



The Open Public Health Journal

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RESEARCH ARTICLE

What Support do family Caregivers For Mental Health Care Users Receive From Healthcare Professionals And Family Members? A Qualitative Study

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Abstract:

Background:

Due to the mental health reforms in developed countries, the focus of mental healthcare services has shifted from hospital-based to community-based care. This suggests that family members are expected to care for their Mental Health Care User (MHCUs). This study aimed to explore the support caregivers for MHCUs receive from healthcare professionals and other family members.

Methods:

The participants were conveniently selected from the primary healthcare centres. Unstructured interviews were conducted with twelve family caregivers. Data were analyzed using Tesch's open coding method. Ethical issues and trustworthiness were followed throughout the study.

Results:

The study revealed two themes, poor support from healthcare professionals and poor support from family members, and seven sub-themes.

Conclusion:

There is a dearth of information about the support offered to family caregivers of MHCUs in the context of South Africa. Training programs for caregivers are recommended to improve psychological well-being and social support while decreasing the caregiver burden.

Keywords: Caregivers, Family members, Healthcare professionals, Mental healthcare users, Mental illness, Supportive role.

Article History

Received: September 29, 2022

Revised: December 30, 2022

Accepted: January 11, 2023

1. INTRODUCTION

Mental illness can affect any person at any stage of life. It is one of the chronic diseases that hamper an individual's economic productivity [1]. Patel *et al.* [2] noted that mental health has long been neglected globally, especially in developing countries where understanding mental illness may indicate mental health illiteracy. The prevalence of mental illness in South Africa seems to be on the rise and needs drastic action by healthcare professionals [3].

A recent report by the South Africa Human Rights Commission on the status of mental health services (2019) maintained that mental health has a major impact both on individuals and on the general population. The recent incident

in Gauteng Province, where over 94 mental healthcare users tragically died, has cast a spotlight on mental healthcare and its associated systemic inadequacies [4].

In the USA, two-thirds of mentally ill American adults are parents [5]. Therefore, this places the responsibility of caring for them on their children's shoulders and on other family members who become their caregivers. Due to the mental health reforms in developed countries, the focus of mental healthcare services has shifted from hospital-based to community-based care [6]; this suggests that family members, particularly spouses, siblings, and children, are expected to care for their MHCUs. However, this has created certain challenges for these caregivers because they lack the proper training in this role.

Expectedly, family caregivers look forward to receiving support from healthcare professionals, namely, doctors, nurses, psychologists, and social workers, in caring for their MHCUs.

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Contrarily, a study done in Australia and New Zealand indicated that family caregivers felt that healthcare professionals overlooked them when making decisions regarding the care of MHCUs [7]. The study in Saudi Arabia also revealed that the burden of care was higher on family caregivers since they did not receive the support they required [8]. Consequently, one of the roles of healthcare professionals could be to prepare and support family caregivers caring for MHCUs.

The importance of caring for MHCUs in the community cannot be undermined. Tyler *et al.* [9] reviewed various interventions intended to ensure continuity of care following the discharge of MHCUs to the community. Despite interventions such as counselling, social service support, and home visits by home-based carers, the support family caregivers expected from the healthcare professionals and family members were perceived to be inadequate. However, visits to the homes of family caregivers by a nurse or social worker were significant in reducing the re-admissions of MHCUs [10]. Those interventions helped stabilize the MHCUs, enabling and assisting the family caregivers in caring for their MHCUs.

A recent Canadian study [11] found that the referral of discharged MHCUs to high-intensity outpatient programs helped reduce re-admissions. Also, in China, psychiatric rehabilitation helped to re-integrate MHCUs back into society [12]. Furthermore, psychosocial support programs in Iran helped increase the skills of family caregivers in managing the different caregiving situations; subsequently, as family caregivers' problem-solving skills improved, their anxieties decreased [13].

A 2020 study indicated that when Non-governmental Organisations in Romania provided home visits and telephonic support to MHCUs, it reduced relapse rates [14]. In addition, healthcare professionals facilitated support groups for family caregivers, alleviating their psychological pressure [15].

