



## Lived experiences of family members caring for a relative with mental illness

Mihloti Eunice Shimange, Marie Poggenpoel, Chris P.H. Myburgh, Nompumelelo Ntshingila\*

University of Johannesburg, South Africa

### ABSTRACT

**Background:** Mental illness may cause a variety of psychosocial problems, such as decreased quality of life for the affected individual's family members and an increased social distance for the individual and family members caring for a relative with mental illness.

**Purpose:** To gain an understanding of the lived experiences of family members caring for a relative with mental illness in Giyani, Limpopo province.

**Design and Methods:** A qualitative, exploratory, descriptive and contextual research design was utilised. Data were collected through in-depth individual interviews with eight participants, observations, and field notes. Data were analysed utilising Tesch's open-coding method, and an independent coder assisted in the analysis process.

**Results:** The results revealed that family members caring for a relative with mental illness were alert about safety aspects related to their relative with mental illness. Participants experienced that their relative was not mentally stable, as evidenced by erratic behaviour. They also experienced challenges in caring for a relative with mental illness and engaged coping strategies in caring for a relative with mental illness.

**Conclusion:** Based on the findings from this study, it was recommended that support interventions for these families by providing mental health education, strengthening the families' existing coping strategies, and building their resilience. The implications for practice for psychiatric nurses and stakeholders in social services were highlighted in supporting the families of relatives with mental illness.

### 1. Introduction

Mental illness refers to conditions that involve changes in emotions, thinking or behaviour and are associated with distress and/or problems functioning in social, work or family activities (American Psychiatric Association, 2020). Mental illness may cause a variety of psychosocial problems such as decreased quality of life for the affected individual's family members, as well as an increased social distance for the individual and family members caring for them (Ae-Ngibise, Korley, Asante, & Owusu-Agyei, 2015).

Mental illness has been recognised as a major source of disability. Persons with mental and psychosocial disabilities represent a significant proportion of the world's population (United Nations, 2021). Globally, it is estimated that 450 million people are affected by mental illness at any given time. These include 121 million people with depression, 24 million with schizophrenia, and 37 million with dementia. Mental illness accounted for 12.3% of the global burden of disease in 2001, and it is estimated that by 2020, depressive disorders will be the second-highest cause of disability (World Health Organization (WHO), 2011). In Africa, between 2000 and 2015, the continent's population grew by

49%, yet the number of lives lost to disability because of mental and substance use disorders increased by 52%. According to Sankoh, Sevalie, and Weston (2018), 17.9 million lives were lost to disability due to mental health problems in 2015. These alarming figures indicate the seriousness of mental illness globally.

According to evidence from some developing countries, there is a high prevalence of individuals with mental illness living with family members (WHO, 2011) who serve as their primary caregivers. It is expected that this burden is more severe in low-income countries as it is aggravated by poverty; consequently, family members suffer psychologically and socially due to caring for a relative with mental illness (Ae-Ngibise et al., 2015). While mental illness is treatable and full recovery is often possible, caregiving responsibilities frequently fall to family members. Approximately one to two-thirds of adults diagnosed with a major mental illness live with or receive primary care from their family members (Castevens, 2011). In the USA and the Peoples' Republic of China (Iseselo, Kajula & Yayha-Malima, 2016), 70% and 93% of psychiatric outpatients live with their families, respectively.

Monyaloue, Mvandaba, Du Plessis, and Koen (2014) state that the burden of caring for relatives with mental illness falls on family

\* Corresponding author at: P.O. Box 524, Auckland Park 2006.

E-mail addresses: [shim3b@gmail.com](mailto:shim3b@gmail.com) (M.E. Shimange), [poggenpoelmarie@gmail.com](mailto:poggenpoelmarie@gmail.com) (M. Poggenpoel), [chrism@uj.ac.za](mailto:chrism@uj.ac.za) (C.P.H. Myburgh), [mpumin@uj.ac.za](mailto:mpumin@uj.ac.za) (N. Ntshingila).

<https://doi.org/10.1016/j.ijans.2022.100408>

Received 3 September 2021; Received in revised form 10 February 2022; Accepted 14 March 2022

Available online 19 March 2022

2214-1391/© 2022 The Author(s). Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

members who provide all the necessary support to these individuals. Family members thus take the most prominent role in caring for people with mental illness (Udoh, Omorere, Sunday, Osasu, & Amoo, 2021), and most of these family members are overburdened by their caregiving role.

