

Experiences of families living with a mentally ill family member

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TO WHOM IT MAY CONCERN

This is to certify that I have language edited the mini-dissertation of Magdeline Monyaluoe Mokoena-Mvandaba entitled “*Experiences of families living with a mentally ill family member*” and that I am satisfied that, provided the changes I have made and suggested are effected to the text, the language is of an acceptable standard.

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DECLARATION

I declare that the mini-dissertation with the title: *Experiences of families living with a mentally ill family member* is my own work, that all the sources used or quoted have been indicated and acknowledged by means of a complete reference, and that this work has not been submitted previously for another degree at any other institution.

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30.08.2013

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SUMMARY

Some families in the Free State Province, specifically in Thabo-Mofutsanyana district, are families living with mentally ill family members. The families accompany the mentally ill family members to designated clinics which offer primary, secondary and tertiary mental health services, and all these levels of care provide care, treatment and rehabilitation of mentally ill persons (SA, 2002:2). Despite the care that these families give to their mentally ill family members, it seemed that they find it difficult to cope living with a mentally ill family member. This is supported by Zergaw, Hailemariam, Alem and Kebed (2008:191) who indicate the economic impact, disruption of daily life, work and family relationships experienced by families living with a mentally ill family member. This was also evident in a study by Du Plessis, Greeff and Koen (2004:4), that, because of a lack of a formal support system for families living with mentally ill family members, and lack of necessary skills to take on the responsibility of caring for mentally ill relatives, mentally ill family members relapse and are readmitted in the mental health care institutions. Adding to this, in most of the families living with mentally ill family members in the Thabo-Mofutsanyana district, it is not known how they cope and are supported. Once there is a clear understanding of how families experience living with mentally ill family members, health care practitioners can give better support to families living with mentally ill family members.

The research objective of this study was to explore and describe the experiences of families living with a mentally ill family member in the Thabo-Mofutsanyana district, to explore and describe the strengths of families living with a mentally ill family member, and to formulate guidelines to support families living with mentally ill family members.

A qualitative, phenomenological design was used which enabled the researcher to understand the way in which the families experience living with a mentally ill family member. The population studied in this research consisted of families living with mentally ill family members in the Thabo-Mofutsanyana district in South Africa. The purposive sampling was used to select

participants with the assistance of a mediator. Permission to conduct research was negotiated with the district manager. Voluntary and informed consent in writing was obtained from all the participants. The sample size was determined by data saturation, which was reached after 14 interviews.

Data analysis was carried out simultaneously with data collection. In consensus discussions, the researcher and the co-coder reached consensus on the main and sub themes. From the research findings, five main themes were identified. The first two themes are the positive and negative experiences of living with a mentally ill family member. The third theme is the concerns of family in staying with a mentally ill family member. The fourth theme is the strengths in coping with a mentally ill family member. The last theme is ways in which family members as families wanted to be supported.

It could be concluded that the experience of families living with mentally ill family members in Thabo-Mofutsanyana district need to be supported. In order to address this support holistically and to enhance quality of life and to lessen the burden the families experience in living with a mentally ill family member, the support should firstly be addressed individually and then as a family. Following that, the collective support can be addressed by a support network system through involvement of the department of health, clinics, rehabilitation centres, community, mental health care workers, giving of medication and establishment support of groups of families living with mental health care users.

From these findings the researcher proposed guidelines to support families living with mentally ill family members, and to increase knowledge in these families on how to handle a mentally ill family member. The researcher also compiled recommendations for nursing practice, nursing education and nursing research in families living with mental health care users.

[Key words: Experience, family, mentally ill family member, mental illness, strengths, support system]

OPSOMMING

Sommige gesinne in die Vrystaat Provinsie, spesifiek in die Thabo Mofutsanyana-distrik, is gesinne wat met geestesongestelde familieledes saamleef. Die gesinne vergesel die geestesongestelde familieledes na aangewese klinieke wat primêre, sekondêre en tersiêre geestelike gesondheidsdienste bied (SA, 2002:2).

Ten spyte van die sorg wat hierdie gesinne aan hulle geestesongestelde familieledes gee, blyk dit dat hulle dit moeilik vind om saam met die geestesongestelde gesinslid te leef. Hierdie word beaam deur Zergaw, Hailemariam, Alem en Kebed (2008:191) wat die ekonomiese impak, ontwinging van die daaglikse lewe, werk en gesinverhoudings wat deur gesinne wat met 'n geestesongestelde gesinslid ervaar word, uitwys. Hierdie was ook weerspieël in 'n studie deur Du Plessis, Greeff and Koen (2004:4), dat, as gevolg van 'n gebrek aan 'n formele ondersteuning vir gesinne wat met geestesongestelde familieledes saamwoon en 'n gebrek van die nodige vaardighede om verantwoordelikheid te neem vir die geestesongestelde gesin, geestesongestelde familieledes terugval in hul behandeling. Om toe te voeg tot hierdie, in die meeste van die gesinne wat met geestesongestelde familieledes in die Thabo-Mofutsanyana-distrik saamwoon, dit nie bekend is hoe hulle die saamleef hanteer en ondersteun word nie. Sodra daar 'n duidelike begrip verkry word van hoe gesinne dit ervaar om met geestesongestelde familieledes saam te woon, die gesondheidsorg-praktisyns beter ondersteuning behoort te gee aan die ondersteunende gesinne.

Die doel van hierdie studie was om die ervarings van gesinne wat met 'n geestesongestelde familielid in die Thabo Mofutsanyana-distrik saamwoon te verken en te beskryf, sterkpunte te verken en te beskryf, en riglyne te formuleer ten einde die betrokke gesinne te kan ondersteun.

'n Kwalitatiewe fenomenologiese ontwerp is gebruik wat die navorser in staat gestel het om die manier waarop die gesinne die saamleef met 'n

geestesongestelde familielid ervaar, te verstaan. Die bevolking wat in hierdie navorsing bestudeer is, bestaan uit gesinne wat met geestesongestelde familieledede in die Thabo Mofutsanyana-distrik in Suid-Afrika woon. Doelgerigte steekproefneming is gebruik om deelnemers te kies met die hulp van 'n middelaar. Toestemming om navorsing te doen is met die distrik bestuurder onderhandel. Vrywillige en ingeligte toestemming is skriftelik verkry van al die deelnemers. Die steekproefgrootte is bepaal deur dataversadiging wat na 14 onderhoude bereik is.

Data-analise is uitgevoer gelyktydig met data-insameling. In die konsensus besprekings het die navorser en die mede-kodeerder konsensus bereik op die hoof- en sub-temas. Uit die navorsingsbevindings is vyf hooftemas geïdentifiseer. Die eerste twee temas is die positiewe en negatiewe ervarings van die lewe met 'n geestesongestelde familielid. Die derde tema is die bekommernisse van die gesin wat saam met 'n geestesongestelde familielid woon. Die vierde tema is die sterk punte in die hantering van 'n geestesongestelde familielid. Die laaste tema is maniere waarop familieledede as gesinne ondersteun wil word.

Dit kan afgelei word dat die ervaring van die gesinne wat met geestesongestelde familieledede in Thabo Mofutsanyana-distrik saamleef, ondersteun moet word. Ten einde hierdie ondersteuning holisties aan te spreek, die kwaliteit van lewe te verbeter en om die las van die gesinne se ervaring in die saamlewe met 'n geestesongestelde gesinslid te verminder, die ondersteuning eerstens individueel en dan as 'n gesin aangespreek moet word. Na die voorafgaande kan die gesamentlike ondersteuning aangespreek word deur 'n ondersteuningsnetwerk, deeglike betrokkenheid van die Departement van Gesondheid, klinieke, rehabilitasie sentrums, gemeenskaps-, geestesgesondheidsorg werkers, gee van medikasie en die vestiging van ondersteuning van groepe of gesinne wat saam met die geestesongestelde lede woon.

Uit hierdie bevindinge het die navorser riglyne voorgestel om gesinne wat met geestesongestelde familieledede saamwoon, te ondersteun, en die kennisvlak in

hierdie gesinne te verhoog van oor hoe om 'n geestesongestelde familielid te hanteer. Die navorser het ook aanbevelings vir die verpleegpraktyk, verpleegonderwys en verpleegnavorsing in gesinne wat met geestesgesondheidsorg gebruikers saamwoon, voorgestel.

[Sleutelwoorde: Ondervinding, gesin, geestesongestelde familielid, geestesongesteldheid, sterkpunte, ondersteuningstelsel]

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SECTION 1: OVERVIEW OF THE STUDY

1. OVERVIEW OF THE STUDY

In this overview, the introduction, problem statement, research questions, research purpose, paradigmatic perspective, research methodology, trustworthiness of the study, ethical considerations, literature control, guidelines and report outline are discussed in detail. The overview is followed by a literature review, and a manuscript according to the criteria of *African Journal of Psychiatry* entitled “Experiences of families living with a mentally ill family member,” as well as a concluding section containing the conclusions, recommendations and shortcomings of the study.

1.1 INTRODUCTION AND BACKGROUND

Deinstitutionalisation of mentally ill patients from long-term hospitalisation to community-based settings remains a challenge in many countries (Uys & Middleton, 2010:6). The transition of hospital-based psychiatric care is evident in the changes that have taken place in state mental hospitals across the United States of America (USA) (Stuart, 2009:617). During the debate of transition of hospital-based care, the advocacy movement articulated a strong belief in the superiority of the community-based treatment model that integrated family and social living. Furthermore, the philosophy of deinstitutionalisation, which was to relocate funding from hospitals to community programmes, led to an era of state hospital closures and downsizing (Stuart, 2009:617). In support of deinstitutionalisation in the USA, the deinstitutionalisation movement in Australia gathered momentum after the 1960s (Newton, Rosen, Tennant, Hobbs, Lapsley & Tribe, 2000:484). The challenge is contributed to by the decentralization of all health care including mental health care (Glendy & Mackenzie, 1998:288). Consequently, the policy of decentralization of all health care became the cornerstone of the World Health Organisation during the 1970s, and it is expressed in the recommendation of the International Declaration on Primary Health Care at Alma-Ata in 1978, known as the Declaration of Alma-Ata (Robertson, Allwood & Gagiano, 2004:418). From 1970 to 2005, there was an 85% decrease in mentally ill patients in state hospitals in the USA with the most reductions during the decade of 1990s (Stuart, 2009:617), while in Australia, the population of psychiatric patients declined from 281 per 100 000 in the early 1960s to 40 per 100 000 in 1992 (Newton *et al.*, 2000:484). Chang and Horrocks

(2006:435) report that Malaysia also moved slowly to the deinstitutionalisation trend from the 1970s onwards, where people with severe and persistent mental illness are treated in the community and in primary health care settings.

Robertson *et al.* (2004:418) state that primary health care is declared to be the key to attain the target of health for all. Furthermore, primary health care is defined as essential, universally accessible, affordable health care provided at the first level of contact, and which should ideally provide promotive, preventive, curative, and rehabilitative services including public health measures and essential drugs (Robertson *et al.*, 2004:418). Stuart (2009:635), who supports this, stated that people seek help for their mental health problems from their primary care provider. Consequently, primary care settings may be the most important point of contact between patients with mental illness and the health care system. In addition, primary health care systems include principles such as intersectoral collaboration, maximum community participation, and self-determination, the involvement of traditional practitioners and mutually supportive referral systems (Uys & Middleton, 2010:68). Furthermore, mental health care services are integrated into the primary health care system, supporting the consensus that health is a partnership between all role players, including service users and families (Robertson *et al.*, 2004:418). Seloilwe (2006:262) confirmed that mentally ill patients and their families are beginning to be viewed as partners in care, because they are expected to play an advocate and supportive role in psychiatry and mental health. However, in many countries, the reality falls far short of this vision (Robertson *et al.*, 2004:418). Uys and Middleton (2010:11) also argue that fundamental change in mental health care has not been easy to implement internationally.

In South Africa, after democratisation in 1994, in line with other countries, the health care system was re-organized in accordance with the primary health care philosophy advocated by the World Health Organization (Mavundla, Toth & Mphelane, 2009:357). These changes are reflected in new mental health legislation passed by parliament during 2002 in the form of the Mental Health Care Act 17 of 2002, where emphasis has shifted to appropriate community-based care, rehabilitation and reintegration into the community (Van Rensburg, 2005:100). Uys and Middleton (2010:11) state that the South African government accepted the policy of a

comprehensive primary health care approach. Although this was not implemented with enthusiasm initially, the ANC (1994:20) indicated that the new government is committed to this approach, as stated in the National Health Plan for South Africa. In addition, according to News24 (2011) in a briefing by the portfolio committee in Parliament, the Minister of Health emphasized that South Africa needs to overhaul the entire health system and move towards primary health care. The primary health care approach has important implications for mental health care services, and among the advantages of inclusion of mental health in primary care, is the involvement of the family in the treatment of the patient and a local social network (Uys & Middleton, 2010:12).

In further support of primary health care, the purpose of the Mental Health Care Act (SA, 2002:02) is to ensure provision of care, treatment and rehabilitation to people with mental illness. Moreover, in terms of Article 27(1) of the South African Constitution of 1996 stipulates that everyone has the right to health care services (SA, 1996:13). During the last two decades, mentally ill patients have been systematically deinstitutionalised (Uys & Middleton, 2010:282). Due to overcrowding in mental hospitals, a process of deinstitutionalisation of mental health care services started, which led to families becoming the main providers of individuals with mental illness (Mavundla *et al.*, 2009:358). For example, Du Plessis, Greeff and Koen (2004:3) confirm that deinstitutionalisation of mentally ill patients was implemented by the government of the North West province, where as many as possible psychiatric patients were discharged from long-term hospitals to be under care of their families.

Furthermore, deinstitutionalisation necessitates that effective community-based mental health services are rendered to support both the family and the mentally ill family member (Du Plessis *et al.*, 2004:4). In contrast, Health Minister Aaron Motsoaledi (2012:5) describes that there are hurdles which face mental health improvement including a lack of community-based mental health services, inadequate public awareness of mental health, stigmatization and discrimination. However, the Free State Province, in line with other provinces also provides primary mental health care services in six districts, including Thabo-Mofutsanyana where the study was conducted. The Provincial Mental Health Policy (8/5/1/3/2010) states that

their vision is to pursuit having a healthy and self-reliant Free State Province community, and they commit to carry this mandate by providing accessible mental health care services at three levels of care, namely: primary, secondary and tertiary mental health care (Free State Province, 2010).

However, Seloilwe (2006:17) states that the shift to a primary health care approach heightened the importance of understanding the effect of this approach on the families living with a mentally ill family member. In research done on this topic in Ireland, findings confirm that family carers play an important role in the care, treatment and rehabilitation of mentally ill family members (O'Doherty & Doherty, 2008:19). Furthermore, family relationships and family support networks form part of patient care and nurses can work directly with families to aid in strengthening these networks (Korhonen, Julkunen & Pietilä, 2008:676). In Hong Kong, government supports the importance of family as a support system, and the role the family plays as a support to its vulnerable members (Glendy & Mackenzie, 1998:288). Moreover, in America, the United States Department of Veterans Affairs (AV) health care system is working to develop family and caregiver support programmes to enable veterans with mental health problems to remain at home with community-based support service (Sorrel & Durham, 2011:24). In addition, Japan is in support of a comprehensive care system that involves support and provision of care at home, arguing that to effectively deal with challenges associated with prolonged hospitalisation of mentally ill patients, it is essential to switch to community psychiatric care system (Fujino & Okamura, 2009:128). Furthermore, family support is seen as very important to the successful rehabilitation and recovery of a person with mental illness (Stuart, 2009:212). Apart from the pure emotional support that is given by carers, there are many other practical examples of support, such as cooking, household chores, assisting with keeping medical appointments and financial support (Jones, 2009:522).

But, contrary to the support the family is supposed to give in Malaysia, a number of families were invariably forced to the role of caregiver to their mentally ill family member, moreover that, not many of the families were ready to accept, or properly prepared to undertake this role (Chang & Horrocks, 2006:436). Even though families are expected to provide care to their mentally ill family members, it seems that they

are faced with many challenges, such as a lack of understanding and skills related to mental illness (Chan, Yip, Cheng & Tam, 2009:67). Similarly, providing continued care and support for people with mental illness is demanding and challenging (Hsiao, 2010:3494). Families often become frustrated, stranded, overburdened and exhausted by the care of their relatives (Seloilwe, 2006:17). In support hereof, in the study conducted in New South Wales, Australia, Wilson (2011:135) indicates that a substantial burden on emotional and social integrity of the family, combined with diminished psychological well-being, caused some family members to question how long they could cope before they reached “the end of their rope”. Furthermore, caring for a person with mental illness can be overwhelming, challenging and a distressing experience (Endrawes, O’Brien & Wilkes, 2007:432).

Ahlström, Skärsäter, and Danielson (2009:309) found that family members are forced to relinquish control of everyday life; family members lose their energy and cannot manage everyday life, families are unstable and emotions influence the atmosphere negatively, and they periodically live in seclusion. In addition, Stjernswärd and Ostman (2008:358) discuss how families express a feeling of not living their own life, struggling to balance relationships, adapting to and re-evaluating their life circumstances, and struggling to voice their ill relatives’ and their own needs. Furthermore, this also has a negative impact on the family member who has chosen not to help the care giving; family members who decide to put their own needs ahead of the needs of their mentally ill family member end up feeling guilty, ashamed, or depressed (Hsiao & Riper, 2010:70). Stuart (2009:212) adds that families, including mentally ill family members do not receive adequate pertinent information about mental illness or effective support from mental health professionals. As a consequence, families feel that their attempt to care is not supported by the health care system (Endrawes *et al.*, 2007:435). In addition, carers frequently feel marginalized and undervalued, and believe that the impact of mental illness on them as carers has not been recognized, and they might feel “invisible” to medical services (Jones, 2009:522).

