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Research Article

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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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 was aimed at exploring 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 support needs of the informal caregivers. Ten semistructured 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 themes presented in this paper are 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, 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.

Keywords: caregiver burden; caregiver needs; caregiver support; informal caregiver; rural context; severe mental disorders; South Africa

1. Introduction

Severe mental disorders (SMDs), including schizophrenia spectrum disorders, depressive disorders, bipolar mood disorders, and substance use disorders, are serious public health concerns [1]. 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 makes them a major contributor to the growth of morbidity and disability [2–4]. In South Africa (SA), SMDs account for 26.1% of the reported cases of mental disorders [5]. A profile of common causes of mental illnesses conducted in Mpumalanga, a rural province in SA, revealed that most mental healthcare users (MHCUs) were diagnosed with SMDs including schizophrenia, major depressive disorders, bipolar disorders, and substance use disorders [6]. Individuals who are diagnosed with SMD often experience serious functional and role impairments and require structure to function within their communities [7, 8]. 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 [9, 10]. These disorders manifest in the early years of adulthood and persist throughout life. Consequently, these disorders

affect people's ability to earn a livelihood and form meaningful relationships, resulting in a need for prolonged care and management [11]. 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 [4]. Individuals who are diagnosed with bipolar mood disorders experience substantial impairments in their mood and daily living activities and therefore 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 [12, 13]. The rate of recurrences and persistent symptoms frequently leads to functional impairments that place emotional strain on patients and their families [13, 14]. Those with substance use disorders often experience cognitive impairments, including problems with thinking, decline in memory, and difficulty focusing their attention [15]. In addition, they exhibit physical aggression and poor social behaviour, which affects their work performance and personal relationships, thus leading to functional impairments with severe influence on MHCUs and their families [16]. The chronic and disabling nature of these mental disorders requires prolonged care and management.

In SA, a persistent mental health treatment gap affects the care and management of persons with SMDs. It is estimated that 75% of those with common mental disorders including depression, anxiety, and substance use do not receive treatment. This treatment gap rises to 92% when including those with SMDs [17]. The provision of mental health services in SA is described as fragmented, limited, or nonexistent, particularly in rural areas where a dehumanising state of mental health is reported [18, 19]. Limited access to mental health services in rural SA has been attributed to poor infrastructure, high transport costs, larger travelling distances to healthcare facilities, and limited human resource availability [20]. A disproportionate distribution of mental health resources exists in urban and rural SA. According to Vergunst [18], the density of psychiatrists in and around the largest city is 3.6 times greater when compared to that of the entire country. In rural SA, there is a lack of psychiatrists and psychologists; thus, mental health services rely primarily on medical officers, occupational therapists, and nurses, who are also scarce resources [18]. In their study, De Kock and Pillay [21] highlighted a lack of medical officers with the ability to prescribe psychotropic medications, subsequently shifting this responsibility to mental health nurses. Consequently, the cycle of inaccessibility to mental health services is perpetuated as only 0.68 mental health nurses are employed per 100,000 population in SA's rural areas [21]. The limited access to mental health services calls for informal caregivers to become key role players in the care and management of those with SMDs [7, 22, 23].

Informal caregivers are either family members, relatives, or community members who provide care without remuneration [24]. Caregiving is identified as a stressful responsibility for informal caregivers and is often accompanied by caregiver burden [25–27]. This is because informal caregivers are required to fulfil this role without any training, and as such, they lack the knowledge and skills to handle the behaviour of persons with SMDs [28]. Two types of caregiver burdens are well-documented, namely, objective and subjective burdens. Objective burden refers to the tangible negative effects of caregiving such as prolonged time spent 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 [29–31]. Previous studies established that informal caregivers require support from family, mental health professionals, and their community to cope with the demands of their caregiving responsibilities [26, 32]. Addo et al. [7] acknowledge the paucity of research on the burden of care brought on by SMDs and call for more research to inform service planning and policymaking in sub-Saharan Africa. According to Bastawrous [33], gaining an in-depth understanding of caregiver burden is crucial for identifying the relevant and responsive strategies for alleviating it. Previous studies conducted in rural SA reported on the generic experiences of caregiving, with many focusing solely on the caregivers of persons with schizophrenia. Therefore, there is limited research reporting on the burden of care experienced by informal caregivers of persons with SMDs and a limited focus on their support needs. To address this gap, the current study was aimed at exploring the experiences and support needs of informal caregivers of persons with SMDs in Bushbuckridge, SA. 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 as follows: (1) What are the experiences of informal caregivers of persons with SMDs? (2) What are the support needs of informal caregivers of persons with SMDs in rural SA?