Various studies have been conducted in South Africa focusing on family members' experiences of caring for a relative with mental illness. A quantitative study was conducted by Magadla and Magadla (2014) in the Eastern Cape, Mdantsane. The authors (Magadla & Magadla, 2014) described the effects of mental illness on the relationships between mental healthcare users and their families, relatives and friends. Another study was conducted in the North West Province by Tlhowe, du Plessis, and Koen (2017), focusing on family members' strengths to limit mentally ill relatives' relapse. Another study conducted in the iLembe District of KwaZulu-Natal Province explored the stigma-related experiences of family members of persons with mental illnesses (Nxumalo & Mchunu, 2017). However, in the context of Giyani, Limpopo Province, South Africa, little is known about the experiences of family members caring for a relative with mental illness. Through observations and conversations with family members caring for relatives with mental illness who were admitted to the psychiatric unit where the researcher (first author) worked, she became aware that they find it difficult and stressful to care for their relatives with mental illness. A study was thus conducted since stigma against families with a mentally ill relative still exists in rural areas, and the healthcare services are limited (Nxumalo & Mchunu, 2017). Therefore, families have an even greater responsibility to provide support and primary care to a family member caring for a relative with mental illness.

The purpose of the research was to gain an understanding of the lived experiences of family members caring for a relative with mental illness.

## 2. Methods

The researcher followed a qualitative research method in the study on which this article is based. Qualitative research is defined as a method that elicits a participant's account of meaning, experience or perceptions (Creswell, 2014). It also produces descriptive data in the participant's own written or spoken words (De Vos, Fouché, Strydom, & Delpont, 2011). The researcher explored and described the lived experiences of family members caring for a relative with mental illness. The researcher followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines to report on this study.

### 2.1. Study design

A qualitative, exploratory, descriptive and contextual research design was applied (Creswell, 2014) to capture the essence of family members' lived experiences of caring for a relative with mental illness. The researcher also followed a descriptive phenomenological approach in this study (Gray, Grove, & Sutherland, 2017) to describe the lived experiences of family members caring for a relative with mental illness. The researcher bracketed her own preconceived opinions according to Husserl's descriptive phenomenological approach (Reiners, 2012). Reiners (2012) is of the view that the qualitative approach creates an opportunity for researchers to thoroughly explore phenomena under study. According to Gray et al. (2017), the purpose of a phenomenological research approach is to describe experiences as they are lived.

### 2.2. Study setting

The researcher worked at a public psychiatric hospital in Giyani, Limpopo Province, South Africa. Giyani is a city surrounded by several villages and administered by the Greater Giyani Municipality, Mopani District (Municipalities of South Africa, 2021). The public psychiatric hospital has 400 beds, of which 394 were in use at the time of data collection. The public hospital admits individuals with different mental

health problems. This public psychiatric hospital has eleven wards and provides services to involuntary and assisted mental health care users. The institution offers specialised psychiatric services to inpatients. The selected public psychiatric hospital has 75 professional nurses, 77 enrolled nursing assistants and 31 enrolled nurses. The staff of this public psychiatric hospital also include medical officers, clinical psychologists, occupational therapist, social workers and pharmacists.

### 2.3. Participants, sample and sampling

The study population was all family members caring for a relative with mental illness. This population was accessible to the researcher as she worked in the public psychiatric hospital where individuals with mental illness were repeatedly admitted, and their family members came to visit them. The researcher decided on a non-probability purposive sampling method (Gray et al., 2017), which involves the researcher's conscious selection of certain participants to be included in a study. The criteria for sampling included all family members caring for a relative with mental illness who were admitted to the public psychiatric hospital where the study was conducted. Participants had to meet the following inclusion criteria:

- Participants could either be male or female
- Participants had to be living with the relative with mental illness
- Participants had to visit their relative with mental illness
- Participants had to be 18 years or older
- Participants had to be able to communicate either in English, Xitsonga, Venda, or Sotho.

Participants were excluded due to the following exclusion criteria:

- Participants who were family members not living with a relative with mental illness
- Participants who did not visit their relative with mental illness
- Participants who were younger than 18.

The family members caring for relatives with mental illness were recruited from the public psychiatric hospital in Giyani, where their relatives were admitted. The unit managers of the wards were asked to identify family members caring for a relative with mental illness when they came to visit their relatives and invite them to participate in the study. The unit managers followed the inclusion and exclusion criteria stipulated by the researcher. The unit managers identified fifteen family members caring for their relatives with mental illness who met the inclusion criteria. The unit managers were requested to inform the family members of the research study and that their contact information would be provided to the researcher. Eight family members accepted the request to participate in the study. The researcher contacted the family members telephonically to make arrangements to interview them.

### 2.4. Data collection

In-depth, individual interviews were conducted where the researcher explored and described the phenomenon and used bracketing to avoid bias in the research. The researcher was a psychiatric nursing student at the time of the investigation with experience in conducting interviews. The researcher explained the purpose of the study to the participants prior to obtaining informed consent. Information letters were given to the family members who participated in the study. Data collection started on 12 October 2018 and was completed on 21 February 2019. The interviews were conducted on different dates at the participants' homes. These were informal and less threatening for the participants, who were allowed to talk freely.

