

# Experiences of Family Members of Persons With Mental Illness: A Qualitative Inquiry

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## Abstract

The shortage of skilled and experienced health workers, lack of facilities, limited psychiatric care and inaccessible mental health care services in the uMsunduzi Municipality in Northern KwaZulu-Natal are causes of concern. With limited access to health services and resources, family members have no choice, but to take care of mentally ill relatives. These underlying problems have warranted the need to explore the experiences of family members living with mentally ill relatives. A qualitative, exploratory, descriptive design was used to collect data by in-depth one-on-one interviews and findings were analyzed using Tesch's method of data analysis. This study showed that the uMsunduzi Municipality needed assistance with resources to support family members living with their mentally ill relatives and family members' lack of knowledge and experience emerged as a major factor that influenced the care, treatment and rehabilitation of their mentally ill relatives. Compounded by inadequate mental health facilities and infrastructure as well as the implications of the non-implementation of the acts, policies, processes and procedures in the uMsunduzi Municipality; this study recommends the need to enhance community education of all health professionals, providing relevant training in mental illness management. A shared decision-making process is vital, so that a collaborative partnership between family members and health professionals across KZN is established. This will in turn enhance the lived experiences of family members and mentally ill patients.

**Keywords:** mental illness, family member, caregiver

## 1. Introduction and background

According to global statistics of mental health one in four people will be affected by mental disorder due to the burden of disease and ill-health (WHO). Mental illness has the potential to impact every aspect of an individual's life and the lives of those close to them, such as family and friends. Individuals diagnosed with mental illness differ due to treatment approaches and the difference in diagnoses and symptoms. Mental illness does not only have an effect on relationships, occupation, recreation and finances, but also on the overall routine of the individual's daily life and the lives of their family members (Papadopoulos, 2009). Sub-Saharan African (SSA) statistics further reveal that one out of three South Africans have been affected or are affected with mental illness (Tzoneva, 2014). The same study argues that mental illness is a challenge, not only for the affected person but also for the persons caring for such individuals. Family support of a person with mental illness is seen as very important to successful rehabilitation and recovery. Practical examples of support go beyond cooking, household chores, assisting with keeping medical appointments and financial support, as emotional support is a crucial element in patient rehabilitation. Continued care and support for people with mental illness can be demanding and challenging, causing families to become frustrated, stranded, overburdened and exhausted (Monyaluoe, Mvandaba, Plessis, & Koen, 2014). South Africa is committed to the national imperative of provision of care, treatment and quality healthcare services. There are nine provinces spread across South Africa, including KZN. Empirical evidence and scholarly literature has revealed that, mental illness has been increasing at a fast pace in the KZN province (Meyer, Staffed, & Jackson 2009; Bayat, Poyraz, & Arikan 2012; Naidoo, 2012). According to Sibiya (2012), KZN has practicing health care professionals practicing as nurses who are not fully equipped with the adequate knowledge, skills and relevant qualifications to manage and treat relevant diseases and conditions, such as mental ill-health.

Equally concerning trends in the province are the operational inefficiency of some of the hospitals, such as the inaccessibility of beds for psychiatric patients (KZN Department of Health, 2015). These problems appear to pose barriers to relatives' access to effective psychiatric care, treatment and rehabilitation. Thus, the burden of managing such relatives and coping with the consequences of a psychiatric disorder lies with family members. The uMsunduzi Municipality in Northern KZN is one such outlying area, with limited access to health services and available resources, where family members have to take on the role as caregivers. These underlying problems in the uMsunduzi Municipality necessitated the need to investigate the experiences of family members living with mentally ill relatives. According to Sibiya (2012), KZN has practicing health care professionals such as nurses that are not fully equipped with the adequate knowledge, skills and relevant qualifications to manage and treat relevant diseases and conditions. Societal stigma with the formal health services is evident in KZN and allocation of budgets to assist psychiatric facilities within KZN reveals a gross inequity. Equally, concerning trends in the province are the operational inefficiency of some of the hospitals, such as the unavailability of beds for psychiatric patients. In these hospital settings, only 25% of beds are available for psychiatric patients. These problems appear to pose barriers to relatives' access to effective psychiatric care, treatment and rehabilitation. Thus the burden of managing such relatives and coping with the consequences of a psychiatric disorder lies with family members. uMsunduzi Municipality in Northern KZN is one such outlying area with limited access to health services and available resources. As a result, family members are being utilized to care for the sick and needy. These prevailing problems in this municipality have made this study timeous in exploring the experiences of family members living with mentally ill relatives.