2. Materials and Methods

2.1. Study Design and Approach. A qualitative, descriptive research design was used to explore the subjective experiences of informal caregivers and their support needs while providing care to persons with SMDs [34]. This design was selected as it allowed the researchers to understand informal caregivers' individual experiences within their caregiving context [35]. The study forms part of a PhD project conducted to establish the extent of the burden of care among informal caregivers in rural SA [27]. The qualitative descriptive design allowed for an in-depth exploration of caregiving experiences [35]. For data collection, semistructured 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 [36].

2.2. Setting. This study was conducted in the Bushbuckridge municipality situated in the north-eastern rural part of Mpumalanga Province, SA. The municipality has a population size of 750,821 and an estimated average annual household income of R16,000.00 (approximately $850) [37]. Due to limited economic opportunities in Bushbuckridge municipality, a majority of those with mental disorders and their families depend on a disability grant as a main source of income [38]. A disability grant is a social welfare grant provided to those with a physical or mental health disability that makes them unfit for work for a period longer than 6 months. The amount of disability grant received is R2180.00 (approximately $127) per month and is spent on food, clothes, electricity, and hospital transport [38]. There are two district hospitals and one regional hospital in the Bushbuckridge municipality. Of the three hospitals, only one district hospital has an inpatient 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 inpatient care are admitted to this unit for care and treatment. In addition, the mental health unit offers outpatient services. Persons with SMDs requiring inpatient and outpatient care are often treated at this facility, and some travel distances of up to 50 km to access the services at this facility. Due to low bed capacity, patients 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. For others, this means travelling long distances to access mental health services, which makes the follow-up of these MHCUs a challenge. The limited access to public transportation requires that they hire private transport, which can cost up to R500.00 (approximately $29) for a single trip. This subsequently adds to the financial burden of the family, as many are dependent on a disability grant as a main source of income [38].

2.3. 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 using a purposive sampling method to select participants who presented with a mild, moderate, or severe burden of care. Potential interview participants who indicated interest in participation were recorded, and their contact details were captured. Once the study commenced, the primary investigator (PI), O.S. contacted those who indicated interest telephonically and invited them 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 provides unpaid care; (2) they are informal caregivers who have provided continuous care for longer than 6 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 [20]. Overall, 12 participants participated in this study between January and June 2022. A sample size of 12 participants was adequate to allow for a full exploration of the burdens and support needs and for answering the research question.

2.4. Data Collection and Management. Prior to data collection, the PI attended a qualitative methodology workshop, which equipped them with skills to conduct semistructured interviews and qualitative data analysis using NVIVO software. Upon 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 was 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. Semistructured interviews were conducted using an interview schedule (Supporting Information 1) [32]. Prior to the interviews, the researcher went through the information sheet detailing the purpose of the study. 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 min, depending on the experiences shared by the participants. Data were collected until saturation was reached, that is, when no new data emerged during the

interview process. 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. 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.

2.5. Data Analysis. Data was analysed systematically using NVIVO 12 software. The analysis followed the six-phase reflexive thematic inductive approach proposed by Braun and Clarke [36]. 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 [39], which in this case were the experiences of the caregivers and their support needs. Firstly, PI conducted data immersion by repeatedly listening to the audio recordings while reading the transcripts. Emerging patterns and meanings from the dataset 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, PI did systematic coding 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, PI sorted all 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 step 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, the 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 the validity of the themes and ensure codes were not missed. Lastly, the findings, recommendations, and conclusions are presented in this study.