The interview sessions lasted 40–60 min and were audio-recorded with permission from the participants. Only the participant and the researcher were present to ensure privacy. The relatives with mental

illness were at the public psychiatric hospital during the interviews. Moreover, field notes were written to support the recorded interviews. The researcher kept records of her observations. The researcher observed non-verbal cues behaviour and the dynamics of the participants, which was clarified verbally with the participants. The researcher had one main question for participants: "What is it like caring for a relative with mental illness?" Follow-up questions, probing, and minimal verbal responses were used to confirm participants' statements (De Vos et al., 2011). Confidentiality was ensured by using codes to identify the interviews. The researcher safely stored all written information and audio-recordings obtained during data collection. The recorded data was put into a password-protected file accessible to the researcher. During the process of conducting the interviews, three research supervisors reviewed each of the interviews. The three supervisors have extensive knowledge of qualitative research.

### 2.5. Data analysis

Data were analysed using Tesch's open-coding method, which comprises eight data analysis steps (Creswell & Poth, 2018). The researcher read all the transcriptions, observations and field notes to get a sense of the data or ideas, then jotted down essential facts as they came to mind. The researcher identified and read the collected data and tried to figure out what it was all about to determine the underlying meaning of the content. After going through all the collected data, the researcher clustered similar topics together and separated those that were unique. In this study, the researcher read all the transcripts from the interviews and highlighted sentences in the data, labelled in the margin according to the themes displayed in the highlighted narratives. Each sub-theme was clustered into themes and named according to the themes represented by the quotes. Data were coded. The researcher marked topics as abbreviated earlier, placed these into coding, and compared data to ensure that no themes were left out. The researcher then grouped data related to reducing the number of sub-themes. The researcher used a table to summarise the identified themes and sub-themes. The researcher made the final decision and ensured that all sub-themes were correctly placed. Data were interpreted at this stage when the researcher analysed the meaning of the collected data. This was done after the researcher had assembled data from each sub-theme (Creswell & Poth, 2018:198). During data analysis, the researcher went through the transcribed interviews and highlighted significant statements, sentences or quotes that provided an understanding of the lived experiences of family members caring for a relative with mental illness. Direct quotes were also extracted from the transcriptions of the in-depth, individual interviews and field notes.

After analysing all the collected data, which consisted of recorded interviews, field notes and observations, these were given to an independent coder. The independent coder – who holds a PhD and is an advanced psychiatric nurse – was purposively selected based on their experience in the qualitative research approach using the same protocol for data analysis, separately from the researcher. The researcher and the independent coder then met for a consensus discussion on the results of the data analysis. The researcher and the independent coder reached an agreement on the identified themes and sub-themes.

### 2.6. Trustworthiness

Lincoln and Guba (2013) description of trustworthiness was adhered to throughout the study. Trustworthiness is confirmed when the findings provide rich descriptions of participants' lived experiences of the phenomenon under investigation, as substantiated by participants (Gray et al., 2017). Measures to ensure trustworthiness include credibility, transferability, dependability and confirmability. To ensure credibility, the researcher adhered to prolonged engagement by conducting the interviews for four months. The researcher also used multiple sources of data collection, namely in-depth individual interviews, field notes and

observations. The researcher engaged in peer debriefing with three supervisors with extensive knowledge and experience in qualitative research. Member checking was also informally undertaken during interviews, where participants were involved in clarifying and summarising their views. To ensure transferability, the researcher purposively selected participants and documented a dense description of the research process. Dependability was promoted by describing all aspects of the study, including the research method, characteristics of the sample and process, and data analysis. The researcher enhanced confirmability by keeping the documents of the audio-recorded interviews, transcribed materials, and field notes as audit material.

### Ethical approval

This study was approved by the Faculty of Health Sciences Research Ethics Committee (reference number REC-01-92-2018), Faculty of Health Sciences Higher Degree Committee (Reference Number HDC-01-71-2018), The National Health Research Database in LP\_2018 and the Limpopo Department of Health S4/2/2. Permission to conduct the study at the hospital was granted by the Head of the Institution.

Human participants were involved in the research and, as such, their rights were protected, so ethical principles were identified and adhered to. Dhai and McQuoid-Mason (2011) indicate there are four principles to be considered when conducting research, namely autonomy, beneficence, non-maleficence and justice. These principles were all adhered to throughout the research project.

## 3. Results

Eight participants who were family members caring for a relative with mental illness participated in the study. Seven participants were women, and one was a man. The participants were between the ages of 43 and 68. Five participants were married, two were single, and one was widowed. The family members who met the inclusion criteria of caring for a relative with mental illness, and who were 18 years and older, were invited to participate. Data were saturated at the sixth interview, and two more interviews were conducted to confirm the themes. A summary of the participants' demographics is presented in Table 1, while Table 2 summarises the themes and sub-themes that emerged from the collected data.

**Table 1**  
Summary of the participants' demographic details.

Participant	Gender	Age	Years in caring	Marital status	Relationship to the relative with mental illness
Participant 1	Male	60	52	Married	Brother
Participant 2	Female	53	35	Single	Mother
Participant 3	Female	67	48	Married	Sister-in-law
Participant 4	Female	50	30	Single	Mother
Participant 5	Female	68	18	Widowed	Mother
Participant 6	Female	49	21	Married	Mother
Participant 7	Female	43	24	Married	Mother
Participant 8	Female	67	47	Married	Sister-in-law

**Table 2**

Themes and sub-themes of the lived experiences of family members caring for a relative with mental illness.

