EXPERIENCES OF FAMILY MEMBERS CARING FOR THEIR MENTALLY ILL RELATIVES AT UMSUNDUZI MUNICIPALITY

Avela Mjajubana (20935117)

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Supervisor	: Prof M.N. Sibiya
Co-supervisor	: Dr V. Naidoo
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Declaration

This is to certify that the work is entirely my own and not of any other person, unless explicitly acknowledged (including citation of published and unpublished sources). The work has not previously been submitted in any form to the Durban University of Technology or to any other institution for assessment or for any other purpose.

Signature of student Date

Approved for final submission

Prof M.N. Sibiya Date

RN, RM, D Tech: Nursing

Dr V. Naidoo Date

RN, RM, D Nursing

Abstract

Background

Individuals diagnosed with mental illness differ due to treatment approaches and the difference in diagnoses and symptoms. Mental illness does not only affect relationships, occupation, recreation and finances, but also the overall routine of the individual's daily life and the lives of their family members. The shortage of skilled and experienced health workers, lack of facilities, limited psychiatric care and inaccessible mental health care services are causes of concern. The uMsunduzi Municipality in Northern KwaZulu-Natal is one such outlying area, with limited access to health services and resources, where family members have to take care of the mentally ill. These underlying problems have warranted the need to explore the experiences of family members living with mentally ill relatives.

Aim of the study

The aim of the study was to explore and describe family members' experiences of caring for their mentally ill relatives and to identify their coping strategies.

Methodology

A qualitative, exploratory, descriptive design was used to explore and describe the experiences of family members living with mentally ill patients in the uMsunduzi Municipality and purposive sampling was used to select participants .Data was collected by in-depth face to face one-on-one interviews with 20 family members caring for mentally ill patients and the findings were analysed using Tesch's method of data analysis.

Findings

Three major themes that emerged from the data analysis were a) caring for a mentally ill relative, b) challenges arising from caring for a mentally ill relative and c) family members' coping mechanisms with caring for a mentally ill relative).

Conclusion

This study showed that the research setting, a rural area in the uMsunduzi Municipality, needs resources to assist family members who care for their mentally ill relatives. It further revealed that the family members were inexperienced, lacking the skills, knowledge and capacity to care, treat and rehabilitate their loved ones. Compounded by inadequate mental health facilities and infrastructure, the implications of the non-implementation of the acts, policies, processes and procedure in the mental health discourse are evidently cause for concern in the uMsunduzi Municipality.

Key words: Family member, mental health, mental health care user (MHCU), mental illness, support system

Dedication

This study of such magnitude is solely dedicated to my mother, Nothembelani Mlatha, my siblings Kungowo, Lwanda, Kwanga Mjajubana and my son Landa Mjajubana.

This study is also dedicated to all patients who suffer from mental illness and all the family members too, who are overburdened and exposed to the day to day frustrations of living with their mentally ill relatives.

Last but not least, my dedication goes to all the healthcare professionals, such as psychiatric nurses and doctors, who provide services to the mentally-ill patients.

Acknowledgement

Pursuing a master's dissertation of this magnitude is a fulfilment that no words can describe except for the Glory of our Almighty God, who has made my academic journey possible.

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GLOSSARY OF TERMS

Family member

For the purposes of this study, a family member is an individual who is biologically or socially related (sibling, spouse, mother or father) to the person with a mental illness or whom the patient regards as family, and who have been living with the patient for a period of six months or more (Stuart 2009: 752).

Mental health

This is a state of well-being in which the individual realises his or her own abilities, can cope with the normal stress of life, can work productively and fruitfully, and is able to make a contribution to his or her own community (World Health Organization [WHO] 2004: 2).

Mental health care user (MHCU)

According to the Mental Health Care Act 17 of 2002, a mental health care user (MHCU) is 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 (South Africa 2002: 10).

Mental illness

The Mental Health Care Act 17 of 2002 defines mental illness as a positive diagnosis of mental illness in terms of accepted diagnostic criteria made by a mental health care practitioner (South Africa 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* 2000: 13).

Support system

Support systems include the family as a support system, the roles family members play as a support structures to its vulnerable members (Glendy and Mackenzie 1998: 288),developing family and caregiver support programmes (Sorrel and Durham 2011: 24), support and provision of care at home, community psychiatric care system (Fujino and Okamura 2009: 128) and other practical examples of support, such as cooking, household chores, assisting with keeping medical appointments and financial support (Jones 2009: 522).

Acronyms

Acronym	Full word/sentence
CINAHL	Cumulative Index of Nursing and Allied Health Literature
DSMMD	Diagnostic and Statistical Manual of Mental Disorders
HIV	Human immune deficient virus
KZN	KwaZulu-Natal
Medline	Medlars Online
MHCUs	Mental health care users
NHPG	National Health Policy Guidelines
PHC	Primary Health Care
PsycINFO	Psychological Information
SADC	Southern African Development Countries
SSA	Sub-Saharan Africa
UN	United Nations
WHO	World Health Organisation

CHAPTER 1: ORIENTATION TO THE STUDY

1.1 INTRODUCTION AND BACKGROUND

According to global statistics of mental health one in four people will be affected by mental disorder due to the burden of disease and ill-health (WHO 2001: 1). Mental illness has the potential to impact every aspect of an individual's life and the lives of those close to them, such as family and friends. Individuals diagnosed with mental illness differ due to treatment approaches and the difference in diagnoses and symptoms. Mental illness does not only have an effect on relationships, occupation, recreation and finances, but also on the overall routine of the individual's daily life and the lives of their family members (Papadopoulos 2009: 15). Sub-Saharan African (SSA) statistics further reveal that one out of three South Africans have been affected or are affected with mental illness (Tzoneva 2014: 14). The same study argues that mental illness is a challenge, not only for the affected person but also for the persons caring for such individuals. Family support of a person with mental illness is seen as very important to successful rehabilitation and recovery. Practical examples of support go beyond cooking, household chores, assisting with keeping medical appointments and financial support, as emotional support is a crucial element in patient rehabilitation. The same study also adds that providing continued care and support for people with mental illness can be demanding and challenging, causing families to become frustrated, stranded, overburdened and exhausted. (Monyaluoe, Mvandaba, Plessis and Koen 2014: 131).