1.2 PROBLEM STATEMENT

Families living with a mentally ill family member might find it difficult to cope. Family carers report high levels of burden related to caring for their mentally ill members (Chan *et al.*, 2009:67). Zergaw, Hailemariam, Alem and Kebede (2008:191) support the economic impact, disruption of daily life, work and family relationships experienced by families living with a mentally ill family member. Furthermore, families of relatives with mental illness were forced to reorganize their household routines, often with detrimental effects to their finances, social relationships, and leisure opportunities (Mavundla *et al.*, 2009:358). Du Plessis *et al.* (2004:4) explain that, because of a lack of formal support systems for families living with mentally ill family members, and lack of skills necessary to take on the responsibility of caring for these relatives, mentally ill family members relapsed and readmissions were common. Moreover, Mavundla *et al.* (2009:358) emphasize that the carers and the mental health care users have access to community-based primary services where they are able to seek psychiatric treatment and collect psychotropic medication, and during their visits to clinics, they interact with primary health care nurse. In my own experience, while accompanying learners for mental health care services for experiential learning, I observed how families interact with mentally ill family members, and it seemed that families have no knowledge and skills related to mental illness, and also do not have knowledge on how to handle a mentally ill family member. In addition, mental health care services (clinics) designated to provide mental health care, and where mentally ill family members attend follow-up appointments, seemed not to have formal support systems for these families. It was thus unclear how these families, living with a mentally ill family member, cope.

In spite of hindrances, some families do cope. Some family members found themselves having to make conscious efforts to avoid being burned out in the course of care giving, by involving themselves in activities and hobbies they find personally satisfying and enriching, while others make deliberate efforts to maintain a normal life-style and try to pursue their usual activities (Abelenda & Helfrich, 2003:28). Endrawes *et al.* (2007:437) added that families managed to survive by living with hope, remembering good times, enduring and accepting reality, and seeking professional help, while other families rely on religious beliefs and obtain hope by

accepting living with a person with mental illness. Furthermore, Haung, Sun, Yen, and Fun (2008:821) state how families used positive thinking and knowledge as a cognitive strategy, and also behavioural coping strategies such as: keeping themselves busy by pursuing personal interest, and furthermore, to emotionally cope, crying is used as a means of emotional release particularly when carers feel upset and distressed. As further support, families receive spiritual help, social support from friends of family members, fellow workers, and neighbours and even support from professionals (Haung *et al.*, 2008:821).

However, in the context of South Africa, specifically in the Thabo-Mofutsanyana district, limited research has been conducted on the strengths of families to cope with mentally ill family members. Zergaw *et al.* (2008:191) suggested that future studies need to focus on how to devise feasible interventions or strategies to lessen economic, social psychological and emotional burdens for family members or carers. Furthermore, in the RISE study which is a research project, where strengthening the resilience of health caregivers and risk groups are explored and described, and which this study formed part of, Koen and Du Plessis (2011:8) explain that people who are exposed to adversity viewed as risk groups. Thus, being at risk in terms of mental health and well-being, influences the daily function and caring for the mentally ill family member. Therefore, in this study, the researcher explored and described experiences of families living with a mentally ill family member, in order to gain insight into difficulties they encounter as well as identify strengths they have in coping while living with a mentally ill family member. In order to explore and describe the problem, the following research questions were asked.

1.3 RESEARCH QUESTIONS

- What are the experiences of families living with a mentally ill family member?
- What strengths do families living with a mentally ill family member have in coping?
- How can families living with a mentally ill family member be supported?

1.4 RESEARCH PURPOSE

Based on the above research questions the objectives of this study are:

- To explore and describe the experiences of families living with mentally ill family members.
- To explore and describe the strengths of families to cope with living with a mentally ill family member.
- To formulate guidelines to support families living with mentally ill family members.

1.5 PARADIGMATIC PERSPECTIVE

Feitsma (2005:5) cites De Vos (2003) description of the paradigmatic perspective as the way in which the researcher views the research field. The researcher selects assumptions for the research from her paradigmatic perspective, which should be applicable to the research domain (Botes, 2002:10). The paradigmatic perspective consists of meta-theoretical, theoretical and methodological assumptions (Botes, 2002:8), and these assumptions are described below.

1.4.1 Meta-theoretical assumptions

Meta-theoretical assumptions are not testable, and deal with the researcher's view on man and society (Botes, 2002:10). The worldview that guide this study is from phenomenological point, thus where the researcher describe and interpreted the experience as it is lived by study participants (Burns & Grove, 2005:27).

The following meta-theoretical assumptions were defined within the researcher's view and they are: man, health, illness and nursing.

1.5.1.1 *Man*

Man is viewed as a human and whole being which operates within psychological, physical, emotional and social spheres of life and experiences phenomena in the environment in which he lives. In this study, “man” refers to the mentally ill patient and his/her family members, who are living in the Thabo-Mofutsanyana district and viewed as human and whole beings, and who experience the phenomenon of living with mentally ill family member.

1.5.1.2 *Health*

The World Health Organisation defines health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (Vlok, 2002:7). In this study, health refers to a state of individual well-being, and being free from mental illness including the families and a mentally ill family member.

1.5.1.3 *Illness*

According to Watson’s philosophy and theory of human caring in nursing (Riehl-Sisca 1989:225), illness is disharmony within a person’s inner self. Illness may be a disease, for example, of the mind, body, or soul, either consciously or unconsciously. In this study, the researcher views illness as any mental illness suffered by any family member.

1.5.1.4 *Nursing*

Watson refers to nursing “concerned with promoting health, preventing illness, caring for the sick and restoring health”. It focuses on health promotion as well as treatment of disease (George, 1990:301). In this study, the researcher viewed nursing as care giving to families living with a mentally ill family member

1.5.2 Theoretical assumptions

Theoretical assumptions were described by the researcher as relevant to this research (Botes, 2002:10). In the context of this study, the following theoretical concepts served as a framework:

1.5.2.1 *Central theoretical assumption*

Exploring and describing the experiences of families living with a mentally ill family member, and their strengths in coping with living with a mentally ill family member will contribute to providing a dense, rich description of this phenomenon. This description, together with relevant literature were used to draw conclusions as a basis for recommendations for nursing education, nursing research and nursing practice, specifically guidelines to support families living with mentally ill family members.

1.5.2.2 *Conceptual definitions*

The following definitions represent a layout of the researcher's use of core concepts that are applicable in this study:

- **Experience**

Brink, Van der Walt and Van Rensburg (2012:121) describe experience from phenomenological point of view as examining human experience through the descriptions that are provided by the people involved. In this study, the experience of families living with a mentally ill family member were explored and described.

- **Family**

A group of people in a household who are attached emotionally, interact regularly, and share concerns for the growth and development of individuals and the family (Stuart, 2009:752). For the purpose of this study, family and carers were used

interchangeably, and were defined as a group of individuals who are bound by strong emotional ties, have a sense of belonging, and a passion for being involved in each other's lives, including a family member diagnosed with mental illness.

- **Mentally ill family member/ Mental health care user**

A person receiving care, treatment and rehabilitation services or using a health service at a health establishment aimed at enhancing the mental health status of a user (Uys & Middleton, 2010:106, SA, 2002:10). Koen and Du Plessis (2011:8) view mentally ill patients as a risk group in terms of their overall mental health and well-being. For the purpose of this study, the terms mentally ill family member and mental health care user were used interchangeably, were viewed as risk group, and were defined as any person who is diagnosed as mentally ill according to the DSM-IV-TR (*Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revision*) classification system (American Psychiatric Association, 2000:13).

- **Mental illness**

It means a positive diagnosis of mental illness in terms of accepted diagnostic criteria made by a mental health care practitioner (SA, 2002:10). In this study, mental illness is defined as any mental disorder classified according to the DSM-IV-TR (*Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revision*) classification system (American Psychiatric Association, 2000:13).

- **Mental health care service / health establishment**

Any group at government, professional, or lay organizations operating at a community, state, national, or international level to aid in prevention and treatment of mental disorders (Mosby's Medical, Nursing, and Allied Health Dictionary, 2002:1080). In the context of South Africa, it refers to any institution, facility, building or place where persons receive care, treatment, rehabilitative assistance, diagnostic or therapeutic interventions or other health services and includes facilities such as

community health and rehabilitation centres, clinics, hospitals, and a psychiatric hospital (SA, 2002:10). In the context of this study, mental health care services or health establishments were defined as the clinic where a mentally ill family member receives care, treatment and rehabilitation including follow-up appointment.

- **Strengths**

These are positive characteristics and strengths that enable individuals to thrive (Bar-On, 2010:57). Koen and Du Plessis (2011:8) cite Koen, Van Eeden and Wissing (2010) who refer to resilience as the fact of having achieved desirable outcomes in the face of adversity or to the qualities that facilitate achievement of desirable qualities under adverse conditions. In the context of this study, strengths mean ways of coping by families living with a mentally ill family member, and strengths and resilience were used interchangeably.

- **Support system**

A network of personal or professional contacts available to a person or organization for practical or moral support when needed (American Dictionary Heritage of the English language, 2000). In the context of South Africa, support systems are the people in the environment of the individual who are available and who can be depended on to help resolve the problem (Uys & Middleton, 2010:274). In this study, support system refers to any adult family member who is living with a mentally ill relative, support groups in the communities, and mental health care practitioners.

1.5.3 Methodological assumptions

According to the Botes model (2002:9), the purpose of nursing research is functional in nature. The research problem and objectives thus direct the research design and methods, and because of the functional nature, nursing research employs “usefulness” as criteria for validity. In this study, the methodological assumptions which guided this study were in line with Botes’ model of research. In this study, the activities of three levels or orders were applied. The first order is nursing practice,

which enabled the researcher to propose guidelines to support families living with mentally ill family members. The second order represents the theory and research methodology. In this study, a phenomenological design was used to explore and describe the experiences of families living with a mentally ill family member. The third order represents the paradigmatic perspective of nursing. In this study, the researcher followed Husserl's philosophy and meta-theoretical assumptions were defined, and theoretical assumptions were described and used as a framework.

1.6 RESEARCH METHODOLOGY

1.6.1 Research design

This research study was a contextual, explorative and descriptive qualitative study (Burns & Grove, 2005:56). A phenomenological design was used and focused on the meaning of lived experiences of human beings (Polit & Beck, 2008:223). This entailed the process of exploring and constructing the meaning of human experiences through intensive dialogue with persons who are living the experience (LaBiondo-Wood & Haber, 2002:144). This design was appropriate because it enabled the researcher to reveal and discover the meaning of experiences namely the experiences of families living with mentally ill family members and their strengths in coping with families living with mentally ill family members. This design was also based on making interpretations and meaning of everyday practices (Brink, Van der Walt & Van Rensburg, 2006:113), such as in this research.

The research was contextual in that individual families living with a mentally ill family member in their home setting, mostly from Southern Sotho families in Thabo-Mofutsanyana district (QwaQwa), and who accompany mentally ill family members to receive care, treatment and rehabilitation at a specific mental health establishment (clinic) were included to obtain data. The context was where mental health services are provided for mentally ill family members. Furthermore, the context, which was the clinic, was chosen because it is where families accompany mentally ill family members for follow-up appointments. The clinic provides mental health services five days per week, from Mondays to Fridays, between 8 o'clock to 4 o'clock in the afternoons. In addition, there are mental health care practitioners such as:

psychiatric nurses, a mental health care district co-ordinator, as well as visiting psychiatrist and psychologist from Bloemfontein, who visit mental health care users monthly, and every Thursday of the third week. Moreover, the clinic is accessible for families living with mentally ill family members. .

It was explorative in that the researcher wanted to understand experiences as it is lived by the families living with mentally ill family members (LaBiondo-Wood & Haber, 2002:144). Meaning was pursued through dialogue processes between the researcher and the participants.

It was descriptive in that little was known in Thabo-Mofutsanyana district about the experiences of families living with mentally ill family members. It was qualitative in that the research intended to thoroughly describe the phenomenon of experiences (Polit & Beck, 2008:220), particularly of families living with mentally ill family members.

1.6.2 Research method

The research method included an exposition of population, sampling method, criteria, sampling size, data collection, and data analysis method.

1.6.2.1 Population

The population included all potential participants selected from a particular group (Holloway & Wheeler, 2002:124). The target population which was studied in this research consisted of the families living with mentally ill family members in the Thabo-Mofutsanyana district in the Free State Province.

1.6.2.2 Sampling

A nonprobability, purposive sampling method was used (Burns & Grove, 2005:352). The researcher selected participants who experienced the circumstances (LaBiondo-Wood & Haber, 2002:148). Moreover, this sampling method was selected because

the researcher purposively identified the participants from a population of families living with mentally ill family members, and furthermore, selected participants from whom she could learn about the experiences of living with a mentally ill family member, namely: parents, brothers, sisters, uncles and aunts (Rossouw, 2005:113; Burns & Grove, 2005:352), and who benefited from the study (Polit & Beck, 2008:355). The research setting which the researcher selected was the clinic where mentally ill family members receive care, treatment and rehabilitation. The research setting which is the 'clinic' is centrally situated at the village, and it serves the community in the village with comprehensive health care services including mental health care services. Furthermore, both the researcher and selected participants were able to travel less than 10kilometers to and from the clinic. Moreover, the research setting was accessible to selected participants because they could walk to and fro. Sampling was carried out with the assistance of a mediator who is the clinic manager, and who works at the clinic and has access to mental health care users. The researcher had an intention of sample size of twenty family members living with mentally ill family member. However, the sample size resulted in interview of fourteen family members. A letter was written to the mediator requesting assistance in the selection of the participants. Both the researcher and the mediator compiled a list of participants who met the selection criteria. The researcher, assisted by the mediator recruited the families of registered mental health care users living with mentally ill family members, and who accompanied their relatives for follow-up appointments at a designated clinic. In this way, the selected sample was more representative of the population because the mediator knew the families living with mentally ill family members. The researcher further met the recruited families at the clinic to confirm appointments with them. The researcher met the families at the clinic on the date which was agreed by both the researcher and the participants. The participants had to comply with the following criteria:

- be family members living with a mentally ill family member in their home;
- be any person who is over the age of eighteen;
- be willing to participate freely; and
- be able to communicate in Sesotho or English.

Ethical permission from the Ethics Committee of the North-West University, Potchefstroom Campus was granted (Annexure A). The researcher requested permission to conduct research in the Free State Province (Annexure B), and consent from the head of the Free State Province's Department of Health was granted (Annexure C). The researcher also requested permission from the district manager (Annexure D), the local area manager of the Thabo-Mofutsanyana district (Annexure E), as well as the clinic manager, in order to get permission to recruit and conduct the research with families living with mentally ill family members. The researcher recruited the families of registered mental health care users who accompany their relatives for follow-up appointments at designated community clinics in the Thabo-Mofutsanyana district (QwaQwa). The sample comprised of family members of families living with a mentally ill family member. A list of families who regularly accompany family members to the community clinic for a month was obtained from the clinic manager in charge of the clinic who was also requested to be a mediator (Annexure F). The researcher also met the recruited families at the clinic and arranged appointments with participants to get both verbal and written consent from them, explained the purpose of the study, the nature of the research, that the interview would be audio-taped, a written consent would be obtained from them, and that participation is voluntary (Annexure G). Having ensured that the participants understood this information, which was checked by asking questions about the information, they were requested to sign a consent form (Annexure H).

1.6.2.3 Sample size

Polit and Beck (2008:358) describe the guiding principle in selecting the sample size as: all participants must have experienced the phenomenon and must be able to articulate what it is like to have a specific lived experience. Thus, in this study it was five families living with mentally ill family members. An initial target of 20 interviews was set. Family members which were actually interviewed were: parent, mother, sister, brother, wife, husband, sister-in-law living with a mentally ill family member. Five interviews were conducted where each family as a group was interviewed, and each member of the family was asked all the three research questions. However, the sample size was determined by the depth of the information that was needed to gain insight into their experiences (Burns & Grove 2005:358). Thus, in this data was

saturated with fourteen interviews. No new participants were purposively interviewed, and the number of participants or families was adequate when the same information was repeatedly given by participants. The researcher no longer learned any new information, resulting in saturation of data.

1.6.3 Data collection

1.6.3.1 *Method of data collection*

The purpose of the study was to explore and describe the experiences of families living with a mentally ill family member and to formulate recommendations to assist families living with mentally ill family members. In order to explore and describe the experiences of these families, the researcher conducted in-depth interviews, where unstructured questions were posed to a family in a language they preferred. Each family had a maximum of four family members, and each of the family was given an opportunity to be interviewed, and talk about his or her own experiences of living with a mentally ill family member. Burns and Grove (2005:542) state that individual members of the family are important resources of information. The use of this technique assisted the researcher to understand the experiences of these families and the impact they made on their experiences. It also allowed both the researcher and the participants to explore the issue of experiences of living with a mentally ill family member (De Vos, Strydom, Fouché & Delpont, 2005:292). The researcher personally interviewed each family member and the following open-ended questions were posed: “What is your experience living with a mentally ill family member?” “What strengths do you have to cope while living with a mentally ill family member?” “How can you as a family living with a mentally ill family member be supported?” These questions enabled the participants to respond freely in the description of living with a mentally ill family member (Streubert & Carpenter, 1999:23). The tape recorder was used to record all information given by each family member as participant. The researcher gave each family member one to two hours to talk freely about his or her experiences without any interruption.

1.6.3.2 Role of the researcher

The researcher started with the interviews in June 2011. The researcher conducted a face-to-face interview with each family member and allowed each participant to share his or her experience of living with a mentally ill family member. Each participant was interviewed once except when the researcher needed clarity. Furthermore, the researcher used interpersonal skills such as: probing, reflecting, minimal responding, and clarifying, listening and open-ended questioning to elicit more information from families living with mentally ill family members (Burns & Grove, 2005:397, 540). All the participants were interviewed in the preferred language such as Southern Sotho or English. While participants shared their experiences, the information was tape-recorded. In addition, for the purpose of recording information and also to synthesize and understand the data after the session, the researcher wrote down field notes such as: descriptive notes, methodological notes and personal notes, as described by Polit and Beck (2008:406). After an interview, the researcher utilised the field notes and jotted down the information, since this helped to recall and explore the process of the interview.