THEMES	SUB-THEMES
Family members experienced being alert about safety aspects related to their relative with mental illness	<ul style="list-style-type: none"> <li>Family members experienced frequent risk assessments of their immediate surroundings               <ul style="list-style-type: none"> <li>Family members experienced the need to provide better security</li> </ul> </li> </ul>
Family members experienced that their relative was not mentally stable, as evidenced by erratic behaviour	<ul style="list-style-type: none"> <li>Family members experienced that their relative with mental illness had childlike behaviour               <ul style="list-style-type: none"> <li>Family members experienced that their relative with mental illness displayed uncontrollable behaviour</li> </ul> </li> </ul>
Family members experienced challenges caring for a relative with mental illness	<ul style="list-style-type: none"> <li>Family members experienced financial challenges               <ul style="list-style-type: none"> <li>Family members experienced caring challenges, which resulted in feeling obliged to care and exhaustion                   <ul style="list-style-type: none"> <li>Family members experienced rumours being spread by community members</li> </ul> </li> </ul> </li> </ul>
Family members engaged coping strategies in caring for a relative with mental illness	<ul style="list-style-type: none"> <li>Family members experienced support from extended family members               <ul style="list-style-type: none"> <li>Family members experienced coming to a realisation about the mental illness, and accepting the reality that it was a lifelong responsibility</li> </ul> </li> </ul>

### 3.1. Family members experienced being alert about safety aspects related to their relative with mental illness

#### 3.1.1. Family members experienced frequent risk assessments of their immediate surroundings

The participants believed they were at risk of being injured or killed by their violent and aggressive relative with mental illness; as such, families lived in fear. Some participants reported they were attacked by their relatives with a mental illness. Family members also described that their relative with mental illness was not safe from the community.

Community members often believed the affected individual was not mentally ill but simply being destructive due to the abuse of drugs. As a result, community members ended up hurting them. This necessitated frequent risk assessments of the relative with mental illness and their surroundings. This finding was supported by the following direct quotations:

*“Sister M it is very much safe here at home because the gate is always locked. I believe you also found it locked. When she is at home, I have to check all the time what she is doing. If I don't check her people may harm her. They think his using drugs”* (P1, 60 years old, brother)

*“I feel very much unsafe sometimes when she is around me. She becomes violent towards the family and community. I don't like to leave her alone at home, because I always want her to be safe”* (P2, 53 years old, mother)

Another participant reported that the safety of her relative with mental illness was at risk as some people hated them or talked bad about them. The participant was scared people might poison her relative with mental illness:

*“Sometimes we are scared about her safety since they poison people in our community. She also walks around a lot, so her safety is not guaranteed, sometimes people hate a person who always ask for food. I must know what she is doing and where she is all the time”* (P3, 67 years old, sister-in-law)

#### 3.1.2. Family members experienced the need to provide better security

The participants described the need to provide better security for their relative with mental illness. This is evident in the following direct

quotations:

*“You see! I decided to stop working in Johannesburg to stay here all my life! I will make sure that I see her from morning every day, I cannot live her alone because when I leave her who is going to look after her because it is not safe?”* (P7, 43 years old, mother)

*“I stayed fulltime here at home and when she wanted to go out I made sure that I go with her wherever she wanted to go”* (P2, 53 years old, mother)

### 3.2. Family members experienced that their relative was not mentally stable, as evidenced by erratic behaviour

#### 3.2.1. Family members experienced that their relative with mental illness had childlike behaviour

The participants mentioned that their relatives with mental illness often displayed behaviours that were only acceptable for children. The participants seemed disturbed by these behaviours. They explained:

*“X is an adult, but her behaviour is equivalent to a child of five years”.* (P1, 60 years old, brother)

*“The truth is that X will never do anything on his own, you must tell him to take a bath and other things”.* (P2, 53 years old, mother)

Another participant mentioned:

*“When he is not in the hospital, he often picks up things on the road and brings them home and plays with them”* (P6, 49 years old, mother)

#### 3.2.2. Family members experienced that their relative with mental illness displayed uncontrollable behaviour

During the interviews, family members related that their experience of caring for a relative with mental illness was challenging. They indicated they sometimes had to deal with difficult situations where they believed their relative with mental illness was misbehaving on purpose. One participant stated:

*“Everything started when she was about to start schooling. She will be very angry for no reason, hit herself on the ground and became very powerful.”* (With a concerned expression on her face) (P3, 67 years old, sister-in-law)

Another participant relayed:

*“I love my boy very much and I try my level best to give him whatever he want but he does not see it. If you can see him when he is angry, the way he looks at me you can be scared. He has this anger face with red eyes, and I cannot stand it.”* (P6, 43 years old, mother)