Naidoo 2012). According to Sibiya (2012: 39), KZN has practicing health care professionals practicing as nurses who are not fully equipped with the adequate knowledge, skills and relevant qualifications to manage and treat relevant diseases and conditions, such as mental ill-health. Equally concerning trends in the province are the operational inefficiency of some of the hospitals, such as the inaccessibility of beds for psychiatric patients (KZN Department of Health 2015). These problems appear to pose barriers to relatives' access to effective psychiatric care, treatment and rehabilitation. Thus, the burden of managing such relatives and coping with the consequences of a psychiatric disorder lies with family members. The uMsunduzi Municipality in Northern KZN is one such outlying area, with limited access to health services and available resources, where family members have to take on the role as caregivers. These underlying problems in the uMsunduzi Municipality necessitated the need to investigate the experiences of family members living with mentally ill relatives.

South Africa is committed to the national imperative of provision of care, treatment and quality healthcare services. There are nine provinces spread across South Africa, including KZN. Empirical evidence and scholarly literature has revealed that, mental illness has been increasing at a fast pace in the KZN province (Meyer, Staffed and Jackson 2009; Bayat, Poyraz and Arikan 2012;
The origin of mental illness, as noted in scholarly literature, has been viewed as a sensitive topic (Overton and Medina 2008; Lorenzo, Matiwane, Cois and Nwanze 2013; Magadla and Magadla 2014). Effects of psychiatric illnesses often display symptoms of poor cognition, stressful behaviour and anger and other related dangerous and unpredictable behaviour (Lorenzo, Matiwane, Cois and Nwanze 2013; Magadla and Magadla 2014). Family members play an important role in the rehabilitation and support of a loved one (Evalvold 2003: 8). Modeste (2015: 2) reveals that family members that come into contact with their mentally ill relatives, may not necessarily have the required knowledge, ability and skill and often spend large amounts of money on care, treatment and rehabilitation. Although this may have its rewards, it can be financially draining on the family. This study was conducted to explore the experiences of the family members living with a mentally ill relative to gain a better understanding of the challenges, as well as the strengths.

1.2 PROBLEM STATEMENT

De Vos, Strydom, Fouche and Delport (2011: 108) define problem statement as a part that captures the essential focus of the study. On the other hand, Brink, Van der Walt and Van Rensburg (2012: 61) describe research problem as an area of concern where there is a discrepancy between the way things are and the way they ought to be. A problem statement articulates the nature, context and significance of a problem (Polit and Beck 2012: 92). According to Sibiya (2012: 39), KZN has practicing health care professionals such as nurses that are not fully equipped with the adequate knowledge, skills and relevant qualifications to manage and treat relevant diseases and conditions. Societal stigma with the formal health services is evident in KZN and allocation of budgets to assist psychiatric facilities within KZN reveals a gross inequity. Equally, concerning trends in the province are the operational inefficiency of some of the hospitals, such as the unavailability of beds for psychiatric patients. In these hospital settings, only 25% of beds are available for psychiatric patients. These problems appear to pose barriers to relatives' access to effective psychiatric care, treatment and rehabilitation. Thus the burden of managing such relatives and coping with the consequences of a psychiatric disorder lies with family members. UMsunduzi Municipality in Northern KZN is one such outlying area with limited access to health services and available resources. As a result, family members are being utilised to care for the sick and needy. These problems indicate that care, treatment, rehabilitation and accessibility of mental health care is a serious challenge for the community of the uMsunduzi Municipality. Therefore, there is a need to explore the experiences of family members living with mentally ill relatives.

1.3 AIM OF THE STUDY

The aim of the study was to explore and describe family members' experiences of mental illness and identify their coping strategies and their needs of caring for their mentally ill relatives in the uMsunduzi Municipality in Northern KZN.

1.4 OBJECTIVES OF THE STUDY

The objectives of the study were to:

- Explore family members' experiences of mental illness.
- Identify the reported needs of family members with a mentally ill relative.
- Determine the strategies utilised by family members to cope with a relative who is mentally ill.

1.5 RESEARCH QUESTION

- What are your experiences of caring mentally ill patient?

1.6 SIGNIFICANCE OF THE STUDY

Improving access, care and treatment in mental ill health is a fundamental right, in both developed and developing parts of the world. Mental health care has been given top priority in South African legislation, guidelines, procedures and programmes. However, the mental health literature indicates that there is a lack of adequate knowledge, skills and relevant qualifications to manage and treat mental illness. Such challenges have necessitated the deinstitutionalisation of the health system. With the advent of deinstitutionalisation, there was recognition of caregivers, or those individuals who are biologically or socially related to the mentally ill person, such as the sibling, spouse, mother or father and others) (Stuart 2009: 752). Shortage of skilled and experienced health workers, lack of facilities, limited psychiatric care and inaccessible mental health care services are causes of concern in South Africa, and uMsunduzi Municipality is not an exception. The problem is that family members, who live with mentally ill relatives, do not have the knowledge or skills to manage them. It is hoped that the findings of this study will offer new knowledge related to experiences of family members caring for relatives with mental illnesses. This study will also assist to enrich the literature and the body of knowledge in the public health domain and benefit decision-makers, policy-makers, practitioners, scholars and academics in improving service delivery to mentally ill patients and their relatives in the uMsunduzi Municipality in Northern KZN.

1.7 OUTLINE OF THE DISSERTATION

Table 1.1 below provides the structure of the thesis.