The abovementioned interpersonal skills which were used are explained below:

- *Exploring*: these are prompting questions that encouraged and stimulated the participants to elaborate on the experiences or to help the participants to release pent-up feelings (Brink *et al.*, 2006:152, Uys & Middleton, 2010:182). The researcher used statements like: “Tell me more” so as to get more information from the participant.
- *Reflecting*: this involved feeding back the participants’ own words and the feeling he/she conveyed (Uys & Middleton, 2010:178). Statements such as: “You say it was very difficult and you were unhappy because your son...”
- *Minimal responding*: this technique allowed the participants to speak and share their thoughts and feelings (Uys & Middleton, 2010:181), using statements like: “hmm...hmm...,” or nodding of the head.
- *Clarifying*: this skill was used to get clarification on the statements of the participants which were unclear to the researcher (Uys & Middleton,

2010:180). The researcher, as the interviewer attempted to understand the basic nature of a statement by the participants, e.g. “Am I right to say that...”, “Could you explain...?”

- *Open-ended questioning*: these are questions that allowed the participants to answer their own words (Brink *et al.*, 2006:205). The researcher used words such as: “Explain to me...”, “How did it happen...?”, “What did he do...?”

1.6.3.3 Physical setting

The interviews took place in a comfortable consulting room at the clinic. The researcher ensured, as far as possible, that the privacy of the participants was protected. The time and setting for the interviews were arranged convenient for both the researcher and the participants. The consulting room was arranged in such a way that: each participant felt free to participate, ensured that the room was free from noise, and the temperature and light conditions were convenient for the participant. The tape recorder was used to capture the participants’ responses, and it was placed in a manner that it should not cause any interference, and all information from each participant should be recorded.

1.6.3.4 Duration of the interview

There was no set time limit for the interview, because the length of the interviews depended on the specific interview situation. However, the estimated time for each interview was between one and two hours. The participants were requested to be available for two hours and also to be patient.

1.6.3.5 Trial run

The researcher conducted a trial run before commencing the study in order to test the feasibility of the questions asked during the interview. The trial run took place in the field, and it enabled the researcher to determine whether the relevant data could be obtained from the participants (De Vos *et al.*, 2005:331). The researcher was advised on this matter by supervisors at the North-West University. The interviews were listened to closely and rich data was gathered during this trial interview and the

questions posed were feasible. This also provided the researcher with the practical information on the necessary arrangements and adjustment that were needed to conduct interviews effectively such as: sitting arrangements, where and how to put the tape recorder, how to pose questions, and how to apply communication skills. Once the researcher was convinced that the relevant data could be obtained and that the needed interviewing skill was mastered, a peer review was conducted with the supervisors at the North-West University. The supervisors were satisfied with the trial run and no changes were made, and the interviewing started. This trial interview was also included in the research and analysed as part of the data gathered in this study.

1.6.3 Data analysis

The interviews which were recorded on the tape recorder were transcribed verbatim. The data analysis began after the first interview and was conducted simultaneously with data collection. The transcripts were translated from Southern Sotho to English with the help of translators from the North-West University, Potchefstroom Campus. After the transcripts were completed, copies were kept safe. The originals were kept separately from the draft copies to ensure against fire damage or loss. The researcher listened to the tape recording while reading the written transcripts on the tape. The researcher read and re-read the transcripts, recalling the experiences of the families. The researcher also made notations of the observation on the transcripts. Thematic content of data analysis was utilised. The co-coder also analysed transcripts individually, and a telephonic consensus discussion was held between the researcher and the co-coder. The same step of protocol which is explained below was followed in all the transcripts.

A description of the data analysis procedure is given below:

- Data collected during the study were transcripts from the tape recordings of the interview.
- The researcher became familiar with the data through reading and re-reading the Southern Sotho or English transcripts, and the researcher immersed in the

data, thus listening to the tape containing feelings, and emphasis. During the reading, the researcher wrote short phrases, ideas, and key concepts of the transcripts.

- To facilitate the analysis, the researcher coded and used different colours to highlight different concepts, for example, bracketing the text, and writing codes beside the bracket (e-Source, 2012:18). The volume of raw data was reduced by the use of codes and coding, and once emerging themes emanated, the irregularities that lead to classification of construction of data (Burns & Grove, 2005:548) were noted.
- The information was classified into categories with the use of symbols (Burns & Grove, 2005:548). For example, A, B, C, D, E. In addition, this conventional and straightforward method is where data is divided into small units of meaning which were systematically named per unit, and grouped together into categories that contain related code (Henning, Van Rensburg & Smit, 2004:102).
- Both the researcher and independent and experienced co-coder coded and categorized the themes following the same procedure independently.
- Depending on the themes that were identified, this provided the researcher with the set of data which was written into the article.
- The final phase of the analysis involved representing and visualizing the data in table form which gave the researcher a brief clear overview of the identified patterns and allowed the researcher to compare the different patterns, thus writing the report (De Vos *et al.*, 2005:334).
- The researcher made a telephonic appointment with the co-coder, who was abroad for consensus discussions, and a telephone discussion took place where each individual came up with tables of categories, and both similarities and differences in categories were identified and consensus reached concerning the categories, and after that the tables were finalized.

1.6.5 Literature control

Phenomenologists believe that literature should be reviewed after data collection and data analysis so that the information in the literature should not influence the

researcher's openness (Burns & Grove, 2005:95). After the data collection and data analysis were completed, the research findings were compared or related to the existing body of knowledge of families living with mentally ill family members. The purpose of literature control in this study was to obtain full exploration of the experiences of families living with mentally ill family members, and the collected data was confirmed by comparing them with relevant literature. The new findings obtained in this research were highlighted as unique findings.

1.7 TRUSTWORTHINESS OF THE STUDY

Rigor in qualitative research is demonstrated through the researcher's attention to accuracy and confirmation of information. The goal of rigor in qualitative research was to accurately represent the participants' experiences (Streubert & Carpenter, 1999:28). Rigor is also associated with openness, scrupulous adherence to a philosophical perspective, thoroughness in collecting data, and consideration of all the data in the subjective theory development. Maintaining openness required discipline. Furthermore, the researcher examined many dimensions of the area being studied and forming new ideas, thus *reconstructing* while continuing to recognize that the present reconstruction was only one of many possible ways of organizing ideas (Burns & Grove, 2005:55). To ensure the trustworthiness of this study, Klopper's (2008) principles for assessing the trustworthiness of the qualitative data were applied, and the researcher used Klopper's work because the original source was not available. In Klopper's work (2008:69), trustworthiness is well developed conceptually and was used to conduct the qualitative research. In this study, the four epistemological standards of trustworthiness including: truth value, applicability, consistency and neutrality are described and applied.

A brief description of each strategy and the criteria that were used in this study are given below:

1.7.1 Truth value

In this study, the credibility was established with the truth of the findings (Klopper, 2008:69). The researcher established confidence in the truth findings with the

participants with regard to their experiences living with mentally ill family members. The information was recorded and written exactly as experienced and perceived and lived by the families. To ensure credibility, the following criteria were implemented namely: prolonged engagement, triangulation, and peer examination (Klopper, 2008:69; Streubert & Carpenter, 1999:29).

- *Prolonged engagement*: this enabled the researcher in the field to check perceptions of the families and allowed the participants to be accustomed to the researcher.
- *Triangulation*: implies the convergence of multiple perspectives for mutual confirmation of data to ensure that all data of a phenomenon have been investigated. In this study, triangulation was achieved by involving an independent co-coder during data analysis (Du Plessis *et al.*, 2004:7).
- *Peer examination*: it involves the researcher's discussion of the research process with impartial colleagues who have experience with qualitative method.

1.7.2 Applicability

This refers to the degree to which the findings can be applied in a different context (Klopper, 2008:69; Streubert & Carpenter, 1999:29). The findings of the research should be applied in the clinical context, such as community psychiatric clinics, at home and the hospital where families accompanying patients for follow up consultations. Furthermore, the findings were transferred to of families living with mental health care users in QwaQwa, and through dissemination of report results. In addition, to meet the strategy of transferability, the research findings should fit into other research context outside the study context. To ensure this, the sample was representative of the population. The following criteria were applied to ensure transferability of the study:

- *Dense descriptions*: this includes providing dense background information concerning the participants and the research context, and setting in order to allow others to determine how transferable the findings are.

- *Selection of sources*: this implies the use of a mediator who is experienced in the research field, and assisted in the selection of participants who were representative of the phenomenon under study.

1.7.3 Consistency

Here, the researcher had to consider whether the findings would be consistent if the inquiry is replicated with the same participants and in the similar context (Klopper, 2008:69). Dependability in this study, relates to the consistency of the research findings (Klopper, 2008:69). A strategy of dependability by applying criteria such as: measures of dense description, prolonged inquiry audit and triangulation was utilised. The abovementioned criteria are explained below:

- *Dense description of methodology*: it includes an accurate description of method of data gathering, analysis and interpretation;
- *inquiry audit*: an independent scrutiny of qualitative data and relevant supporting documents by an external reviewer, to confirm the dependability and conformability of qualitative data (Polit & Beck, 2008:755); and
- *triangulation*: implies the use of alternative data gathering method in order to compensate for the weakness of one method of data collection.

1.7.4 Neutrality

Neutrality means, the researcher should be free from bias during the research process by ascending to open context, and be willing to continue to let go of sediment views, and be disciplined. Furthermore, the results were described by writing the findings solely of the participants, and not of the researcher's view (Klopper, 2008:70; Streubert & Carpenter, 1999:29). Conformability was achieved when truth value and applicability of the research data are established (Klopper, 2008:70). To ensure that data is free from bias, the researcher used the following criteria:

- *Conformability audit*: field notes consisting of observational, theoretical and methodological notes were stored, and a literature control was conducted to ensure the conformability of the research findings was established.
- *Triangulation*: theoretical perspectives which test the strength of the researcher's ideas.

1.8 ETHICAL CONSIDERATIONS

Before the study was undertaken, certain fundamental principles were adhered to (Brink *et al.*, 2006:32). The research formed part of the RISE study, for which ethical approval was granted by the Ethics Committee of the North-West University Potchefstroom Campus Ref no. NWU-0079-10-S1). The researcher also applied to Head of Department of Health in the Free State Province to request approval to conduct research. Permission was granted by the mentioned Department. A letter was written to the manager of the Thabo-Mofutsanyana district (QwaQwa) where the research was conducted, and a letter to the clinic manager to request her assistance to serve as a mediator in selecting the participants.

The researcher was guided by three ethical principles namely: the principle of respect for persons, beneficence and justice, and these principles were based on the human rights that need to be protected in this research namely: the rights to self-determination, privacy, anonymity and confidentiality (Brink *et al.*, 2006:31).

A brief description of each principle is given below:

1.8.1 Principle of respect for persons

Each participant's individual autonomy and their right to self-determination were considered. An individual participant has the right to decide whether to participate in a study, without the risk of penalty or prejudicial treatment. (Brink *et al.*, 2008:32). In addition, he/she has the right to withdraw from the study at anytime, refuse to give

information or ask clarification about the purpose of the study. The recruited families decided for themselves whether they wanted to participate in this study without the risk of penalty or prejudice, which could be perceived as forms of coercion by the researcher. The participants were informed that they may refuse participation and / or withdraw from the study at any point in time without explaining their reasons for doing so (Burns & Grove, 2005:194).

The researcher obtained voluntary informed consent from all the participants prior data collection to ensure that ethics were upheld (Burns & Grove, 2005:193). Information regarding the purpose of the study, how it would be conducted, what questions would be asked during the interviews and what would be expected from the participants during the study were provided in writing to interested persons. Then the participants were given enough time to decide whether to participate in the study (Brink *et al.*, 2006:37).

Written consent forms were presented to the participants and they had to sign these in the presence of the researcher and witnesses, prior to the commencement of data collection. As some of the participants were Sotho speaking, and some literate, the researcher read and interpreted the information included in the documents so that they could comprehend the documents including the consent forms. Participants were asked questions to determine that they understood the information provided (Brink *et al.*, 2006:37). If any questions arose, the researcher answered them before written consent was obtained from the participants.

1.8.2 Principle of beneficence

To adhere to this principle, the well-being of the participants had to be secured before commencing the study, and who had the right to protection from discomfort and harm (Brink *et al.*, 2006:32). The general guideline was that the risk should not exceed the potential benefits of the study. This included physical, spiritual, economical, social or legal harm.

Although conducting interviews was non-invasive and pose a minimal threat of bodily harm to participants, the researcher kept in mind that the participants could be

emotionally upset by the interviews as they had to recall the potentially upsetting experiences of living with a mentally ill family member. In the case of emotional discomfort during interview, the researcher facilitated the debriefing by giving the participants the opportunity to ask questions or air complaints and if necessary, refer them for counselling to the psychologist.

1.8.3 Principle of justice

This principle includes the participants' rights to fair selection and treatment (Brink *et al.*, 2006:33). The participants were selected for the reasons directly related to their experiences of living with a mentally ill family member, and not because they were available or easily manipulated by the researcher. The participants were selected with fairness since they were the population in general (Brink *et al.* 2006:33). The agreement between the researcher and the participants was respected, such as appointments, date and time for interview.

The right to confidentiality was based on the right to privacy (Brink *et al.*, 2006:34). The participants' privacy was protected by using a private consulting room where they could speak freely without being interrupted or overheard. The participants were assured that shared information would remain confidential. The conversation which was shared with the participants was tape recorded, and the participants were assured that the information collected would remain private. Consequently, privacy was ensured through anonymity and confidentiality. The researcher kept the identity of the participants' secret, and their names were not mentioned in the final report (Brink *et al.*, 2006:34). There were 14 participants and as a way of identification, each participant was provided with a number as well as the role each participant plays in the family. The process of confidentiality was ensured as far as possible by not divulging or making data gathered available to any person. However, for the benefit of other researchers and publication, the participants' anonymity would be protected. The recorded interviews and transcriptions of the interviews were stored, so that nobody would have access to the documents (Brink *et al.*, 2006:35)

1.8.3 Procedures for protecting human rights

The ethical principle of voluntary participation and protecting the participants from harm were formalized in the concept of “informed consent” (Brink *et al.*, 2006:35). In order to obtain the participants’ consent, each participant was provided with comprehensive and clear information regarding his/her participation. This was done verbally. The researcher discussed the proposed research project with the participants in the language they preferred, Southern Sotho and English. The cognitive ability of the participants was also taken into account. After providing verbal information, the participants and researcher signed the informed consent form. A sample of the informed consent form is provided (see Annex H).

1.9 PROPOSED GUIDELINES

From the research findings and conclusions, support guidelines were proposed for families living with a mentally ill family member in order to help them cope and become more resilient, based on their experiences shared during interviews and themes that were identified by the researcher and the co-coder.

1.10 REPORT OUTLINE

The report was written in article format including the following elements:

1. Overview of the study.
2. The research findings which are written in the format of an article with the title “Experiences of families living with a mentally ill family member.” The article has been prepared for submission to *African Journal of Psychiatry* (see page 34).
3. Conclusions, recommendations, shortcomings and guidelines to support families living with mentally ill family members in the Thabo-Mofutsanyana district.

1.11 LITERATURE REVIEW

A literature review was conducted to ground the research and to formulate the unstructured interview. The following themes were investigated:

- The concepts “experience”, “resilience / strengths”, and “support system”.
- The available literature on experiences, strengths, and the support of families living with mentally ill family members.

The following data was used: Academic Search Premier, CINAHL, library loans and the World Wide Web.

1.11.1 Existing experiences, strengths, and the support of families living with mentally ill family member.

1.11.1.1 International experiences, strengths and support of families living with a mentally ill family member: a literature review

Experiences of families living with mentally ill family members seem to be an international challenge, even though families are expected to provide care to their mentally ill family members. This is also highlighted by Hsiao (2010:3494) who states that providing continued care and support for people with mental illness is demanding and challenging. In addition, this phenomenon is evident in a study conducted in Norway, where the adolescent’s experiences and perspective in living with a mentally ill family members were explored (Trondsen, 2012:178), and the findings indicate that the family members living with mentally ill family members experience some challenges in everyday life, and how their lives are profoundly influenced by their parents’ mental illness, with difficult and practical and emotional challenges to handle. The following are the challenges which are communicated and emphasized by adolescents, and are comprised of five subtopics:

- Lack of information and openness.

- Unpredictability and instability.
- Fear.
- Loneliness.
- Loss and sorrow (Trondsen, 2012:178).

To further support the above, Rose, Mallinson and Gerson (2006:45) report that the relatives, who were caring for moderately severe and severe mentally ill family members, rated family management of illness as poor or fair by almost 66.7% of the participants. In addition, the participants report the greatest extent of burden in the following areas:

- worry about the future;
- poor concentration;
- upset house hold routine;
- feeling quilt about not doing enough; and
- feeling trapped and being upset by changes in the patient.

In spite of negative experiences and the burden the families living with mentally ill families have, some families do cope and have strength to living with a mentally ill family member. Koen and Du Plessis (2011:8) cite Richard (2002) who refers resilience as a personally trait and coping ability, and refers to individual's strengths, flexibility, capacity, for mastery and resumption of normal functioning after excessive stress. In Ireland, O'Doherty and Doherty (2008:22) found that families developed a wide range of coping strategies and styles while living with a mentally ill family member. The following are ways in which families use for coping while living with a mentally ill family member:

- Active behavioural style strategies.
- Active cognitive style strategies.
- Avoidance style strategies.