### 3.3. Family members experienced challenges caring for a relative with mental illness

#### 3.3.1. Family members experienced financial challenges

Financial challenges were a concern for almost all the participants. They indicated that they had limited time to work and provide for their family as they had to look after their relative with mental illness. They shared that their small income was mostly from their relative with mental illness' disability grant and part-time jobs. Some depended on child support grants as well as disability grants for their relatives with mental illness for survival, as they had no other source of income. Participants shared:

*“I have piece-jobs because when I look at the money that my sister is receiving meanwhile I also have kids' neh!”* (P1, 60 years old, brother)

*“The grant that she is receiving is only R1700.00 and it is not enough to cover all the expenses in the house.”* (P4, 50 years old, mother)

Another participant mentioned:



*"My husband and I we don't work, my husband is receiving a social grant. We use his social grant money to pay for other expenses."* (P8, 67 years old, sister-in-law)

*"This is my gift from God, I must do everything within my means to take care of her forever."* (P6, 49 years old, mother)

### 3.3.2. Family members experienced caring challenges, which resulted in feeling obliged to care and exhaustion

During the interviews, most participants indicated that caring for a relative with mental illness was not easy and time-consuming. They stated they found it difficult to care for a relative with mental illness and themselves at the same time. This finding was supported by the following direct quotations:

*"When he is back from the hospital, I can't even go to meet with other women of my age group since I must take care of him."* (P2, 67 years old, sister-in-law)

*"When the mother was still alive she used to remind me that I must continue to take care of him even when she is dead."* (With a sad face) (P3, 67 years old, sister-in-law)

### 3.3.3. Family members experienced rumours being spread by community members

During the interviews, participants shared that they experienced gossip from community members as disturbing, and it was affecting them; especially since some of the gossip was also from close relatives. Participants reported community members made nasty comments about them because they are related to someone with mental illness. Other community members treated the relative with mental illness strangely whenever they came to their home. These claims are supported by the following quotations:

*"People are talking a lot since they don't know the challenges here at home."* (P1, 60 years old, brother)

*"I'm now a bad person here in the community when I allow the child to play outside. They believe that I do it intentionally for her to hurt or scare other kids."* (P4, 50 years old, mother)

*"Other members of the community think the child just behave like this because he likes fighting."* (P7, 43 years old, mother)

### 3.4. Family members experienced engaged strategies in caring for a relative with mental illness

#### 3.4.1. Family members experienced support from extended family members

Some participants reported receiving support from extended family members; for instance, one participant referred to his wife, who helped look after their relative with mental illness. Another participant reported that her siblings were supportive of her and her relative with mental illness:

*"This woman is the person that I am talking about neh! (pointing at his wife). Which means according to me even if I can die, there is a person who can remain and look after X."* (P1, 60 years old, brother)

*"My siblings know much about my challenges, and they are even available to assist."* (P4, 50 years old, mother)

#### 3.4.2. Family members experienced coming to a realisation about the mental illness, and accepting the reality that it was a lifelong responsibility

Participants reported that they accepted their relative with mental illness. This helped them in coping with the situation. Participants explained:

*"I have accepted this situation since I know where everything started."* (P7, 43 years old, mother)

*"Even though I have some challenges, I must just accept for life to go on."* (P3, 67 years old, sister-in-law)

## 4. Discussion

The identified themes and sub-themes in this study (see [Table 2](#)) were derived from the participants' direct quotes. Field notes and observations were included in the results. It was determined that family members caring for a relative with mental illness experienced being alert about safety aspects related to their relative with mental illness. They shared that their relative was not mentally stable, as evidenced by erratic behaviour. They also experienced various challenges in caring for their relative with mental illness, and engaged some coping strategies in their caring role.

In this study, it was found that participants conducted frequent risk assessments to ensure their relative with mental illness' safety. This finding is supported by a study conducted in Ghana and Tanzania ([Ise-selo, Kajula, & Yahya-Malima, 2016](#)), where family members were concerned about their relative's safety, which resulted in anxiety. In this study, anxiety was demonstrated by participants' frequent risk assessments. The family members felt the need to conduct these risk assessments because they were afraid someone might harm their relative with mental illness, or that the relative with mental illness may be aggressive or violent towards others. [Desmarais et al. \(2014\)](#) and [Tsigebrhan, Shibre, Medhin, Fekadu, and Hanlon \(2014\)](#) agree that people with mental illness are more likely to be victims of violence than victimising others. However, it is also known that at least 40% of family members have experienced violence at the hands of a relative with mental illness since the onset of the illness ([Labrum & Solomon, 2017](#)).

