongly with cultural identity and it is through this that informal caregiving has been socialised as a primary role for women (Qadir et al., 2013). In fact, some cultures make no distinction between the role of a caregiver and the role of a woman (Donovan & Williams, 2015). Additionally, familism, another sub-component of cultural duty and obligation, is centred on the belief that care must be provided by the family and is seen as a sign of loyalty to one's family (Parveen et al., 2013). It is important to consider these concepts in the context of this study since caregiving is imbedded in the relations between the informal caregivers and their care recipients.

In rural South Africa, there is a cultural expectation for women to assume the caregiver role and oversee the day-to-day running of households (Cheteni et al., 2019). As part of their traditional role, female caregivers are expected to occupy multiple roles, including being a mother, house maintainer, worker, and a key emotional supporter for their male counterparts (Gloria et al., 2018). It is therefore not surprising that most female informal caregivers (49.3%) in this study presented with moderate-to-severe levels of objective burdens. The findings of this study affirmed the perceptions of gendered cultural expectations as many informal caregivers are women and mostly the mothers of the MHCUs. It can therefore be concluded that the role of cultural duty and obligation and its effects on caregiver health must be explored. There should be culturally sensitive strategies that help the informal caregivers fulfil their caregiving responsibilities as expected without compromising their health and wellbeing (Nápoles et al., 2010). To ensure relevance to the Bushbuckridge community and sense of ownership, recommended strategies for alleviating burden related to gender should be negotiated in keeping with the cultural practices and not enforced on the community.

While many informal caregivers use their internal coping resources, such as their resilience and resourcefulness, the stressors experienced, the limited access to caregiver-orientated services, and the limited support from family and community compromise their ability to cope with the demands of caregiving. Previous studies recognise positive appraisal, positive cognition, and personal religiosity as closely linked with greater resilience, good health outcomes, and positive adaptation (Fortune et al., 2005; Zauszniewski et al., 2009; Hsu & Tung, 2010). In contrast to the previous

studies, the informal caregivers in this study demonstrated that resilience and resourcefulness are not enough to counter the effects of the stressors they experience in their caregiving responsibilities. This is evident in the high levels of burdens and subsequent negative health effects reported by the caregivers. This could be because building internal resources such as resilience and resourcefulness requires external resources such as social support and family psychoeducational programs and the informal caregivers have limited access to these resources (Bademli & Duman, 2011; Fallahi Khoshknab et al., 2014; Zhang et al., 2021). While some of the informal caregivers expressed having access to external resources for coping, including access to medication, social worker services, and social support from family, community, and religious organisations, it is important to note that these services are only available to a few participants. None of the participants reported being part of a psychoeducation program or support group. The few participants who receive financial and emotional support from family, social support from the local community, including neighbours, community leaders, and community organisations such as churches reported to deal better with their struggles even though they are burdened by the day-to-day demands of caregiving (not continuous). This shows that in the midst of persistent stressors, external resources should supplement internal resources to enable optimal coping.

Lack of knowledge on mental conditions and handling skills for MHCUs, lack of skills for structuring engagement of MHCUs in daily activities, and lack of empowerment lead to caregivers living in a constant state of fear, worry, helplessness, and hopelessness (Objectives 1, 2, & 4). To mediate the effects of the burden, caregiver-driven strategies, which relates to the individual level strategies led by the informal caregivers for the informal caregivers, were identified, with caregiver empowerment as an overriding strategy for alleviating burden (Objectives 2 & 4). Previous studies (Objective 3) conducted in China (Chien et al., 2020) and Thailand (McCann et al., 2015) evaluated empowerment interventions that include guided self-help interventions such manual-guided problem-solving based self-learning programme and the Good Mood Guide. Other identified empowerment strategies include mindfulness and empowerment interventions such as mindfulness-based stress reduction programmes (Hou et al., 2013), an integrated empowerment program (Hyun et al., 2019), and stress management training (Chadda, 2014). These interventions were identified to empower informal caregivers to learn about the conditions of the MHCUs and how to handle them, learn about the community resources to seek support and services, and develop problem-solving skills to facilitate self-care (Hou et al., 2013; Hyun et al., 2019). Task

sharing can be used to implement these strategies in a low-resourced context setting like Bushbuckridge because it can be implemented by training peer facilitators to facilitate support groups to empower informal caregivers with skills to provide optimal care for their care recipients with a SMD (Singla et al., 2018)

7.3.2 Interpersonal level

Interpersonal relates to social networks, including family and peers who are available within the informal caregivers' immediate environment to offer support. The findings from this study revealed that some of the informal caregivers receive emotional and financial support from their families (Objective 2). Some informal caregivers reported receiving tangible support from their neighbours who help with taking the MHCUs to the hospital and monitoring medication compliance (Objectives 2 & 4). Informal caregivers who receive support from their families and neighbours in this study reported to cope better with the demands of their caregiving. Wang et al. (2020) describe social support as the interpersonal resources accessed and mobilised by individuals when undergoing the stress of life. Commonly, sources of social support include networks of family, friends, neighbours, and community members (Zhong et al., 2020). Previous studies linked the availability of social support to better emotional and physical health for those with higher levels of stressors, particularly in rural areas where greater health challenges outweigh available resources (Bardach et al., 2011; Sun et al., 2019; Zhong et al., 2020).

The support that some families and neighbours extend to informal caregivers in this study speaks to humanness, caring, and compassion, which aligns to the philosophy of Ubuntu. Engelbrecht and Kasiram (2012) and Dolamo (2014) describe Ubuntu as an African humanism philosophy that is centred in humanness, caring, sharing, and compassion and calls for individuals to come together and look out for each other. The findings in this study affirm that some of the families and neighbours in the study context are able to acknowledge their sense of responsibility towards the informal caregivers as fellow humans (Chigangaidze, 2021). It is for this reason that they are willing to withstand the destructive behaviours exhibited by the MHCUs and help informal caregivers handle an aggressive MHCU, assist with arranging transport for them to get to hospital, and assist with supervising medication. While only some of the informal caregivers received support from their families and neighbours, the findings in this study showed that Ubuntu underpins the philosophy and the way of life for some members of the Bushbuckridge community

(Engelbrecht & Kasiram, 2012). It is therefore important that the spirit of Ubuntu be harnessed to reintroduce humanness to communities and build support for informal caregivers within their communities.

Identified interpersonal level factors such as creating an opportunity for collective experiences are important for arousing a sense of hope among the informal caregivers (Objective 2). The informal caregivers expressed that seeing other informal caregivers with their care recipients during hospital follow-up visits gives them an opportunity to share their experiences, which creates a sense of belonging. This findings highlight the importance of creating platforms for informal caregivers to come together to share their experiences, and this can be achieved by setting up support groups for caregivers within the hospital that can be conducted while they wait to be seen by the physician. Sustainability support groups can also be implemented at the community level closer to where the informal caregivers reside (Chien et al., 2018; Yesufu-Udechuku et al., 2022).

Caregiver-guided strategies such as peer-led support groups and peer-assisted psychoeducation were identified as suitable strategies for strengthening support for informal caregivers at the interpersonal level (Objective 3). Strategies such as the Family-led Peer Support Group Program and family-led mutual support programmes have been linked with improved patient and family functioning. Through these strategies informal caregivers are supported to gain practical skills for caregiving, such as appropriate handling of MHCUs, enhancing their help-seeking, and reducing their feelings of guilt (Chien & Chan, 2013; Chien et al., 2018). The findings in the current study (Objectives 1–4) emphasised the need for interpersonal level strategies, including emotional and financial family support, financial, assistance with help-seeking, and the distribution of caregiving duties among family members. In addition, extended families and neighbours are a vital resource to support informal caregivers within their immediate surroundings.

7.3.3 Organisational level

The findings of the study (Objectives 2, 3, & 4) revealed that the current mental health services are insufficient to address the burdens experienced by the informal caregivers. The limited availability of institution-based mental health services was identified as a contributing factor affecting the delivery of caregiver-orientated mental health services. Even though the service providers (Objective 4) reported providing some caregiver services, including health talks,

psychoeducation, and family therapy, these services are only made available on an interim basis, usually upon request from the caregivers. Furthermore, the services are only accessible to those who can afford transport to visit the hospital. This is concerning considering the financial constraints and the distances the informal caregivers and their care recipients need to travel to access services (Objectives 1 & 2). The continued inaccessibility of mental health services highlights the lack of prioritisation of mental health services, which is a constant challenge in LMICs (WHO, 2014b; Matlala et al., 2018). The health talks and psychoeducation focus on meeting the needs of the MHCUs and rarely focus on the promotion of caregiver wellbeing, which indicates the lack of prioritisation of caregivers' health and wellbeing (Akbari et al., 2018).

Identified strategies for alleviating informal caregiver burden are mostly at the organisational level and include health worker-guided, intersectoral, and community-based strategies (Objectives 3 & 4). Health worker driven strategies relate to organisational level interventions facilitated by health care workers for alleviating burden of care among the informal caregivers. The service providers in keeping with existing literature identified integration of caregiver care into standard care, which can be offered through conducting regular health screenings and referrals for further management where indicated (Ramírez et al., 2017). Additionally, standard care interventions such as ensuring availability of occupation-based interventions for equipping caregivers with skills for handling and structuring engagement of MHCUs' in activities were indicated. There should also be interventions that focus on improving participation in daily activities, also known as occupation-based intervention, for the informal caregivers. Occupation-based interventions include physical exercise and social and leisure activities to help prevent or minimise the effects of burden among caregivers (Souza et al., 2017). In addition, studies conducted in Colombia (Souza et al., 2017) and Brazil (Ramírez et al., 2017) identify various standard care interventions found effective in reducing burden and building social support, and this includes multimodal interventions such as general medicine, psychiatry, psychology, family therapy, neuropsychological rehabilitation, occupational therapy, telepsychiatry, and ensuring availability of emergency teams. Psychoeducation was identified as a prominent strategy for improving knowledge about the MHCUs condition with a focus on symptom recognition, crisis management, and emergency planning. It is important to note that psychoeducation should go beyond knowledge translation and should also focus on skills development. Psychoeducation was highlighted to facilitate development of skills for handling and communicating with MHCUs, enabling awareness and

identification of available resources such as welfare services, and building skills for self-employment and managing day-to-day activities (De Souza et al., 2016; Zhou et al., 2020).

Studies conducted in LMICs, including Brazil (Tabeleão et al., 2018), Indonesia (Dewi et al., 2019) and Botswana (Ntsayagae, 2017), identify various effective psychoeducation programmes that improve caregiver coping skills and quality of life, reduce psychological strain, anxiety, and stress, and enhance recovery among the MHCUs. According to Chadda (2014), psychoeducation interventions should be offered on a continuous basis and the number of sessions can vary between 10–12 or 15–16 sessions that are presented weekly or fortnightly at the beginning and once a month for the later sessions.

To implement organisational level strategies in a low-resourced settings like Bushbuckridge, a task shifting approach must be adopted to extend mental health services to informal caregivers (WHO, 2008a; South African Department of Health, 2023). Singla et al. (2018) emphasise that non-specialist providers such as CHWs and peers in LMICs can be trained to deliver effective services as effectively as specialists in high-income countries, and this can be strengthened through the provision of regular supervision (Singla et al., 2014). Healthcare workers, including physicians, nurses, psychologists, social workers, and occupational therapists, can develop training packages for mid-level and lay health workers such as occupational therapy technicians, CHWs, and home-based carers to conduct routine health screenings and facilitate psychoeducation programmes. Training packages for psychoeducation should be designed and delivered at the caregivers' literacy level.