It is evident in the findings that most of the participants of the study reported use of active behavioural coping strategies, such as seeking support from other people and

talking, while only five participants reported a combined use of all three coping styles (O'Doherty & Doherty, 2008:25).

But contrary, in a study conducted in Portland, Jivanjee and Kruzich (2011:115) point out how youth and parents with mental health conditions face significant obstacles in obtaining service and support as they negotiate the transition from adolescence to adulthood. However, the findings indicate that youth and parents appreciated service providers who were compassionate, well trained and responsive to needs, and that they appreciated family and peer support (Jivanjee & Kruzich, 2011:121). The following are ideal supports need by families:

- Families support.
- Peer support and leadership development groups.
- Accessible, appropriate services.
- Responsive, compassionate service providers.
- Optimal support and service will be more likely when young people and families are included in service planning and delivery (Jivanjee & Kruzich, 2011:115).

1.11.1.2 Experiences, strengths and support of families living with mentally ill family member in developing countries and South Africa.

Despite the challenges the families seem to be facing, the families as a unit as well as individual members might have their own way of coping and finding some kind of satisfaction within the bounds of the adversity of having a mentally ill family member (Ahlström *et al.*, 2009:309). Abelenda and Helfrich (2008:29) refer to this family resilience, as the manner in which family members experience a process of constructive change and growth in response to serious psychiatric disorders in loved ones. Somehow, care giving becomes a source of satisfaction, enhances self-esteem and provides insight about own personal strengths and values (Abelenda & Helfrich, 2008:29). This phenomenon is evident in a study conducted in Ohio, where the I-FAST home-based treatment model was implemented within the community mental health system, and families were found to have resilience, strengths and

resources that can be used in building solutions and achieving change (Lee, Greene, Hsu, Solovey, Grove, Frase, Washburn & Teater, 2009:397). Glendy and Mackenzie (1998:2910) also found that family carers developed a wide range of strategies to cope with long-term care giving by accepting and taking positive action, learning to accept and reconcile the disabilities or deviant behaviours in the chronically ill family members over time, and avoiding dissatisfaction and disappointment that would have resulted from unrealistic expectations of their relative. Furthermore, Abelenda and Helfrich, (2008:28), from the field of occupational therapy in mental health, cite Spanoil (1987) who states that some family members developed strategies to take care of themselves such as: accepting the reality of the disability, distancing, which relate to separating from behaviour they cannot change, and setting limits by being firm about the behaviour they like or do not like. Seloilwe (2006:268) states that some families work cooperatively with mentally ill relatives, they do not compete or provoke them, and at times, family members suppress their emotions and let that of the mentally ill family member take precedence, and to cope with daily activities, families constantly negotiate the care giving.

In developing countries and societies, the experiences of people living with mentally ill are not well understood, not fully described, and stigmatized (Mavundla *et al.*, 2009:359). Lauber and Rossler (2007:157) indicate that there is a wide tendency to stigmatize and discriminate people with mental illness in Asia. This is further supported that stigma experienced from family members is pervasive and moreover social disapproval and devaluation of families with mentally ill individuals are an important concern.

In South Africa, Health Minister Aaron Motsoaledi (2012:5) argued that there are hurdles which face mental health improvement including lack of community-based mental health services, inadequate public awareness of mental health, stigmatization and discrimination. Furthermore, families with mentally ill family members experience additional stress, and Greeff, Vansteenwegen and Ide (2006:285) state how the situation impact on two levels such as: on each individual family member, as well as on the family as a system. To confirm this, Du Plessis *et al.* (2004:4) indicate that the government of the North West Province implemented deinstitutionalisation where many mental health care users were discharged from the hospital to be under care

of their family members. However, many mental health care users relapsed and were readmitted in the institutions because their family members had no knowledge and skills on how to care for their mentally ill family members. To further support this, Mavundla *et al.* (2009:359) indicate that, although families brought their relatives with mental illness to the rural clinics to collect medication regularly, the patients still relapsed. In addition, it was observed that when people with mental illness experienced side-effects, they often decided to stop taking the medication without consulting health professionals.

Despite the hindrances, families living with mentally ill family members seemed to be coping. Greeff *et al.* (2006:293) report that the results indicate the characteristics that are possible indicators of family resilience such as: family hardiness, a passive coping strategy and family coherence, social support, and mobilization of the family.

Support for families living with mentally ill family members remains a challenge in South Africa. This is evident in the study conducted in a rural community in Limpopo Province, South Africa, where families living with mentally ill members stated their experiences with the health-system as social ostracism of mental health care users and their care givers, rejection by the community and the health-care professionals (Mavundla *et al.*, 2009:362). However, Greeff *et al.* (2006) indicate the resources that made families to be resilient while living with a member with as psychological disorder. The following are resources in the family:

- Support from the children was named as the leading recovery factor.
- Commitment and cohesion of the family.
- Fostering hope or positive attitude.

In terms of resources from the community, support was reported as follows:

- Support from the family.
- Support from the medical world.

It can be concluded that although families living with mentally ill family members, they still experience many challenges that need to be addressed. In addition, some families have developed strengths and strategies on how to cope while living with a mentally ill family member. It is also evident that some families do get support, however only 10% of health professionals provide support to these families specifically during stressful periods (Greeff *et al.*, 2009:295). In this study, the researcher explored and described the experiences and strengths of families living with mentally ill family members. Furthermore, the researcher wanted to know how families want to be supported in order to formulate guidelines in supporting while living with their mentally ill family members.

SECTION 2: ARTICLE

2. Article

Full title: “Experiences of families living with a mentally ill family member.”

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Guidance for Authors on Preparation and Submission of Manuscripts to African Journal of Psychiatry (AJOP)

Material submitted for publication is accepted on condition that it meets the requirements of the Editor-In-Chief. The publisher reserves the copyright of the material published. All authors must give consent to publication, and the AJOP does not hold itself responsible for statements made by contributors. The Journal's primary aim is the publication of review and original articles, case reports and letters to the editor aimed at specialist mental health care and other professionals working in the neurosciences as well as primary care practitioners. All material will be sent for peer review.

Manuscript preparation

1. Copies should be neatly typewritten, with double spacing and wide margins. The manuscript should be submitted electronically. The authors are required to state that their material is original and not previously published or currently submitted elsewhere.
2. All abbreviations should be spelt out when first used in the text and thereafter used consistently.
3. Scientific measurements should be expressed in SI units throughout, with two exceptions: blood pressure should be given in mmHg and haemoglobin values in g/ dl.
4. Authors' full name(s) & surname, affiliation & correspondence address (including email address) to be set out in full on the cover page of the article.
5. All articles (review, original research etc) are to have an abstract, giving a brief succinct overview of the article. The abstract should reflect the essence of the article and be 200 to 250 words. For an Original Research article, the abstract should be structured as follows: Objective, Method, Results and Conclusion.

6. Authors must give a minimum of three key words and should use the MeSH (Medical subject headings list of index medicus) catalogue.
7. A clear statement on ethical issues in clinical and animal research must be provided; conflict of interest and patient confidentiality issues must be indicated.
8. For multi authored articles, the International Committee of Medical Journal Editors (ICMJE) states that, there are three necessary conditions one must meet in order to claim (co) authorship:
 1. Substantial contributions to conception and design, or acquisition of data, or analysis and interpretations of data.
 2. Drafting the article or revising it critically for important intellectual content.
 3. Final approval of the version to be published.

Those, and only those who meet all three of the above stipulations, can be named authors, while those who meet only some of the requirements or otherwise facilitate the research by contributing to funding, data collection, editorial work, etc. should be named in the “Acknowledgement” section

Accordingly, multi-authored articles need a declaration of relative contribution.

Illustrations

1. Figures consisting of all material which cannot be set in type, such as photographs, should be forwarded electronically.
2. Tables and legends for illustrations should be typed on separate sheets and should be clearly identified. Tables should carry Roman numerals, I, II, III, etc, and illustrations Arabic numerals, thus: 1, 2, 3, etc.

3. Where identification of a patient is possible from a photograph the author must submit consent to publication signed by the patient, or by the parent or guardian in the case of a minor.
4. If any tables or illustrations submitted have been published elsewhere, written consent to republication should be obtained by the author from the copyright holder and the author (s).

References

1. References should be inserted at the end of the sentence, outside the full stop, as superior number, and should be listed at the end of the article in numerical order. Do not list them alphabetically.
2. It is the author's responsibility to verify references from the original sources.
3. References should be set out in the Vancouver style, and only approved abbreviations of the journal titles should be used; consult the List of Journals Index Medicus for the details. Names and initials of all authors should be given unless there are more than six, in which case the six names should be given followed by "et al". First and last page numbers should be given.

Journal references should appear as follows:

- a. Peter S. Acute hamstring injuries. Am J Sport Med 1994;129(7):395-400.

Book references should be set out as follows:

- a. William G. Textbook of Sports Medicine. 2nd Edition:
Butterworth, 1989:101-104.
- b. Vandermere P, Russel P. Biomechanics of the hip joint.
In:Nordien PE. effcoat A, eds, Clinical Biomechanics. Philadelphia: WB Saunders, 1990:472-479.

4."Unpublished observations" and "personal list" may be cited in the text, but not the reference list. Manuscripts accepted but not published can be included as references followed by "(in press)".

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Abstract

The research objectives of this study were to explore the experiences of families living with a mentally ill family member in Thabo-Mofutsanyana district of the Free State Province in South Africa, to explore and describe the strengths they use in coping while living with mentally ill family members, and to propose guidelines to support families living with mentally ill family members. In order to achieve these objectives, the researcher gathered data by conducting unstructured in-depths interviews with participants, analysed data with the help of an experienced co-coder and related the data to relevant literature. Five themes emerged from the data analysis: Positive experiences of families living with a mentally ill family member, negative experiences of families living with a mentally ill family member, families' concerns of staying with a mentally ill family member, strengths in coping with a mentally ill family member, and support of families living with a mentally ill family member. Several conclusions were drawn by the researcher from these themes. In order to address some concerns that were indicated by these families, and to strengthen their strategies in coping as families, the researcher proposed guidelines for mental health care practitioners in order to strengthen the support of families living with a mentally ill family member. Furthermore, further studies are needed to implement these guidelines and to evaluate their effectiveness.

[Key words: Experience, family, strengths, mentally ill family member, support system]

1. INTRODUCTION

In South Africa, Mavundla, Toth and Mphelane [1] state that after democratisation in 1994, in line with other countries, the health care system was re-organized in accordance with the primary health care philosophy. The new Mental Health Care Act 17 of 2002 reflects the changes in mental health legislation [2]. Van Rensburg [3] states that the emphasis has shifted to appropriate community-based care, rehabilitation and reintegration into the community care. This is supported by Uys and Middleton [4] who indicate that the South African government accepted the policy of a comprehensive primary health care approach. Although this was not implemented with enthusiasm initially, the ANC [5] indicates that the new government is committed to this approach, as stated in the National Health Plan for South Africa. In further support of primary health care, the purpose of the Mental Health Care Act [2] is to ensure provision of care treatment and rehabilitation to people with mental illness. In the Free State Province, where the Thabo-Mofutsanyana district is situated, and in line with other provinces, the province also provides primary health care services. This is supported by having the Provincial Mental Health Policy 2004 [6] with its vision in pursuit having a healthy and self-reliant Free State Province community.

Uys and Middleton [4] state that, during the last two decades, mentally ill patients have been systematically deinstitutionalised. This is confirmed by Mavundla, Toth and Mphelane [1] that due to overcrowding in mental hospitals, a process of deinstitutionalization of mental health care services started which led to families becoming the main providers of individuals with mental illness. To further support this, Du Plessis, Greeff and Koen [7] indicate that deinstitutionalisation of mentally ill patients was implemented by the government of the North West Province, where as many as possible psychiatric patients were discharged from long term hospitals to be under care of their families.

Families living with a mentally ill family member might find it difficult to cope. Du Plessis, Greeff and Koen [7] explain that, because of the lack of formal support systems for the families living with mentally ill family members, and lack of necessary skills to take on responsibility of caring for these relatives, and as a result, mentally ill

family members relapse and readmissions are common. In my own experience, while accompanying learners for mental health care services for experiential learning, I observed how families interact with mentally ill family members. It seemed that families have no knowledge on how to handle a mentally ill family member. In addition, mental health care services (clinics) designated to provide mental health care, and where mentally ill family members attend follow up appointments, seemed not to have a formal support system for these families. This became unclear how these families living with a mentally ill family member cope. The researcher could confirm the statement after spending some time in the research field as part of the preparation for this study.

Therefore, the focus of this study was to develop the guidelines to address the gap in supporting the families living with mentally ill family members. Moreover, in South Africa, in the Free State Province and specifically in the Thabo-Mofutsanyana district, limited research has been conducted on the strengths of families to cope with mentally ill family members. Furthermore, Zergaw, Hailemariam, Alem and Kebede [8] suggest that future studies need to focus on how to devise feasible interventions or strategies to lessen economic, social psychological and emotional burdens for family members and carers. This support has the relevance of the research project for the nursing discipline.

The above argumentation resulted in the following research problem: Families living with mentally ill family members in Thabo-Mofutsanyana district utter a gap in the support of living with a mentally ill family member. The following questions were formulated to target this problem:

2. RESEARCH QUESTIONS

- What are the experiences of families living with a mentally family member in the Thabo-Mofutsanyana district?
- What strengths do families living with a mentally ill family member have in coping?
- How can families living with mentally ill family members be supported?

These research questions led to the following objectives:

- To explore and describe the experiences of families living with a mentally ill family member.
- To explore and describe the strengths of families to cope with living with a mentally ill family member.
- To formulate guidelines to support families living with mentally ill family members.

3. METHODS

The research method in this study consisted of sampling, data collection and data analysis. The determination of a paradigmatic perspective preceded the execution of the research method.

3.1 Paradigmatic perspective

In the initial phase of the study, a paradigmatic perspective was determined, which implies the way in which the researcher views the research material [9]. The paradigmatic perspective for this study was based on assumptions applicable to research domain Botes [10] and on Burns and Grove [11] that the phenomenology is description of an experience as it is lived by study participant and interpreted by the researcher. The phenomenon in this project was the experiences of families living with a mentally ill family member. This project contains the characteristics of a scientific process because a scientific and systematic approach was used [12].

3.2 Sampling method

The population studied in this research consisted of families living with a mentally ill family member in the Thabo-Mofutsanyana district in the Free State Province in South Africa. Purposive sampling was used to select participants who complied with the sample criteria mentioned below, and who voluntarily agreed to participate. The sampling was carried out with the assistance of a mediator who is working for a clinic

in the Free State Province Department of Health (FSDoH) that is dealing with mental health care users in the Thabo-Mofutsanyana district and who are well known to the families living with mentally ill family members. In this way, the selected sample was more representative of the population because the mediator forms part of the current support system for families living with a mentally ill family member.

When the participants were selected, they were given information concerning the research and briefed of what is expected from them as participants. The participants were provided with sufficient understandable information concerning their voluntary participation in the research. This information was adjusted to the language and the knowledge level of the families living with mentally ill family members in the Thabo-Mofutsanyana district [11, 12]. It also included an explanation of the objectives of the research, the way in which confidentiality was ensured and the voice recording of the interviews. After ensuring that the participants understood this information, which was checked by asking participants questions, they were asked to sign a consent form.

3.3 Sample size

Sample size was determined by data saturation [11]. The process of purposive sampling in this study continued until a sufficient amount of data of the studied population was obtained to be able to draw valid conclusions, and the new participants were interviewed until no new themes were recorded. This implied that interviewing new participants continued until 14 interviews were conducted, after which the experiences of living with a mentally ill family member were totally clear and a pattern in the data had become evident.

3.4 Data collection

Congruent with the qualitative, phenomenological research design that was chosen for this study, data was collected by in-depth interviews with families living with mentally ill family members in the Thabo-Mofutsanyana district. The interviews were conducted from June 2011 until August 2011. A tape recorder was used to record the interviews which all lasted for approximately 45 minutes to an hour. The

interviews were predominantly guided by two open-ended questions. Additionally, the researcher used interpersonal skills for probing in order to get the participants to express their experiences and strengths to cope in living with a mentally ill family member [11]. The central open-ended questions were:

- What are your experiences living with a mentally ill family member?
- What strengths do you have to cope while living with a mentally ill family member?
- How can you as a family living with a mentally ill family member be supported?

Experts in qualitative research were consulted to evaluate these questions and a trial run within the field was undertaken. The interviews took place in a comfortable room at one of the clinics which provides mental health care services in the Thabo-Mofutsanyana district. There was no set time-limit for the interviews, because the length of the interviews strongly depended on the specific interview situation. After the interviews, field notes which were used to supplement and verify the voice recording were written down as soon as possible [9].

3.5 Data analysis

After having recorded the interviews on a tape recorder, they were transcribed verbatim. The data analysis commenced after the first interview and was carried out simultaneously with the data collection. The transcripts were translated from Southern Sotho to English with the help of translators from the North-West University. A work protocol was developed by the researcher according to which data was analysed. The initial data analysis guided decisions concerning further data collection [11]. Open coding was used for analysing the transcribed data and an experienced co-coder coded the data independently [11]. During telephonic consensus discussions, the researcher and the co-coder discussed the coding themes and consensus was reached on the main and subcategories in order to ensure the trustworthiness of the data analysis [11, 13, 14 and Table 1].