Table 1.1: Outline of the dissertation

CHAPTER	TITLE	OUTLINE
1	Overview of the study.	Introduces and provides an overview of the study by identifying the topic of enquiry, research questions, and study aims. Background information on mental illness and the role of caregivers of mentally ill relatives is provided in order to highlight the importance of the topic and justify this study.
2	Literature review	Analysis of existing literature and evidence serves to inform the study's focus and design. Literature reviewed highlights such issues as the complexity of caring for the mentally ill patient in the context of their environment, culture, society and relevant and available support structures.
3	Theoretical framework	Presents the theoretical framework that guides this study.
4	Research methodology.	Provides a detailed description of the study methodology with the rationale for the research design and methodological selection, implementation strategies and ethical considerations. The study population, sample, data collection, and data analysis methods are described in order that the reader may appreciate the intricacies of study design and the potential for research findings.
5	Presentation of findings.	Presents the results of qualitative data using thematic analysis. Key findings include and elaborate on the themes and sub themes.
6	Discussion of findings.	Discusses the findings of the study in relation to the mentally ill patient and those caring for him/her by reviewing and interpreting data obtained.
7	Conclusions, limitations recommendations	Conclusions drawn from the findings are presented and the limitations and strengths of the study are identified in this chapter. Recommendations are made in relation to the key findings of the study.

1.8 SUMMARY OF THE STUDY

Chapter 1 provided an overview of the study by identifying the topic of enquiry, research questions, and study aims. Background information regarding mental illness and the role of caregivers of mentally ill relatives was provided to highlight and justify the importance of the topic. Chapter 2 will discuss a review of relevant literature pertaining to experiences of family members living with mentally ill relatives to provide a broader perspective of the topic under study.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

The previous chapter provided an overview of the study by identifying the topic of enquiry, research questions, and study aims. Other relevant information regarding mental illness and the roles of those persons caring for mentally ill relatives was provided in order to highlight the importance of the topic and justify the undertaking of this study. Chapter 2 presents a review of relevant literature that provides an orientation to the study.

2.2 SOURCES OF LITERATURE

Google Scholar, Ebscohost, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medlars Online (Medline), Psychological Information literature, (PsycINFO), Sabinet, Science Direct, were some of the search engines and databases that were used to source the relevant literature. Peer-reviewed published journal articles and online sources were also considered for the study. The following keywords were used: care giving, caregiver role, family role, mental illness, coping, family, mental illness, primary caregiver, family caregivers, mental illness, as well as specific conditions such as care giving in schizophrenia, bipolar disorders and stigma associated with caring for a mentally ill family member. Various Health Acts, policies, strategic plans, guidelines and procedures in national and provincial government were some of the official documents that were consulted and bibliographies of individual studies were also reviewed to identify pertinent journals that are not electronically available.

2.3 GLOBAL VIEW OF MENTAL ILLNESS

Mental illness is a topic of academic and scholarly literature worldwide, both in developed and developing nations (Ferlito and Dhai 2018; Ayano 2018; Naidoo, Van Wyk and Joubert 2016; Prinsloo and Hesselink 2015; Magadla and Magadla 2001; Burn 2014; Burn 2011). The causes, effects and management of mental illness has captured the interest of academics, scholars and researchers alike (South Africa 2002; Greef and Vansteenwagen 2006; Overton and Medina 2008; Uys and Middleton 2010; Lorenzo, Matiwane, Cois and Nwanze 2013; Magadla and Magadla 2014; Pillay 2017).

Other extensive studies of health reform with unrestricted rights of people with mental disorders are rampant in developed countries such as America, Brazil, Europe, Canada, New Zealand and Asia (Tipple and Speak 2009; American Psychiatric Association 2013; WHO 2014; Franca, Modena and Confalonieri 2016). Authors further note that although these studies can provide insight into the general health landscape of these developed countries, a similar pattern of the prevalence of mental illness is also evident in the lesser developed countries. Studies have also revealed that 14% of the global burden of this disease has resulted in mental disorders and by 2020, this figure will rise to 15%. This observation confirms that the prevalence of mental disorders is going to impact the sufferer as well as his or her family members and loved ones. According to Marimbe-Dube (2013: 13), mental illness is often viewed by communities as a family problem rather than a community problem and family members of those individuals affected by a mental disorder, may be called upon to provide caregiving roles that could become very challenging and highly pressurised. In low and middle-income countries throughout the world, mental health services are scarce and are unable to service the entire population (Marimbe-Dube 2013: 15). The same study revealed that the shortage of mental health workers is 17.3% per 100 000 population in low-income countries and 14.9% per 100 000 population in middle-income countries.

Despite the lack of mental health service resources in these countries, the study concluded that the burden of care for people with severe mental illness frequently falls on family members and the communities in which they live. A study done in India showed that family members are the primary caregivers of persons with mental illnesses in most of the non-western world, playing multiple roles in care of persons with mental illness, including taking day-to-day care, supervising treatment, transportation and taking care of the financial needs (Chadda 2014: 221). The same study has revealed that family members experience stress and face multiple challenges. Family members develop different kinds of coping strategies to deal with the burden of caring for a mentally ill relative and an unhealthy coping style is likely to adversely affect the family member. Therefore, it is important to take care of the needs of the family members as this has a parallel effect on the care of the mentally ill relative. A family member, who is able to cope with the stressors of caring for an ill family member, can effectively participate in the patient's rehabilitation and well-being (Monyaluoe *et al*. 2014: 131).

2.4 AFRICAN PERSPECTIVE OF MENTAL ILL HEALTH

The African continent is one of the fertile grounds of the world and the richest continent (Adejuwon 2014: 50). Within the entire continent, the Southern African Development Countries (SADC) set the scene for the essential requirements, prevention and promotion of health care, indicating the support for the rights of the mentally ill. Within their cultural beliefs, Africans are of the notion, that they can live without ever experiencing mental illness (Atindanbila and Thompson 2011: 417), yet 14% of the global burden of mental illness is pertains to SSA. This statistic indicates that most of the African countries experience a high percentage of mental illness. Another challenge is the rights and needs of people with mental health illness, which is a huge cause for concern in countries like South Africa, Botswana, Cameroon, Chad, Congo Lesotho, Namibia, Somalia and Swaziland (Kakuma *et al*. 2010; Sibiya, Ngxongo and Bhengu 2018). Arthur (2012: 1-8) points out that disparities in health care still exists, due to inaccessibility and unavailability. The reality is that African societies are still grappling with the mounting concerns related to health infrastructure and resources (Lwonga and Mosha 2013: 2).