## **2. Methods**

### *2.1 Study Design*

Mental ill health has been a relatively unexplained and elusive phenomenon and those diagnosed with this disorder are sometimes difficult to treat and manage. This study utilized a qualitative, exploratory, descriptive design to explore the experiences of family members living with mentally ill patients in the uMsunduzi Municipality.

### *2.2 Study Site*

This study was conducted in the rural setting of the uMsunduzi Municipality in the province of KZN. It is estimated that the uMsunduzi area is home to about 600 000 people from different cultural groupings and comprises rural areas that are governed by municipal by-laws and common laws. The researcher selected the area because it has only two provincial hospitals specializing in mental ill-health, Townhill and Fort Napier provincial hospitals, serving an estimated population of over half a million.

### *2.3 Population and Sampling*

The researcher used purposeful sampling by selecting participants who were caring for relatives diagnosed with a mental illness. The researcher used a snowballing technique to gather data, a technique where participants refer the researcher to other prospective participants who meet the inclusion criteria (Polit & Beck, 2012). This was beneficial to identify suitable participants and to contact participants who were out of reach. Participants or informants with whom contact has already been made can use their social networks to refer the researcher to other people in the community, who could potentially participate in or contribute to the study. Furthermore, with an introduction from the referring person, it made it easier for researchers to establish a trusting relationship with the new participant (Polit & Beck, 2012) Participants selected for this study had to be over the age of 18, caring for a mentally ill relative and residents of the uMsunduzi Municipality.

### *2.4 Data Collection*

In-depth, face-to-face semi-structured interviews were conducted to collect data from the participants. An interview guide was used to facilitate the discussion during the interview sessions and was translated into IsiZulu was used to conduct interviews for those participants who were not familiar with English. The interview guide comprised a demographic section as well as questions to guide the interview. The leading question was: "*What are your experiences caring for a mentally ill relative?*" This was followed by probing questions to elicit detailed information. In order to ensure privacy and comfort of the participants, the researcher conducted interviews at the residences of the participants. Each interview lasted approximately 45 minutes and permission was sought from the participants to use a voice recorder during the interview sessions.

### *2.5 Data Analysis*

After analysis of the in-depth interviews with the family members, a thematic framework was used to categorize findings as they emerged and organize them into themes and sub-themes, allowing the researcher to get both

objective and subjective responses from the participants who provided their personal reflections on caring for their mentally ill relatives.

### 2.6 Trustworthiness

Trustworthiness, according to (Brink et al., 2012), is a way of ensuring data quality or rigour in qualitative research. To ensure credibility of the study, the same interview guide was used throughout the study. Credibility was ensured through space triangulation which was achieved by interviewing participants from different types of households to ensure their privacy and comfort. The researcher ensured dependability of the study by requesting the supervisors to review the data and by developing an audit trail of all original audio records of interviews and discussions on a disc. Transferability was maintained, whereby, the researcher ensured that the context of the study and the participants are adequately described so that the findings can be applied to other settings similar to the one researched. To ensure confirmability the researcher interpreted and analysed the data through identifying themes and sub-themes which were supported by the use of direct quotations from the interviews in order to eliminate subjectivity and bias.

### 2.7 Ethical Considerations

The study commenced after the ethics clearance was granted by the Institutional Research Ethics Committee (IREC). The researcher ensured that participants understand the benefits of the study by providing detailed explanations before obtaining written, voluntary consent. Codes, instead of the participant's names were used on the data collection sheets to ensure that participants remained anonymous and that their responses could not be linked to individual names or families.

## 3. Results

Qualitative content analysis yielded three main themes and its related sub-themes (Table 1) below.