The participants shared that their relatives with mental illness displayed erratic behaviour, described as childlike and uncontrollable. Stereotypical characterisations of intellectual disability often elicit perceptions of vulnerability, childlike innocence, and dependency ([Ditchman, Lee, Kosyluk, & Jones, 2016](#)). The participants' experiences of their relative not being mentally stable based on their erratic behaviour were in keeping with the findings of other studies conducted in different contexts. [Trondsen \(2012\)](#) confirms families are concerned about the behaviour of their relative with mental illness and sometimes even fear the individual's unpredictable and socially unacceptable behaviour. [Rose \(2011\)](#) stated that many families have the frightening experience of realising they have no control over their relative with mental illness, especially if they display unacceptable behaviour. A study by [Monyaloue et al. \(2014\)](#) stated that family members caring for relatives with mental illness were concerned with some of their relatives' behaviours. These concerns related to verbal abuse, damage to property, poor personal hygiene and disrupting other people's lives, as well as roaming around aimlessly. Unusual or strange behaviour was described as any behaviour that was not appropriate to the circumstances. It occurred when a person was unnaturally moody, aggressive, euphoric, or mild-tempered. Moreover, individuals with mental illness frequently acted impulsively. According to [Kay, Poggenpoel, Myburgh, and Downing \(2018\)](#), family members are unaware of the unpredictable behaviours that their relatives may experience, and these behaviours often lead to confusion and the destruction of relationships between family members and their relatives with mental illness.

The participants in this study mentioned experiencing challenges in caring for their relatives with mental illness. This theme was congruent with existing literature from a study conducted by [Mokgothu, Du Plessis, and Koen \(2015\)](#). These authors indicated that family members caring for relatives with mental illness need to be empowered, even though they had the strength and were acknowledged for taking care of their relatives financially, emotionally and physically. In this study, family members caring for relatives with mental illness reported often being unable to generate an income and frequently relied on the financial support of their relative's disability grant to meet their basic needs. This

finding is similar to the study conducted by Isasele, et al. (2016), where family members of relatives with mental illness used grants to pay for any health expenditure associated with mental illness, as they could not work and care for their relatives at the same time.

In a review of family carers' role in cases of severe mental illness, Rowe (2012) summarised the obligations of a family carer. Rowe (2012) suggested that they provide safe care while balancing involvement, risk management, information sharing, and knowledge acquisition. Providing care reduced carers' own free time and social activities (Fiorello & Sabatini, 2011; World Health Organization, 2003). These findings were similarly evident in this study, where participants mentioned they did not have the time to socialise with their peers. Instead, they were involved in the emotional and physical work of sustaining caring, comfortable and loving relationships with their relative with mental illness. Rowe (2012) further adds that the role of family members entails more instrumental support, such as engaging in shared activities, accompanying affected family members socially and to medical and support service appointments, and so on.

McCann, Bamberg, and McCann (2015) relayed that family members of mentally ill relatives found their roles emotionally and physically demanding. In their study, participants also shared that stress increased if their family member was heavily sedated or admitted to residential care. Increased levels of stress were also associated with criticism from other family members. Radfar and Fallahikhoshknab (2014) explored the experiences of family members caring for relatives suffering from depression and highlighted the economic and social costs of care.

In this study, participants explained they were bound to remain at home and look after their relative with mental illness when they were not admitted to the hospital. They reported that it is not easy to go out with them, and they did not feel they could leave them alone.

Family members caring for relatives with mental illness experienced stigma from the community in the form of isolation, community neglect, labelling and stereotyping. This finding was similar in studies conducted by Nxumalo and Mchunu (2017) and Isesele et al. (2016). Family carers heard nasty comments from the community as a result of being associated with a person with mental illness, and sometimes experienced challenges and discrimination when attempting to engage with members of the community.

The participants articulated they employed coping strategies in caring for a relative with mental illness. These coping strategies included support from family members and accepting the reality of their relatives' mental illness. These findings are similarly reported in the meta-synthesis conducted by Ntsayagae, Poggenpoel, and Myburgh (2019); they concur that support brings families together, and families can provide necessary items for their relative with mental illness.

Croft (2013) stated that disbelief and denial were the first reactions to appear following the relative's diagnosis with mental illness, followed shortly thereafter by blame and anger. The last reaction to appear was acceptance, where family members accepted their relative's diagnosis; it was often seen as proof they were not going to fight against the diagnosis. Croft (2013) further said that accepting the reality of mental illness is a long process, and it does not reduce the frustrations that originate from unrealistic objectives. During the interviews, most participants reported that they accepted their relative had a mental illness and that their condition was incurable. According to Isesele et al. (2016), acceptance was also the most frequently mentioned coping strategy among their participants.

Evidence suggests that caring can have a negative impact on carers' social support and networking. This is an important consideration, as support for carers may be a protective factor that helps to alleviate some of the stresses involved in their role (Magliano, Fiorillo, De Rosa, & Maj, 2011). A supportive and accepting environment is thus indispensable for the optimisation of socio-professional therapy and rehabilitation of a relative with mental illness.

## 5. Strengths and limitations

The exploration and description of the participants' experiences in a rural community was the strength of this study. Furthermore, the researcher provided the experiences from the participants in detail and in-depth. Most participants were women, indicating that women were more affected by the caregiving role. There were also challenges finding participants to be included in the research, as most prospective participants made excuses when they had to meet for the interviews. The researcher had challenges obtaining approval from the Limpopo Department of Health to conduct the research, which led to delays in completing the study. Some families were also not comfortable being audio-recorded, as they feared their recordings might end up on social media, exposing their situation to the public. The researcher reassured them and secured the privacy and confidentiality of their information.