Intersectoral strategies relate to services offered through collaborations between health and non-health sectors to increase access to mental health services to the informal caregivers and the MHCUs (Brooke-Sumner et al., 2016). Although the *National Mental Health Policy Framework and Strategic Plan 2023–2030* does not specify services directed at informal caregivers, the call for intersectoral collaborations in extending mental health services aligns well with the findings of this study (South African Department of Health, 2023). Identified intersectoral strategies (Objectives 2, 3, & 4) include collaborations between health and other government sectors such as the South African Police Services, forensics, Department of Home Affairs, Department of Social Development, and local government through platforms such as case flow to extend access to CMHS. Collaborations should be formed between health and social services to provide support

for minor caregivers, raise awareness on available grants, assist with social grant applications for MHCUs and caregivers, and provide tangible support, including food parcels. Additionally, collaborations with local government can facilitate allocation of resources to people with mental disabilities in the community, including access to housing for MHCUs and caregivers. Intersectoral strategies can be implemented by establishing referral pathways between formal mental health services and community stakeholders, and by training stakeholders such as the South African Police Services and community leaders on mental disorders and handling of MHCUs (South African Department of Health, 2023).

The community-based strategies identified at the organisational level include strengthening existing primary healthcare systems, community support groups, basic counselling, conducting home visits, building family support systems, and awareness raising through existing community platforms such as community dialogues and community radio stations. Previous studies highlight the need to ensure availability of community-based, facilities including recreational facilities for caregivers, placement facilities, day centres, sheltered employment, avocational and respite care facilities for MHCUs as viable community-based strategies for alleviating informal caregiver burden (Chen et al., 2019; Bonsu et al., 2020). The WHO recommendations regarding organisation of mental health services call for strengthening CMHS. In response to this call, the *National Mental Health Policy Framework and Strategic Plan 2023–2030* proposes strengthening CMHS through the development of community residential care, day-care services, and outpatient services (South African Department of Health, 2023). The development of these services is crucial for proper rehabilitation and providing respite care for MHCUs, which will reduce the level of dependence of MHCUs on their caregivers and allow informal caregivers time to attend to other tasks, thus reducing the burden of care among the informal caregivers.

7.3.4 Community level

The analysis of findings in this study (Objectives 2 & 4) highlighted the limited access to community-based mental health services as the main contributor to the burden of care among the informal caregivers. In instances where some CMHS are made available, individual level factors such as the informal caregivers' inability to accept assistance from CHWs influence the delivery of these services. The limited awareness of the role of CHWs could be the cause of the informal caregivers' reluctance. This highlights the importance of ensuring that communities are well

orientated to CHWs and the unique role they play, especially since they are considered a vital resource for improving health coverage and access in LMICs (Tseng et al., 2019). However, lay health workers such as CHWs and home-based carers were identified as not offering services due to lack of focus on and limited training in mental health. Ojha and Pant (2018) highlight the need to create adequate and sustainable training opportunities for lay health workers providing services at community level to ensure successful implementation of task shifting.

Informal caregivers who lack community support and those who reported experiencing stigma were susceptible to caregiver burden and the negative health impact (Objectives 1, 2, & 4). Community level strategies, including community-based and intersectoral strategies, were identified to alleviate burden among the informal caregivers (Objectives 3 & 4). Community-based strategies involve using community resources to provide caregiver support at household, community, and organisational level. The findings of the current study call for strengthening community-based strategies by using existing community platforms such as community dialogues and local radio stations to raise awareness on mental disorders, gender roles in caregiving, stigma reduction, and building caregiver support within the community. Studies conducted in China (Ng et al., 2018) and India (Rai et al., 2018) identify community-based interventions such as community mental health early intervention projects and the Reducing Stigma among Healthcare Providers (RESHAPE) programme as useful in reducing burden among the informal caregivers. The interventions were shown to result in more desirable effects on caregiver and patient psychosocial wellbeing than psychoeducation and standard care and to reduce demand on institution-based mental health services (Ng et al., 2018; Rai et al., 2018).

The complexities of providing caregiver-orientated mental health services has been acknowledged in the findings of this study, and the need for collaboration with other non-health sectors and community stakeholders has been identified (Objectives 3 & 4). Intersectoral collaborations should be formed with religious organisations, traditional healers, and community leaders like municipality ward councillors and traditional leaders. The collaborations could be useful to strengthen emotional and social support, help informal caregivers in emergencies, facilitate access to food parcels, and provide safe houses for MHCUs and their caregivers. Studies conducted in Iran (Khosravi et.al., 2022) and Jordan (Suleiman AlMakhamreh, 2018) investigated spiritual-based interventions, including implementing a spiritual-based programme aimed at reducing stress, anxiety, and depression among the informal caregivers, and found these to have positive

effect on the stress and anxiety of the informal caregivers. These studies also highlight the need for turning to traditional healers and spiritual leaders as cost-effective and available supportive resource for informal caregivers.

Collaborative interventions such as participatory care models and caregiver involvement in program development and implementation were identified as effective in reducing caregiver burden and increasing caregiver resilience (Sinha Deb et al., 2018; Zoladl et al., 2020). The need for participatory care models is consistent with the principle of participation outlined in the *National Mental Health Policy Framework and Strategic Plan 2023–2030* that calls for involvement of MHCUs in the planning and development of services (South African Department of Health, 2023). In order for intersectoral strategies to be effective, the findings of this study pointed to the importance of collaborative stakeholder training to improve their knowledge of mental disorders and raise their awareness on the support needs of the informal caregivers. It is through training that proper referral pathways across various sectors and stakeholders can be developed and strengthened (Truter, 2023). Therefore, successful implementation of intersectoral strategies can be done through adopting task sharing where traditional healers and religious organisations should be trained to work collaboratively with health workers to provide caregiver support. Task sharing can also be adopted by building collaborations between community mental health workers, traditional leaders, and ward councillors to assist with help-seeking for aggressive MHCUs and medication management.

7.3.5 Policy level

The findings in this study highlighted a lack of policies and guidelines to direct caregiver-orientated mental health services (Objectives 2, 3, & 4). Policy related factors, including lack of prioritisation of mental health services for MHCUs and informal caregivers, limited infrastructure, limited human resources, regression of CMHS, and limited budget allocations, were identified as influencing the delivery of caregiver-orientated mental health services. The findings in this study are reflective of the continuous challenges that affect the delivery of mental health services within South Africa.

Previous studies outlined various policy and legislature strategies for alleviating burden, including the implementation of national health insurance schemes, advocacy for a strong mental health

policy, integration of caregiver actions, interventions into national mental health care plans, and provisioning fee-free mental health services (Ayalew et al., 2019; Bonsu et al., 2020; Behrouian et al., 2021). The findings in this study emphasised the need for policies and guidelines to be practical with clear action points that outline the resources required, their availability, and responsible persons to drive the implementation process.

Identified policy level strategies include integration of caregiver actions, interventions into national and provincial mental health care plans, improving infrastructure for community-based mental health services, and increasing financial and human resources to facilitate delivery of standard care for MHCUs and their caregivers. Policy level strategies can be implemented by adopting the participatory care model (Zoladl et al., 2020), which can be done by involving caregivers in policy, program development, and implementation. In addition, this can be done by adopting a task shifting approach, which can be done by developing training programmes for lay and mid-level workers to extend access to community-based mental health services and facilitate the provision of caregiver-orientated services in the community. Furthermore, training can be increased, mental health professionals allocated, and strategies for stigma reduction programs developed and implemented (Ambikile & Iseselo, 2023) to reduce reluctance among healthcare service workers. Research like this study should be used to inform the development of responsive policies, especially since it empowers informal caregivers to have a voice in the development of services that are tailored to their needs.

7.4 STUDY STRENGTHS AND LIMITATIONS

The studies conducted in this PhD used various designs to answer the research question and address the study's aim. Employing quantitative and qualitative methods in the conceptualisation of the burden of care among the informal caregivers was useful as it allowed for the in-depth understanding of the burden and formed a basis for the development of strategies responsive to the needs and context of the informal caregivers (Dawadi et al., 2021). The findings from the quantitative study allowed us to demonstrate the presence and the level of severity of the burden experienced by the informal caregivers. Conducting a qualitative study allowed us to gain an in-depth understanding on the individual and contextual factors that contribute to the burden of care experienced by the informal caregivers. In addition, the informal caregivers were able to express their coping strategies and their needs to help alleviate the burden, which is important for the

development of responsive strategies. Informal caregivers are the forgotten voices in the healthcare system, and by doing this research, informal caregivers were empowered to share their lived experiences, which is crucial for service providers and policy makers to develop and implement relevant and sustainable caregiver-orientated services.

Conducting all interviews in the participants' homes added to the richness of the data as it enabled the in-depth understanding of the contextual factors that contribute to the burden experienced by the informal caregivers. For example, travelling to the participants homes, I was able to determine the distances that informal caregivers and MHCUs need to travel to get to the hospital and the inaccessibility of the roads and public transport that influence the accessibility of mental health services within Bushbuckridge municipality. I am a local resident of the Bushbuckridge municipality and a first language speaker of Xitsonga, the language used to conduct the interviews, and familiar with the cultural practices within the research site. This made it easier to build a rapport with the participants and allowed for transfer of empathy, which created a safe space for participants to relate their difficult experiences encountered in their caregiving role.

Having service providers' perspectives on the burden of care experienced by the informal caregivers was important as it validated the experiences of the informal caregivers and the inherent difficulties they experience in their role. In addition, service providers expanded on the underlying problems affecting the delivery of caregiver-orientated mental health services from the health sectors and other governmental sectors such as social development. This was also important as establishing the service providers views helped establish their level of awareness of caregiver burden, which is important for the development of practical and sustainable services for caregiver support, particularly in low-resourced settings where access to mental health services is limited. Conducting a scoping review focused on support strategies in LMICs enabled the identification of evidence-based strategies for alleviating burden within low-resourced settings similar to the study context, thus making these strategies feasible for implementation. The proposed strategies for alleviating burden in this study were based on the input of the informal caregivers, the service providers, and existing literature, thus making them responsive to the local context and similar contexts with limited access to mental health resources.

Detailed limitations of the studies conducted in this PhD were presented in each paper. The study considered informal caregivers who had some contact with the mental health system, thus

excluding other participants who do not have access. As stipulated by the participants in this study, accessing mental health services is a serious challenge that contribute to their burden of care. The omission of other participants means that the proposed strategies may be responsive to a certain group of informal caregivers within the Bushbuckridge municipality. The fact that the inclusion criteria was set to include adult informal caregivers who are above the age of 18, excluded caregivers who are minors, and as seen in the findings of this study, service providers highlighted the involvement of minors in caregiving of their parents with a SMDs to be at high risk of developing caregiver burden. Future studies should work together with school-based health teams and CHWs to identify these minors and ensure the criteria for inclusion is set to include this group of informal caregivers. There was very limited time to explore the views of community-based stakeholders outside of the health sector (i.e., local government, traditional leaders and healers, religious organisations, Department of Social Development, South African Police Services) to establish their understanding of their role in supporting the informal caregivers of persons with SMDs. Future studies should explore the community stakeholders' perspectives on their role in supporting informal caregivers of persons with mental disorders within the community. Initially, I planned to conduct a validation of the strategies; however, due to time constraints and limited financial resources, I postponed the validation to the post-doctoral stage.

CHAPTER 8
CONCLUSION

This study aimed to explore the burden of care among the informal caregivers of persons with SMDs to inform the development of strategies for alleviating burden among informal caregivers of persons with SMDs in Bushbuckridge, Mpumalanga province. This section describes the recommendations for future studies and the implications for practice, health education, and research.