Table 1. Experiences of family members caring for their mentally ill relatives

THEMES	SUB-THEMES
1. Caring for a mentally ill relative.	1.1 Coping strategies when caring for a mentally ill relative.
	1.2 Support systems for families living with mentally ill relatives.
	1.3 Knowledge deficiencies related to mental illness management.
	1.4 Nurses' attitude, skills, knowledge and capacity to care for mentally ill patients.
	1.5 Inadequate resources and infrastructure for mentally ill patients.
2. Challenges arising from caring for a mentally ill relative.	2.1 Overcoming challenges.
	2.2 Mental illness stigmatization in the community.
3. Family members' coping mechanisms with caring for a mentally ill relative.	3.1 Multi-disciplinary approach.
	3.2 Governmental commitment.
	3.3 Traditional, spiritual and cultural role in managing mentally ill relatives.

### 3.1 Caring for a Mentally Ill Relative

The burden of mental illness lies with the father, mother, brother, sister, among others, as family members living with mentally ill relatives. This theme is the thrust of this study and warranted intensive empirical inquiry. Participants reported that they felt uncomfortable when caring for a mentally ill relative. The majority of participants remained unclear and confused of how they should care for someone who has a mental illness, characterized by the lack of skills, knowledge and capacity to care, treat and rehabilitate their relatives living with mental illness. Despite the lack of support, participants felt that they are also unaware of their relatives' state of mental illness as encapsulated by the following quotations:

*"...The mental condition of my daughter was unknown to me."* (Participant #4)

*"I don't have much exposure to living with my mental ill sister."* (Participant #3)

*"Caring for my mentally ill sister can be challenging and difficult experience"* (Participant #7).

Due to psychiatric institutions being structurally over-burdened, overcrowded and inaccessible, family caregivers expressed a concern with finding support and felt that healthcare workers were not empathetic and lacked communication skills when treating their patients. The following statements support this:

*"For the past two days, I have slept on the hospital's floor due to space constraint... I have been angered and frustrated by the lack of medication."* (Participant #5)

*"...we wait for hours, from the morning till the afternoon...they have their breaks, laugh joke and even shout at us...they don't seem to understand our pain"* (Participant #7)

### 3.2 Challenges Arising From Caring for a Mentally Ill Relative

The effects of psychiatric illnesses on patients are often displayed as symptoms of poor cognition, stressful behaviour and anger and other related dangerous and unpredictable behaviour. Family members, when asked how they handled these challenges, had different views and different ways of coping with such challenges. Some family members said that they resorted to locking away their mentally ill relatives when they had visitors. The following responses allude to the above:

*"My mentally ill brother sometimes attacks some community members due to his mental illness."* (Participant #5)

*"If visitors are around I always locked my father in his room..."* (Participant #2)

Family members also stated that shame and embarrassment were closely associated with stigma. This is evident in the following statements:

*"I have been deliberately isolated and excluded on matters concerns our neighbourhood since caring for my mentally ill sister."* (Participant #14)

*"I felt humiliated by my community members' over-reaction to mental illness due to our father's mental status."* (Participant #1)

### 3.3 Family Members Coping Mechanisms With Caring for a Mentally Ill Relative

Whilst family members develop different kinds of coping strategies to deal with the burden of caring for a mentally ill relative, some coping mechanisms could adversely affect the family member. Family members also resort to multi-disciplinary approaches to cope with the care, treatment and rehabilitation of their mentally ill relatives. One participant responded by saying:

*"...since being aware of my son's mental illness I usually consults with professional health workers..."* (Participant #9)

It was apparent from the study's findings that the South African government's commitment to development has increased the demands and expectations of public health, including mental health care of many of the people living in rural areas. The following participant responses noted this;

*"In improving access, care, treatment and rehabilitation there is hope for mental health recovery."* (Participant #10)

*"Government must address the developmental challenges of unemployment, poverty and inequality in mental healthcare."* (Participant #20)

Most of the participants emphasized how important it is to pray and how strong God is, and if you believe in him, He will give you strength, and you will be able to cope, no matter how difficult the situation is. The participants responded by saying:

*"On my daily prayers I have sought for God's divine intervention"* (Participant #11)

*"For seeking help my first encounter was my traditional healer followed by my Pastor."* (Participant #8)