Similar calls of care, treatment, awareness and rehabilitation were made in other SADC countries such as Botswana and Zambia (Kakuma *et al*. 2010; Sibiya, Ngxongo and Bhengu 2018). In Botswana, research on family caregivers' burden with primary source of psychological support due to inadequate resources, revealed that families were demotivated and over-burdened (Seloilwe 2006: 262).

Another topic addressed in the Botswana study was the human and material resources in mental ill health across SADC countries. In Zimbabwe, there is a great deal of empirical research on human and material resources (Mudzingwa 2007; WHO 2011; Zimbabwe.Ministry of Health and Child Welfare 2005). Regarding human resources, empirical evidence indicates that shortage of skilled and experienced health workers, lack of facilities, limited psychiatric care and inaccessible mental health care services are a cause for concern in Zimbabwe. This finding is supported by the fact that Zimbabwe's health system operated and accounted for 57% of skilled capacity in human resources, which implies that family caregivers in rural areas face huge problems when caring for loved ones. A newspaper report on the Zimbabwean mental health system stated that the underlying problem is a shortage of human and material resources which further decreases the viability of a country's health system (Mudzingwa, 2007). In Zambia, mentally ill patients are considered dangerous and are stigmatised thereof. This stigmatization and societal misunderstanding of people with mental illness (Kapungwe *et al*. 2010) plays a major role in the persistent suffering of the person afflicted with a mental illness(Kakuma *et al*. 2010) and increases the financial burden of the caregiver (Marimbe-Dube 2013: 30).

2.5 SOUTH AFRICAN CONTEXT OF MENTAL ILLNESS

One out of every three South Africans have been affected with mental illness (Tzoneva 2014: 14). South Africa is continuously facing challenges with the implementation of improvements to its health care system (Sibiya, Ngxongo and Bhengu 2018: 1). South Africans, according to the Constitution of Republic of South Africa (Act No. 108 of 1996), are guaranteed a fundamental right to health care (South Africa 1996: 29). Both the Mental Health Act (Act No. 17 of 2002), and the National Health Act (Act No. 61 of 2003) protect the rights for dignity and health care of people living with mental disorders (South Africa 2002; South Africa 2003). The National Health Policy Guidelines (NHPG) for Improved Mental Health (South Africa 2004) advocates compulsory admission, patient and property protection, right to appeal and reporting abuse, and the formation of Independent Review Boards to review in particular mental disorder treatment regimens and management (South Africa 2004: 2).

The Minister of Health, Dr Motsoaledi, states that there are many challenges facing improvement in mental health such as lack of community-based mental health services (Motsoaledi 2012: 5). Lack of public awareness of mental health, stigmatisation and discrimination of the individual and family members as well as the family as a system still exists (Greef, Vansteenwagen and Ide 2006: 285). For family members with mentally ill relatives, lack of adequate health information contributes to added stressors (Lwonga and Mosha 2013: 2). Lack of support systems for families living with mentally ill relatives resulted in lack of knowledge and skills related to mental illness and how to manage a mentally ill individual. This was further aggravated by lack of health education and health promotion programmes (Naidoo, Van Wyk and Joubert 2016: 4).

2.6 CONTEXT OF MENTAL ILLNESS IN KWAZULU-NATAL(KZN)

Empirical evidence and scholarly literature on mental health illness has been increasing rapidly in KZN (Meyer Staffed and Jackson 2009; Bayat, Poyraz and Arikan 2012; Naidoo 2012). Amongst the provinces, KZN is best suited for empirical studies because it is a predominantly rural area. This province is home for hundreds of people with household settings on the crest of hills or near rivers (Stats SA 2011). It is very densely populated (KZN Department of Health 2015). The KZN Department of Health increased its focus on health reform at community and primary health care (PHC) level.

Across the globe, governments of many countries have acceded to the World Health Organisation (WHO) Rehabilitation, A Call for Action 2030, United Nations Commission of Human Rights (2007) and the United Nations General Assembly Convention of Rights of People with Disabilities (2007). These international treaties, protocols and agreements stipulate that developing and emerging nations as well as the developed countries observe this global commitment to fight against mental ill health. African countries, including South Africa, are also obligated to conform to these international protocols and agreements in caring for people with mental illness. The burden of mental disorder and its management across the globe is estimated at 14%, with the highest percentage noted in developing countries and impacting negatively on the quality of lives of relatives, caregivers and friends of the mentally ill patients.

Family members who act as caregivers are sometimes burdened, physically, emotionally and financially when caring for a relative suffering from mental illness and this burden is exacerbated by lack of adequate health information, resulting from the lack of promotion programmes (Naidoo, Van Wyk and Joubert 2016: 4) and lack of knowledge and skills related to mental illness (Lwonga and Mosha 2013: 2). These problems impede the coping mechanisms and impacts negatively on the person diagnosed with such an illness, his or her caregiver and society as a whole.

2.7 FAMILY INTERPRETATION OF MENTAL ILLNESS

It is widely believed that many of the issues concerning integration of services requires deinstitutionalization. Health reformists cite that the concept of deinstitutionalization needs a shift from centralized, integrated and community-based services provided within the legal framework (Du Plessis *et al*. 2004; Van

Rensburg 2005; Uys and Middleton 2010; Petersen and Lundi 2011; Mokoena-Mvandaba 2013; Pillay 2017). In contrast, Pillay (2017: 144) cautions that the deinstitutionalization process is complex, fraught with problems and should not be embarked lightly. Through deinstitutionalization, the focus is on community care, which implies that, when people are mentally ill, they receive care and treatment from a wide range of people in the community, not limited to their family, friends, peers, physicians or mental health specialists.