4. TRUSTWORTHINESS

To ensure further trustworthiness of this study, the researcher applied Klopper's (2008) principles for assessing the trustworthiness of qualitative data [14]. In Klopper's article [14], trustworthiness is well developed conceptually and was used by the researcher in conducting qualitative research. The article describes four epistemological standards of trustworthiness; truth value, applicability, consistency and neutrality, which were applied to this research. The researcher had an engagement with the research field for three months, which afforded an opportunity to check perceptions of the families and allow the participants to be accustomed to the researcher. Once the researcher had built a trusting relationship within the research field, participants came forward on their own initiative because they were willing to participate. This increased the credibility of the research, which also ensured triangulation where an independent co-coder was involved during data analysis [5]. Furthermore, the credibility of the research was increased by reframing, repetition and expansion of the interview questions. In addition, the interpretation of data by an experienced co-coder and the cross-checking of the data in consensus discussions enhanced the credibility of the research findings. The previously discussed purposive sampling method, and the use of the mediator who is experienced in the field and who assisted in the selection of participants who were representative of the phenomenon under study contributed to the transferability of the study. Furthermore, the researcher kept observational, theoretical and methodological and personal field notes which ensured conformability of the findings. Dense description of methodology of data gathering, analysis and interpretation increased dependability of the study. Peer examination by discussing the research process with experienced experts in qualitative research increased credibility of the study. These experienced experts did not express concerns about trustworthiness of the findings.

4. ETHICAL CONSIDERATIONS

This study formed part of RISE project, with ethical clearance from Ethics Committee of the Faculty of the North-West University, Potchefstroom Campus and Head of the

Department of Health in the Free State Province, and this was to ensure that the research is scientifically and ethically justified. This study could have been especially threatening to human rights due to the high stigmatisation of families living with mentally ill family members in South Africa. Since this also applies to Thab-Mofutsanayana district, a primary concern in this research was confidentiality. Privacy for the participants was ensured at both types of venue and identity of the participants was kept confidential at all times. Because all participants had the right to know what participating in this study entailed and to voluntarily participate, informed consent was ensured before all interviews [12]. The participants were protected from physical and psychological discomfort and an experienced psychologist was available for referral to support the participants after interviews when needed [12].

The researcher adhered to the ethical aspects linked to this research and the project was carried out with integrity and in a scientifically honest fashion.

6. RESULTS OF THE STUDY

The results of this study could be summarised in Table I. (See page 87)

7. DISCUSSION OF FINDINGS

The research findings of the experiences of families living with a mentally ill family member were related to the existing body of knowledge of the families living with mental health care users. In doing so, a full identification of the needs for support for families living with a mentally ill family member was obtained and the collected data was confirmed by relating them to relevant literature.

Families living with a mentally ill family member need support consistent with their view, to be able to cope with living with a mentally ill family member. Every family member and a family as a unit need strength and support from other people. Families living with mental health care users who were studied in this research have support, but they also need specific support in order to be able to cope in living with a mentally ill family member. Furthermore, a family's support is influenced by the family's resilience, thus a constructive change and growth in response to the serious psychiatric disorders in loved one [16]. The experiences of families living with a mentally ill family member were explored and described in this study, and the families' strengths in coping while living with mentally ill family members and by considering the various support needs.

After data analysis and the consensus discussions with the co-coder, five main themes were identified in the research findings. The first three themes were the positive and negative experiences of families living with a mentally ill family member, and the families' concerns of staying with a mentally ill family member. The responses to the first guiding question asked in the interview: "What is your

experience in living with a mentally ill family member?” resulted in these themes and they included a diversity of experiences which are described in the following paragraph. The second guiding question posed in the interviews: “What strengths do you have to cope while living with a mentally ill family member?” resulted in a response that is captured in the following main themes of families finding ways to cope with their mentally ill family members, some have even decided to avoid these patients, while some people and institutions were most of the families’ strengths in coping. The third guiding question asked in the interviews was the following: “How can you as a family living with a mentally ill family member be supported?” This resulted in a response that is captured in the following main themes: Department of Health, clinics, rehabilitation centres, community and / or neighbours, mental health care workers such as doctors, nurses, and social workers, medication and support groups for families. The main themes are discussed and confirmed by relating them to relevant literature.

7.1 Positive experiences of families living with a mentally family member

The research findings reflected a diversity of experiences of families living with a mentally ill family member. The positive experiences, which most families have learned living with a mentally ill family member are addressed in the first main theme: Experiences of acceptance, assistance by community members, education by nurses, treatment, people and institutions with the attempt to assist were expressed, which are described below.

7.1.1 Accepting living with mentally ill family member

This subtheme deals mainly with acceptance of families living with a mentally ill family member. Participants reported that they had to accept whatever mentally ill family members do, even if the mentally ill family member would not listen to them. Furthermore, because of their mental illness, family members had to do some of the things for them such as: making sure that he or she gets food, clothing, as well as attend to follow-ups on a monthly basis. Therefore, most family members reported that the mentally ill family members needed care every day. Most families stressed that they have learned to accept and live with their mentally ill family members even

though there are those who feel that they are in-competent to play their role as a family:

“I had to understand the situation and accepted to live with the condition,... stayed in that condition in order to know this person”.

In addition, what is also positive about other participants was that they wanted to live with a mentally ill family member despite the experiences they were going through. Participants reported that they never wanted to leave the family; instead they wanted to know and understand their mentally ill family member better. One participant stated:

“Ache! ...ke amohetse maemo ao keleng ho ona (I’ve accepted the situation), ke bile le mathata a mangata (I came across many problems). Ntho e ntshwenyang ke ho tsuba hona ha hae(I’m only worried about the rate at which he smokes)... ke ntho e mbuisang ka pelo (that is one thing that worries me) empa, (however), ke mo amohetse (I’ve accepted him), kena le tshupo ya hore meriana etla mothusa (and I feel that the treatment is going to help him),...ke se ke tlwaetse ho phela le yena (I’m used to living with him)...keya morata (I love him). Ke se ke ithutile ho phela le yena (I’ve learned to live with him) ...ha ho letho leo nka leetsang (there is nothing I can do) ...I can’t change anything ...he is my brother”.

The study revealed that family members living with mentally ill family members felt as though they are incompetent to play their role as a family, because as family members, each member treats a mentally ill family member differently. In support hereof, some family members indicated how incompetent they are, as well as not functioning as a family. One participant stated:

“But my wife is there for him, as she would allow him to do whatever he wants to do.and my wife has tolerated that. He does not want to listen to me because, he does not want to listen to me...he does not listen to me...his life style is somehow different because he is smoking”.

To confirm the subtheme, Sales, Schuhli, Dos Santos, Waidman & Marcon [17] in their investigation, characterized by qualitatively and underpinned by Martin Heidegger’s existential phenomenology, analysed the relatives’ experiences when

they took care of a schizophrenic member, and the sub-theme learning to live with mentally ill person emerged. Contrary to this, Lee, Ko & Shu [18] in the study which was designed to describe the care giving experiences of male care giver in families with a member suffering from mental illness, indicate that having no choice but to accept the trials of physical labour emerged as one of the themes.

7.1.2 Assistance by community members

Even though families were taking care of their mentally ill family members, it is evident that they were not alone. The study revealed that some families were assisted by community members. Some families were assisted in things like: looking after the mentally ill when the family members are not around, reprimanding the mentally ill when misbehaving, or taking him to the clinic for treatment. One participant said:

“But I have even requested one of my neighbours to check on her. There is a certain lady who is very young, who is of my daughter-in-law’s age, she is staying at home, I have requested her to check on her on what might happen”.

The families reported that they got assistance from community members compared to the relatives. Some community members seemed to be giving more support to the families living with a mentally ill family member without any prejudice. One participant said:

“Even now he is just by himself because there is a change in his life, and even now he is looking after my cattle. Yeah, he is a shepherd but there is somebody who is also assisting him with the work, he is able to look after the cattle”.

But, contrary to the assistance that the families got from the community members, some participants reported that the relatives fail to assist, instead they stigmatized them. The families living with mentally ill family members articulated how their relatives distanced themselves from their families, and the relatives do not even want to know about their mentally ill family member. To support the motion that the relatives do not assist these families, one participant expressed the following:

“There is no support that we get from the relatives as I’ve mentioned that we are all by ourselves...you know how relatives are...particularly when a family member has mental illness....you know ...some relatives drift away, and they do not want to be associated with a mentally ill person”.

To further support that families were not supported and stigmatized by relatives, one participant said: *“Hi, the relatives stay a bit far...yeah...hi, they don’t know her life, yeah!...because when this illness started, we would inform them but they never had any interest to come and check on her,...yes sister, instead they would laugh at her”.* This is confirmed by Sales *et al* [17] who pointed out the experiences of prejudice against the schizophrenic persons and experience of daily life through family conflicts.

7.1.3 Education by nurses

The study revealed that families invest much time in acquiring the medication for mentally ill family members. They accompany them to designated clinics for follow-up appointments, and for collection of medication. Many family members ensure their mentally ill family members get their treatment at the clinic to prevent them from defaulting and relapsing. They also need to supervise their mentally ill family members to ensure that their medication is taken correctly. This is supported by Mavundla *et al* [1] that families of mentally ill family members in rural South Africa accompany them to the clinics for collection of medication as they often refuse to collect it themselves. In order to give effective care for their own mentally ill family member, other families reported that they want nurses to teach them how to give treatment. Education was reported to be one of the most important needs for these families. The families reported how they want nurses to teach them things like: signs and symptoms of relapse, how to handle a mentally ill person when he or she has relapsed and is aggressive, and how and when to seek assistance. One participant said:

“They must come and teach us how to handle him when he has relapsed, and when he is aggressive, and how and when to seek assistance. He sometimes refuses to

take treatment and he becomes aggressive and when I'm not there ,... if they teach one or two people it would be much better".

The families reported that they do have information of living with a mentally ill family member. However, the families reported that they do not have enough information on how to handle their mentally ill family members, as well as the illness itself. The participants considered nurses to be people with better knowledge when it comes to mental illness. Therefore, they reported that they only have superficial knowledge and they want nurses to give them more information. One participant said:

"Uh! ... as a family... I think we can get information from the nurses. They can teach us how to handle a mentally ill person because... truly we don't have enough information, we do know when he relapses but, it is just a superficial knowledge. I don't have an answer. I think the nurses are the ones who have all the knowledge. They are the one who should give direction about the health of the patient...uh".

Du Plessis *et al* [4] support that the family renders practical help to the patient during times when he is not able to do tasks because of mental illness which he suffers. To further support this, Mavundla *et al* [1] confirmed that mentally ill family members experienced problems in maintaining personal and environmental hygiene and often required assistance. Furthermore, Hsiao and Van Riper [27] indicate that many mentally ill family members continue to rely on their families for ongoing care and support throughout their lives

7.1.4 Treatment

Family members mentioned that their mentally ill family members get treatment from the clinic. Furthermore, participants reported that they want the best treatment for their mentally ill family members. In addition, family members reported that mentally ill family members improve when they are given treatment. However, some families reported that their mentally ill family members abuse dagga, which worsens the condition. In this study, the abuse of dagga does not only affect the mental status of the mentally ill, but also strains the relationship between family members and the mental health care user. Furthermore, there is misuse of monthly grants which the

mental health care user receives from the government. One family member reported that she wants the best treatment for her brother who is abusing dagga, and she mentioned that she wants him to be rehabilitated. The participant related her situation as follows:

“He smokes dagga and he has been continuously using dagga ... and that is one thing that I need to be assisted with... he is abusing dagga a lot... and that is what worsened his condition... and I feel that the use of dagga is one thing that worsen his condition and he smokes from seven, ten minutes passed seven, and so on...”.
“The only support that I need is for him to be sent for rehabilitation with regard to his smoking. Secondly... if he can be given some work to do”.

This finding is confirmed by the Mental Health Care Act 2002 [2] which states that the purpose is to ensure provision of care, treatment and rehabilitation to people with mental illness.

This positive experience is directly related to the needs of rehabilitation of mental health care users by mental health care practitioners, which is one of the limitations in terms of support to be given to families living with mentally ill family members.

7.1.5 People and institutions

The participants reported that they wanted the mentally ill family members to get help. The participants explained that as they care for their mentally ill family members, they even take them to other people and institutions in order to get help. Many families indicated that they took their mentally ill family member to the following: traditional healers, prophets, churches, clinics, and hospitals with the attempt to assist them.

- *Traditional healers*

In this study, the participants were families living with mentally ill family members, who were Southern Sotho, who still practice and believe in traditional healers. The participants revealed that they took their family members to traditional healers, while others even stayed in the traditional healers' place. The participants explained that

this was the best attempt where their mentally ill family member gets assistance. One husband of the mentally ill indicated that he took the wife to different people without any help. The following quotation supports these results:

“I only have trust in Jehova, because... medical doctors, when I go to the medical doctors, the traditional healers, the prophet... ahee! ... Mme, hake bone thuso ya letho (I don't get any help), ke nnete ha ke bone thuso ya letho (it is true I don't get any help)”.

Another participant reported how as a family they took their mentally ill family member to stay at the traditional healer's place in order to get care. This resulted in financial and economic strain because they had to pay and buy food for the family member while staying with the traditional healer. Furthermore, the participant expressed that the mentally ill family member would visit them, while they would continue to give her traditional medication. This is evident that some families in Thabo-Mofutsanyana district still make use of traditional healers. The participant related her situation as follows:

“My mom would take her to medical doctors as well as traditional healers, but all in vain. Yes, traditional healers with the hope that she will be better, but only to find out that the condition would just subside. Whilst she is at the traditional healer's place, she would come and visit us at home, and we would continue to give her traditional medication. Despite all that, she would be aggressive towards us, and I would call my next door neighbour to come and help me”.

This finding is confirmed by Lauber and Rossler [23] who found that most studies from the Asia report state that it is common that symptoms of patients with mental illness are caused by supernatural influences and require as a consequence treatment by a traditional healer. Similar findings were reported by Mavundla *et al* [1] that some family members took their mentally ill family members to alternative healing system such as traditional healers to receive traditional medicine as they associated mental illness with witchcraft.

- *Prophets*

Prophets seemed to be of assistance to some families living with a mentally ill family member, while other families seemed not to have hope in some including the prophet. One family member indicated that he tried to get assistance from many people for his mentally ill family member, but all in vain. Jehova was expressed as one of the trust:

“I only have trust in Jehova, even the prophet...achee!.. Mme, ha ke bone thuso ya letho(I don't see any help), ke nnete hake bone thuso ya letho (it is true I do not see any help), but yeah!... because of the grace of the Lord, His the only thing that makes me alive”.

- *Churches*

In this study, churches were used as institutions to assist families living with mentally ill family members. The participants explained that they took their mentally ill family member to church, because they believed that mental illness was caused by witchcraft. They were confused, and thought that the mentally ill was a person with spirituality. One family member stated how she intervened:

“... I took her to my church which is St John Church,... took her to Methodist Church... took her to Methodist church, took her to the clinic,... and support her and her husband was not staying with her”.

- *Clinics*

Participants also reported that they took their mentally ill family members to the clinic. Despite the monthly treatment that the mentally ill collect from the clinic, families would go to the clinic to get some advice on the treatment of a mentally ill family member. Some families would accompany the mentally ill to the clinic to make sure that they get their treatment. The participants reported how the clinic is helpful and explained that if it were not for the nurses at the clinic, the mentally ill family members would not have improved. . It is evident that some families took their

mentally ill family members to the clinics to seek assistance. This is supported by the quotation:

“The clinic has also helped a lot because she is collecting her treatment on monthly basis,... and it has helped a lot because it made the condition to subside and she is no longer roaming around the streets,...”.

It is evident that participants appreciated the assistance they get from the clinic. Some participants believed that nurses at the clinic have been very helpful, and they always consult them for advice. One participant said:

“Yes,... and then... it went on and on, he attended the clinic and was assessed by mental health care practitioner who put him on treatment, and we were requested to take responsibility to take care of him and he should attend monthly treatment. Isn't that we trust them, because we always consult the nurses at the clinic, and they would give me advises”.

- *Hospitals*

Additionally, some participants reported how they used the hospital when they were in crisis. They explained how they struggled to handle their mentally ill family member when he / she fought and physically assaulted them. The results revealed how the family members managed to strain and refer the mentally ill family member to the hospital. In contrast, the report revealed how the hospital gave better treatment, and how the patient was given an injection which brought about a change in the life of the mental health care users. This is evident in the following statements:

“He was physically assaulting us... you know how mentally ill person is... he is very strong... we only managed him by physically restraining and referred him to the hospital”.

It is evident that families relied on the hospital for assistance when family members were aggressive and uncontrollable. The report revealed how the hospital managed to handle the mentally ill family member better than the family. Furthermore, the

mentally ill was administered an injection which made the families have more faith in the hospitals. Having arrived at the hospital was expressed as helpful:

“When we arrived at the hospital... they gave him two injections, and they requested me to remove restrains. He slept for about three hours, and later he woke up and he recognized me,... he requested me to give him some food and I bought for him one, and after that he was fully awake, and since that incident he is much better, he had another episode after a very long time”.

7. 2 Negative experiences of families living with a mentally ill family member

This second main theme includes the negative experiences of families living with a mentally ill family member. The results revealed how the families living with a mentally ill family member had negative experiences. The experiences such as a person without a life, accusations, difficulties and pain, witchcraft and spirituality, risk of injuries or killings, health problems are described below:

7.2.1 Person without a life

One participant described his negative experience of living with a mentally ill family member. The participant reported that it is like living with a person who does not have a life. He mentioned things that the mentally ill family member would do, such as: wake up at night, wash herself, fight with a family member, go out for the whole day without anybody’s knowledge, and then he would chase after her, and do all sorts of things. The following quote indicates the experience of a person living with a person without a life:

“Mme (mam), to live with a person who does not have life... who... who has mental illness is difficult because, even during the night when she is asleep she wakes and wash and do all sorts of things, and you’ve got to fight with her. During the day when she gets out of the yard, she would be out for the whole day, you will hear someone... someone somewhere saying... hey! thusang (please help!)... Ntate o hokae? (man where are you?)... ho thata (you see, it is very difficult)... Mme (mam).”