8.1 RECOMMENDED FUTURE RESEARCH

- Future studies should employ community-based participatory research to ensure access and inclusion of the omitted informal caregivers in the community. This research should also integrate the views of other service providers outside of the health sector, such as religious organisations, traditional healers, traditional leaders, and local government stakeholders, regarding their role in supporting the informal caregivers of persons with SMDs in the community.
- Future studies should target community-based stakeholders outside the health sector, including local governance, traditional leaders and healers, and religious organisations, to ensure development of sustainable and comprehensive caregiver-orientated services and to enhance ownership of strategies for supporting informal caregivers.
- Future studies should include the views of the MHCUs as active recipients of the care provided by the informal caregivers to ensure that their needs are fully represented and to create an opportunity to evaluate the implications of their behaviour on their caregivers.
- Future studies should look at the implications that the severity of the MHCUs' condition and the subsequent functional limitations has on the caregiving experiences.
- Future studies should investigate the impact of religion and cultural beliefs on the caregiving experiences.
- Following this study, the researchers aim to validate the proposed strategies for alleviating burden. This will be done by convening panel stakeholders, which includes informal caregivers and mental health professionals at various levels of healthcare i.e. provincial, district and sub district levels. Identified stakeholders will be required to follow a set of

guidelines to validate the strategies to ensure the feasibility of these strategies to the Bushbuckridge community. Additionally, a training program will be developed in collaboration with the stakeholders to help capacitate the CHWs with knowledge and skills for supporting the MHCUs and their caregivers.

8.1.1 The implications arising from the study findings

8.1.1.1 Practice implications

- The findings in this study affirmed the complexity of delivering comprehensive mental health services that meet the needs of both the MHCUs and their caregivers. Through the findings of this study, it is clear that such services must extend beyond the health sector, calling for community-based decentralisation of mental health services. Programmes aimed at improving the mental health of the MHCUs and their caregivers should be developed and implemented through shared collaborations between health and other governmental departments including the South African Police Services, Department of Social Development, home affairs, and local government. Additionally, collaborations should be formed with traditional leaders in the community and non-health service providers such as traditional healers and spiritual and faith-based healers.
- The findings in this study highlighted an urgent need for the integration of caregiver-orientated mental health services in daily clinical practice at institutional and community-based levels. This should be done by incorporating health screenings for all informal caregivers of persons with SMDs, which can be conducted during the MHCUs' clinic, hospital, and follow-up visits.
- It is important that the provision of caregiver-orientated mental health services should start by using existing resources within the community. This includes training available occupational therapy technicians, CHWs, and home-based carers to conduct health screenings and offer support to the informal caregivers. CHWs should be upskilled for screening, a collaborative programme must be developed, and supervision should be made available.
- The findings emphasised the importance of strengthening psychosocial rehabilitation for MHCUs and adopting recovery-orientated models to ensure MHCUs gain the necessary

skills to function independently within the community, which will help reduce the strain on their caregivers.

- Community-based resources such as day centres, sheltered employment, vocational and respite care facilities should be made available for MHCUs to allow the informal caregivers some respite from the caregiving responsibilities and ensure the MHCUs have structure to engage in activities to improve their function.
- The findings in this study calls for more actionable policies and guidelines that clearly outline services that are specifically directed at developing and implementing services for informal caregivers of persons with SMDs. Such policies should be accompanied by clear procedure documents to guide their implementation within the respective context. In addition, policies should be specific about the resources and the responsible personnel for driving the development and implementation of caregiver-orientated mental heal services. The researchers intend to publish a policy brief to highlight the key findings of the study and an urgent call for development of caregiver-orientated policies in mental health.

8.1.1.2 Implications on health education

- I recommend that current curricula in mental health education should emphasise the health and wellbeing of secondary populations such as caregivers. There should be strong emphasis on equipping future healthcare professionals to look at other populations affected by mental disorders. Mental health curricula should shift from a biomedical focus to a recovery-orientated focus to ensure services offered focus on the rehabilitation of MHCUs to develop necessary skills for independence, which will limit their dependence on their informal caregivers. Resources for upskilling healthcare professionals in mental health should focus on those who have interest in the delivery of mental health services. This will ensure the limited resources are directed to those who are invested in advancing the delivery of effective mental health services.
- In the South African context where the healthcare system is overcome by persistent crises related to the shortage of healthcare professionals, I recommend that training be made available for upskilling lay health workers and mid-level workers. Training should be made available for community-based workers such as CHWs and home-based carers to attain the

necessary skills to offer basic screening and rehabilitation and for them to extend mental health services directed at MHCUs and the informal caregivers within the community.

8.1.1.3 Implications on research

- Previous studies conducted in Africa focused on exploring the burden of care experienced by the informal caregivers in mental health. This study broadened the research database on informal caregiving in mental health. It is necessary for research to shift focus from only exploring the experiences of the informal caregivers in caregiving to investigating context-specific interventions aimed specifically at reducing the burden of care among the informal caregivers.

8.2 PERSONAL REFLECTIONS

I have learned the importance of understanding the participants' context when conducting research. As a resident of Bushbuckridge, having an awareness of the local context, the culture, and language of the participants helped me relate better to their experiences and to extend empathy to them, which was useful for establishing a rapport and made it easier for the participants to relate their lived experiences in caregiving. I have learned that conducting research in participants' home context is important when trying to understand complex phenomena such as caregiver burden as it enabled me to observe some of the factors that contribute to burden that caregivers may not be able to articulate or give a voice to.

Going in to this research, I had preconceived ideas that the health sector was responsible for developing and implementing the strategies for supporting the informal caregivers. Conducting this research made me realise the complexities of caregiver burden and the importance of intersectoral collaborations to ensure the development and implementation of sustainable services for caregiver support. This helped ensure the strategies I recommended for alleviating burden among the informal caregivers are more comprehensive and integrate the various role players in caregiver support.

My interactions with the informal caregivers helped me realise the importance of giving a voice to the voiceless, and at the end of my interviews, the informal caregivers appreciated the opportunity to share their experiences as they had never had an opportunity or platform to do so. This gave me

a better understanding of the need to ensure that service users such as MHCUs and caregivers are given a platform to share their experiences to ensure services are tailored towards meeting their needs.

I now realise that informal caregiver burden is an ongoing struggle and that the needs of and support for informal caregivers should take priority in all healthcare platforms. It is necessary to prioritise and hear the voices of the caregivers.

8.3 CONCLUSION

Informal caregivers of persons with SMDs are susceptible to burdens in their caregiving role, and this has serious implications for their emotional, mental and physical health. Although the literature and service providers acknowledge the burdens experienced by the informal caregivers and the need for support, there is limited access to caregiver-orientated services that support these informal caregivers in their role. Given the complexity of caregiver burden, multilevel strategies are required to alleviate the burden of informal caregivers of persons with SMDs within a low-resourced setting. Informal caregivers must be empowered with skills to handle and structure activities for MHCUs and to seek information and used resources available for support. Caregiver-orientated services should be integrated into existing clinical practice. Efforts should be directed towards the development and implementation of caregiver-orientated services at the community-based level to ensure accessibility. This can be achieved through intersectoral collaborations between the health sectors and various community-based stakeholders. Mental health policies should outline services for informal caregivers with a clear outline of the resources required to develop and implement such services, as well at the responsible personnel for ensuring the implementation and sustainability of these services.

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APPENDIX A: WITS ETHICAL APPROVAL

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research and Postgraduate Affairs

TO: Ms O Silaule
School of Therapeutic Sciences
Department of Occupational Therapy
Medical School
University

E-mail: Olindah.Silaule@wits.ac.za

CC: Supervisor: Drs N Nkosi-Mafutha and F Adams
<Nokuthula.Nkosi-Mafutha@wits.ac.za>
and <HREC-Medical Research Office@wits.ac.za>

FROM: Mr Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 2021/01/21

REF: R14/49

PROTOCOL NO: **M200957** (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)

PROJECT TITLE: *Developing guidelines for alleviating caregiver burden amongst informal caregivers of persons with severe mental disoders in Bushbuckridge, Mpumalanga Province*

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to Government funding of the University.

MSWorks2000/Iain0007/Clearscan.wps

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R49 Ms O Silaule

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M200957

NAME: (Principal Investigator)	Ms O Silaule
DEPARTMENT:	School of Therapeutic Sciences Department of Occupational Therapy Medical School University
PROJECT TITLE:	*Developing guidelines for alleviating caregiver burden amongst informal caregivers of persons with severe mental disoders in Bushbuckridge, Mpumalanga Province*
DATE CONSIDERED:	2020/10/02
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Drs N Nkosi-Mafutha and F Adams
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2021/01/21

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **September** and therefore reports and re-certification will be due in the month of **September** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator

2021/01/21
Date

APPENDIX B: MPUMALANGA RESEARCH SECOND APPROVAL

health
MPUMALANGA PROVINCE
REPUBLIC OF SOUTH AFRICA

Indwe Building, Government Boulevard, Riverside Park, Ext. 2, Mbombela, 1200, Mpumalanga Province
Private Bag X11285, Mbombela, 1200, Mpumalanga Province
Tel I: +27 (13) 766 3429, Fax: +27 (13) 766 3458

Utiko Letemphilo | Departement van Gesondheid | UmNyango WezeMaphilo

Enq: 013 766 3766/3511
Ref: MP_202010_010

Research Approval Letter

Ms Olindah Silaule
WITS EDUCATION CAMPUS, KHANYA BLOCK
Parktown, 2193

TITLE: **APPLICATION FOR RESEARCH APPROVAL: DEVELOPING GUIDELINES FOR ALLEVIATING CAREGIVER BURDEN AMONGST INFORMAL CAREGIVERS OF PERSONS WITH SEVERE MENTAL DISORDERS IN BUSHBUCKRIDGE, MPUMALANGA PROVINCE**

Dear Ms Silaule

The Provincial Department of Health Research Committee has approved your research proposal in the latest format you sent.

- Approval Reference Number: MP_202010_010
- Data Collection Period: 01/02/2021 to 12/08/2022.
- Approved Data Collection Facilities:
  * Ehlanzeni District Municipality (Clinics & CHCs)
  * Tintswalo Hospital

Kindly ensure that conditions mentioned below are adhered to, and that the study is conducted with minimal disruption and impact on our staff, and also ensure that you provide us with a soft or hard copy of the report once your research project has been completed.

Conditions:
- *Researchers not allowed to make copies or take pictures of medical records.*
- *Kindly notify the facility manager BEFORE you start with data collection to ensure that conditions are conducive in the facility*

Kind regards

DR C NELSON
MPUMALANGA PHRC CHAIRPERSON
DATE: 31 | 01 | 2021.

MPUMALANGA
THE PLACE OF THE RISING SUN

APPENDIX C: MPUMALANGA RESEARCH FIRST APPROVAL

health
MPUMALANGA PROVINCE
REPUBLIC OF SOUTH AFRICA

Indwe Building, Government Boulevard, Riverside Park, Ext. 2, Mbombela, 1200, Mpumalanga Province
Private Bag X11285, Mbombela, 1200, Mpumalanga Province
Tel I: +27 (13) 766 3429, Fax: +27 (13) 766 3458

Litiko Letemphilo | Departement van Gesondheid | UmNyango WezeMaphilo

Enq: 013 766 3766/3511
Ref: MP_202010_010

Research Approval Letter

Ms Olindah Silaule
WITS EDUCATION CAMPUS, KHANYA BLOCK
Parktown, 2193

TITLE: **APPLICATION FOR RESEARCH APPROVAL: DEVELOPING GUIDELINES FOR ALLEVIATING CAREGIVER BURDEN AMONGST INFORMAL CAREGIVERS OF PERSONS WITH SEVERE MENTAL DISORDERS IN BUSHBUCKRIDGE, MPUMALANGA PROVINCE**

Dear Ms Silaule

The Provincial Department of Health Research Committee has approved your research proposal in the latest format you sent.