In another study, family caregivers who received professional support showed lower caregiver burdens and positive psychological well-being [16]. Similarly, family therapy improved their quality of life [13, 17]. In Ethiopia, nurses' negative attitude towards MHCUs resulted in the latter and their familial caregivers not receiving the support they had anticipated [18]. Caregiving is a responsibility that burdens family caregivers; therefore, professional support is crucial. However, despite this much support being considered essential, family caregivers continue to receive minimal support from healthcare professionals in general [19].

In contrast to Ethiopia, similar studies showed that nurses in Ghana supported patients and their caregivers. However, MHCUs assaulted and threatened nurses during home visits [20]. Therefore, these healthcare workers could provide neither their patients nor the caregivers with the necessary professional support because they feared for their lives. Likewise, South Africa has introduced a system of treatment partner and family psycho-education strategies to reduce the number of relapses of MHCUs and support family caregivers to reduce the burden of care falling solely on them [21]. However, there is scant

research on the support received by caregivers within the South African context; hence the present study seeks to explore how healthcare professionals and other family members provide support to caregivers for MHCUs. The study endeavors to answer the question, 'what support do family caregivers for MHCUs receive from health care professionals and other family members?'

2. METHODS

2.1. Study Setting and Design

The study was conducted in the Vhembe District, South Africa. Vhembe is one of the five districts within Limpopo province and is located in the north of the province and shares borders with the districts of Capricorn and Mopani to the east and west, Zimbabwe to the north, Mozambique through Kruger National Park to the east and Botswana to the northwest [22]. The district has a total population of 1,393,949 people. Fifty-four percent of the total population are women and 46 percent are men. About 56.2% fell below the poverty line, lower than 840 RR/person/month [23]. Healthcare within the district is provided by 116 Primary healthcare clinics and 8 Primary healthcare centres.

This study used a qualitative, exploratory, and descriptive research design. The descriptive qualitative approach is useful in providing understanding and summarising an area of interest and was appropriately selected for this study to explore and describe support provided to family caregivers of mental health users by health care professionals and other family members. This approach enabled the researchers to gain a more in-depth insight into how the healthcare professionals and other family members of mental healthcare users support caregivers. It also allowed the first author to observe non-verbal cues from the caregivers of MHCUs during the interviews.

2.2. Sampling of Health Facilities and Study Participants

The study population was comprised of the family caregivers of MHCUs. Non-probability sampling was used to select four Primary healthcare centres based on the high rate of defaulters. The participants were selected using convenience sampling in the selected primary healthcare centres in the Vhembe District as they accompanied the MHCUs to the facility to collect treatment. Twenty-four family caregivers of MHCUs who defaulted treatment were sampled, six per primary healthcare centre. The first author personally invited them to participate in the study considering the distance and accessibility of families. None of them refused to participate. In addition, participants were both male and female, 18 years and older, and stayed with MHCUs at the time when this study was conducted. The researchers assumed that the defaulting could denote challenges for MHCUs and their caregivers. In this light, the researchers endeavored to explore how healthcare professionals and other family members support caregivers for mental healthcare users in the family. Although there is no norm for the greatest number of MHCUs in qualitative research as a result of its temperament, the researchers in this study have recognized a sample size of 12 to be sufficient as saturation of data was achieved before the twenty-fourth participant.

2.3. Data Collection

The study used an in-depth individual interview to elicit variations in caregivers’ experiences regarding the support they receive from healthcare professionals and family members. The first author obtained participants’ informed consent before conducting interviews in their homes. In addition, the principles of autonomy, respect, confidentiality, beneficence, and maleficence were observed. The interviewer asked a broad question during the interview to begin the discussion. The following question was used to guide the interview. “What support do you receive from health care professionals and other family members when providing care to the MHCU at home?” The question was developed in English and translated into three local languages (Tshivenda, Xitsonga, and Sepedi). This was followed by probing questions to solicit more information from the participants. The interviews were conducted between September and November 2020 by a male professional nurse who was a master’s student at the time of data collection. Each in-depth individual interview took about 30 and 45 minutes. It needs to be stated that the interviewer and the participants were not related in any way, and Coronavirus protocols were followed. Furthermore, throughout the interview, the researcher paid interest to non-verbal facts such as moods, tone of voice, facial expressions, and the incidents associated with the phenomenon under study to record data. In addition, interviews were voice recorded using a voice recorder with participants’ permission to ensure the quality and validity of the data. Twelve participants were interviewed and considered to be adequate due to data saturation, a situation where no new information emerged. No repeat interviews were conducted.