To ensure trustworthiness, credibility was ensured by the PI creating a safe and free space for the participants to express themselves. Participants were allowed to express themselves using their vernacular, which allowed for an in-depth exploration of their caregiving experiences. Where necessary, the PI prolonged the interview sessions with the participants. An experienced qualitative researcher was invited to conduct an audit trail on the analysis process. After the audit, PI revisited the fifth step to refine, define, and name themes. The findings were presented to two research supervisors, and peer briefings were held to promote the quality and truthfulness of the findings. Member checking was conducted to allow participants to provide their input on the findings [40]. The PI conducted the member checking by sharing the research findings with the participants, and due to the long distance between the PI and the research participants, the process was conducted telephonically. The findings were summarised, and participants were invited to give their thoughts on the findings, detailing whether this captured their experiences. Following this, participants were asked to share additional thoughts on the findings and any information they felt was not adequately captured. Dependability was achieved by ensuring that all interviews were audio-recorded and by keeping a journal to document field notes, which included the PI's thoughts and observations from the interviews and analysis process. This allowed the PI to keep an audit trail of the data collection and analysis process. To ensure conformability, triangulation was conducted by listening to the audio recordings of the interviews and reviewing field notes and observations that allowed for reflexivity.

3. Findings

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

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 a disability grant (58.7%). The care recipients are considered relatively stable (83.3%), and many are diagnosed with schizophrenia (58.3%).

The participants were asked to describe their experiences and support needs when providing care to a person with an SMD and two themes were identified from the inductive data analysis, namely, caregivers' experience of burden in caregiving (Theme 1) and caregivers' expressed support needs (Theme 2). Each theme has subthemes that provide a comprehensive representation of the findings (Table 3). Theme 1 outlines the burdens experienced by informal caregivers, such as the difficulty and strain the caregivers attribute to their caregiving role. This theme is divided into five subthemes, namely, dealing with the chronic nature of an SMD, the experience of MHCU's disruptive behaviour, the experience of financial strain, the experience of stigmatisation, and the role of the strain of caregiving. Theme 2 describes the views of the informal caregivers on the support

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 years	5	41.7
11–20 years	7	58.3
Daily caregiving (in hours)		
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 the care recipient	8	66.7
Different from the care recipient	4	33.3

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

they require to enable them to cope with the demands of providing care. This theme is divided into three subthemes, namely, access to mental health services, caregiver empowerment, and social support. A concept map (Supporting Information 2) provides a visual summary demonstrating the links between the themes, subthemes, and codes generated during the data analysis process of this study.

3.1. Theme 1: Caregivers' Experience of Burden in Caregiving Role

3.1.1. Dealing With the Chronic Nature of a SMD. The informal caregivers expressed the burden of dealing with the

Table 3: Themes and subthemes representing the informal caregivers' experiences of burden and support needs.

Themes	Subthemes
Caregivers' experience of burden in caregiving	Dealing with the chronic nature of a SMD
	Experience of MHCU's disruptive behaviour
	Experience of financial strain
	Experience of stigmatisation
	Role of strain of caregiving
Caregivers' expressed support needs	Access to community-based mental health services
	Need for caregiver empowerment
	Need for social support

chronic nature of an 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 MHCU. One of the participants explained, "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 a short-lived recovery. 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).

3.1.2. Experience of MHCU's 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 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 from taking them to the 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 results in substance abuse, which worsens their conditions and leads to disruptions within their households. 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).

3.1.3. 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 the basic needs of the MHCUs, including buying toiletries, self-care products, and food. One participant explained, "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 the 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. (TBM 102)

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)

3.1.4. 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 contributes 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. Some of the participants expressed their 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 MHCUs 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. (TBM 79)

3.1.5. 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 well-being 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. (TBM 04)

The chronic nature of SMDs and MHCUs' constant need for supervision results 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 shifts as they adjusted 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. (TBM 73)

3.2. Theme 2: Caregivers' Expressed Support Needs

3.2.1. Access to Community-Based Mental Health Services. The interviews revealed that the currently 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 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 of 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).

3.2.2. Need for Caregiver Empowerment. This subtheme 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 the 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 lacked 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 place 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)

3.2.3. 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 needed emotional support from the family and that they would cope better with their responsibilities if their family would check 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. (TBM 102)

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 from the MHCU to help cover their daily needs and travel costs to the 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 feel 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 house) 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)

4. 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 SA. 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 the family and 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 the 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 an SMD results in objective and subjective burdens [27, 41, 42]. The experiences of the informal caregivers indicate the presence of an objective burden as they raised concerns about the tangible demands of providing care [28], 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 h/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 could not get one because they had 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 [25, 43]. 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 to 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 [38]. Wright [38] 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 does not last a month. The fact that caregivers expressed having difficulty providing food raises a serious concern about food security among caregivers and persons with SMDs. Studies conducted in rural Ethiopia reveal that one-third of the households that have a person with an SMD are affected by food insecurity. Limited access to disability payments, discrimination, and low annual household income precipitate this problem [44, 45]. 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 well-being 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 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 [46].