- Approval Reference Number: MP_202010_010
- Data Collection Period: 01/02/2021 to 12/08/2023.
- Approved Data Collection Facilities:
  * Ehlanzeni District Municipality (Clinics & CHCs)
  * Tintswalo Hospital

Kindly ensure that conditions mentioned below are adhered to, and that the study is conducted with minimal disruption and impact on our staff, and also ensure that you provide us with a soft or hard copy of the report once your research project has been completed.

Conditions:
- *Researchers not allowed to make copies or take pictures of medical records.*
- *Kindly notify the facility manager BEFORE you start with data collection to ensure that conditions are conducive in the facility*

Kind regards

DR J SIGUDLA
MPUMALANGA PHRC
DATE: 18/07/2022

MPUMALANGA PROVINCE
DEPARTMENT OF HEALTH
18 -07- 2022
PRIVATE BAG X11285
NELSPRUIT 1200

MPUMALANGA
THE PLACE OF THE RISING SUN

APPENDIX D: EHLANZENI DISTRICT APPROVAL

health
MPUMALANGA PROVINCE
REPUBLIC OF SOUTH AFRICA

No.3, Government Boulevard, Riverside Park, Ext. 2, Mbombela, 1200, Mpumalanga Province
Private Bag X11285, Mbombela, 1200, Mpumalanga Province
Tel I: +27 (13) 766 3429, Fax: +27 (13) 766 3458

Lilitko Letamphilo | Departement van Gesondheid | UmNyango Wezempilo

MPUMALANGA PROVINCE OF SOUTH AFRICA
EHLANZENI DISTRICT OFFICE NO 1
PRIVATE BAG X 11273
58 ANDERSON STREET NELSPRUIT 1200
Date Received: 2020 -08- 31
DISTRICT MANAGER'S OFFICE
DEPARTMENT OF HEALTH

1. Name & contact no. of Applicant	Olindah Silaule 078 2035213		
2. Title of Study: Developing guidelines for alleviating caregiver burden amongst informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga Province.			
3. Aim and population target: This study seeks to develop and validate guidelines for alleviating burden amongst informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga province.			
4. Period to undertake the study	**From:** 2021 January **to:** 2023 April		
5. Resources Required from Facility/Sub-district/Community			
5.1: Facility Staff Required to assist with the Study	**Yes x** **How many:** Nurses: PHC managers within Bushbuckridge sub-district (+ 5 preferable number, a convenience sampling method will be used based on their availability to participate) Doctors: N/A Other, please specify: Community health workers within Bushbuckridge sub-district (+ 10, sampling size is estimated based on qualitative study, if saturation is not reached more may be required to participate)		**NO**
5.2: Patient Records/Files	**Yes**		**NO x**
5.3: Interviewing Patient at Facilities	**Yes x**		**NO**
5.4: Interviewing Patients at Home	**Yes**		**NO x**
5.5: Resource Flow (Are there benefits to Patients/community)	**Yes** Please list:		**NO x**
5.6: Resource Flow (Are there benefits to Facility/District)	**Yes** Please list:		**NO x**
6. Availability of Required Clearance			
6.1: Ethical Clearance	**Yes** Clearance Number:	**Pending** x	**NO**
6.2: Clinical Trial	**Yes** Clearance Number:	**Pending**	**NO** x
6.3: Vaccine Trial	**Yes** Clearance Number:	**Pending**	**NO** x
6.4: Budget	**Yes x** Source of fund: Consortium for Advanced Research in Africa(CARTA)		**NO**

Please note that this letter is not an approval to undertake a study, but a support letter from identified facility/district.
i.e. the CEO/District Manager acknowledges to have been consulted on the study

Declaration by Applicant:
I Ms . Olindah Silaule agree to submit/present the result of this study back to the CEO/Institution/District.

Comment by CEO/CD/DM/PM: **Supported / ~~Not Supported~~**
conducting of the study is supported subject to MP DOH Research and Ethics Committee requirements

Signature of CEO/CD/DM/PM
Name: D Mdluli

Stamp/Date: 02/09/2020

APPENDIX E: BUSHBUCKRIDGE SUB-DISTRICT APPROVAL

health
MPUMALANGA PROVINCE
REPUBLIC OF SOUTH AFRICA

R565 Hazyview, Kruger National Park Road, Hoxane Multi-purpose Centre,
Mkhuhlu 0246, Mpumalanga Province
Private Bag X9309, Mkhuhlu, 0246, Mpumalanga Province
Tell: (023) 708 0024, int: +27 (13) 708 0024/46/56/184/94
Fax: (023) 708 0200, int: +27 (13) 708 0200

Litiko Letemphilo Departement Van Gesondheid Lisekyonge WezeMpilo

ENQ: RS Mabika: 072 679 5677

TO : **MS OLINDAH SILAULE**
: **PHD CANDIDATE: UNIVERSITY OF WITWATERSRAND (WITS)**

FROM : **MS XT SLINDA-MASUKU**
: **ACTING DEPUTY DIRECTOR- PHC: BUSHBUCKRIDGE SUB- DISTRICT**

DATE : **27 NOVEMBER 2020**

SUBJECT : **SUPPORT FOR RESEARCH UNDERTAKING IN SELECTED PHC FACILITIES IN BBR SUB-DISTRICT IN EHLANZENI DISTRICT FROM 2021 TO 2023**

1. The above matter bears reference;
2. The Bushbuckridge Sub-district is hereby grant the support and allow the above-mentioned candidate to conduct her research activities at the following selected PHC facilities for the period as indicated above: Oakley, Thokozane, Marite, Cottondate, Islington, Ludlow, Gottenburg, Hluvukani CHC, Morelpuso, Welverdiend, Brooklyn, Justicia, Lillydale, Kildare, Agincourt CHC, Arthurseat, Utah, Calcutta, Cork, Goromane and Belfast clinic.
3. It is the believe of the Sub-district management that this research undertaking will go a long way in improving the management of mental health in the district and sub-district in particular.

Hoping that you will find this letter of support in order.

Regards,

XT SILINDA-MASUKU: ADD

BUSHBUCKRIDGE SUB-DISTRICT
27 / 11 / 2020

MPUMALANGA
THE PLACE OF THE RISING SUN

APPENDIX F: TINTSWALO HOSPITAL APPROVAL

health
MPUMALANGA PROVINCE
REPUBLIC OF SOUTH AFRICA

MPUMALANGA
THE PLACE OF THE RISING SUN

No 3 Government Boulevard, Riverside Park, Ext 2, Mbombela, 1200, Mpumalanga Province
Private Bag X11285, Mbombela, 1200, Mpumalanga Province
Tel I: +27 (13) 766 3429, Fax: +27 (13) 766 3458

Utilise : Utsenga Ir | Department van Gesondheid | UmNyango WezeMpilo

1. Name & contact no. of Applicant	Olindah Silaule 078 2035213
2. Title of Study: Developing guidelines for alleviating caregiver burden amongst informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga Province.	
3. Aim and population target: This study seeks to develop and validate guidelines for alleviating burden amongst informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga province.	
4. Period to undertake the study	From: 2021 January to: 2023 April

5. Resources Required from Facility/Sub-district/Community			
5.1: Facility Staff Required to assist with the Study	**Yes x** **How many:** Nurses: One(1) Doctors: One (1) Other, please specify: N/A		**NO**
5.2: Patient Records/Files	**Yes**		**NO x**
5.3: Interviewing Patient at Facilities	**Yes x**		**NO**
5.4. Interviewing Patients at Home	**Yes x**		**NO**
5.5: Resource Flow (Are there benefits to Patients/community)	**Yes** Please list:		**NO x**
5.6: Resource Flow (Are there benefits to Facility/District)	**Yes** Please list:		**NO x**
6. Availability of Required Clearance			
6.1: Ethical Clearance	**Yes** Clearance Number	**Pending x**	**NO**
6.2: Clinical Trial	**Yes** Clearance Number:	**Pending**	**NO x**
6.3: Vaccine Trial	**Yes** Clearance Number:	**Pending**	**NO x**
6.4: Budget	**Yes x** Source of fund: Consortium for Advanced Research in Africa(CARTA)		**NO**

Declaration by Applicant:
I Ms . Olindah Silaule agree to submit/present the result of this study back to the CEO/Institution/District.

Comment by CEO/CD/DM/PM: **Supported / Not Supported**

The study will assist to improve service delivery at Tintswalo Hospital

Signature of CEO/CD/DM/PM **Stamp/Date:** 29.09.2020

Please note that this letter is not an approval to undertake a study, but a support letter from identified facility/district i.e. the CEO/District Manager acknowledges to have been consulted on the study

APPENDIX G: FACULTY PROTOCOL APPROVAL

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Private Bag 3 Wits, 2050

Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

20 October 2020
Person No: 0504217T
PAG

Ms OM Silaule
No. 7 York road
Occupational therapy department(Khanya building)
Parktown
2193
South Africa

Dear Ms Olindah Silaule

Doctor of Philosophy: Approval of Title

We have pleasure in advising that your proposal entitled *Developing guidelines for alleviating caregiver burden amongst informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga Province.* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX H: PARTICIPANT INFORMATION SHEET FOR INFORMAL CAREGIVERS

WITS UNIVERSITY

Project Title: <u>Developing strategies for alleviating caregiver burden amongst informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga Province.</u>

Good day!

My name is Olindah Silaule and I am a PhD student at the University of the Witwatersrand. I wish to invite you to participate in my research that aims to describe how to develop strategies for alleviating burden amongst informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga Province.

What are the objectives of the study?

The objectives of the study are to:

1. To describe the extent of subjective and objective caregiver burden amongst the informal caregivers of persons with severe mental disorders.
2. To describe the lived experiences of informal caregivers of persons with severe mental disorders

What would participation involve?

We would like to find out the extent of caregiver burden experienced by the informal caregivers of persons with severe mental disorders within the Bushbuckridge sub-district. If you choose to participate, you will be asked to complete a caregiver burden measure and relate your experience of providing care to a person with severe mental disorder. As part of this process, you will be asked to complete a demographic questionnaire that helps the researcher know more about your experience you have in caregiving. You will also be asked to complete a caregiver burden measure which is a questionnaire consisting of a list of statements that can be used to identify your

experience of providing care to your loved one with a mental disorder. To complete this questionnaire you will be asked to select the numbers ranging from 1–5 indicating the extent to which various aspects of your life has changed due to caregiving; “1=a lot more (better)” “2 = a little more (better)” “3=the same” “4=a little less (worse)” “5=a lot less (worse)”. After this the researcher will conduct data analysis to establish the level of burden experienced, you may be contacted to participate in the second part of the study which will consist of interviews to explore the experiences of caregiver burden. The burden measure will be completed once and will last a maximum of 30 minutes. The interview will also be completed once and may last for a period of around an hour. This interview will be audio recorded. Data collection is expected to commence from March 2021 to April 2022.

Will I benefit from participating in the study?

There are no direct benefits to you in this study, however, at the end of this study recommendations will be made to the mental health coordinators at the province, district and Bushbuckridge sub-district, as well, as the mental healthcare professionals within the Bushbuckridge sub-district so they may explore the implementation of the strategies in practice.

Are there any risks involved in participating in the study?

There are no risks involved in this study. However, relating to experiences of caregiving may be accompanied by emotional distress. Therefore, should you be identified to experience this recommendations will be made that you seek necessary assistance to address the emotional distress. Should you require assistance from the from the hospital-based counsellor or psychologist arrangements will be made with the relevant healthcare professional at your nearest hospital i.e. Tintswalo, Mapulaneng or Matikwana Hospital to provide necessary intervention.

Is participation voluntary and confidential?