2.7.1 Cultural/Traditional

Naidoo (2011:18) justified the beliefs about health and illness are deeply rooted in a person's culture. The findings of this study also noted that the response of a patient or family member to the diagnosis or treatment may be strongly influenced by his or her values and culture (Naidoo 2011: 18). Although Naidoo's work focused on the experiences of critical care nurses of the death and dying in an Intensive Care Unit (ICU), it sheds light in the understanding of why health care professionals must become familiar with other cultures to be well-positioned to deliver effective health care services (Naidoo 2011: 19).With their cultural convictions, Africans belief that they can live without ever experiencing mental illness (Atindanbila and Thompson 2011: 457), yet 14% of the global burden of mental illness is particular relevant to SA. The above proposition befits the description that most of the Africa countries experienced a high percentage of meatal health illness as this disease become prevalent. UMsunduzi Municipality located in KZN is best suited to be under empirical enquiry because is predominately rural area. This confirms the need to investigate a number of cultural issues (Sibiya *et al*. 2018: 5) experienced by family members caring for mentally ill relatives in uMsunduzi Municipality

2.7.2 Traditional healers and ancestors

In the uMsunduzi Municipality, in rural KZN, people believe in traditional healers and ancestors. Community members prefer to take their mentally ill family members to traditional healers (*sangomas*). Mokoena-Mvandaba (2013: 4) focused their study on the family members living with mentally ill family members in the Thabo-Mofutsanyane District in the Free State Province and found that traditional healers are noted to assist family members living with mentally ill family members to cope (Mokoena-Mvandaba 2013: 56).. In another study, Sibiya *et al*. (2018: 3) provided an illuminating account of the traditional, cultural norms in rural community of eThekwini district in KZN. In African thinking, mental disorder is perceived to be caused by supernatural powers. Consequently, African traditional healers are widely sought after to meet medical and psychotherapeutic needs (Atindanbila and Thompson 2015: 453). Although the above studies may have not dealt with the uMsunduzi Municipality, the findings are valuable in providing insight into the role of traditional and cultural and belief in the mental health sector. There is very little written in African literature about the practices of traditional healers, which also justifies the need to conduct this study.

2.7.3 Stigmatization

Health literature is helpful in documenting debates that arose on the role of stigma in mental health illness. Stigmatization plays a major role in the persistent suffering, disability and economic loss associated with mental illness (Kakuma et al. 2010: 116). In South Africa, published reports suggest that there are hurdles facing improvement in mental health such as lack of community based mental health services, lack of public awareness of mental health, stigmatization and discrimination (Motsoaledi 2012: 5), on individual family member as well as a family as a system (Greeff, Vansteenwegen and Ide 2006: 285). Scholarly literature attests to this assertion (Hugo, Boshoff, Traut, Zungu-Dirwayi and Stein 2003; Botha, Koen and Niehaus 2006 and Lupuwana, Simbayi and Elkonin 1999, Mavundla and Uys 1997; Mavundla 2000; Lethoba, Netswera and Rankhumise 2006) and concludes that, people with mental illness are often victimised and face unfair discrimination such as difficulty in accessing housing and employment.

These scholars previous provide similar views about stigmatizing attitudes on mentally ill relatives displayed by both mental health nurses (Mavundla and Uys, 1997; Mavundla 2000; Lethoba, Netswera, Rankhumise, 2006) and the community (Hugo, Boshoff, Traut, Zungu-Dirwayi and Stein 2003; Botha, Koen, Niehaus and 2006; Lupuwana, Simbayi and Elkonin 1999) on mental health care users. Although scholarly literature shows that stigmatization, is highly prevalent and there is also an urgent need to provide high quality mental health care and protect the rights of individuals with mental health conditions.To,date there is silence about the role of stigma on family members caring for mental ill relatives in uMsunduzi Municipality located in KZN.

2.7.4 Family network or support

In countries such as Ireland, Hong Kong, America, the United States, Japan, there is ample empirical evidence documented in health literature on family support (Seloilwe 2006; Korhonen, Julkunen and Pietilä, 2008; Glendy and Mackenzie 1998; Fujino and Okamura 2009; Stuart 2009). Most of these studies point to family members' role in the care, treatment and rehabilitation of mentally ill family members, strengthening family networks (Korhonen, Julkunen and Pietilä 2008: 676), family as a support system, and the role the family plays as a support to its vulnerable members (Glendy and Mackenzie 1998: 288), developing family and caregiver support programmes (Sorrel and Durham 2011: 24), support and provision of care at home, community psychiatric care system (Fujino and Okamura 2009: 128) and other practical examples of support, such as cooking, household chores, assisting with keeping medical appointments and financial support (Jones 2009: 522).

In South Africa, support for families caring for their mentally ill family members remains a challenge as evident in rural areas like Limpopo, Free State and some parts of KZN, allowing the findings of this study to offer new knowledge related to experiences of family members caring for relatives with mental illnesses.

2.8 THE COPING STRATEGIES FOR MENTAL ILLNESS

Coping strategies are a vital component in the rehabilitation of one who is mentally ill and in many countries documentary literature on mental illness health considered recognition of culture, tradition, ancestors, stigmatization and family support in mental health care is still of great concern. Although family based interventions, is termed reliable, some prefer an array of services and support from people, institutions and beliefs as follows:

2.8.1 People

For family members with mentally ill relatives, lack of adequate health information contributes to stress (Lwonga and Mosha 2013: 2). Families living with a mentally ill family member look to each other or the community for assistance.

2.8.2 Traditional healers and cultural beliefs

In keeping with their traditional beliefs, Africans believe that they can live without ever experiencing mental illness (Atindanbila 2011; Atindanbila and Thompson 2011), yet 14% of the global burden of mental illness is particularly relevant to SSA. The same authors also note that above notion is contradictory as most of the African countries experienced a high prevalence of mental illnesses and in order to cope with living with a mentally ill family member, some family members prayed and placed their faith and trust in God Almighty.

2.9 INSTITUTIONS OF MENTAL HEALTH

In South Africa, there are various institutions and services that are provided for mental health care, such as community clinics and support groups for relatives and loved ones. These facilities are either long term or short term facilities and offer ongoing therapy, even as an out-patient service.