2.4. Data Analysis

After the audio records were listened to severally and transcribed verbatim, it was read repeatedly to make sense of the participants’ experiences. The transcripts which were proofread were positioned in categories. The researchers analyzed data using Tesch’s eight steps of data analysis. After the analysis, themes and sub-themes were identified followed by the procedure suggested by Creswell [24]. The first author returned to the caregivers to provide feedback about preliminary findings and establish their reactions.

2.5. Trustworthiness

Trustworthiness was maintained throughout the study by using four concepts from Lincoln and Guba (1985), as cited by [25]; namely, credibility, dependability, confirmability, and transferability. Firstly, to ensure credibility, the researcher created a trusting relationship with participants, whereby participants were free to express themselves in their own vernacular; in addition, the researcher had prolonged engagement with the participants during the interview sessions. To ensure transferability, selected participants were representative of the population and its characteristics. Dependability was achieved using a voice recorder and field notes during the data collection to ensure accuracy; moreover, hard copies of transcripts, observations, and field notes were kept ensuring an audit trail. Lastly, confirmability was ensured by recording the true responses of the participants. This was achieved by triangulation, using a voice recorder, observation,

and field notes.

2.6. Ethical Approval

The Research Ethical Committee of the University of Venda approved the study (Ref: SHS/19/PDC/43/0811). The Limpopo Provincial Department of Health and District Municipality’s health department granted permission to conduct the study. Participants were fully informed about all aspects of the study through an information letter given to them before they consented to participate. They were assured that the information shared would not be linked to any of them as pseudonyms would be used. They were informed that they could terminate their participation at any interview stage if they became uncomfortable.

3. RESULTS

3.1. Demographic Characteristics of Participants

Twelve participants participated in this study. The age range of the participants was 30-60 years. Eleven participants were females, and one was male. Six participants were married, three were single, two were widowed, and one was divorced. Six of the twelve participants were unemployed; three were employed, and three were pensioners. All participants were immediate family members of MHCUs. Two participants were the wives of relevant MHCUs, two were sisters, one was a brother, one was a niece, and six were mothers of MHCUs. The minimum number of years the participants had cared for their MHCUs was six years. However, one specific participant had been caring for the MHCU for 39 years.

3.2. Themes and Sub-themes

Two themes and seven sub-themes emerged during data analysis, as described in Table 1 below.

Table 1. Themes and subthemes.

Themes	Sub-themes
1.1 Poor support from healthcare professionals	1.1.1 Unwillingness to motivate social grant
1.2 Poor support from family members	1.1.2 Need for experts support
	1.1.3 Lack of commitment by healthcare professionals
	1.2.1 Belittling parents by MHCUs
	1.2.2 Aggressive behavior
	1.2.3 Death of family members
	1.2.4 Lack of concern from family members

3.2.1. Theme 1: Poor Support from Healthcare Professionals

Caregivers indicated receiving inadequate support from the healthcare professionals, that is, nurses, social workers, doctors and other multidisciplinary team members. This theme comprises the following sub-themes: unwillingness to motivate social grants, the need for expert support, and the lack of commitment by healthcare professionals.

3.2.1.1. Sub-theme 1.1 The Unwillingness of Healthcare Professionals to Motivate Social Grants for MHCUs

Participants raised concerns that not all MHCUs are

receiving a permanent social grant from the government. They further indicated that the MHCUs under the qualifying national norm of 60 years are only considered for a temporary grant withdrawn when the patient's condition is stable. Participants who are experiencing this problem further indicated that they expected doctors, social workers, and nurses to motivate a permanent social grant for all MHCUs since this condition is incurable. This was asserted by the following quote:

“My son's disability grant was terminated; we went to the social workers who gave us a letter to take to the South African Social Security Agency (SASSA). At SASSA, they gave him six months grant instead of a permanent one. His doctors were supposed to have motivated for a permanent grant.” (Participant 2).