Your participation is completely voluntary and you may withdraw from the research at any point. The data that you share will remain anonymous. You will be assigned a research code during data collection and any identifying data will be removed or altered to maintain anonymity.

How will the findings of the study be disseminated?

This study will be written up as a doctoral thesis which will be available online through the university library website. The study will also be submitted for publications in peer-reviewed journals. All information related to the study will be available to you upon request.

Does the study have ethical approval?

The Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg (*insert HREC number)* has approved this study. A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research. If you have any concerns over the way the study is being conducted, please contact the Chairperson of this Committee who is Dr Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

If you have any questions regarding the research, please feel free to contact me on the details listed below.

Yours sincerely,

Researcher / PhD Student
Olindah Silaule
Email: Olindah.silaule@wits.ac.za
Tel: 078 2035 213/ 011 717 3714

Research Supervisor
Dr Nokuthula Nkosi-Mafutha
Email: nokuthula.nkosi-mafutha@wits.ac.za
Tel: 011 488 3094

Research Supervisor
Dr Fasloen Adams
Email: Fasloen.Adams@wits.ac.za
Tel: 011 717 3701

Thank you for reading this Study Information Sheet.

Date: _____

APPENDIX I : PARTICIPANT INFORMATION SHEET FOR SERVICE PROVIDERS



Project Title: <u>Developing strategies for alleviating caregiver burden amongst informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga Province.</u>

Dear participant

My name is Olindah Silaule and I am a PhD student at the University of the Witwatersrand. I wish to invite you to participate in my research that aims to describe how to develop strategies for alleviating burden amongst informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga Province.

What are the objectives of the study?

The objectives of the study are to:

1. To describe existing strategies for alleviating caregiver burden in low and middle-income countries (LMICs) through a scoping review.
2. To describe the community mental health services for alleviating caregiver burden amongst the informal caregivers within a low-resourced community in Mpumalanga Province, SA.

What would participation involve?

We would like to find out what community mental services are provided to informal caregivers of persons with severe mental disorders within the Bushbuckridge municipality. If you choose to participate, you will be required to answer questions related to the types of services offered, who provides the services and where these services are accessed. As part of this process, you will be expected to complete a demographic questionnaire that helps the researcher know more about your experience you have in community mental health services for informal caregivers. The interview

will be carried out in the area that is of convenience to you. Each interview will be conducted once and will last for a period of 30 to 90 minutes. Data collection is expected to commence from March 2021 to April 2023.

Will I benefit from participating in the study?

There are no direct benefits to you in this study, however, at the end of the study, we will present our findings that you may find useful to implement in practice.

Are there any risks involved in participating in the study?

There are no risks involved in this study.

Is participation voluntary and confidential?

Your participation is completely voluntary and you may withdraw from the research at any point. The data that you share will remain anonymous. You will be assigned a research code during data collection and any identifying data will be removed or altered to maintain anonymity.

How will the findings of the study be disseminated?

This study will be written up as a doctoral thesis which will be available online through the university library website. The study will also be submitted for publications in peer-reviewed journals. All information related to the study is available to you upon request.

Does the study have ethical approval?

The Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg (*insert HREC number)* has approved this study. A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research. If you have any concerns over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za.

If you have any questions regarding the research, please feel free to contact me on the details listed below.

Yours sincerely,

Researcher / PhD Student

Olindah Silaule

Email: Olindah.silaule@wits.ac.za

Tel: 078 2035 213/ 011 717 3714

Research Supervisor

Dr Nokuthula Nkosi-Mafutha

Email: nokuthula.nkosi-mafutha@wits.ac.za

Tel: 011 488 3094

Research Supervisor

Dr Fasloen Adams

Email: Fasloen.Adams@wits.ac.za

Tel: 011 717 3701

APPENDIX J: PARTICIPANT WRITTEN CONSENT FORM



PARTICIPANT CONSENT FORM

Project Title: Developing strategies for alleviating caregiver burden amongst informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga Province.

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto;
2. I was given time to read it, or had it read to me, in the language I best understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time;
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the study would immediately be destroyed, unless I give consent for it to be retained
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study, I am free to speak to any of these contacts.

Contact details:

Olindah Silaule, Principal Investigator, telephone no. 011 717 3701, or by e-mail at Olindah.silaule@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za. Ms. Z Ndlovu or Mr. Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of Participant: _____

Date: _____

Place: _____

Signature or mark: _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

APPENDIX K: PARTICIPANT CONSENT FOR AUDIO RECORDING

WITS UNIVERSITY

PARTICIPANT CONSENT FOR AUDIO RECORDING

Project Title: Developing strategies for alleviating caregiver burden amongst informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga Province.

I hereby consent to the audio recording of the interview.

I understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify me will be removed,
- The recordings will be erased within either (a) two (2) years of the publication of the research findings, or (b) six (6) years, if no publications arise from this research
- Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg
- Direct quotes from my interview, without any information that could identify me, may be cited in the research report or other write-ups of research.

Name of Participant: _____

Date: _____

Place: _____

Signature or mark: _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

APPENDIX L: CAREGIVER DEMOGRAPHIC QUESTIONNAIRE

PART A: Demographic questionnaire (Caregiver: Objective 2)

Participant code	
Age	
Gender	
Educational level	
Marital status	
Employment status	
Relationship with care recipient	
Years caring for the care recipient	
Diagnosis of the care recipient	
Daily hours of caregiving	
Average monthly household income	

Estimated monthly medical costs	
Residence (same as that of care recipient)	YES NO

APPENDIX M : CARE RECIPIENT DEMOGRAPHIC QUESTIONNAIRE

PART B: Demographic questionnaire (Care recipient: Objective 2)

Gender	
Age of care recipient	
Educational level of care recipient	
Marital status	
Employment status	
Diagnosis of the care recipient	
Age of onset	
Disease status of the care recipient	☐ Stable ☐ Unstable ☐ Relatively stable
Number of hospitalisations in the previous year	
Number of family members living in the household	

APPENDIX N: BURDEN MEASURE

Objective and subjective burden measure by Montgomery, Gonyea, and Hooyman (1985)

Measurement of Objective Burden

Rating system: 1=a lot more (better);2= a little more (better); 3=the same; 4=a little less (worse); 5=a lot less (worse).

Amount of time you have to yourself 1 2 3 4 5

Amount of privacy you have 1 2 3 4 5

Amount of money you have available to meet expenses 1 2 3 4 5

Amount of personal freedom you have 1 2 3 4 5

Amount of energy you have 1 2 3 4 5

Amount of time you spend in recreational and/or social activities 1 2 3 4 5

Amount of vacation activities and trips you take 1 2 3 4 5

Your relationships with other family members 1 2 3 4 5

Your health 1 2 3 4 5

Measurement of Subjective Burden

Rating system: 1=a lot more (better);2= a little more (better); 3=the same; 4=a little less (worse); 5=a lot less (worse).

I feel it is painful to watch my (relative) age 1 2 3 4 5

I feel useful in my relationship with my (relative) 1 2 3 4 5

I feel afraid for what the future holds for my (relative) 1 2 3 4 5

I feel strained in my relationship with my (relative) 1 2 3 4 5

I feel that I am contributing to the well-being of my (relative) 1 2 3 4 5

I feel that my (relative) tries to manipulate me 1 2 3 4 5

I feel pleased with my relationship with my (relative) 1 2 3 4 5

I feel that my (relative) doesn't appreciate what I do for him/her as I would like 1 2 3 4 5

I feel nervous and depressed about my relationship with my (relative) 1 2 3 4 5

I feel that my (relative) makes requests which are over and above what s/he needs 1 2 3 4 5

I feel that I don't do as much for my (relative) as I could or should 1 2 3 4 5

I feel that my (relative) seems to expect me to take care of him/her as if I were 1 2 3 4 5

the only ones/he could depend on

I feel guilty over my relationship with my (relative). 1 2 3 4 5

Burden score:

Objective burden _____

Subjective burden _____

Mild burden score Moderate burden score Severe burden score

APPENDIX O: PERMISSION TO USE BURDEN SCALE

Olindah Silaule

From: Nancy R Hooyman <hooy@uw.edu>
Sent: Monday, November 23, 2020 1:08 AM
To: Olindah Silaule
Subject: Re: permission to use the Montgomery, Gonyea, & Hooyman's Caregiver Burden Scale

Dear Olindah

You are most welcome to use the burden scale. Your study is important to understand burdens of caregivers of persons with mental illness, an area where considerable more research is needed.

Good luck to you with your study.

Nancy Hooyman

Nancy R. Hooyman
Endowed Gerontology Professor and Dean Emeritus
UW School of Social Work
4101 15th Avenue NE
Seattle, WA. 98105
Sent from my iPad, please excuse brevity and typos

On Nov 22, 2020, at 4:16 AM, Olindah Silaule <Olindah.Silaule@wits.ac.za> wrote:

> Good day,
>
> I trust that this email finds you well and safe. My name is Olindah Silaule, a PhD candidate at the University of the Witwatersrand, South Africa. The focus of my PhD is on "Developing guidelines for alleviating caregiver burden amongst informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga Province". One of the objectives that I will be focusing on is describing the subjective and objective burden amongst the informal caregivers of persons with severe mental disorders. For this objective, I am planning to use your subjective and objective burden scale(Montgomery, Gonyea, & Hooyman, 1985). Based on my knowledge this scale has not been used

APPENDIX P: INTERVIEW GUIDE FOR INFORMAL CAREGIVER INTERVIEWS

Interview guide for informal caregivers (Objective 2)

Objective: Exploring the views of the informal caregivers of people with severe mental disorders on their experience of caregiver burden and resources/support needed to address this.

Type of interview: Semi-structured interview

Estimated Duration: App 45 min (*to be reviewed once all interviews have been conducted)*

Arrangements for the interview: The researcher will contact the participant to set up a meeting at a time and place that is suitable/ preferable to the participant (participants were part of the previous study done for objective 1). The researcher will ensure that all the COVID-19 protocols and guidelines are adhered to during the interviews: The interviews will be structured to ensure adequate social distancing between the researcher and the participants. The researcher will provide hand sanitisers and ensure that pens used for signing of consents are sanitised after each use. Facemasks will be provided for those who do not have masks during the time of the interview.

Introduction of the session:

The researcher will welcome the participant and thank them for participating in the study. Following this, the researcher will explain that the purpose of the interview is to have an open discussion about their views related to their experience of caregiver burden and resources/support needed regarding their own personal experience. They will be informed that their experience of burden (*burden in this context will be described as the challenges/ difficulty encountered in relation to providing care to their family member with a mental disorder*) established in the previous study makes them a suitable participant in this study that aims to develop strategies for alleviating the caregiver burden.

Before the commencement of the interview, a questionnaire detailing the characteristics of the care recipient and caregiver will be completed,

Interview questions:

The interview will start with an open-ended question (*This is to allow for the capturing of the aspects of the caregivers experience from their perspectives***):**

Q1: Please can you tell me about your experience of caring for your family member (son/daughter/husband/wife/sibling/granddaughter/ mother/father) with a mental disorder.

Translation of Q1: Ndzi kombela mi ndzi hlamusela hi ntokoto lowu minga na wona loko miri karhi mi hlayisa n'wana/nuna/nsati/kokwana/ manana/tatana wa n'wina loyi a vabyaka hi mavabyi ya miehleketo.