## 6. Conclusion

Several studies have been conducted on the experiences of family members of relatives with mental illness; however, this study focused on a specific rural context in South Africa. While this article was based on a small-scale study that focused on the lived experiences of family members caring for a relative with mental illness in Giyani, Limpopo Province, it provided significant insight into the lives of these individuals. Those family members who participated in the study by sharing their realities, hopes and interactions, made the issues they face in their everyday lives a little more visible. The findings from this study revealed the challenges faced by these families and the coping strategies that assisted them in managing their situation. The study has provided an avenue for the family members of relatives with mental illness in Giyani to become more visible. Where there is more visibility, there is a hope of appropriate intervention and support. Interventions of support could be recommended for these families in terms of providing them mental health education on managing uncontrollable behaviours, finding resources to assist in challenges, such as financial constraints, and learning how to manage the feelings that come with caring for a relative with mental illness. The support interventions could also strengthen the families' existing coping strategies and build on their resilience. The implications for practice for this study have emphasised key stakeholders' role in supporting family members of relatives with mental illness. The findings of this study highlighted the role of psychiatric nurses in providing support and mental health education to the family members and the community. Furthermore, the findings of this study highlighted the role of psychiatric nurses in the management of stigma in the community. The other key stakeholder in social services has been the continuous provision of disability grants to families of mentally ill relatives to assist with financial challenges. A research study should be done in the public psychiatric hospital in Giyani to investigate how to support the psychiatric nurses in providing care and management of individuals and their families in providing mental health care services.

## Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Mihloti Eunice Shimange reports financial support and article publishing charges were provided by University of Johannesburg.

## Acknowledgements

The researcher thanks all the participants for sharing their experiences, including the supervisors of the study for their most valuable work and input in this study.