7.2.2 Accusations

In addition, some family members accused themselves for having mentally ill family members. The participant reported that as family members they even accuse and blame themselves of having a mentally ill family member in the family. One participant reported that some neighbours perceived and regarded them as mentally ill people. Furthermore, participants explained how they would feel embarrassed and ashamed, and this feeling of embarrassment was fuelled by the actions performed by their mentally ill family member. Again, the family would feel as if it has been cursed. The following quotes were expressed by some of the family members:

“Eish!... because of our neighbours, I felt like I am also like her. Yeah... people perceived us as mentally ill people too. They treated us like mentally ill people... as if we are all mentally ill, we felt ashamed because of the things like... she would insults, run away, cover her head with her panty, verbal insults and we would run after her... I mean things like that”.

These indicate clearly how families felt, and accused themselves for having a mentally family member. As a result, participants even experienced the situation where one would ask himself or herself some questions. One participant said:

“I had to learn a lot during the time when I was still angry with her... and I even asked God to say... what have we done?”

7.2.3 Difficulties and pain

It seemed that the families were experiencing some difficulties, and they were also experiencing much pain. Some participants, on the other hand had some difficulties because people around their area knew that they are living with a mentally ill family member, while the other participant reported that it was difficult because he is self-employed, and had to provide for the family. One participant stated:

“It is very difficult because people around our area know that he is mentally ill.” “It is very difficult because I’m not working and I’m self-employed... but whatever I put on the table, I share with him”.

Some families expressed their emotions, where they reported how painful it was when looking at their circumstances. It was painful because the mentally ill family members would do things that were unacceptable, for example, undressing in public, and behaving like children. Despite these circumstances, they continue to live with the mentally ill family member, and said:

“It was painful in the sense that my daughter was not like this... particularly when she does unusual things. Uh! things like... unable to stay still... I mean she keeps on doing funny things that do not make us happy”.

Stjersward and Ostman [19] confirm these by stating how families expressed a feeling of pain not living their own life, struggling to balance relationships, adapting to and re-evaluating their life circumstances, struggling to voice their ill relatives’ and their own needs.

7.2.4 Witchcraft and spirituality

In this study, some families revealed that they still believe in superstition and witchcraft. The results revealed how some family members believed that their mentally ill family members suffered from mental illness because of witchcraft, while others believed that they suffered due to spirituality. Some participants reported that their family members were bewitched because they were intelligent, and as a result, the families experienced bad emotions. Two families reported that mental illness started while their mentally ill family members were young and still at school. The following was expressed:

“I asked the family members about the condition by saying... what kind of illness is this?... they were not sure because, they were saying... it is like she is having stress or witchcraft... they were also confused, they did not know exactly what was the problem, they would say... it seems as if she is the person with spirituality...”.

Families were confused about the cause of mental illness. Furthermore, Chan, Yip, Cheng and Tam [20] indicate that families were expected to provide care to their mentally ill family

members even though they were faced with many challenges such as lack of understanding about mental illness and skills related thereto.

7.2.5 Risk of injuries or killings

During the interviews, it became clear that families are at risk of being injured or killed by their violent and aggressive mentally ill family members, and as such, families live in fear. Some family members reported that they were attacked by their mentally ill family members. Destruction to property was reported as experienced by many families, moreover the results revealed that it is one of the risks of injuries. The families also reported how they are afraid of being killed when the mentally ill destroy their property. The following statements were expressed by the families to indicate that they are at risk of or being killed by their own family members:

“She is destroying things Mme (mam)... she is destructive... she destroys anything she touches, she destroys...she is destructive... it is true she is destructive.” “He smashed everything, removed the windows, removed coal stove from home in the presence of the police, and sold everything... we used to call the police”.

To support the above mentioned theme, one family member reported how their lives are at risk of injuries, and how they were attacked by their mentally ill family member. Mavundla *et al* [1] had similar findings, with one participant in his study, stated that physical aggression and destructive behaviour from the mentally ill is an aspect that puts their own physical and mental well-being at risk and is seen as a barrier to provision of their support. The following was reported:

“It happened the other time that,... when I was just about to go to the clinic for consultation, after having prepared myself,... as I was just about to go out... he quickly woke up and physically attacked my daughter, and we managed to push him out of the house and closed the door”.

7.2.6 Mental and health problems

In this study, some families were affected by the negative experiences of living with a mentally ill family member resulting in some health problems. The results indicate the mental and health problems which were common amongst the family members. The participants reported that they suffered different mental and health problems, in so much as that some of them are even receiving treatment. The mental health problems are: confusion, stress, depression, and hypertension. Each mental and health problem is discussed below as experienced by different family members.

- *Confusion*

One family member expressed that the family was confused when the illness started. She reported that as a person who was new in the family, she did not understand the illness, but she stayed in that family in order to understand the condition. The participant explained her situation:

“They were also confused in that they did not know exactly what the problem was.”

- *Stress*

One participant reported that her sister’s illness started when they were still very young and still at school. Furthermore, she reported how they used to struggle as their mother was the only bread winner, and had to live with her sister who is mentally ill. She reported that she could never study properly because she experienced stress. Her sister would take her books and throw them away. The participant expressed the following:

“I would complain to my mom and become inpatient with her, and request my mom that I cannot tolerate my sister, and I would be stressed up”.

Similar findings were reported by Mavundla *et al* [1] that the fact that families adjust their social lives to the needs of their relatives with mental illness is a source of stress, as they no longer have time for themselves.

- *Depression*

Participants suffered from depression because of some behaviour by their mentally ill family members. Some participants were depressed as a result of strained relationships and conflicts between them and the mentally ill. One participant reported that he was depressed when the mentally ill family member refused to wash, neglects his personal hygiene, and behaves like a child, and as if he is not educated. The participant reported that when he was depressed, he would isolate himself, and would not want to speak to anybody. The participant frowned as he stated the following:

“Yes, and sometimes it makes you feel depressed, you don’t feel like talking to anybody”.

Similar findings are reported by Trondsen [22] who found in her studies that many of the adolescents expressed that mental illness had led to the strained relationship and ambivalent feelings towards their parents.

- *Hypertension*

One participant, on the other hand suffered from hypertension because she had hoped her son would complete his studies. When her son started complaining that he is hearing voices, and seeing things that other people cannot see, she realised that there was something wrong. . The participants started to worry when she realised that whatever her son is saying does not make sense. The participant explained that he felt sad, and used to cry almost every day, and she experienced

episodes of high blood pressure which also needed attention. The participant expressed her situation as follows:

“I feel very sad when I think that my son was okay... and he was not like this,... my heart is very sore”. “The same applies with me right now... I’m suffering from high blood and I’m on monthly treatment... yes, Mme (mam)”.

The aforementioned findings could not be confirmed by the available literature and is therefore a unique finding in this study.

7.3 Families’ concerns regarding staying with a mentally ill family member

The third theme which emerged from the interviews concerns of families living with a mentally ill family member. The results revealed how families were concerned with some of the behaviours of their mentally ill family members. The concerns which the families reported are: aggression, violence, verbal abuse, dagga abuse, heavy smoking, damage to properties, disrupting other people, and personal hygiene.

- *Aggression*

Many participants expressed how their family members displayed aggressive behaviours in their homes. The participants reported that the mentally ill do not cooperate, instead they become aggressive. In addition, when they are aggressive, they do not interact with anybody, instead they isolate themselves from other members of the family. The participants expressed how they experienced fear during the episode of aggression, and they would physically strain the person in order to try and calm him or her down. One participant explained that when she realised that the mentally is angry, she keeps quiet and does not say anything. The mentally ill family member would stay in bed for the whole day. One participant related the situation as follows:

“When I sometimes talk to him, he does not want to listen to me. He becomes aggressive”. “... sometimes he becomes a changed person all together, and becomes very angry”.

Trondsen [22] reported how family members of parents with mental illness applied the strategy of “emergency alert mode” as activity for adjustment and performance aimed at avoiding difficult situations, particularly when their parents are angry and depressed.

- *Violence*

The participants as families were also concerned about the violence in their families. Most participants reported that their mentally ill family members have episodes of violence, and as relatives they are sometimes physically assaulted. The findings revealed that the mentally ill family member would be so strong that the family members are forced to restrain him. The only hope and help that the family would seek during this violent situation, is by calling the police or referring the person to the hospital. The participants reported that they experienced panic, and fear for their lives. One participant related how her brother would fight and physically assault them. The participant related her situation:

“Yes... he was assaulting us,... he was physically assaulting us”. “We had to restrain his arms and legs, and we struggled a lot because he was very strong”.

- *Verbal abuse*

The study indicated that most family members are verbally abused by their mentally ill family members. Families indicated that they are frustrated as they are consistently verbally attacked. Verbal abuse such as shouting and outburst of anger are common behaviours which are displayed. Most participants reported that verbal abuse is often used, particularly when the mentally ill does not want to listen to them, and when he or she wants things to be done his or her own way. There are many ways in which families are verbally abused, for example, insulting, and cursing the family. The participant expressed his situation:

“He does not listen to me... or he would just shout or have an outburst of anger”.

The other participant related how they were embarrassed by the fact that her sister insulted other relatives:

“When we met at funeral as families, my sister mentioned unfounded and offensive stories, and the relatives took exception as if we are the one who instructed her to insult them”.

Lauber and Rossler [23] reported that 52.7% of patients with schizophrenia were considered by their family members to be highly violent. This is consistent with the findings of this study.

- *Marijuana abuse*

The participants reported that they are concerned and worried about the manner in which their mentally ill family members abuse dagga. Some mentally ill members were reported to receive monthly grants from the government to meet their basic needs, however, it seemed to have negative implications. The basic needs such as groceries and clothing are priorities which needed to be met. Instead, the grant is used to feed the addictive habit. The report revealed that the family members are discouraged, helpless, and demotivated when they see this behaviour. Moreover, the participants also feel that if the mentally ill members continue to abuse dagga, the condition worsens. On the other hand, one participant indicated that when his brother did not smoke dagga, his condition worsened, and that prevented them from getting support from other relatives.

“He smokes dagga and he has been continuously using dagga... he is abusing dagga a lot... and I feel that the use of dagga is one thing that worsen his condition”.

- *Heavy smoking*

In this study, it was reported that some mentally ill family members are heavy smokers. This is demonstrated in the frequency in which the person smokes. One participant voiced his concern that he is worried about his brother’s health because smoking is a health hazard. The participant reported that his brother smoked a cigarette every ten minutes. On the other hand, another participant reported that her

brother has never smoked dagga, but he smokes tobacco, Boxer more often. He stated that his brother smokes continuously:

“He is smoking Boxer... time and again he takes puffs. Yes... uh! ... when it comes to smoking, he smokes all the time”.

It is thus clear that participants viewed the life style and the health of the mentally ill family members as being in danger. This attitude and behaviour of the mentally ill family members exacerbate their conditions.

No evidence of smoking could be found in the available literature, which makes these findings unique.

- *Damage to property*

The fact that mentally ill family members were reported to be aggressive, violent, and damaged property is reported in some cases. This is related to property which is owned either by the mentally ill, or the property which belongs to the family. One husband reported that his wife was destructive because, he claimed that she destroyed whenever and whatever she touches in the house. The destructive behaviour is associated with anger, as one family member reported that the family tried not to be harsh with her. The participant related his situation:

“She is destroying things, Mme (mam)... she is destructive... she is destroying anything she touches,... she can destroy everything,... it is true that she is destructive”.

The findings revealed that this destructive behaviour resulted family living with damaged furniture. The family experienced a situation where the property such as furniture, dishes, and clothes were destroyed, and they were left with nothing, and had to start life afresh and buy new ones. As a result of that, one family had to bear some financial implications, and the whole family felt destroyed.

“... he smashed our family house,... demolished everything until we no longer have anything. My mother died without a place to stay because he destroyed everything... and we started a new life”.

Mavundla *et al* [1] confirm with the findings of their study that participants reported that their mentally ill relatives sometimes destroy household property, as well as other people's property, and as a result they suffer from financial burden from the money spent on repairing or replacing such property.

- *Disruption of other people*

The behaviour of a mentally ill person does not only affect the family but it affects other people including community members. The people which were disturbed by the mentally ill include: nurses, neighbours, and relatives. The disruption occurred in different settings. Firstly, it is claimed that the mentally ill family member went to the clinic, and disrupted everybody including the nurses. Another report indicated how a mentally ill family member caused disruption at the funeral, which resulted in other relatives feeling insulted, and they even abandoned their meals. As a result, the families are in conflict, they do not talk to each other, even though they belong to one clan. To support the first statement, one husband reported:

“... living with a person with mental illness is very difficult because, sometimes she will come to the clinic and disrupt everybody, even the clinic people can tell you if they want to say the truth”.

“Something happened the other time, something like ‘mhvango’ (something embarrassing) she annoyed everybody and the people had to leave... my uncle, my grandmother, they all refused to eat and left the place”.

- *Poor personal hygiene*

The participants raised their concerns that their mentally ill family members do not want to wash resulting in poor personal hygiene. Most participants reported how they struggle to get mentally ill family members wash. They refuse to do so and

consequently neglect their personal hygiene. The mentally ill receives disability grants for their illness, and the families buy groceries including cosmetics to cater for them. For some participants that brought some sense of discouragement and helplessness, while one participant reported that she would try to motivate her mother-in-law to wash, but she would refuse and run away and run all over the village.

“She would refuse to wash... she would run away and be all over the village and say... ‘leave me alone’ just like that... she would refuse to wash, and she would refuse to eat”.

Unfortunately, some families have young children in their homes that can be infected. One participant expressed his concern that poor personal hygiene may result in cross-infection, particularly of dirty hands that carry micro-organisms. He reported the incident where his brother would get into the kitchen, open the fridge and touch the food with his dirty hands.

“There are lot of things that are happening, and we are staying with young children at home, he does whatever he wants to do, for example,... when he gets into the kitchen, which is one area that needs to be kept clean... he would cook, touch food from the fridge without having washed the hands,...”.

But, contrary to this study, Chang and Horrocks [24] conducted a study in Malaysia, and reported that most of the Chinese family care givers whose mentally ill relatives had un-stabilized mental illness needed complete care for their personal hygiene.

7.4. Strengths in coping with a mentally ill family member

The fourth theme that emerged from the question, states: “What strengths do families living with a mentally ill family member have in coping? Families living with mentally ill family had to find ways to cope with the mentally ill family members. During the interviews, two sub-themes emerged to indicate how the families cope in living with a mentally ill family member: difficulties and avoidance to cope, and people and institutions that gave families strength to cope.

7.4.1 Difficulties and avoidance

Some participants expressed that it was difficult to cope living with a mentally ill family member. The participants reported the experiences and some behaviours of their mentally ill that made it difficult to cope, for example, not listening to them, refusing to eat, being lazy to work, aggression, and violence. They mentioned that the mentally ill are unstable people who can change their behaviour at any time. Because of this uncertainty, the families are unable to predict the next behaviour. In addition, when mentally ill family members are presented with psychotic symptoms, they do not know how to handle them. As a result, the participants reported that as families, they find it an extra burden and find it difficult to cope with. One participant related his situation:

“I’ve got to run and look for her, and run after her because... Mme (mam) it is a burden, it is difficult “.

Some participants had to learn to avoid their mentally ill family members in order to cope. In this study, the findings indicated that avoidance was used by some of the family members as a strategy to cope. Avoidance was used when family members did not want to argue, nor be irritated by the mentally ill, or when they wanted to tolerate the behaviour. One participant related how she used to avoid her sister:

“I should not be angered by what she saying. I used to be angry, I’ve learned to humble myself and avoid her”.

O’Doherty and Doherty [25] had similar findings, with participants who used avoidance style strategy such as: avoiding discussions, avoiding contact with relative, and blocking it out.

7.4.2 People and institutions used as strengths

In order for families living with mentally ill family members to cope, some had to resort to some people and certain institutions. In this study, participants reported that

they find such people and institutions to be helpful in terms of giving strength to coping. God Almighty, traditional healers and ancestors, and government for disability grant are discussed below:

- *God Almighty*

Participants expressed where they got strength from to cope while living with a mentally ill family member. All the participants explained how they prayed to God the Almighty to help them. They reported that they believed in prayer, and got their strength through prayer. One participant related how they as a family used to pray, because they relied solemnly on the prayer. 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. One participant is quoted:

“I get the strengths from God... without God you can’t survive”. To indicate how families believed that their survival is through prayer one participant from the same family said:

“With me... I just survive because of the Grace of God. Every morning when I wake up I pray... and what make me cope is love and prayer... I get strengths through prayer”.

- *Traditional healers and ancestors*

Some participants believed in traditional healers and ancestors. It is common in the area of Thabo-Mofutsanya district for participants to use traditional healers because the area is partly rural, more so some community members prefer to take their mentally ill family members to traditional healers (Sangomas). Therefore, it is evident in this study that participants expressed how traditional healers assisted them to cope. In one family, even though the mentally ill family member was under the care of the traditional healer, she did not experience any cure which was expected,

however, it gave them some strength to cope, and they were relieved as a family. The participant said:

“Yes, we took her to the traditional healer with the hope that she will be better, but only to find out that the condition would just subside. She used to stay at the traditional healer’s place so that he should take care of her”.

They also expressed that they believe in ancestors, and they mentioned that the ancestors give them strength to cope. For them to get strength, they had to tell the ancestors what they want, and they listened to them, and consequently, give them what they want. One participant explained:

“You would be telling them what you want... request them what you want, whether this and that... and they would listen to you, and give you what you want”.