3.2.1.2. Sub-theme 1.2 Caregivers Need Support from Healthcare Experts

In addition to the unwillingness of healthcare professionals to motivate for a permanent social grant, the need for support from healthcare experts in relation to counselling, education to handle the patient during an acute stage at home, knowing signs and symptoms of relapse, and monitoring if the patient is taking the medication regularly has been raised by the study participants: *“To be honest with you I am tired, not that I don't want to take care of my brother who has completely lost his mind, wandering all over, and requiring me to guard him day and night, but I feel that I do not have the energy anymore because I am also old as you see. I wish there was someone skilled in caring for mentally ill persons to assist me in taking care of my brother or placing him in a mental hospital for good”* (Participant 4).

Another participant said: *“The nurses are not supporting us. I don't have the necessary skill to manage him. I am not a nurse, (she laughs). Nurses are trained to take care of such patients and they know what to do if they become violent.”* (Participant 2).

3.2.1.3. Sub-theme 1.3 Lack of Commitment by Healthcare Professionals

Participants revealed that nurses, and social workers, never bothered to visit them in their homes. One participant commented on providing caregivers with cell phones to regularly communicate with the healthcare nurses regarding the patient's progress and other economic challenges, as it would boost their morale. Participants also raised concerns regarding the lack of medications for MHCUs at the local clinics that require them to take these MHCUs to the hospital, which is an additional expense: *“My child relapsed because she missed her monthly injection, and the clinic nurse said that the injection was out of stock. Instead of arranging an ambulance to take us to the hospital, she showed no sign of feeling pity, she continued saying 'next' calling the next patient to come into the consulting room, and she just said that I must take her to the hospital which is 25km away from my village. I told myself that missing once is nothing, we will wait for the next stock”*. (Participant 6).

Another participant said the following excerpt to attest to the lack of commitment by healthcare professionals., *“What*

aggravates his behavior is that he does not go for check-ups at the hospital. I wish nurses can come and inject him at home as they used to do previously. At that time, he used not to be admitted frequently compared to now” (Participant 5).

Another participant said *“We 'implying to all family members' told the home-based care workers about our uncle's behavior of threatening us with a machete, implying panga or a large heavy knife used for cutting sugarcane and as a weapon. The home-based care workers told the social workers about it, the social workers came to talk to him. He convinced them that he would change, and they believed him, but they did not make follow-up on whether he changed or not”* (Participant 3).

3.2.2. Theme 2: Poor Support from Family Members

Regarding the theme 'poor support from family members, the following sub-themes were cause for concern: belittling family members by MHCUs, aggressive behavior of MHCUs, death of family members, and lack of concern from siblings.

3.2.2.1. Sub-theme 2.1 Belittling Family Members

Most participants expressed a similar experience that the patient lacked respect toward everyone in the family. One participant indicated that her son threatened to kill her if she could not give him money for drinks and cigarettes. Considering the participant's emotional state of mind and her age of 60 years, one could observe immense stress and fatigue cues. The participant was repeatedly shaking her head sideways and murmuring *'no, no, oh God I am tired'* and followed by a moment of silence and started crying. The participants further indicated that their MHCUs lack a sense of respect because they abuse drugs such as alcohol and marijuana. A new traditional drug concept 'Nyaope', which comprises a mixture of cocaine, marijuana and other chemicals undescribed was mentioned that is commonly used by their MHCUs in the surrounding villages and becoming a popular drug in the entire country.

The excerpt presented below attests to the behavior of belittling family members by the MHCU, which could be the cause of poor support from other family members.

“He undermines us, especially his father, who is also mentally ill. He says I must tell my husband to take his medication, not him. If we had other family members staying with us, I think we would be able to manage him. Our families do not support us and we need them” (Participant 8).

3.2.2.2. Sub-theme 2.2 Aggressive Behavior of MHCUs

The threats and assaults of family members by the violent MHCU were also overwhelmingly mentioned as contributing factors to poor family support.

“We used to rely on our uncle, who used to come and calm him down. But since he assaulted him, he is reluctant to help us. His aunt also does not want to be involved anymore since he accused her of killing her husband. We have no one to assist us when he becomes aggressive” (Participant 3).