## References

- Ae-Ngibise, K. A., Korley, D., Asante, K. P., & Owusu-Agyei, S. (2015). The experience of caregivers living with serious mental disorders. A study from rural Ghana. *Global Health Action*, 8(26957). <https://doi.org/10.3402/gha.v8.26957>
- American Psychiatric Association (2020). <https://www.psychiatry.org/patients-families/what-is-mental-illness>. (Accessed 11/06/2020).
- Casstevens, W. J. (2011). A family group work application of cognitive behavioral therapy of psychosis for community mental health settings. *Families in Society*, 92(2), 199–202. <https://doi.org/10.1606/1044-3894.4099>
- Creswell, J. W. (2014). *Qualitative inquiry and research design. Choosing amongst five approaches* (4th Edition). Thousand Oaks, CA: Sage.
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design choosing among five approaches* (6th Edition). Thousand Oaks, CA: Sage.
- Croft, B. P. S. (2013). Care integration in the patient protection and affordable care act: Implications for behavioural health. *Administration and Policy in Mental Health and Mental Health Services Research*, 40(4), 258–263.
- De Vos, A. S., Fouché, C. B., Strydom, H., & Delpont, C. S. L. (2011). *Research at grassroots for the social sciences and human science professions*. Pretoria: Van Schaik.
- Desmarais, S. L., Van Dorn, R. A., Johnson, K. L., Grimm, K. J., Douglas, K. S., & Swartz, M. S. (2014). Community violence perpetration and victimization among adults with mental illnesses. *American Journal of Public Health*, 104(12), 2342–2349. <https://doi.org/10.2105/AJPH.2013.301680>
- Dhai, A., & McQuoid-Mason, D. (2011). *Bioethics human rights and health law: Principles and practice*. Cape Town: Juta.
- Ditchman, N., Lee, E., Kosyluk, K., & Jones, N. (2016). *How stigma affects the lives of people with intellectual disabilities: An overview*. In: Scior, K., Werner, S. (eds.) *Intellectual disability and stigma: Stepping out from the margins*, pp. 31–47. London: Palgrave Macmillan.
- Fiorillo, D. F., & Sabatini, F. (2011). *Quality and quantity: The role of social interactions in individual health, health econometrics and data group*. UK: University of York.
- Gray, J. R., Grove, S. K., & Sutherland, S. (2017). *Burns and Grove's the practice of nursing research: Appraisals, synthesis, and generation of evidence*. St. Louis, MO: Elsevier.
- Iseleso, M. K., Kajula, L., & Yahya-Malima, K. I. (2016). The psychosocial problems of families caring for relatives with mental illnesses and their coping strategies: A qualitative urban based study in Dar es Salaam. *Tanzania. BMC Psychiatry*, 16, 146. <https://doi.org/10.1186/s12888-016-0857-y>
- Kay, L.M., Poggenpoel, M., Myburgh, C.P. & Downing, C. (2018). Experiences of family members who have a relative diagnosed with borderline personality disorder. *Curatationis*, 1(1). Pretoria, South Africa. <https://dx.doi.org/10.4102/curatationis.v4i1i1.1892>.
- Labrum, T., & Solomon, P. L. (2017). Rates of victimization of violence committed by relatives with psychiatric disorders. *Journal of Interpersonal Violence*, 32(19), 2955–2974. <https://doi.org/10.1177/0886260515596335>
- Lincoln, Y.S. & Guba, E.G. (2013). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Magadla, M. & Magadla, N. (2014). Effects of mental illness on relationships amongst families, relatives and friends with mentally ill members. *African Journal for Physical, Health Education, Recreation and Dance (AJPHERD)*, September (Supplement 3):126–135.
- Magliano, L., Fiorillo, A., De Rosa, C., & Maj, M. (2011). The National Mental Health Project Working Group. Available from: <https://doi.org/10.1111/j.1600-0447.2005.00719>. (Accessed 20/08/19)
- McCann, T. V., Bamberg, J., & McCann, F. (2015). 'Family carers' experience of caring for an older parent with severe and persistent mental illness. *International Journal of Mental Health Nursing*, 24, 203–212.
- Mokgothu, C. M., Du Plessis, E., & Koen, M. P. (2015). The strengths of families in supporting mentally ill family members. *Curatationis*, 38(1).
- Monyaloue, M., Mvandaba, M., Du Plessis, E. D., & Koen, M. P. (2014). Experiences of families living with a mentally ill family member. *Journal of Psychiatry*, 17(5). <https://doi.org/10.4172/Psychiatry.1000131>
- Municipalities of South Africa. (2021). Greater Giyani Local Municipality. Available from (Access 14/08/2021) <https://municipalities.co.za/overview/1128/greater-giyani-local-municipality>.
- Ntsayagae, E., Poggenpoel, M., & Myburgh, C. (2019). Experiences of family caregivers of persons living with mental illness: A meta-synthesis. *Curatationis*, 42(1), 1–9. <https://doi.org/10.4102/curatationis.v42i1.1900>
- Nxumalo, T., & Mchunu, G. G. (2017). Exploring the stigma related experiences of family members of persons with mental illness in a selected community in the Ilembe district. *Kwazulu-Natal. Health SA Gesondheid*, 22, 202–212.
- Radfar, M. F., & Fallahikhoshknab, M. (2014). Turbulent life: The experiences of the family members of patients suffering from depression. *Journal of Psychiatric and Mental Health Nursing*, 21, 249–256.
- Reiners, G. M. (2012). Understanding the differences between Husserl's (descriptive) and Heidegger's (interpretive) phenomenological research. *Journal of Nursing and Care*, 1(5), 1–3. <https://doi.org/10.4172/2167-1168.1000119>
- Rose, L. E. (2011). Understanding mental illness. *The experience of families of psychiatric patients*. *Western Journal of Nursing Research*. University of Maryland: Baltimore.. <https://doi.org/10.1177/019394590202400505>
- Rowe, J. (2012). Great expectations: A systematic review of the literature on the role of family carers in severe mental illness, and their relationships and engagement with professionals. *Journal of Psychiatric and Mental Health Nursing*. <https://doi.org/10.1111/j.1365-2850.2011.01756.x.Epub>
- Sankoh, O., Sevalie, S., & Weston, M. (2018). Mental health in Africa. *The Lancet Global Health*, 6(9), E954–E955. [https://doi.org/10.1016/S2214-109X\(18\)30303-6](https://doi.org/10.1016/S2214-109X(18)30303-6)
- Tlhowe, T. T., du Plessis, E., & Koen, M. P. (2017). Strengths of families to limit relapse in mentally ill family members. *Health SA Gesondheid*, 22, 28–35. <https://doi.org/10.1016/j.hsag.2016.09.003>
- Trondsen, M. (2012). Living with a Mentally Ill Parent. *Qualitative Health Research*, 22(1): 174–88.
- Tsigebrhan, R., Shibre, T., Medhin, G., Fekadu, A., & Hanlon, C. (2014). Violence and violent victimization in people with severe mental illness in a rural low-income country setting: A comparative cross-sectional community study. *Schizophrenia Research*, 152(1), 275–282. <https://doi.org/10.1016/j.schres.2013.10.032>
- Udoh, E.E., Omorere, D.E., Sunday, O., Osasu, O.S. & Amoo, B.A. (2021). Psychological distress and burden of care among family caregivers of patients with mental illness in a neuropsychiatric outpatient clinic in Nigeria. *PLOS ONE*, 16(5):e0250309. <https://doi.org/10.1371/journal.pone.0250309>.
- United Nations. (2021). Mental Health and Development. *Department of Economic and Social Affairs Disability*. Available from: <https://www.un.org/development/desa/disabilities/issues/mental-health-and-development.html>. (Accessed 26/08/2021).
- World Health Organization. (2003). *Mental health atlas*. Geneva: World Health Organization.
- World Health Organization. (2011). *Mental health atlas*. Geneva: World Health Organization.