- *Government disability grants*

Some mentally ill family members receive their monthly support grants. Some mentally ill family members collect their support grants at pay points, and sometimes their family members accompany them or families to collect the grants for them. These support grants that they get is to maintain them as well as to meet their basic needs. Some participants reported that they are happy because, their mentally ill family members receive support grants with which they can support their family. The support grants that they receive are not enough, and there is somehow misuse of money by some mentally ill family members. Despite the mismanagement that is taking place, it has brought some relieve in the families. One participant reported that it is her sole responsibility that every month she accompanies the mentally ill family member to collect his money. Furthermore, the mentally ill burial society is paid out of the support grant. Another participant revealed how the support grant assisted her sister because there are children to be taken care of. In addition, if she was not receiving any grant she would be struggling, because the mentally ill was a hard worker and used to work. The participant said:

“I think the disability grant that she gets has assisted us a lot. It gives us courage, and if it was not because of the grant... life could have been very difficult”.

According to Mavundla *et al* [1], financial support was reported by the families which include the provision of spending money, as well as groceries and clothes. Of the eight families interviewed, four had access to government support grants of the care receivers and were able to utilize it effectively. This is inconsistent with the result of this study.

7.5 Support to families living with a mentally family member

During interviews, the third question asked was: “How do you want to be supported as a family?” This is the fifth theme that emerged as: support of families living with a mentally ill family member. All participants felt that they wanted to be supported while they lived with mentally ill family members in their homes. The participants reported that the support they need will consistently give them courage in the care for their mentally ill family members. The subthemes that emerged as support the families want are: people and institutions, for example, department of health, clinics, rehabilitation centres, community and / or neighbours, home visit, mental health care users, support groups, and medication.

- *Department of health*

One participant mentioned that as a family they want to build relationships amongst themselves as families living with mentally ill family members. The participant said that the community is unreliable. The participant mentioned that some of the community members laugh at them, and do not accept their situation. However, as families they want people from the Department of Health to assist them. She mentioned that people from the Department compared to the community are reliable, and they would not change, and that their work is to assist people. The participant is quoted as:

“And sometimes the community is unreliable... you will never know because people are unpredictable, sometimes they get annoyed... a human being is very funny... yes, people from the department of health will never change, that is their work”.

This finding could not be confirmed by the available literature and is, therefore, a unique finding in this study.

- *Clinics*

Participants mentioned that their mentally ill family members attend follow-up visits at the clinic. Despite the fact that the mentally ill do follow-up visits, the family members want to be assisted by the clinic. Some participants expressed that they feel as if the clinic could do nothing that could bring change to their lives as families living with a mentally ill family member, for example, investigations with regard to treatment for the mentally ill takes, so that it can make them feel better. Some participants reported that the clinic people should listen to them, particularly when they come to them and explain their problems. If they do that, they will feel supported, and they will not despair. One participant said:

“The assistance that I’m expecting is...to see a change in her... I see change when she attends follow ups at the clinic... hmm... as if the clinic could do something”.

There is evidence found which confirms the findings of this research on the clinic as a support system, thus Mavundla *et al* [1] indicated that although families brought their relatives with mental illness to rural clinics to collect their medication regularly, the patients still relapsed.

- *Rehabilitation centres*

Some participants complained that their mentally ill family members do not want to do anything when they are at home, particularly after taking treatment. The mentally ill would stay at home without doing any house-hold chores. The behaviour which was reported as demonstrated more often, was staying in bed the whole day, or lethargy and too lazy to do anything including personal hygiene. In addition, some participants expressed how their mentally ill family members are addicted to and abuse dagga. They suggested that they would like to see them sent for rehabilitation for help. Rehabilitation centres were expressed by some participants as areas where

they can get support from, because they mentioned that as the mentally ill are sent to such areas, they will be taught many things including how they could change their lifestyle, and maximize their full potential in order to do things for themselves, for example, do gardening, cooking, shopping, maintain good personal hygiene, and so on. One participant said:

“If it is possible, his life should better be rehabilitated more than it is right now”. “I don’t know because, we want the very patient to be rehabilitated... yeah! ... because the burden I have... yeah! ...”.

In this study, it is thus clear that the participants want their mentally ill family members who deserve to be rehabilitated, to be sent to rehabilitation centres.

- *Community and neighbours*

Some participants mentioned that they expect the community to support the mentally ill family member as well as them as a family. They explained that they expect the community to respond in a supportive way, particularly when the mental health care user is not clean, and when he or she is talking irrelevant things. Furthermore, they should not mock and laugh at them, but rather help and support them. The neighbours seemed to have played an important role in supporting these families. As a result, the families expressed that they want their neighbours to continue to support them. One participant explained that the support they get from their neighbours make them feel brave, and they are no longer afraid to walk in the street. Consequently, they reported that they relate well with them, and they even visit and relax with them. Furthermore, some neighbours feel free to stay with a mentally ill family member and their families. One participant is quoted:

“... our neighbours have supported us because they know her condition”. “Yes, our neighbours around us, we got a lot of support”.

It is thus clear that families living with a mentally ill family member get support from the community and neighbours. However, they want them to continue to give support to them

- *Home visits*

Home visits were expressed as something that should be done by nurses from the clinic. Many participants related how they want nurses to visit them at their homes. They felt that it is important that the nurses visit them to check whether their mentally ill family member take treatment well. They felt that nurses should occasionally supervise them on how to give the mentally ill medication and this would assist in the prevention of relapse by mental health care users. Again, they felt that it would strengthen and build a good relationship between the nurse, family, and mental health care user, thus resulting in a better support system.

“I expect that there should be nurses who should visit her, and check on her on daily basis whether she gets her treatment. Sometimes they should come and visit the families to go and check whether she gets her treatment properly”.

These findings could not be confirmed by the available literature and is therefore a unique finding in this study.

- *Mental health care professionals*

Participants mentioned that they want mental health care professionals to support them. In this study, mental health care professionals were described as: nurses, doctors, and social workers. Others wanted support from nurses and doctors working at the clinic. They felt that nurses and doctors should teach them how to handle mentally ill family members, and while the social workers were the ones to rehabilitate them. Furthermore, they wanted the social workers to give them some work to do. Some participants were specific and said that they wanted the mentally ill family members, particularly those who smoke dagga, to be rehabilitated. In addition, they should be encouraged to look after their personal hygiene. One participant felt that accommodation is the problem, because he was worried that his brother stays in a shack. Furthermore, his concern was that his brother uses a paraffin stove which might be dangerous for him. He felt that the social worker should come and teach

him about safety. He expressed that if his brother lived in a reasonable and dignified house, it would be much better. One participant explained:

“Uh! ... as a family,... I think we can get the information from the nurses, and the doctors. They can teach us how to handle a mentally ill person... because ... truly we don't have enough information, we do not know when he relapses, but we just have superficial knowledge”.

Contrary to what participants expressed in this study, Tronden's [22] finding revealed that seeking support from the professionals, adolescents living with mentally ill parents described finding it difficult to confide everything about their family situation to them. However, Sales *et al* [17] in their study felt the need to implement programs of capacitation and permanent education of health care professionals so that they may give mentally ill persons and their families the best physical conditions to face the difficulties brought about by the disease.

In this study, it is thus clear that mentally ill family members want to be supported by mental health care professionals.

- *Support groups*

Some participants mentioned that they should come together as families, and form a support group that could work for them. They explained that they have a lot of experience on how a mentally ill family member behaves, and information which they can share. One participant indicated that they can also share information on: treatment, the illness itself, stress, and many other things that can better and empower their knowledge. Participants were aware that their mentally ill family members suffer from different mental disorders; therefore, it is important for them to know about all these illnesses. The participant expressed:

“Hmm!... it is just like that... we can share a lot of information,... because these illnesses are not the same, and some people suffer from stress... some have different illnesses... I don't know”.

Jivanjee and Kruzich (2011:126) had similar findings, where participants eagerly described the support they had received from other parents who had also raised a child with a serious mental health condition.

Another participant believed that it is better if the mentally ill family members come together and form a support group. During support group sessions they should talk about their experiences and illnesses. Furthermore, they should exercise, share information, build relationships, make friendships, and enjoy themselves. They also felt that nurses should form part of the support group so that when the mentally ill ask questions, they would be able to give answers in relation to their mental illness, for example, stigma, what to do when one experiences side effects, and many more. The participant explained:

“That they should talk about their illnesses, and just enjoy being together. They should talk about their experiences and share those experiences, and enjoy the moment”. “The nurse should be there, they should ask her questions in relation to their mental illnesses”.

This is supported by Chang and Horrocks [24] who recommend that mental health care nurses need to help family care givers to cope with stress and stigma of their relatives’ mental illnesses through psychological education or family intervention.

- *Medication*

Medication seemed to play an important role in the support of the families. Some expressed that they also want their mentally ill family members to continuously receive their medication at the clinic. One mother indicated that her son normally goes to clinic on a monthly basis to collect his medication, while some days he goes alone. In addition, she wanted her son to be stable; therefore the clinic should continue to give medication. One participant reported that their mentally ill family members are doing well after having received injection. But, when the mentally ill misses treatment, he gets out of control. This was supported by another participant who explained that when her brother takes medication he feels better. Similarly, one

participant reported that there is an improvement in his son since he receives medication. The participant related her situation:

“He was that kind of a person, but for now... and now that he is attending treatment at the clinic, oh no! ... he is gradually becoming better...”

In this study, it is thus clear that families living with a mentally ill family member want their mentally ill family member to continue to receive their medication, which was considered to be supportive.

7.6 CONCLUSIONS

Five categories emerged from the data analysis: Positive experiences of families living with a mentally ill family member, negative experiences of living with a mentally ill family member, families’ concerns of staying with a mentally ill family member, strengths in coping with a mentally ill family member, and support to families living with a mentally ill family member. Several conclusions were drawn from these categories.

7.6.1 Experiences of families living with a mentally ill family member

From data obtained from the families living with a mentally ill family member after asking them what was their experience in living with a mentally ill family member, the first three categories emerged, namely positive experiences of living with a mentally ill family member, negative experiences of families living with a mentally ill family member and families’ concerns of staying with a mentally ill family member.

The following conclusions can be drawn from their experiences:

- One of the themes that emerged was the positive experiences which families living with a mentally ill indicated, and explained how they had learn to live with mentally ill family members. They had to do everything for the mentally ill including satisfying basic needs. However, some participants felt they are incompetent to play this role as a family.

- Some families were assisted by community members to care for their mentally ill family members. Even though they received assistance from community members, some participants were not assisted by their relatives, instead they were stigmatized including the mentally ill family member. As they were stigmatized as families, they also withdrew from the community and did not want to mix with other people.
- Participants continue to give treatment to mentally ill family members while at home. Unfortunately, not all of them knew how to do so. They felt nurses should teach them how to administer treatment.
- Two participants were disturbed by the fact that their mentally ill family members abuse dagga; therefore they requested them to be rehabilitated.
- People and institutions such as traditional healers, prophets, churches, clinics, and hospital were resorted to in order to seek help, however, without recovery.
- One participant experienced and expressed his wife as a person without a life. She could not sleep at night, wash herself, and would run away and refuse to eat.
- Living with a mentally ill family member was quite stressful to some families, and they blamed and accused themselves. They felt that they have forsaken God. It was difficult and painful to some families.
- Some participants were not sure of or even knew the causes of the illness; instead they associated the causes with witchcraft or spirituality.
- Some participants felt that their lives are in danger. They felt as families that they are at risk of being injured or killed by their violent and aggressive mentally ill family members.
- As a result of living with a mentally ill family member, some participants developed health problems, for example confusion, stress, depression and hypertension.

- All participants expressed some concerns of staying with mentally ill family members. These concerns include aggression, violence, verbal abuse, dagga abuse, heavy smoking, damage to properties, disrupting other people, and poor personal hygiene.

7.6.2 Strengths in coping with a mentally ill family member

The participants in this study answered the question: “What strengths do you have in coping as a family living with a mentally ill family member?” The strengths and ways of coping by families living with mentally ill family members could be identified. The following conclusions could be drawn:

- Although all families in this study are living with their mentally ill family members, some participants in this study found it difficult to cope.
- Some participants felt that the way their mentally ill family members behaved made it difficult for them, because sometimes they felt that they could not handle them.
- Some participants felt that their mentally ill do not want to listen to them, they get out of control and become aggressive and as a result they experience a lot of burden.
- Some family members, as a way of coping, had decided to avoid the mentally ill members, for example, not talking to them or walking out.
- Most participants managed to cope and received strengths from the following people and institutions: They prayed to God Almighty, consulted traditional healers, made requests from the ancestors, and relied on government disability grants which the mentally ill receive on monthly basis.

7.6.3 Support to families living with a mentally ill family member

The participants in this study answered the question: “How can you be supported as a family living with a mentally ill family member?” It can be concluded by the researcher that: Families living with mentally ill family members in this study felt that they are not effectively supported. They felt that they need institutions and people to support them so that they can provide better care to their mentally ill family members. The institutions and people that were mentioned were: Department of Health, clinics, rehabilitation centres, community and neighbours, home visits, mental health care professionals, support groups, and medication.

- Most participants felt that they do not have any knowledge, but the Department of Health was in a position to provide the skills with regard to mental health issues. Therefore, more investigations should be conducted, particularly on treatment for mentally illness.
- All participants felt that the clinic is doing a good job, moreover that they see change in the lives of their mentally ill family members. They felt that they lack knowledge on how to handle a mentally ill person, and they had no empowerment.
- Two participants were troubled by the fact that their brothers mismanaged their support grants and abuse dagga. They felt that their mentally ill family members should be rehabilitated as they could not do any activities including poor personal hygiene.
- Some participants felt that community and neighbours do not support them, as they laugh, mock, and stigmatised the families including the mentally ill family members.
- Home visits were mentioned as something that the mental health care professional no longer do, for example nurses do not supervise families at home on how to give treatment. On the other hand, the social workers fail to educate and train community on health and safety at home.

- All participants felt that mentally ill family members and the families do not support each other. They felt that they could form support groups, where they could share information, build relationships, as well as friendships amongst themselves.

7.7 GUIDELINES PROPOSED TO SUPPORT FAMILIES LIVING WITH A MENTALLY ILL FAMILY MEMBER

In congruence with the objectives of this study, guidelines for effective support for families living with a mentally ill family member in the Thabo-Mofutsanyana district in the Free State Province have been proposed. The purpose of these guidelines is to improve and strengthen the support given to the families living with mentally ill family members in this area. These guidelines were developed from the conclusions drawn by the researcher, based on the experiences of participating families living with mentally ill family members and relevant literature, and the experiences were reflected in Table I.

The guidelines are meant to be implemented by mental health care practitioners, particularly nurses working at the clinics in this area. They must be used in conjunction with existing policies and protocols, and within the legal framework of the Mental Health Care Act 17 of 2002 [2], in order to support the families living with mentally ill family members more effectively. The rationale of these guidelines is that when families living with mentally ill family members are supported by the nurses, community members, relatives and the families themselves, the mental health of the mentally ill as well as the family as a unit will improve. Therefore, these guidelines are to be implemented and supervised by mental health care practitioners (nurses) who should be the backbone of the support system for the families. Furthermore, they should empower the families and the community members who have been supporting these families and their mentally ill family members.

- The mental health care practitioners (nurses) can address the challenges of family members who felt incompetent, and strengthen the families that are competent in giving basic care to their mentally ill family members by teaching them basic skills. This can be done by giving them health education at the

clinic according to the needs of the families. This includes skills such as: how to handle an aggressive patient, whom to call, where to refer the mentally ill to, as well as the rights of mental health care users.

- An education program can be implemented at the clinic for families living with mentally ill family members. This education program should be structured in such a way that both the families and the mentally ill family member are accommodated. This can be done by conducting workshops, seminars, in-service training related to mental health issues for families living with a mentally ill family member, for example causes of mental illness, treatment, personal hygiene and many more, for families living with mentally ill family members in the Thabo-Mofutsanyana district.
- Stigmatization and discrimination of families living with mentally ill family members including the mentally ill can be reduced by holding awareness campaigns periodically. This can be done by mental health care practitioners in conjunction with the families and interested stakeholders who are assisting with mental health activities, for example, non-governmental organizations and in this way that will be one way of support to these families.
- Mental health practitioners can play a major role in advocating for mental health care users for rehabilitation. Rehabilitation should be comprehensive in the sense that it should look at psychological, social, and physical being of the mental health user. The process of rehabilitation of mental health care users who abuse dagga can be facilitated by the mental health care practitioner (nurse) through communication and engagement with other health care professionals, for example social workers.
- Home visits can be met by drawing the clinic programme in such a way that mental health practitioners visit families of mentally ill family members in their homes. While they visit families in their homes, this will allow them to assess the home situation, give information on certain topics, and also supervise them in giving medication.

- Cultural support and spiritual support can be facilitated by integrating traditional healing and spirituality in the current health care system of families living with mentally ill family members. In addition, mental health care practitioners (nurses) should encourage religious organizations and churches to be open about mental illness, and offer support to the families and refer the mentally ill to the relevant community mental health resources, for example, clinics, hospitals, and community centres.
- Mental health care practitioners (nurses) can support and assist families living with mentally ill family members to establish a support group. This could be met by identifying and recruiting all families living with mentally family members in this area, and who are interested in joining the support group. The support group can start with a small number of family members, and the steps or principles of establishing a support group can be followed. As the group develops, it can be left to the families to take ownership. . Furthermore, families living with mentally ill family members should be encouraged to support and encourage other families to disseminate correct information about mental illness within the community.

7.8 CONCLUDING REMARKS

In conclusion, it can be stated that the objective of exploring the experiences and the strengths of families living with a mentally ill family member in the Thabo-Mofutsanyana district was met and led to the formulation of guidelines to support these families. The experiences and strengths framework and guidelines that were developed in this study can serve as useful tool for mental health care practitioners who are working with families that are living with a mentally ill family member. They can guide and empower other professional nurses, family members, community members, relatives, and other health care practitioners in the Thabo-Mofutsanyana district in assisting families living with mentally ill family members in improving and strengthening their support network. The guidelines can also be applied to other comparable settings in other provinces because there are some families living with mentally ill family members in South Africa. Further research studies to investigate

into the impact of the support given by the mental health care practitioners to families living with mentally ill family members, would be useful.