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, Poggenpoel, and Myburgh's [31] 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 about their illness affects 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 the burden among caregivers of those with SMDs [47], and there is a high co-occurrence reported between substance abuse and SMDs such as schizophrenia and bipolar mood disorders [48, 49]. Higher alcohol, cannabis, nicotine, and cocaine use have been reported among those with schizophrenia than in the general population [50], and this leads to high relapse rates [51]. 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 patients' violent behaviour and caregiver burden [26, 52, 53]. 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 well-being of other family members, thus affecting family functioning. As a result, the informal caregivers have to worry about the well-being of the entire family, which adds to their caregiving burden. Previous studies highlight that stressful family environments lead to physical and psychological distress in the families of MHCUs [54–56].

Understanding the sources of burden as well as the needs of the informal caregivers is important for the development of intervention programmes, to improve patient outcomes, and to ensure caregivers' well-being [57]. 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 [58] reveals that access to services, resources, and support for MHCUs and their caregivers is important to alleviate the 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 [59]. The World Health Organization states that community mental health services are accessible and effective in promoting quality of life for both MHCUs and their families [60]. Therefore, having such facilities will ensure proper rehabilitation for MHCUs and enable them to gain the necessary functional skills to be more independent. This will eliminate role strain for informal caregivers and allow them time to engage in activities of their choice, including income-generating activities to reduce their financial burdens. Tirfessa et al. [44] 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 [61].

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 [62, 63]. Similarly, psychoeducation is effective in increasing caregivers' knowledge about mental disorders, which enables them to cope effectively with their caregiving duties, thus improving their well-being [64, 65]. 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 [66]. It is therefore necessary to implement task shifting by training lay workers to help support informal caregivers within the community [67].

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. [68] 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, Poggenpoel, and Myburgh [31] 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 [69, 70]. It is therefore important to ensure that caregivers are trained to care for and manage MHCUs. Additionally, policymakers 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 family members confirms 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 [26, 62]. 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 [71]. 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 [56] 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 SA. The need for support expressed by the informal caregivers clearly shows the difficulties they face in coping with the demands of their caregiving roles. The findings in this study highlight the unique role played by informal caregivers in supporting the recovery of those with SMDs. Despite the challenges they encountered, the caregivers' expressed needs were centred on building their capacity to provide quality care for their care recipients. This shows the level of concern that informal caregivers have for the health and well-being of their care recipients. This calls for urgent action to develop and strengthen strategies for supporting informal caregivers to strengthen support for persons with SMDs, particularly in resource-constrained contexts like rural SA. A study by Ong et al. [72] revealed that informal caregivers who received support experienced lower levels of caregiver burden and positive psychological well-being which increased the quality of care they offered to the MHCUs.

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 a burden in their caregiving duties but who were not included in the first study. 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.

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, for some caregivers, there was limited space for privacy, which affected their ability to share their experiences freely.

5. 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 SA [20], 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 an objective burden. These findings support those of the first quantitative study [20] that there is a high level 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 informal caregivers.

On the practice level, the findings show an urgent need to integrate caregiver interventions in routine clinical practice. These interventions should aim to improve caregivers' knowledge and skills in handling 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 well-being. 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 policymakers 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 SA 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 well-being 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 in the findings of this study, the caregiver burden is multidimensional, and as a result, interventions targeted at alleviating the burden require multisectoral collaboration between health, social development, local government, and community organisations.

Future studies should aim to investigate the impact of SMDs on the family as a unit and the subsequent implications on the informal caregiver. Additionally, future studies should explore the perspectives of the various stakeholders including mental health professionals, religious organisations, government, and community organisations on their role in supporting informal caregivers of persons with SMDs in resource-constrained contexts.

Data Availability Statement

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

Disclosure

The statements made and views expressed are solely the responsibility of the authors.

Conflicts of Interest

The authors declare no conflicts of interest.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.

Supporting Information 1. File S1: Outline of the interview schedule that was used to guide the semistructured interviews with the participants in this study.

Supporting Information 2. File S2: Concept map which provides a visual summary demonstrating the links between the themes, subthemes, and codes generated during the data analysis process of this study.

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