Another one said: *“I cannot manage him when he becomes violent. There is nowhere I can run to as I am unable to walk. I*

have tried to get people around here, to assist me by taking him to the clinic or hospital but sometimes they refuse as they are afraid of him. They are not his relatives; therefore, they are not much concerned about him. What more can I do at my age? Whatever happens to me, is fine” (Participant 12).

The participants were asked if they were seeking assistance from police services. The response to the question by participant (12) was, “No nurse, I don’t want him to go to jail, he will be killed by other criminals, much as I feel tied sometimes, I care for him, God love him so”.

3.2.2.3. Sub-theme 2.3 Death of Family Members

The passing on of family members also came up during the interviews as the cause of the lack of family support. Participants indicated that the loss of their parents and siblings changed their lives drastically. The following excerpt from a participant confirms this:

“We are the only surviving siblings. Our parents, elder brother, and younger sister have died. Because he fights with my wife, I am the only one who is responsible for his well-being. What can I do? I cannot abandon him; he is my blood. Our parents are watching everything I do. He is my responsibility” (Participant 9).

Another participant said: “We stay being two, my younger brother died in 2015. My nephew is in Gauteng and married there. Around here, we have our aunt, but she is too old to help me. I have no one to assist me to look after my brother. I do everything for him” (Participant 4).

3.2.2.4. Sub-theme 2.4 Lack of Concern from Family Members

All the participants generally raised the lack of concern from family members and relatives. One of the female participants appeared to be stressed out facially, and was asked what else was bothering her, she indicated that other family members just don’t care about assisting her. Below is what a participant said:

“I stay with him and his sister’s children. All my children are married; they have their own homes. I try to talk to him, but he does not listen to me. His brothers do not want to get involved anymore. They are tired of his behavior. It is my responsibility; I too am tired. At my age, I have no strength anymore.” (Participant 10)

4. DISCUSSION

This study explored the support healthcare professionals and other family members provided to caregivers in caring for their mental healthcare users. Support means encouraging someone to succeed [26]. Family caregivers sometimes feel exhausted with no desire to continue caring for their MHCUs; therefore, help from healthcare professionals and family members is of paramount importance. In the current study, participants reported that healthcare professionals did not support them. Doctors were perceived as unsupportive in terms of motivating for the permanent social grant, while nurses were perceived to be unsupportive by not doing home visits. Similarly, social workers were perceived to be unsupportive as

they failed to make follow-ups when matters affecting the MHCUs were reported to them. Nurses are essential members of a multi-disciplinary team. According to Delaney [27], nurses are direct healthcare providers and constitute the largest share of the total accessible primary care workforce. Nurses provide both general and mental health care in rural and underserved areas.

Nurses are experts in the provision of care to mental healthcare users because they are trained in managing them. Furthermore, they are the first healthcare professionals MHCUs and family caregivers would meet. Therefore, family caregivers rely on them for support in caring MHCUs [28]. According to Batra *et al.* [29], caring for MHCUs is a tedious and long-term responsibility; therefore, the importance of professional support cannot be underestimated. The multidisciplinary team has the responsibility of supporting family caregivers and providing them with information related to mental illness, financial support, and how to resolve conflicts between them and MHCUs [29].

Participants also reported that in the past nurses used to go to the villages with mobile clinics and the MHCUs who did not attend the mobile clinic were followed up at their homes, and treatment was given. Currently, nurses do not provide that service, leading to an increased number of relapses which in turn causes poor mental health in caregivers. This finding is consistent with Chen *et al.* [15] and Kim *et al.* [30], who found that home visits improved treatment adherence and reduced re-hospitalization rates of MHCUs in China and Korea. Similarly, caregivers reported that social workers did not make follow-ups when the matter of threats by the MHCUs was reported to them. As indicated previously, family caregivers have not been trained to provide care to MHCUs. Therefore, healthcare providers should intervene when MHCUs threaten caregivers, as they have the necessary skills to do so. Family caregivers feel supported when healthcare professionals respond to their cries when experiencing challenges in caring for the MHCUs.