**** Following the open-ended question the questions in the table below will be asked.*

Main questions	**Probing questions**
• Describe the different burdens you have encountered since you started providing care to your family member/ relative with a mental disorder. *Translation: mi nga hlamusela hi mintshikelelo leyi minga hlangana na yona hi mpfhuka mi sungula ku hlayisa xaka ra n'wina leri vabyaka hi mavabyi ya miehleketo.* • How have these burdens impact your life? *Xana mintshikelelo leyi yi mi tshikelela njani?*	• Tell me about the time when caregiving has been challenging/worse • How did you encounter these burdens? • How did you know you were encountering these burdens? • In your opinion, o What makes caregiving easier? o What makes caregiving more difficult?
What are the sources of burdens related to providing care to your family member/relative? *Xana hi swihi swilo leswi mi vangelaku mitshikelelo loko miri karhi mi hlayisa xaka ra*	• What does the typical day of caregiving look like for you? • What causes/ contributes to some of the challenges?

n'wina leri vabyaku hi mavabyi ya miehleketo? *<u>Note</u>: questions generated from the results of previous study (extent of subjective and objective burden: Objective 3)*	
What resources/support have you obtained/received since you started providing care to your family member/relative? *Xana i nseketelo wihi lowu mi nga wu kuma hi mpfhuka mi sungual ku hlayisa xaka ra n'wina leri vabyaku hi mavabyi ya miehleketo*	• When do you feel most supported? • What has helped you in taking care of your family/relative with a mental disorder? • What do you think might help other caregivers?
What further resources/support do you need to provide better care to your family member/relative? *Xana i nseketelo wihi lowu mi wu dingaka ku va mi nakekela xaka ra n'wina ku antswa.*	• What would really help you in fulfilling the role of the caregiver? • What do you think this resources/support should entail? • Where would you like to access this resources/support? • How would accessing this resources/support assist in alleviating your burden? • What advice would you give to another caregiver who is providing care to his or her loved one with a mental disorder?

APPENDIX Q: DEMOGRAPHIC QUESTIONNAIRE FOR COMMUNITY HEALTH WORKERS AND PRIMARY HEALTH CARE SUPERVISORS

Participant code	
Age	
Gender	
Occupation	
Designation	
Number of years employed	
Number of years in current position	
Qualifications	

APPENDIX R: INTERVIEW GUIDE FOR COMMUNITY HEALTH WORKERS' FOCUS GROUP

Interview guide: Community Health Workers' focus group

Target population	The focus group will be facilitated with the Community Health Workers currently working within clinics in Bushbuckridge local municipality.
Objectives	To describe stakeholder's perceptions of the formal and informal community mental health services for alleviating caregiver burden among the informal caregivers within a low-resourced community of Bushbuckridge, Mpumalanga.
Arrangements for the FDG	The researcher will contact the Bushbuckridge PHC coordinator telephonically to arrange a date for the FGD. This will be set so it coincide with the PHC managers monthly meeting currently held at Hoxani college of education in Mkhuhlu, Bushbuckridge. The session will run parallel to that of the PHC managers in separate venues. The researcher will ensure that all the COVID-19 protocols and guidelines are adhered to during the FGD: The interviews will be structured to ensure adequate social distancing between the facilitator and among the group participants. The researcher will provide hand sanitisers and ensure that pens used for signing of consents are sanitised after each use.
Facilitator	The researcher will facilitate the FGD with the CHWs. Arrangements have been made with a minute taker who will be responsible for transcribing the recording and translating them from Tsonga to English.
Session duration	The session is estimated to last between 45–60 minutes

Introduction of the session: ***session to be facilitated in Tsonga the local language within the Bushbuckridge community.***

Introductions: The facilitator will welcome and introduce herself to the participants. She will then thank them for their willingness to participate in the study. The facilitator with then ask each participant to introduce themselves (*before audio recording commences).* Following this, the facilitator will explain that the purpose of the interview is to have an open discussion about their views related to the existing formal and informal community mental health services for alleviating caregiver burden amongst the informal caregivers within Bushbuckridge municipality. They will be informed that their experience of as a community health worker within the Bushbuckridge municipality makes them a suitable participant in this study that aims to develop the strategies for alleviating caregiver burden.

Explanation of the procedure: The facilitator will request permission for note-taking and for audio recording the session. Participants will be informed that if uncomfortable with being audio recorded they may indicate so that when it's their turn to speak the recording can be paused. Following this, consent forms and demographic questionnaires will be distributed and collected after completion and stored in a designated box. Following this, they will engage in a group discussion for approximately an hour, the discussion will be guided by the questions asked by the facilitator. Refreshments will then be served at the end of the discussion.

Setting norms/ground rules: The facilitator will ask the participants to come up with the norms for the session (this may include but not limited to, turning off mobile phones, listen to each other, please do not interrupt etc.)

Interview questions:

The interview will start with an open-ended question:

Q1: Could you give me three or four words that you would use to describe you experience of working with families/ carers of people with mental disorders within the community

Note: each participant will be given the post-it where they will record their responses. The facilitator will use the responses to guide the discussion on the various experiences the CHWs have. This will also be directed to capture the specific services they have offered, opportunities and challenges associated with offering these services. The topics below will be used to guide the discussions.

**** Following the open-ended question the questions in the table below will be asked.*

Topics:

a. **Perceptions on provision** of community mental health services for alleviating caregiver burden amongst the informal caregivers
    - ❖ **Probing questions:**
        - ➢ Can you share with us the types of community mental health services that are you provide to the families/carers of persons with mental disorders
        - ➢ Who prescribes these services for you to offer to the families/carers?
        - ➢ What do the services you offer entail?
        - ➢ How often do you provide these services?
        - ➢ Which stakeholders do you work with in the community in order to provide the services to the families/cares of persons with mental disorders
        - ➢ In your opinion, what has been the outcomes associated with these community mental health services for the informal caregivers?

b. **Perception on factors** impacting on delivery of the community mental health services to informal caregivers
    - ❖ Probing questions:
        - ➢ Can you share with us the factors that facilitate your ability to offer the services to the families/carers of persons with mental disorders?
        - ➢ Can you share with us the factors that hinder your ability to offer the services to the
    - ❖ ***In cases where there are no specific interventions/ support strategies for the informal caregivers:***
        - ➢ What do you consider to be the implications for the lack of such interventions/support strategies?
        - ➢ What do you think is required in order to have these interventions/ support strategies for the informal caregivers?

Closure:

The facilitator will summarise the key messages from the discussion. Following this, the facilitator will ask the participants if they have anything else they wish to share relate to the community mental health services within the areas they serve. If not, they will be thanked for their participation and the session will be terminated.

APPENDIX S: INTERVIEW GUIDE FOR PRIMARY HEALTH CARE SUPERVISORS' FOCUS GROUP

Interview guide: PHC managers focus group

Target population	The focus group will be facilitated with seven (7) PHC Cluster managers within the Bushbuckridge local municipality
Objectives	To describe stakeholder's perceptions of the formal and informal community mental health services for alleviating caregiver burden amongst the informal caregivers within a low-resourced community of Bushbuckridge, Mpumalanga.
Arrangements for the FDG	The researcher will contact the Bushbuckridge PHC coordinator telephonically to arrange a date for the FGD. This will be set so it coincide with the PHC managers monthly meeting currently held at Hoxani college of education in Mkhuhlu, Bushbuckridge. The researcher will ensure that all the COVID-19 protocols and guidelines are adhered to during the FGD: The interviews will be structured to ensure adequate social distancing between the facilitator and amongst the group participants. The researcher will provide hand sanitisers and ensure that pens used for signing of consents are sanitised after each use.
Facilitator	An identified facilitator with experience in FGDs will be responsible for facilitating the session. A research assistant will be assigned to take notes during the discussion.
Session duration	The session is estimated to last between 45–60 minutes

Introduction of the session:

Introductions: The facilitator will welcome and introduce herself to the participants. She will then thank them for their willingness to participate in the study. The facilitator with then ask each participant to introduce themselves (*before audio recording commences).* Following this, the facilitator will explain that the purpose of the interview is to have an open discussion about their views related to the existing formal and informal community mental health services for alleviating caregiver burden amongst the informal caregivers within Bushbuckridge municipality. They will be informed that their experience of as a PHC manager within the Bushbuckridge municipality makes them a suitable participant in this study that aims to develop the strategies for alleviating caregiver burden. The facilitator will then clarify some of the concepts that will be used during the discussion.

Clarification of concepts for the participants:

- *Informal caregivers: In this study, an informal caregiver relates to a family (parent, siblings, relatives etc.), a neighbour, or any community member responsible for looking after a person with a mental disorder without any remuneration.*
- *Caregiver burden: In this study, burden is described as the challenges/ difficulty that the informal caregiver experiences when after a person with a mental disorder.*
- *Formal community mental health services: are specialised services that are provided by staff in health and social welfare including care in day centres, rehabilitation facilities, community centres, home help, and outpatient services at PHC facilities.*
- *Informal community mental health services: non-specialised services provided by other sectors other than health and/or social development services these include care from families, friends, traditional healers, religious organisations, village workers, lay community workers and NGOs.*

Explanation of the procedure: The facilitator will request permission for note-taking and for audio recording the session. Participants will be informed that if uncomfortable with being audio recorded they may indicate so that when it's their turn to speak the recording can be paused. Following this, consent forms and demographic questionnaires will be distributed and collected after completion and stored in a designated box. Following this, they will engage in a group discussion for approximately an hour, the discussion will be guided by the questions asked by the facilitator. Refreshments will then be served at the end of the discussion.

Setting norms/ground rules: The facilitator will ask the participants to come up with the norms for the session (this may include but not limited to, turning off mobile phones, listen to each other, please do not interrupt etc.)

Interview questions:

The interview will start with an open-ended question (*This is to allow for the capturing of the aspects of the caregivers experience from their perspectives***):**

Q1: Please can you tell me about your perceptions on the burden of care encountered by the informal caregivers when caring for a person with a mental disorder.

Note: each participant will be given post-it note where they will write down their responses. Following this, a short discussion will be conducted to get the different views from each participant.

**** Following the open-ended question the questions in the table below will be asked.*

Topics:

c. **Perception** on the community mental health services
    - ❖ **Probing questions:**
        - ➢ Can you please tell us about the formal mental health services exist within the communities that you serve?
        - ➢ Can you please tell us about the informal mental health services exist within the communities that you serve?
        - ➢ Can you explain who is responsible for offering these services?
        - ➢ Can you explain who the target population/s for these services are?

d. **Perception of need** for community mental health services targeted specifically at informal caregivers
    - ❖ **Probing questions:**
        - ➢ Do you think there is a need for community mental health services targeted specifically at informal caregivers of persons with mental disorders?
        - ➢ What type of formal and informal community mental health services do you think informal caregivers require in order to support them caregiving role.

- What do you think the community mental health services aimed at informal caregivers of persons with mental disorders should entail?
- Who would you consider to be suitable in providing these community mental health services to the informal caregivers?
- What strategies should be done to ensure that these services are accessible and utilised by the informal caregivers?

e. Perceptions on provision of community mental health services for alleviating caregiver burden amongst the informal caregivers

❖ **Probing questions:**

- Can you share with us the types of formal community mental health services that are provided to help alleviate burden among informal caregivers of persons with mental disorders.
- Can you share with us the types of informal community mental health services that are provided to help alleviate burden among informal caregivers of persons with mental disorders.
- What do the available community mental health services entail?
- Which of the following interventions/support strategies are you familiar with, which are you currently offering?
    - community-based interventions, psychoeducation interventions, support groups, CBT, spiritual-based interventions, smart phone-based interventions, mindfulness and empowerment interventions, collaborative interventions, financial support, social support, counselling, occupation-based interventions, policy and legislature, access to mental health care, standard care.
- Who is responsible for delivering the community mental health services?
- Which stakeholders outside of the mental healthcare system are involved in developing and delivering of these community mental health services?
- What is the accessibility and utilisation of these community mental health services?
- In your opinion, what has been the outcomes associated with these community mental health services for the informal caregivers?