2.9.1 Department of Health

The Department of Health states, in its preamble to the Constitution of Republic of South Africa (Act No. 108 of 1996) (South Africa 1996: 1) that it is a fundamental right of each South African citizen to expect the appropriate care and treatment within the health systems’ mandate of the country. Within this constitutional mandate, in Chapter 2 of the Constitution, the Bill of Rights also protects the rights of every South African citizen, inter alia, to basic health care services and dignity of life. (South Africa 1996: 1). In accordance with the Constitution, both the Mental Health Act (Act No. 12 of 2002) and the National Health Act (Act No. 61 of 2003) protect the human rights, dignity, life and healthcare for people living with mental disorders (South Africa 2002; South Africa 2003).

Lund, Petersen, Kleintjes and Bhana (2012: 402) state that there appears to be a growing policy impetus to improve the health system. The White Paper for Transformation of the Health System in South Africa was published in 1997. One of its aims was that all levels of government, national, provincial, district and local jurisdictions, provide planned, co-ordinated, comprehensive and community-based health services, including mental health services (South Africa 1997: 136). Another policy framework, the National Health Policy Guidelines for Improved Mental Health in South Africa (2004: 2) advocated compulsory admission of patients, protection of relatives’ property, reporting abuse and assisting with the formation of Independent Review Boards (South Africa 2004: 2). However, there is still a disjuncture between policies and implementation of service delivery (Freeman 2013: 262).

2.9.2 Government Disability Grants

The Constitution of South Africa, Mental Health Act (Act No. 12 of 2002) and the National Health Act (Act No. 61 of 2003) protects the human rights, dignity, life and healthcare of people living with mental disabilities (South Africa 2002, South Africa 2003). Through its service delivery guidelines and protocols the

National Department of Health committed itself to reducing poverty and unemployment through a provision of the disability grants.

2.9.3 Hospitals and Clinics

The major concern in the KZN Province is the operational inefficiency which is evident in some of the hospitals and clinics. In these public health facilities, only 25% of beds are available for psychiatric patients. There is also a lack of access to health care institutions (Mathiti 2006: 215). Despite the fact that the mentally ill do follow-up visits, the family members want to be assisted by the clinic. Allocation of budgets to psychiatric facilities within KZN reveals a gross inequity.

2.9.4 Rehabilitation centres

Although there are robust constitutional and policy obligations on South Africa as a country in terms of the Constitution of Republic of South Africa (Act No. 108 of 1996), the Mental Health Act (Act No. 12 of 2002) and the National Health Act (Act No. 61 of 2003) to protect the rights of people living with mental disorders (South Africa 2002; South Africa, 2003). Lund, Petersen, Kleintjes and Bhana (2012: 402) state that there appears to be a growing policy impetus to improve not only the health systems, but also community health care rehabilitation centres which have remained underdeveloped.

2.9.5 Support groups

A number of studies point to family members' role in the care, treatment and rehabilitation of mentally ill family members. Strengthening family networks (Korhonen, Julkunen and Pietilä, 2008: 767), family as a support system, and the role the family plays as a support to its vulnerable members (Glendy and Mackenzie 1998: 288), developing family and caregiver support programmes (Sorrel and Durham 2011: 24), support and provision of care at home, community psychiatric care system (Fujino and Okamura 2009: 128), and other practical examples of support, such as cooking, household chores, assisting with keeping medical appointments and financial support are cited (Jones 2009: 522).

2.10 SUMMARY OF THE CHAPTER

This chapter presented the thoughts, views, assumptions and studies conducted by different authors and researchers on experiences of family members living with mentally ill relatives. Scholarly articles and government policies were cited and discussed to inform the study's focus and design. The following chapter will present the theoretical framework that guided the study.

CHAPTER 3: THEORETICAL FRAMEWORK

3.1 INTRODUCTION

This chapter presents the theoretical framework that guided the study. A framework is an abstract, logical structure of meaning. It guides the development and organization of the study (Burns and Grove 2009: 126). The theoretical framework guides the researcher in the interpretation of results and directs the research process. It is a frame of reference that forms the basis for observations, definition of concepts, research designs, interpretations and generalizations (LoBiondo-Wood and Haber 2010: 141). To gain a deeper understanding of to the topic under study, the researcher adopted the Pearlin’s Caregiving Stress Process Model to foreground the experiences of the family members caring for their mentally ill relatives.

3.2 PEARLIN’S CAREGIVING STRESS PROCESS MODEL

This study adopted theoretical framework as a way to understand the experiences of family members caring for their mentally ill relatives at the uMsunduzi Municipality in Northern KZN. In order to understand a deeper inquiry, the researcher adopted the Pearlin’s Caregiving Stress Process Model (Figure 3.1). This model derived from the work of Pearlin’s (Pearlin’s *et al*. 1990:583) as shown in Figure 3.1 below. In their seminal work Pearlin’s *et al*. (1990: 583) stress process model was designed to assess the informal caregiving process affecting the care giver. Accounting to this proposed model illustrated in Figure 3.1, caregiver stress can occur as a consequence of a process, which comprises of a set of interrelated conditions, including the socio-economic characteristics and resources of caregivers and the primary and secondary stressors to which they are exposed. This theoretical grounding of this research can also be applied to the South African scenario in Northern KZN where the uMsunduzi Municipality is located.

Pearlin *et al*. (1990: 583) noted that primary stressors are stressors such as hardships and problems directly inherent in caregiving, while secondary stressors fall into the following two categories:

1) The strains experienced in roles and activities outside of caregiving.
2) The intrapsychic strains, involving the diminishment of self-concepts.

Coping and social support can potentially intervene at multiple points during the stress process. Figure 3.1 illustrates these two types of stressors emphasising the challenges faced by family members caring for mentally ill relatives.