Research has shown that in countries in which family caregivers are supported by healthcare professionals, the burden of caring is bearable. Niksalehi *et al.* [31] argued that family caregivers in Iran were supported through family psycho-education therapy. The therapy improved their awareness of the mental illness, treatment compliance, and relapse-prevention strategies. In addition, the study by Opare *et al.* [21] emphasized the role of nurses in Ghana in supporting this type of caregiver, although MHCUs assaulted and threatened nurses during home visits. Nonetheless, the assaults should not discourage healthcare professionals from supporting family caregivers in their homes, instead, healthcare professionals should develop strategies to prevent the assaults. Similarly, family members in the current study should be assisted with strategies to ensure they continue with the provision of care to MHCUs.

Jeyagurunathan *et al.* [32] demonstrated that single or widowed family caregivers faced more challenges in Singapore due to the absence of a spouse who could offer support and share the distress. Spouses caring for a spouse who was an MHCU reported more psychological stress as they felt that they had lost a confidant, household co-manager, and child-

rearing assistant [32]. It could be an indistinguishable situation in the current study since most family caregivers are single due to divorce, the death of a spouse, or never married. Therefore, family cohesion is essential, especially to the family caregivers, as they would not bear the caring role alone.

Although possible reasons that prevent family members from being involved in the care of MHCUs could be aggression of the MHCUs, these should be dealt with because if family caregivers do not receive assistance, they could become stressed and suffer from depression because of continuous physical and emotional exhaustion. Therefore, a form of relief is mandatory. In Malaysia, family caregivers of advanced age who had cared for the MHCUs for longer suffered from higher stress levels [33].

5. LIMITATIONS

The study was conducted among 12 family caregivers. Secondly, the study focused on family caregivers within a rural setting. Therefore, the qualitative nature of the study and low sample size limit the generalisability of the findings.

6. RECOMMENDATIONS

There is a dearth of information about the support offered by health professionals and family members to family caregivers of mental healthcare users in the context of South Africa. Notwithstanding, this present study aimed to provide insights into support received by family caregivers of MHCUs, therefore, training programs for caregivers are recommended in order to improve psychological well-being and social support while decreasing caregiver burden. Nurses should pay attention to the emotional needs of caregivers of patients with chronic mental illnesses and provide social support. Giving caregivers information about the disorder's nature and methods for dealing with patients' problems can improve their psychological well-being and reduce feelings of burden. Family members should rotate the caring responsibilities to prevent the burnout that could lead to depression. Family unity may reduce the incidence of MHCUs threatening or assaulting one family member. Future quantitative studies should focus on caregivers or health professionals and not both. Furthermore, future studies must be conducted to explore in-depth the psychological impact of caring for violent MHCUs by family members. Introducing counseling sessions by health workers would be essential to improve the self-esteem and the worth of MHCUs in the family and community in which they live.

CONCLUSION

The current study increased our knowledge of the support offered by health professionals and family members to family caregivers of MHCUs. Family caregivers rely on Health professionals for support in caring MHCUs. The study also revealed that social workers did not make follow-ups when the matter of threats by the MHCUs was reported to them. Furthermore, doctors were unsupportive in terms of motivation for the permanent social grant. Lack of concern from other family members in assisting with certain responsibilities and caregivers lacking skills for dealing with the aggressive patient at home was revealed. Caregivers' ignorance supported the

latter to seek help from police stations. Although the study did not focus on socioeconomic factors, the family setting could tell that some of the caregivers live in a poverty-stricken environment.

LIST OF ABBREVIATIONS

(MHCUs) = Mental Health Care User

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The study received ethical approval from the University of Venda Ethics Committee (Ref: SHS/19/PDC/43/0811).

HUMAN AND ANIMAL RIGHTS

No animals were used for studies that are the basis of this research. All the humans were used in accordance with the ethical standards of the committee responsible for human experimentation (institutional and national), and with the Helsinki Declaration of 1975, as revised in 2013 (<http://ethics.iit.edu/ecodes/node/3931>).

CONSENT FOR PUBLICATION

All family caregivers voluntarily participated in this study and gave informed consent.

AVAILABILITY OF DATA AND MATERIALS

Data presented in this study can be obtained from the first author [N.R.] on reasonable request.

FUNDING

None.

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial and otherwise

ACKNOWLEDGMENTS

Our gratitude goes to caregivers of mental healthcare users.

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