- ***<u>In cases where there are no specific interventions/ support strategies for the informal caregivers:</u>***
  - What do you consider to be the implications for the lack of such interventions/support strategies?
  - What do you think is required in order to have these interventions/ support strategies for the informal caregivers?

Closure:

The facilitator will summarise the key messages from the discussion. Following this, the facilitator will ask the participants if they have anything else they wish to share relate to the community mental health services within the areas they serve. If not, they will be thanked for their participation and the session will be terminated.

APPENDIX T: INVITATION LETTER FOR FOCUS GROUPS

TO **: MR RS MABIKA**

: ACTING DEPUTY DIRECTOR-PHC: BUSHBUCKRIDGE SUB-DISTRICT

FROM **: MS OLINDAH SILAULE**

: PHD CANDIDATE: UNIVERSITY OF THE WITWATERSRAND

DATE **: 25 OCTOBER 2022**

SUBJECT **: INVITATION TO PARTICIPATE IN FOCUS GROUP DISCUSSIONS ON COMMUNITY MENTAL HEALTH SERVICES WITHIN BUSHBUCKRIDGE SUB-DISTRICT.**

Dear Mr Mabika

My name is Olindah Silaule and I am a PhD student at the University of the Witwatersrand. I wish to invite you, the PHC supervisors and community health workers within the Bushbuckridge municipality to participate in focus group discussions that will contribute towards understanding the community mental health services within Bushbuckridge sub-district. The findings from the focus group discussions will inform the development of strategies for addressing caregiver burden among the caregivers of persons with severe mental disorders within Bushbuckridge.

The aim is to facilitate these discussions with the PHC supervisors and a maximum of 12 community health workers serving under the various clinics and/or community health centres in Bushbuckridge. On the scheduled day, the research team that comprises of the researcher, a focus group discussion facilitator and two minute takers will run facilitate a session with the participants.

The sessions will run parallel in separate rooms each with a facilitator and an allocated minute taker. The focus group discussions will be conducted once and will last for a period of 60 to 120 minutes.

More background information on the study and the sessions is included in the email.

The focus group discussions will take place on **21 November 2022 and will start at 09h00 at Hoxani College of Education,** Mkhuhlu**.**

Please do not hesitate to contact me if you have any queries related to the invite or the study.

Yours faithfully,

_____

Olindah Silaule

Email: olindah.silaule@wits.ac.za

Tel: 078 2035 213/ 011 717 3701/14

APPENDIX U: DATA TRIANGULATION TABLE

PROPOSED STRATEGIES FOR ALLEVIATING BURDEN BASED ON THE MULTILEVEL APPROACH

FRAMEWORK COMPONENTS	SUMMARY OF FINDINGS		PROPOSED STRATEGIES (Informed by informed by findings from the scoping review, service providers' interviews and FGDs and the South African National Mental Health)
INDIVIDUAL FACTORS	*Intrapersonal factors including caregiver and care recipient demographic characteristics that contributes to the burdens encountered by informal caregivers of persons with* SMDs *in their caregiving role.*		
Caregiver characteristics	*Relates to caregiver demographic characteristics that predisposes them to burden in their role of caregiving*		
Age	Objective 2	Minor caregivers providing care to a parent with a mental disorder and having to drop out from school to provide care	**Community level: Community based strategy** School health services: Conduct screening to identify minor caregivers **Organisational level: Intersectoral strategy** Social services: Family therapy to strengthen support for minor caregivers. Assist with social grant application
	Objective 3 and 4	Early to middle aged caregivers leaving work to fulfil caregiving duties	**Individual level: Caregiver-driven strategy** Caregiver empowerment Skills for structuring engagement in ADLs and IADLs including washing/bathing, making a simple meal, basic home management and maintenance skills i.e. assisting with chores around the household like cleaning the house. **Interpersonal level :Community based strategy** Family support: distribution of caregiving duties **Organisational level: Community based strategy** Placement facilities for MHCUs Proper rehabilitation for MHCUs to facilitate independence Day-care facilities

			Skills development for MHCUs to facilitate independence
	Objective 3 and 4	Older caregivers are responsible for caregiving and facing a decline in their health status	**Individual level: Caregiver-driven strategy** Caregiver empowerment Seeking help for encountered burdens **Organisational level: Health worker driven strategy** Integrating caregiver care in to routine clinical care Conducting caregiver health screenings at least once every 6 months Issue referrals to other service providers as needed **Policy level: Policy and legislature strategy** Adoption of task shifting Training of lay health workers including community health workers, home-based carers and ward-based outreach teams to conduct caregiver health screenings **Community level: Community based strategy** Implementation of task shifting Lay health workers including community health workers, home-based carers and ward-based outreach teams to conduct caregiver health screenings at least once every 6 months Allocation of mental health champions
Gender	Objective 3 and 4	Caregivers are mostly female with higher levels of objective burden due to disruptions in routines	**Individual level: Caregiver-driven strategy** Caregiver empowerment Skills for structuring engagement in ADLs **Organisational level :Health worker driven strategy** Ensure availability of occupation-based interventions for caregivers Facilitate caregiver participation in physical exercise social and leisure activities **Community level: Community based strategy** Implementation of task shifting

			Training of lay health workers i.e. community health workers, home-based carers and ward-based outreach teams and mid-level workers i.e. occupational therapy assistants and technicians on occupational-based interventions for caregivers Lay health workers and mid-level workers to facilitate caregiver participation in physical, social and leisure activities
		Female caregivers experiencing role restriction	**Individual level: Caregiver-driven strategy** Caregiver empowerment Skills for structuring engagement in ADLs **Interpersonal level: Community based strategy** Family support: distribution of caregiving duties **Organisational level: Community based strategy** Placement facilities for MHCUs Proper rehabilitation for MHCUs to facilitate independence Day-care facilities Skills development for MHCUs to facilitate independence Respite care Availability of temporary placement facilities for MHCUs to relieve caregivers **Policy level: Policy and legislature strategy:** Improving access to mental health services Improving access to standard care for MHUs and caregivers: general medicine, psychiatry, psychology, family therapy, neuropsychological rehabilitation, and occupational therapy Improving access to standard care for MHCUs and caregivers: availability of emergency teams
		Both male and female caregivers reported mild-to-moderate subjective burdens	**Interpersonal level: Caregiver-driven strategy:** Caregiver empowerment Facilitation of peer-led support groups

			Community level: Community based strategy Task shifting Training of peer support group facilitators to conduct support groups within the community. **Organisational level: Health worker driven strategy** Integrating caregiver care into routine clinical care Conducting caregiver health screenings at least once every 6 months Issue referrals to other service providers as needed
Education	Objective 3 and 4	Low levels of education among caregivers, most with secondary level of education and primary school level and some with no education.	**Interpersonal level: Caregiver-driven strategy** Caregiver empowerment Facilitation of peer-led support groups**,** peer-assisted psychoeducation **Community level: Community based strategy** Implementation of task shifting Mental health champions within the community clinics should be identified to conduct training of peer support group facilitators Mental health professionals and mental health champions to conduct training of lay health workers to deliver psychoeducation **Organisational level: Health worker driven strategy** Integrating caregiver care in to routine clinical care Delivering psychoeducation at the literacy level of the caregiver **Policy level : Policy and legislature strategy** Improving access to mental health services Training mental health professionals to communicate at a literacy levels of the caregivers. Facilitating development of collaborative interventions: caregivers to give input on mental health programme development
Cultural beliefs	Objective 2 and 3	Culture determines caregiving responsibilities i.e.	**Community level: Community based strategy**

		females are obligated to provide care	Awareness regarding gender roles Hosting community dialogues Using community resources e.g. community radio stations
		Cultural beliefs influenced help-seeking behavior. Caregivers still sought help from traditional healers while receiving medical assistance for their care recipients and this caused relapses	**Individual level: Caregiver-driven strategy** Caregiver empowerment Seeking information on available services **Organisational level: Health worker driven strategy** Caregiver psychoeducation Basic information on mental disorders Information on warning signs of relapses i.e. looking at implementation on prelapse programme within the community. Information on medication management Information on caregiver health **Community level: Intersectoral strategy** Task sharing Collaboration between formal and informal mental health service providers Ensuring availability of spiritual-based interventions
Religious beliefs	Objective 2 and 4	Religious beliefs influenced help-seeking. Caregivers sought help from religious organisations while receiving medical assistance for their care recipients and this caused relapses	**Individual level: Caregiver-driven strategy** Caregiver empowerment Seeking information on available services **Organisational level: Health worker driven strategy** Caregiver psychoeducation Basic information on mental disorders Information on warning signs of relapses Information on medication management Information on caregiver health **Community level: Intersectoral strategy** Task sharing Collaboration between formal and informal service providers Ensuring availability of spiritual-based interventions

Economic status: grants, child-headed family/care (need to hire someone)	Objective 2,3 and 4	Higher levels of financial burdens prevalent among the caregivers Most informal caregivers are unemployed and depended on social grants i.e. old age pension and disability grant Employed caregivers need leaving jobs due to caregiving duties Unemployed caregivers forego employment opportunities due to caregiving duties School going caregivers leaving school to provide care	**Individual level: Caregiver-driven strategy** Caregiver empowerment Seeking information on available services Seeking help from immediate support systems i.e. family **Organisational level: Intersectoral strategy** Social services: Financial support: awareness raising on available grants. Assisting with grant application processes and issuing of food parcels. **Interpersonal level: Community based strategy** Family support: financial support and distribution of caregiving tasks **Organisational level: Community based strategy** Placement facilities for MHCUs Appropriate and comprehensive rehabilitation for MHCUs to facilitate independence Day-care facilities Skills development for MHCUs to facilitate independence i.e. compliance to treatment, and basic life skills like home management and maintenance.
Care recipient's characteristics	*Relates to care recipients' demographic characteristics that predisposes them to burden in their role of caregiving*		
Age	Objective 4	Most were in their productive stages in the age ranges of 20 and 39 years.	**Interpersonal level: Community based strategy** Family support: distribution of caregiving duties **Organisational level: Community based strategy** Placement facilities for MHCUs Proper rehabilitation for MHCUs to facilitate independence Day-care facilities for MHCUs Skills development for MHCUs to facilitate independence Respite care facilities for MHCUs Availability of temporary placement facilities for MHCUs to relieve caregivers Vocational training facilities for MHCUs Skills development to facilitate entry to supported employment

			Sheltered employment for MHCUs Skills development to facilitate productivity among MHCUs
Gender	Objective 4	Most were young males and being looked after by female caregivers	**Interpersonal level: Community based strategy** Family support: help-seeking and emotional support **Community level: Intersectoral strategy** Support from traditional leaders Management of mental disorders and medical help-seeking Support from community leaders and ward councillors Assisting with help-seeking for aggressive MHCUs Assisting with medication management to be integrated as part of the prelapse programme.
Employment	Objective 4	Most care recipients received a disability grant mainly managed by caregivers, which caused conflicts.	**Individual level: Caregiver-driven strategy** Caregiver empowerment Caregiver accountability on disability grant management **Organisational level: Health worker driven strategy** Social worker intervention Disability grant management **Organisational level: Intersectoral strategy** Social services: Social workers to support disability grant management **Community level: Community based strategy** Task shifting Lay health workers to monitor disability grant management
Diagnosis	Objective 3 and 4	Majority of care recipients were diagnosed with schizophrenia and psychotic disorders Mostly chronic with poor recovery Exhibited violent and aggressive behaviours Poor functioning: Dependence in ADLs/iADLs	**Organisational level: Health worker driven strategy** Caregiver psychoeducation Basic information on mental disorders Information on warning signs of relapses Information on medication management Information on caregiver health **Individual level: Caregiver-driven strategy** Caregiver empowerment Skills for handling MHCUs