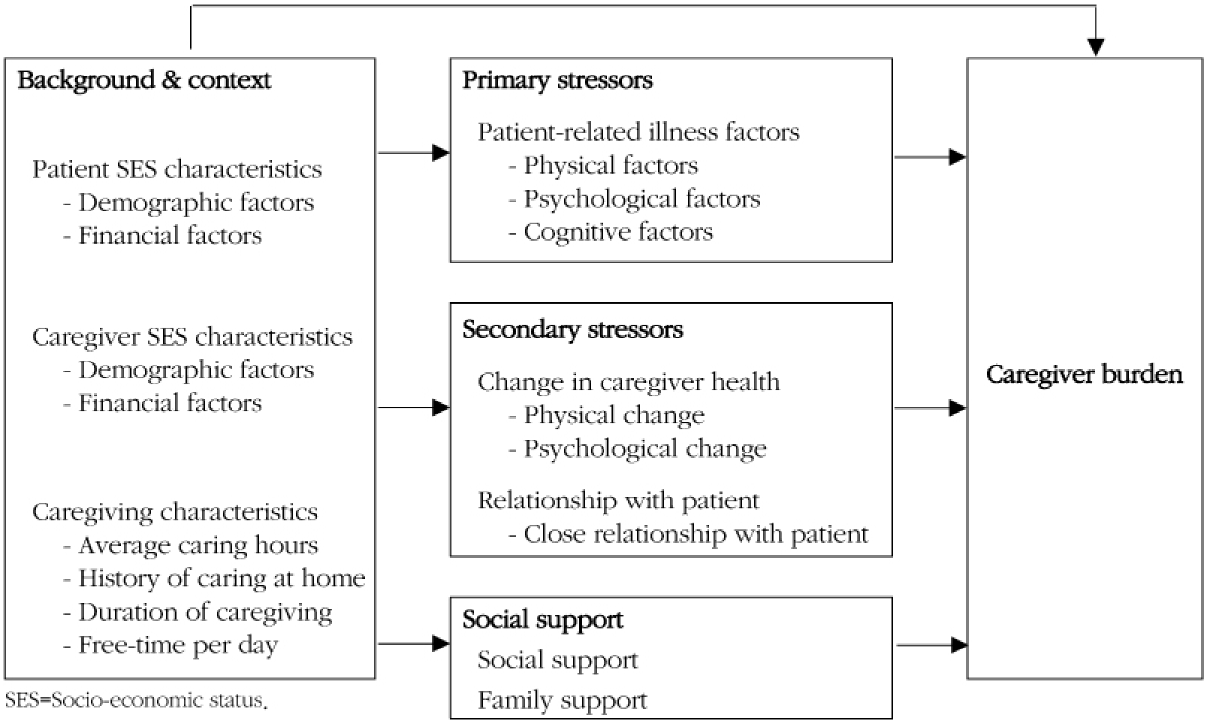

Figure 3.1: Pearlin's Caregiving Stress Process Model

According to Pearlin *et al*. (1990: 583), application of this model has allowed the researcher to understand not only the direct relationships between constructs of interest and the outcomes, but also the indirect effects through intervening constructs. Within the context of this study, this theoretical model is applied to examine the experiences of family members caring for their mentally challenged relatives, how they make meaning of their situation and how they manage the stress symptoms that arise from the situation as depicted in Figure

3.1. The application of the theoretical framework will be discussed in detail in Chapter 6.

3.3 SUMMARY OF THE STUDY

Chapter 3 provided an explanation of the theoretical framework that guided the study. This framework was adopted to gain a deeper understanding of the lived experiences of family members caring for their mentally ill relatives in the uMsunduzi Municipality in Northern KZN. The Pearlin’s Caregiving Stress Process Model was applied to foreground the experiences of the family members caring for their mentally ill relatives, and to elucidate the burden carried by family members who are caring for their mentally ill relatives.

CHAPTER 4: RESEARCH METHODOLOGY

4.1 INTRODUCTION

In this chapter, the method that was used to conduct the study will be discussed. This is a step by step systematic process that the researcher used to answer the research question (Alvesson and Sköldberg 2009: 3). The research methodology includes study design, the setting, population, sampling frame, approach and technique, sample size, data collection method, data processing and analysis and report (Brink, Van der Walt and van Rensburg 2012: 17). To explore and describe experiences of the family members caring for mentally illrelatives, the methodology and research design will be discussed in detail.

4.2 RESEARCH DESIGN

Grove Burns and Gray (2013: 195) describe a research design as a detailed plan according to which the research is conducted. Babbie and Mouton (2010: 31) further explain that a research design is a blueprint of how one intends to conduct the study. This study utilised a qualitative, exploratory, descriptive design to explore the experiences of family members living with mentally ill patients in the uMsunduzi Municipality.

4.2.1 Qualitative research

Polit and Beck (2012: 221) define qualitative research as social research carried out in the field or natural setting and analysed largely in non-statistical ways. Qualitative researchers often collect data at the site where participants experience the problem under study. Hennink, Hutter and Bailey (2011: 9) argue that qualitative researchers study people in their natural settings, to identify how their experiences and behaviour are shaped by the context of their lives, such as the social, economic, cultural or physical context in which they live. According to Grove, Burns and Gray (2013: 23), qualitative research is appropriate when the researcher wants to examine the experiences of human beings in the natural environment. This design was also based on making interpretations and meaning of everyday practices such as in this research (Brink, Van der Walt and Van Rensburg 2012: 113). This qualitative research used a subjective approach to define the life experiences of family members and add meaning to them. The study took place in the real-world setting where the participants reside, thereby allowing the experiences of participants to be described in their own words.

4.2.2 Exploratory research

Exploratory research is designed to increase the knowledge of a field of study (Grove, Burns and Gray 2013: 25). Exploratory design sheds light on the various ways in which a phenomenon is manifested and on underlying processes (Polit and Beck 2012: 640). In this study, the researcher intended to use exploratory design to better understand the experiences of the family members living with mentally ill patients in the uMsunduzi Municipality. Exploratory research is relevant as this is a new and unexplored topic.

4.2.3 Descriptive research

Descriptive research aims to explore and analyse a particular phenomenon. (Grove, Burns and Gray 2013; Kumar 2010). The purpose of qualitative research is to provide a detailed account or description of the phenomenon under study in order to understand the meaning of an experience (Burns and Grove 2009: 201).Mental ill health has been a relatively unexplained and elusive phenomenon and those diagnosed with this disorder are sometimes difficult to treat and manage. The aim of this study was to explore and describe the experiences and views of family members living with mentally ill relatives in the uMsunduzi Municipality.