## 4. Discussion of Results

Whilst caring for a relative, who has a mental illness, is a very personal experience, it rarely happens in isolation. Mental illness as a phenomenon encompasses cultural, ethnic, spiritual, social components and caregivers often have to consider these factors when trying to understand the very nature of the illness and its effects on the person and their loved ones. Based on the analysis of the findings, this study observed that family members lacked

experience to care, treat and rehabilitate their mentally ill relative. This is possibly due to a lack of skills, knowledge and capacity to care, treat and rehabilitate their relatives living with mental illness, having negative bearing on the family members' coping experience when caring for their mentally ill relative. Koen, Ryke, Walson and Eeden (2017), agree and states lack of skills, knowledge and capacity to care for the sick and needy in a society can be detrimental to the well-being of the community. Results also allude to family members being unable to participate in their relatives' care, treatment and rehabilitation for mental illness. Mokoena-Mvandab, (2013), noted that a lack of knowledge and skills of mental illness and its repercussions, causes failure to attend follow-up appointments which in turn can negatively impact on the family members' illness causing a relapse in their condition. It is further evident that mental health education or health education programmes failed to support the experiences of family members living with mentally ill relatives. The decreased presence of health care staff and unavailability of proper health care programmes raised huge concerns for the promotion of the caregiver and patient alike. This is consistent with Mafuru and Maboe (2017, who revealed that the challenge of lack of information and programmes is a barrier to mental healthcare. There are growing concerns regarding nurses' attitude, skills, knowledge in the medical and nursing fraternity (Meiring, Visser, & Themistocleous, 2017; Mntlangula, Khuzwayo, & Taylor, 2017; Sibiyi, 2012). Naidoo and Sibiyi (2013), point out that, although nursing is a caring profession, the attitudes of certain nursing staff can deter patients from seeking treatment. (Meiring, Visser & Themistocleous 2017), agree with the KZN Department of Health that practicing health care professionals such as nurses are not fully equipped with the adequate knowledge, skills and relevant qualifications to manage and treat relevant diseases and conditions (KZN Department of Health, 2015). These challenges coincide with the findings of this study. Understaffing and increased patient volumes are other reasons that place unnecessary burden on nursing staff (Meiring, Visser, & Themistocleous, 2017). The participants in this study have agreed that failure to address these challenges resulted in negative experiences by family members living with mentally ill relatives. The operational inefficiency that has resulted in KZN not being equipped with an adequate number of psychiatric beds have concurred with participants' responses that the family caregivers' burden, with inadequate psychological support, stems from inadequate resources (Seloilwe, 2006: 262; Sibiyi et al., 2018). Bhengu (2016), agrees that psychiatric institutions are structurally over-burdened, overcrowded and inaccessible creating barriers to effective psychiatric care, treatment and rehabilitation.

The study also found that the stresses and stigmatization of mental illnesses are contributory factors to the ineffective coping skills of the caregiver. Lorenzo, Matiwane, Cois and Nwanze (2013) and Magadla and Magadla (2014), suggest that the effects of psychiatric illnesses often caused patients to display symptoms of poor cognition, stressful behaviour and anger towards each other and their family members and are, sometimes, viewed as dangerous people in society. It was noted that, while caring for their mentally ill relatives, the attitude of family members towards mental illness contributed to the feeling of shame and embarrassment. As this feeling is closely associated and linked to stigmatization, embarrassment is often seen as a source of disgrace (Tlhowe, Du Plessis, & Koen, 2017). This led to an element of social exclusion towards a mentally ill patient and their relatives for fear of unnecessary problems and disruption. In addition, this guilt and humiliation together with embarrassment of the symptoms and the behaviour of the patient cause family members to live an isolated life. This study revealed that participants employed diverse means of coping with caring for their mentally ill relatives. Findings of the study clearly indicated, that the burden of managing and coping with such relatives lie with family members. It was evident that, through a multi-disciplinary approach and adequate referral systems, family members were able to cope with the care, treatment and rehabilitation of their mentally ill relatives. Trying to find alternatives in an attempt to find solutions and seeking information from family members caring for mentally ill patients were deemed vital during the consultative process of a patient (Marimbe-Dube, 2013). This was consistent with study findings from Dowing, Pogenpoel and Myburgh, (2017), who revealed that, when individuals with mental health challenges engage in a partnership with other health professionals, they become empowered, appreciated and motivated to overcome their own challenges. This suggests that holistic community care approach such as teamwork and partnership from all members of the multidisciplinary team, for the promotion of care and rehabilitation of the mentally ill patient. Koen, Ryke, Watson and Van Eeden (2017) agree that engaged community involvement gives society a sense of responsibility. Although social grant payments assisted and alleviated the financial caregiving burden of family members, participants indicated the need for additional income in the form of an increase in social grants to adequately support their mentally ill relatives. Spiritual, traditional and cultural coping strategies, appeared to dictate the way family members rendered care and coped with a mentally ill relative. Sibiyi et al. (2018), states that there are a number of cultural issues experienced by family members caring for mentally ill relatives in the uMsunduzi Municipality and tradition and beliefs do play an insightful role. In order to cope, while living with a mentally ill family member, some family members prayed to God the Almighty to help them. They reported that they believed in prayer, and got their strength through constantly praying to God.