			Facilitation of treatment compliance Acceptance of MHCUs **Community level: Community based strategy** Task shifting Training of peer support group facilitators: life skills, handling of MHCUs, coping skills Training lay health workers to deliver psychoeducation: basic information on mental disorders, warning signs of relapses, medication management and caregiver health
Disease status	Objective 4	Most were reported to be relatively stable in spite of reports of symptoms such as isolation from family, aggression, disappearance from home and irritable moods.	**Organisational level: Health worker driven strategy** Caregiver psychoeducation Knowledge on mental disorders Identification of early signs of relapses **Individual level: Caregiver-driven strategy** Caregiver empowerment Knowledge on signs and symptoms of mental disorders Knowledge on early warning signs of relapses **Community level: Community based strategy** Implementing task shifting Lay health workers to monitor medication compliance and track treatment defaulters Lay health workers to conduct screening for disease status of a MHCU **Policy level: Policy and legislature strategy** Improving access to community based mental health services Task shifting: training lay health workers to deliver mental health services within the community
INDIVIDUAL FACTORS	*Relates to the needs, adaptability, stress response and coping skills used by the informal caregivers to handle the demands of their caregiving.*		
Caregiver needs	Objective 1–4	Identified caregiver needs: Access to CMHS Placement and skills training facilities Support from mental health professionals (*home visits*,	**Policy level: Policy and legislature strategy** Adoption of participatory care model in policy and program development and implementation Caregiver involvement in all program elements

		counselling, and tracking of the MHCUs' progress) Empowerment: Information on handling of MHCUs Flexible admission policies Support from: Emotional support from family Social support from religious organisations Counselling from religious organisations Government support: financial support and food parcels Housing support from community organisations	Improving access to community based mental health services Task shifting : training of lay health workers on community support for caregivers **Individual level: Caregiver-driven strategy** Caregiver empowerment Skills on handling of the MHCUs' behavior **Interpersonal level: Community based strategy** Family support: strengthening emotional support **Community level: Community based strategy** Task shifting Training lay health workers to provide information on available resources e.g. grant in aid for caregivers **Organisational level: Community based strategy** Placement facilities for MHCUs Proper rehabilitation for MHCUs to facilitate independence Day-care facilities for MHCUs Skills development for MHCUs to facilitate independence Respite care facilities for MHCUs Availability of temporary placement facilities for MHCUs to relieve caregivers Vocational training facilities for MHCUs Skills development to facilitate entry to supported employment Sheltered employment for MHCUs Skills development to facilitate productivity among MHCUs **Organisational level: Intersectoral strategy**: Collaboration with community stakeholders Social services: improving access to information on different grants. Improving access to tangible support i.e. food parcels Local government: use of case flow as a strategy to facilitate allocation of resources to people with mental disabilities in the

			community including access of housing for MHCUs and caregivers
Caregiver adaptability and stress response	Objective 1–4	Experience of existential responsibility Meeting the health and wellbeing of a MHCU Meeting the physical needs of a MHCU Enabling participation in daily occupations Lack of knowledge and skills Experience of existential anxiety Fear of continuity of care in the event of caregivers' death Fear for MHCUs' future Powerlessness Experience of negative health effects Decline in emotional, physical and mental health Unavailability during MHCUs' follow-ups Rejection of help from lay health workers	**Individual level: Caregiver-driven strategy:** Caregiver empowerment Skills for structuring engagement in ADLs and IADLs Stress management skills Seek information on available resources for support Participation in driven self-help interventions **Policy level: Policy and legislature strategy:** Improving access to community based mental health services Task shifting : training of lay health workers on community support for caregivers Improving access to standard care for MHCUs and caregivers: general medicine, psychiatry, psychology, family therapy, neuropsychological rehabilitation, and occupational therapy **Community level: Community based strategy:** Implementation of task shifting Lay health workers including community health workers, home-based carers and ward-based outreach teams to conduct caregiver health screenings at least once every 6 months Registered counsellors to facilitate empowerment and stress reduction programs
Caregiver coping skills	Objective 1–4	Identified coping strategies Avoidant coping strategies Emotional focused coping Self-sacrifice Identified internal resources for coping Resourcefulness Resilience Perseverance Patience with the MHCU	**Individual level: Caregiver-driven strategy:** Caregiver empowerment Strengthening internal coping resources: Guided self-help interventions Participation in peer-led support groups/programmes **Community level: Community based strategy:** Task shifting Training of peer support group facilitators

			Exercising self-control towards MHCU Acceptance of caregiving responsibility Having unconditional love Religious coping Sharing experiences with peers	Training lay health workers on setting up and facilitation of support groups Registered counsellors to offer basic counselling services Registered counsellors to offer empowerment and stress reduction programs
CONTEXTUAL FACTORS		*Relates to a range of factors influencing the experiences of the informal caregivers in their role this includes factors from the immediate context where caregiving takes place. Interpersonal relates to the social networks including the family and peers within the informal caregiver's immediate environment. Community relates to the access to* CMHS, *the societal and attitudinal factors influencing the caregiving experience.*		
Caregiving context	Duration of caregiving	Objective 3 and 4	Prolonged hours spent on caregiving (19–24 hours) Many years spent in caregiving (11–20 years)	**Individual level: Caregiver-driven strategy** Caregiver empowerment Skills for structuring engagement in ADLs **Interpersonal level:** **Community based strategy:** Family support: distribution of caregiving duties **Organisational level:** **Community based strategy** Placement facilities for MHCUs Proper rehabilitation for MHCUs to facilitate independence Day-care facilities for MHCUs Skills development for MHCUs to facilitate independence Respite care facilities for MHCUs Availability of temporary placement facilities for MHCUs to relieve caregivers Vocational training facilities for MHCUs Skills development to facilitate entry to supported employment Sheltered employment for MHCUs Skills development to facilitate productivity among MHCUs
	Residence	Objective 3 and 4	Majority stayed in the same residence as care recipients (81.2%) Some residences had 6–10 residents in the household, caused conflicts as MHCUs neglect their surroundings	**Community level:** **Intersectoral strategy**: Collaboration with community stakeholders Local government: use of case flow as a strategy to facilitate allocation of resources to people with mental disabilities in the community including access of housing for MHCUs and caregivers

	Number of care recipients	Objective 4	Many had one care recipient, but some had two care recipients (16.7%)	**Organisational level: Health worker driven strategy** Integrating caregiver care in to routine clinical care Health screenings to look at the number of care recipients **Community level: Community based strategy:** Task shifting Lay health workers to enquire about the number of care recipients during health screenings
Interpersonal factors	Family level	Objective 1–4	Caregivers' mistrust of family members with caregiving duties Caregivers' taking over caregiving duties to protect other family members MHCUs' behavior impacting family unit Lack of family support: immediate and extended Family stigma towards caregiver and MHCU	**Individual level: Caregiver-driven strategy** Caregiver empowerment Seeking help from the family **Organisational level: Health worker driven strategy** Access to social worker and psychology services Family therapy to reduce stigma within families **Interpersonal level: Community based strategy** Family support: distribution of caregiving duties **Community level: Community based strategy** Task shifting Lay health workers to set up stigma reduction programs Task sharing Collaboration between community based mental health professionals and traditional leaders to raise awareness: community dialogues Using community resources to raise awareness: local radio stations
	Peer level	Objective 1–4	Experienced universality in sharing experiences with peers	**Interpersonal level: Caregiver-driven strategy** Caregiver empowerment Facilitation and participation in peer-led support groups **Community level: Community based strategy** Task shifting Training of peer support group facilitators

				Training lay health workers on setting up and facilitation of support groups
Community factors	Access to CMHS Availability Affordability Appropriateness	Objective 1–4	Lack of caregiver-orientated services Shortage of human resources: lack of specialists i.e. psychiatrists, psychologists, burdened mental health professionals Rurality of Bushbuckridge municipality: difficulty attracting skilled practitioners Limited knowledge of mental disorders among lay health workers including community health workers, home-based carers, ward-based outreach teams Lack of referral pathways between hospital and community-based service providers Long distances to hospital to access services, difficulty caused by financial strain Limited collaborations between formal and informal mental health service providers Access to medical support enabled caregivers to cope: medication and hospitalisation Access to social services: home visits and arrangements for substance abuse rehabilitation	**Policy level: Policy and legislature strategy** Improving access to community based mental health services Task shifting : training of lay health workers on caregiver support within community Improving access to standard care for MHCUs and caregivers: general medicine, psychiatry, psychology, family therapy, neuropsychological rehabilitation, and occupational therapy Increasing training and allocation of psychiatric nurses in local clinics Improve infrastructure for community based mental health services Develop and implement national and provincial mental healthcare plans with clear guide on referral pathways for caregiver services **Community level: Community based strategy** Task sharing Collaboration between community based mental health professionals and informal service providers i.e. traditional healers, religious organisations Implementation of task shifting Lay health workers including community health workers, home-based carers and ward-based outreach teams to provide caregiver support **Organisational level: Community based strategy** Establishing referrals between institution-based mental health service providers and community based mental health service providers i.e. lay health workers **Organisational level: Intersectoral strategy** Collaboration with community stakeholders

				Training of stakeholders including SAPS, community leaders on mental disorders
	Social factors	Objective 4	Identified external resources for coping Family support: emotional and financial support Community support: help-seeking and medication support Religious support: prayer and emotional support	**Interpersonal level: Community based strategy** Strengthening family support **Community level: Community based strategy** Strengthening community support Task sharing Collaboration between community based mental health professionals and informal service providers i.e. religious organisations
	Attitudinal factors	Objective 2 and 4	Experience of community stigma: exploitation of caregiver and MHCU Stigma and fear of MHCUs by lay health workers Lack of prioritisation of mental health services, impacted by staff attitudes towards mental illness	**Policy level: Policy and legislature strategy** Development and implementation programs aimed at reducing stigma among mental healthcare providers **Organisational level: Health worker driven strategy** Participation in stigma reduction programs Improving staff attitude towards MHCUs Improving handling of MHCUs **Community level: Community based strategy** Task shifting Training of lay health workers Lay health workers to set up stigma reduction programs Task sharing Collaboration between community based mental health professionals and traditional leaders to raise awareness: community dialogues Using community resources to raise awareness: local radio stations
POLICY FACTORS		*Relates to the national and local policy factors that impact on the caregiving experiences and availability of caregiver-orientated services.*		
National and local policies		Objective 1,2 and 4	Lack of flexible admissions in substance abuse management Lack of prioritisation of mental health affects funding Lack of guidelines and policies direct service delivery: lack of referral	**Policy level: Policy and legislature strategy** Adoption of participatory care model in policy and program development and implementation Caregiver involvement in all program elements

		guidelines between institution and community-based service providers Limited infrastructure for mental health Regression of community based mental health services	Integration of caregiver actions and interventions into national and provincial mental health care plans Improving access to community based mental health services Task shifting : training of lay health workers on caregiver support within community Increasing training and allocation of psychiatric nurses in local clinics Improve infrastructure for community based mental health services

APPENDIX V: LETTER FROM LANGUAGE EDITOR

Karien Hurter
LANGUAGE EDITOR

KARIEN HURTER
Copy Editor and Proofreader
Email: karien.hurter@gmail.com
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3 November 2023

To Whom It May Concern:

This letter is to confirm that *Developing strategies for alleviating caregiver burden among informal caregivers of persons with severe mental disorders in Bushbuckridge, Mpumalanga province* by Olindah Mkhonto Silaule was edited by a professional language practitioner. It requires further work by the author in response to my suggested edits. I cannot be held responsible for what the author does from this point onward.

Regards,



Karien Hurter

APPENDIX W: EXAMPLE OF MAP OF THEMES GENERATED FROM NVIVO