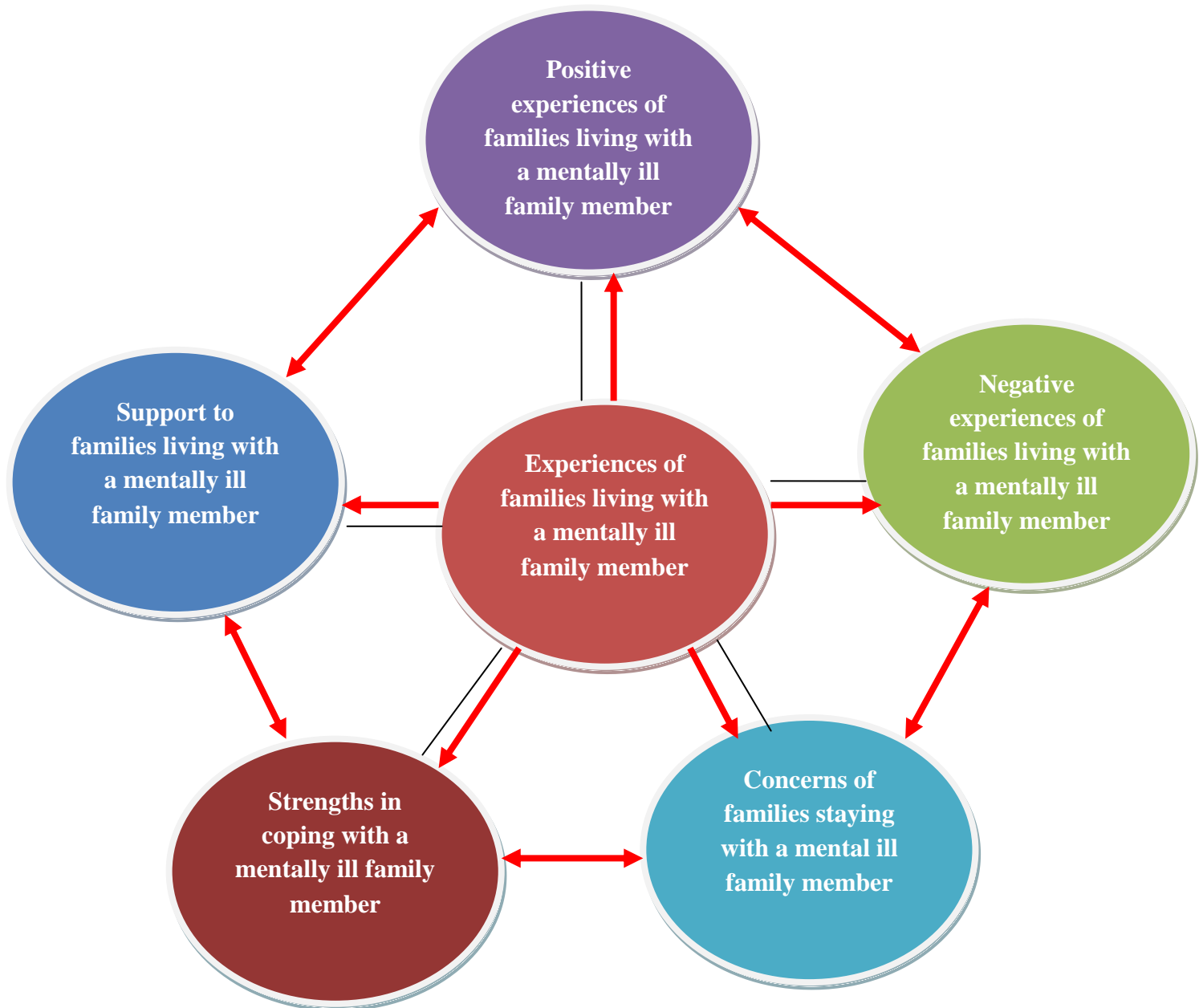
TABLE I: EXPERIENCES OF FAMILIES LIVING WITH A MENTALLY ILL FAMILY MEMBER

COLUMN A	COLUMN B	COLUMN C	COLUMN D	COLUMN E
Positive experiences of families living with a mentally ill family member	Negative experiences of families living with a mentally ill family member	Families concerns of staying with a mentally ill family member	Strengths in coping with a mentally ill family member	Support of families living with a mentally ill family member
Most families have learned to accept to live with their mentally ill family member even though there are those who feel that they are incompetent to play their role as a family	One husband described his mentally ill wife as a person who does not have a life	Families mentioned the following concerns of living with a mentally ill family member:	Some families find ways to cope with their mentally ill family members, others have even decided to avoid these patients	Some families mentioned that they want the following people and institutions to support them while living with a mentally ill family member:
Some community members also assist families that have mentally ill patients even though other relatives are not assisting these families, instead they stigmatize them	Some family members accuse themselves for having a mentally ill family member, some have even said it's like God has forsaken them	Aggression	Some people and institutions are most of the families strengths in coping with mentally ill family members:	Department of health
Other families want nurses to teach them how to give treatment in order to care for their own mentally ill family members	All families mentioned that it is difficult and painful to live with a mentally ill family member	Violence	God Almighty	Clinics

<p>One family member mentioned that she wants the best treatment for his mentally ill brother, such as rehabilitation for dagga abuse</p>	<p>Some families view mental illness as witchcraft while others believe that it is spirituality</p>	<p>Verbal abuse</p>	<p>Traditional healers and ancestors</p>	<p>Rehabilitation centres</p>
<p>Most families took their mentally ill family members to the following people and institutions with the attempt to assist them:</p>	<p>Families are at risk of being injured or killed by their violent and aggressive mentally ill family member</p>	<p>Marijuana abuse</p>	<p>Government disability grant</p>	<p>Home visits</p>
<p>Traditional healers</p>	<p>Some families experience the following health problems as results of living with mentally ill family members:</p>	<p>Heavy smoking</p>		<p>Mental health care professionals e.g doctors, nurses, and social workers</p>
<p>Prophets</p>	<p>Confusion</p>	<p>Damage to property</p>		<p>Support groups</p>
<p>Churches</p>	<p>Stress</p>	<p>Disruption of other people</p>		<p>Medication</p>
<p>Clinics</p>	<p>Depression</p>	<p>Poor personal hygiene</p>		<p>Home visits</p>
<p>Hospitals</p>	<p>Hypertension</p>			

Main themes are presented in a diagram 1. Below:

DIAGRAM 1: *Experiences of families living with a mentally ill family member*



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**SECTION 3: CONCLUSIONS, LIMITATIONS, RECOMMENDATIONS AND
GUIDELINES TO SUPPORT FAMILIES LIVING WITH A MENTALLY
ILL FAMILY MEMBER**

3. CONCLUSIONS, LIMITATIONS, RECOMMENDATIONS AND GUIDELINES TO SUPPORT FAMILIES LIVING WITH A MENTALLY ILL FAMILY MEMBER

3.1 INTRODUCTION

In the article, the research findings were discussed. This consisted of the experiences of the participants in living with a mentally ill family member. The findings were supported by direct quotes from the participants during the interviews. Relevant literature confirmed the findings from this research study. From these experiences the need for support for families living with a mentally ill family member in order to propose guidelines for effective support for these families in caring for the mentally ill family members were identified.

3.2 CONCLUSIONS

Five themes emerged from the data analysis: Positive experiences of families living with a mentally ill family member, negative experiences of living with a mentally ill family member, families' concerns of staying with a mentally ill family member, strengths in coping with a mentally ill family member, and support to families living with a mentally ill family member. Several conclusions were drawn from these themes.

3.2.1 Experiences of families living with a mentally ill family member

From data obtained from the families living with a mentally ill family member after asking them what was their experience in living with a mentally ill family member, the first three categories emerged, namely positive experiences of living with a mentally ill family member, negative experiences of families living with a mentally ill family member and families' concerns of staying with a mentally ill family member.

The following conclusions can be drawn from their experiences:

- One of the themes that emerged was the positive experiences which families living with a mentally ill indicated, and explained how they had learn to live with mentally ill family members. They had to do everything for the mentally ill including satisfying basic needs. However, some participants felt they are incompetent to play this role as a family.
- Some families were assisted by community members to care for their mentally ill family members. Even though they received assistance from community members, some participants were not assisted by their relatives, instead they were stigmatized including the mentally ill family member. As they were stigmatized as families, they also withdrew from the community and did not want to mix with other people.
- Participants continue to give treatment to mentally ill family members while at home. Unfortunately, not all of them knew how to do so. They felt nurses should teach them how to administer treatment.
- Two participants were disturbed by the fact that their mentally ill family members abuse dagga; therefore they requested them to be rehabilitated.
- People and institutions such as traditional healers, prophets, churches, clinics, and hospital were resorted to in order to seek help, however, without recovery.
- One participant experienced and expressed his wife as a person without a life. She could not sleep at night, wash herself, and would run away and refuse to eat.
- Living with a mentally ill family member was quite stressful to some families, and they blamed and accused themselves. They felt that they have forsaken God. It was difficult and painful to some families.

- Some participants were not sure of or even knew the causes of the illness; instead they associated the causes with witchcraft or spirituality.
- Some participants felt that their lives are in danger. They felt as families that they are at risk of being injured or killed by their violent and aggressive mentally ill family members.
- As a result of living with a mentally ill family member, some participants developed health problems, for example confusion, stress, depression and hypertension.
- All participants expressed some concerns of staying with mentally ill family members. These concerns include aggression, violence, verbal abuse, dagga abuse, heavy smoking, damage to properties, disrupting other people, and poor personal hygiene.

3.2.2 Strengths in coping with a mentally ill family member

The participants in this study answered the question: “What strengths do you have in coping as a family living with a mentally ill family member?” The strengths and ways of coping by families living with mentally ill family members could be identified. The following conclusions could be drawn:

- Although all families in this study are living with their mentally ill family members, some participants in this study found it difficult to cope.
- Some participants felt that the way their mentally ill family members behaved made it difficult for them, because sometimes they felt that they could not handle them.
- Some participants felt that their mentally ill do not want to listen to them, they get out of control and become aggressive and as a result they experience a lot of burden.

- Some family members, as a way of coping, had decided to avoid the mentally ill members, for example, not talking to them or walking out.
- Most participants managed to cope and received strengths from the following people and institutions: They prayed to God Almighty, consulted traditional healers, made requests from the ancestors, and relied on government disability grants which the mentally ill receive on monthly basis.

3.2.3 Support to families living with a mentally ill family member

The participants in this study answered the question: “How can you be supported as a family living with a mentally ill family member?” It can be concluded by the researcher that: Families living with mentally ill family members in this study felt that they are not effectively supported. They felt that they need institutions and people to support them so that they can provide better care to their mentally ill family members. The institutions and people that were mentioned were: Department of Health, clinics, rehabilitation centres, community and neighbours, home visits, mental health care professionals, support groups, and medication.

- Most participants felt that they do not have any knowledge, but the Department of Health was in a position to provide the skills with regard to mental health issues. Therefore, more investigations should be conducted, particularly on treatment for mentally illness.
- All participants felt that the clinic is doing a good job, moreover that they see change in the lives of their mentally ill family members. They felt that they lack knowledge on how to handle a mentally ill person, and they had no empowerment.
- Two participants were troubled by the fact that their brothers mismanaged their support grants and abuse dagga. They felt that their mentally ill family members should be rehabilitated as they could not do any activities including poor personal hygiene.

- Some participants felt that community and neighbours do not support them, as they laugh, mock, and stigmatised the families including the mentally ill family members.
- Home visits were mentioned as something that the mental health care professional no longer do, for example nurses do not supervise families at home on how to give treatment. On the other hand, the social workers fail to educate and train community on health and safety at home.
- All participants felt that mentally ill family members and the families do not support each other. They felt that they could form support groups, where they could share information, build relationships, as well as friendships amongst themselves.

3.3 LIMITATIONS OF THE STUDY

As a qualitative study, the research findings were contextual and cannot be generalised to families living with a mentally ill family member in other parts of South Africa or the world. Neither can they be generalised to families assigned to families living with a mentally ill family member in the Thabo-Mofutsanyana district, even in the same area of the Free State Province. Furthermore, a relatively small sample of 14 was included in the study. This challenge was addressed by rich and clear description of the research process.

Therefore, the research findings cannot be generalised to families living with a mentally ill family member in other clinics in the same district. Lastly, interview data were the only source of information gathered from the participants on which the findings were based. Other data gathering methods could have enriched the data as well as the research findings, for example, analysis of narrative reports of families living with a mentally ill family member. Furthermore, data analysis of transcripts was undertaken separately by the researcher and the co-coder. Although consensus was reached, it was held telephonically because the co-coder was in the USA, which

could have resulted in limited communication due to distance, and the researcher experienced negative financial implications.

Main themes are presented in a diagram 1. Below:

DIAGRAM 1: *Experiences of families living with a mentally ill family member*



3.4 RECOMMENDATIONS

The following recommendations are made for future nursing practice, nursing education and nursing research.

3.4.1 Nursing education

Training of mental health care practitioners does not occur at the primary health clinic but at training institutions. However, mental health care practitioners, and the student nurses at the clinics and hospitals, the formal training and in-service training programme should focus on education and training mental health care practitioners who would educate and empower the families living with mentally ill family members of how to handle a mentally ill family member. Furthermore, mental health care practitioners and the students should be taught the principles of how to establish a support group. The content on home visits should be reinstated in the curriculum of comprehensive four programme (R425), and the mental health care practitioners should also educate the families of a mentally ill family member.

3.4.2 Nursing research

Further research on the impact of support given to the families living with a mentally ill family member will enrich the existing framework of knowledge. The findings of this study as well as the effectiveness of the proposed guidelines must be evaluated in the future research.

3.5 RECOMMENDATIONS FOR NURSING PRACTICE

3.5.1 Guidelines proposed to support families living with a mentally ill family member

Findings of this research can be used in the clinic, and other mental health care centres by mental health care practitioners, student nurses, and other health

professionals who deal with mental health care users. The focus of support should be on the families living with mentally ill family members.

In congruence with the objectives of this study, guidelines for effective support for families living with a mentally ill family member in Thabo-Mofutsanyana district in the Free State Province have been proposed. The purpose of these guidelines is to improve and strengthen the support given to the families living with mentally ill family members in this area. These guidelines were developed from conclusions drawn by the researcher, based on the experiences of participating families living with mentally ill family members, and the experiences were reflected on Table I.

The guidelines are meant to be implemented by mental health care practitioners, particularly nurses working at the clinic in this area. They must be used in conjunction with existing policies and protocols, and within the framework of the Mental Health Care Act 17 of 2002. The rationale of these guidelines is that when families living with mentally ill family members are supported by the nurses, community members, relatives and the families themselves, the mental health of the mentally ill as well as the family as a unit will improve. Therefore, these guidelines are to be implemented and supervised by mental health care practitioners (nurses) who should be the backbone of the support system for the families. Furthermore, they should empower the families and the community members who have been supporting these families and their mentally ill family members.

- The mental health care practitioners (nurses) can address the challenges of family members who felt incompetent, and strengthen the families that are competent in giving basic care to their mentally ill members by teaching them basic skills. This can be done by giving health education at the clinic according to the needs of the families. This includes skills such as: how to handle an aggressive patient, whom to call, where to refer the mentally ill family member to, as well as the rights of the mental health care user.
- An education program can be implemented at the clinic for families living with mentally ill members. This education program should be structured in such a way that both families and the mentally ill are accommodated. This can be

done by conducting workshops, seminars, in-service training related to mental health issues for families living with a mentally ill family member, for example, causes of mental illness, treatment, personal hygiene and many more, for families living with a mentally member in the Thabo-Mofutsanyana district.

- Stigmatization and discrimination of families living with mentally ill family members including the mentally ill can be reduced by holding awareness campaigns periodically. This can be done by mental health care practitioners in conjunction with the families and interested stakeholders who assist with mental health activities, for example, non-governmental organizations and in this way it would be one way of support to these families.
- Mental health practitioners can play major role in advocating for mental health care users for rehabilitation. Rehabilitation should be comprehensive in the sense that it should look at psychological, social and physical being of the mental health care user. The process of rehabilitation of mental health care users who abuse dagga can be facilitated by mental health care practitioner (nurse) through communication and engagement with other health care professionals, for example, social workers.
- Home visits can be met by compiling the clinic programme in such a way that mental health practitioners visit families of mentally ill family members at their homes. While they visit families in their homes, this would allow them to assess the home situation, give information on certain topics, and also supervise them in administering medication.
- Cultural support and spiritual support can be facilitated by integrating traditional healing and spirituality in the current health care system of families living with mentally ill family members. In addition, mental health practitioners (nurses) should encourage religious organizations or leaders and churches to be more open about mental

illness, and offer support to the families and refer the mentally ill to the relevant community mental health resources.

- Mental health care practitioners can support and assist families living with mentally ill family members to establish support groups. This could be met by identifying and recruiting all families living with mentally ill members in this area, and who are interested in joining the support groups. The support groups can start with small numbers of the family members, and the steps or principles of establishing a support group can be followed. As a group develops, it can be left to the families themselves so as to take ownership. Furthermore, families living with mentally ill family members should be encouraged and encourage other families to disseminate correct information about mental illness within the community.

3.6 CONCLUSIONS BY RESEARCHER

The objectives of the research namely: to explore and describe the experiences of families living with a mentally ill family member, to explore and describe the strengths of families to cope with living with a mentally ill family member, and to formulate guidelines to support families living with mentally ill family members thus have been met. Appropriate literature was examined, although little data has been published on the experiences of families living with a mentally ill family member, particularly in South Africa. Almost all existing literature focuses on experiences of families living with mentally ill family members internationally. It is likely that this research will promote further investigation into the impact of support given by the mental health care practitioners to families living with mentally ill family members.

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