## 5. Conclusion

This study showed that the research setting, a rural area in the uMsunduzi Municipality needs assistance with resources to support family members living with their mentally ill relatives. Family members' lack of experience emerged as a major factor that influenced the care, treatment and rehabilitation of their mentally ill relatives. The implications of the poor enforcement and non-implementation of the acts, policies, processes and procedures in the mental health discourse are evident in the uMsunduzi Municipality. It is concluded that the underlying causes of the inexperience of family members are lack of skills, knowledge and capacity, lack of support for mental health, lack of awareness, lack of mental health information and programs. Nurses' attitudes, skills, knowledge and capacity to care, treat and rehabilitate mentally ill patients as well as inadequate mental health facilities and infrastructure also affected the care of the mentally ill patients by their families. The aforementioned factors necessitate an urgent call for intervention in the mental health sector, particularly in the uMsunduzi Municipality. Stemming from participant's responses in this study, the multidisciplinary approach in caring for the mentally ill person from diagnosis to rehabilitation was found to be lacking in the uMsunduzi Municipality. Participants suggested that, in addition to a proper health service infrastructure, there was a need for a team approach from health care personnel such as referral mechanisms, health education programmes and other services to support those with mental illnesses. Traditional and cultural beliefs featured dominantly in participants' responses, which indicated how society and family members handled issues of mental illness. Irrespective of the area or the vicinity where mentally ill persons reside, the actual caregiving experiences takes an emotional toll on all persons caring for the mentally ill. Therefore, family members need to have support networks in place, not only to assist in providing care, but also for their own emotional wellbeing.

## 6. Recommendations

Based on the findings of this study, the following recommendations are suggested with special reference to nursing education, institutional management and practice, policy development and implementation and further research and are as follows:

### 6.1 Legislation, Development and Implementation of Policy

A post-apartheid South Africa has laid a firm foundation for various laudable acts, policies, procedures and processes for the public health sector. These legislative and policy frameworks are not limited to the Constitution of Republic of South Africa, Mental Health Act and the National Health Act. Therefore, policy frameworks, such as the National Health Policy Guidelines for Improved Mental Health should be subject to ongoing independent review boards to review mental disorder treatment regimens and management.

### 6.2 Institutional Management and Practice

Area managers and operational managers need to track and manage progress in the implementation of acts, policies, guidelines and procedures, to be proactive in improving the family members' capacity to care, treat and rehabilitate their mentally ill relatives and thereby counteract the negative experiences resulting from the lack of skills, knowledge and capacity to treat and rehabilitate mentally ill relatives. It is incumbent for area managers and operational managers to be proactive in strategizing coping styles to improve the family members' experience of caregiving. Psychiatric nursing upskilling, in the form of workshops, seminars and ongoing formal and informal nurse education, should be part of the workplace skills development plan. Will this not only generate new knowledge amongst nurses, but will also, assist their nursing and medical management of psychiatric patients as well as improve interpersonal relations between the nurse, the patient and the patient's caregiver.

### 6.3 Community Education and Healthcare Professional's Education

This study recommends the need to enhance community education of all health professionals, providing relevant training in mental illness management. Family members living with mentally ill relatives should be included in a shared decision-making process so that a collaborative partnership between family members and health professionals across KZN is established, enhancing the lived experience of family members and patients alike.

### 6.4 Further Research

The researcher suggests that further research on this topic be conducted on a wider scale. This study is limited in its generalizability due to a small sample size. Therefore, it is suggested that a larger study be conducted on family members in and around KZN to ascertain their experiences of living with mentally ill relatives.

## Competing Interests Statement

The authors declare that there are no competing or potential conflicts of interests.

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