4.3 RESEARCH SETTING

Research setting is the physical location in which data collection takes place (Polit and Beck 2012: 743). Creswell (2014: 173) states that researchers intentionally select sites for the purpose of obtaining the necessary and required information. Therefore, the researchers should select the settings that will provide the relevant information. This study was conducted in the rural setting of the uMsunduzi Municipality in the province of KZN. It is estimated that the uMsunduzi area is home to about 600 000 people from different cultural groupings and comprises rural areas that are governed by municipal by-laws and common laws. The researcher selected the area because it has only two provincial hospitals specializing in mental ill-health, Townhill and Fort Napier provincial hospitals, serving an estimated population of over half a million. It is evident that this poses a huge service delivery problem regarding access for mentally ill patients.

4.4 SAMPLING PROCESS

Sampling is the process of selecting a portion of the population to represent the entire population (Polit and Beck 2012: 391). Purposeful sampling is the selection of participants that will highly benefit a study (Polit and Beck 2012: 517). The researcher used purposeful sampling by selecting participants who were caring for relatives diagnosed with a mental illness. The researcher used a snowballing technique to gather data, a technique where participants refer the researcher to other prospective participants who meet the inclusion criteria (Kumar 2010: page). This was beneficial to identify suitable participants and to contact participants who were out of reach. Participants or informants with whom contact has already been made can use their social networks to refer the researcher to other people in the community, who could potentially participate in or contribute to the study. Furthermore, with an introduction from the referring person, it makes it easier for researchers to establish a trusting relationship with the new participant (Polit and Beck 2012: 766).

The sample in this study consisted of family members who were caring for mentally ill relatives and data collection continued until data saturation was reached. Data saturation occurs when themes and categories in the data become repetitive and redundant, such that no new information can be gleaned by further data collection (Polit and Beck 2012: 357).

4.4.1 Inclusion criteria

- Participants selected for this study had to be over the age of 18 and residents of the uMsunduzi Municipality who were caring for a mentally ill relative.

4.4.2 Exclusion criteria

- Participants who were less than 18 years old.
- Participants who did not reside in the uMsunduzi Municipality area and were not caring for a mentally ill relative.

4.5 DATA COLLECTION TOOL

In-depth, one-on-one face-to-face semi-structured interviews were conducted to collect data from the participants. An in-depth interview is a one-to-one method of data collection that involves an interviewer and an interviewee discussing specific topics in depth. In-depth interviews are used when seeking information on individual, personal experiences from people about a specific issue (Hennink, Hutter, Bailey 2011: 109). Brink, Van der Walt and van Rensburg (2012: 160) state that in the one-on-one face-to-face semi-structured interviews, the interviewer can have a great deal of influence on the outcome where attributes like gender, ethnic origin, manner of speaking and clothing can influence the answers provided by participants. However, interviews are one of the most important ways of gathering data in a qualitative study. During interviews questions can be clarified where misunderstanding occurs and follow-ups can be done if necessary (Polit and Beck 2012). Semi-structured interviews are also useful when the subject that is being investigated is complex, controversial and personal in nature. (De Vos *et al*. 2011: 32).

An interview guide was used to facilitate the discussion during the interview sessions (Appendix 3a). An interview guide translated into IsiZulu was used to conduct interviews for those participants who were not familiar with English (Appendix 3b). Semi-structured interviews allow the participants freedom to express their opinion or understanding of the phenomenon under study, without the restrictions of close ended questions or the interviewer’s opinion (Grove, Burns and Gray 2013: 271).

The interview guide comprised a demographic section as well as questions to guide the interview. The leading question was: *“What are your experiences caring for a mentally ill relative?* This was followed by probing questions to elicit detailed information. In order to ensure privacy and comfort of the participants, the researcher conducted interviews at the residences of the participants. Each interview lasted approximately 45 minutes and permission was sought from the participants to use a voice recorder during the interview sessions.

4.6 PRE-TESTING OF THE DATA COLLECTION TOOL

In order to establish whether the research questions would adequately answer the objectives of the study a pre-test of the data collection tool, was conducted before the commencement of this study. Polit and Beck (2012: 761) define a pilot study or pre-test of data collection tools as a critical examination of the understanding of each question and its meaning. The pre-test of the data collection tool was conducted with two family members caring for mentally ill relatives with similar characteristics in the uMsunduzi Municipality. The results indicated that these participants clearly understood the research questions. Consequently, no changes were made to the family members’ interview guide.

4.7 DATA ANALYSIS METHOD

Data analysis involves a systematic application of a process or processes of managing and organising qualitative data, which brings order, structure and meaning to the mass of data collected (Brink, Van der Walt and van Rensburg

2012: 18). Qualitative data analysis is an active process where the researcher has to scrutinise carefully and deliberately data that she/he has gathered, often reading data over and over again until meaning or deeper understanding of data is achieved (Polit and Beck 2012: 19). Analysis of qualitative data involves categorising data into segments with symbols or abbreviations used to classify words or phrases. This is known as coding (Brink, Van der Walt and van Rensburg 2012).

In qualitative research studies, data analysis is done concurrently with data collection and is done throughout the study (Brink, Van der Walt and van Rensburg 2012:18). Qualitative analysis techniques make use of words rather than numbers as a basis and this strategy is contextual in nature. Analytical reasoning skills are required when conducting content analysis (Burns and Grove, 2009). Tesch's eight step open coding approach (Creswell, 2013: 234) was utilised to analyse the data as follows:

- Reading through all transcripts to get a general impression of the collected data.
- Writing down main thoughts that emerged from data.
- Making a list of all topics. Similar topics were clustered together. These topics were primarily organised as major topics, unique topics and leftover topics.
- Abbreviation of topics as codes were written next to the corresponding segments in the data. Any other topics or codes that emerged were also written next to the appropriate segment of the text.
- The most descriptive wording for the topics were used as sub-categories.
- Grouping together of the related topics and emerging list of categories.
- Preliminary analysis of data by assembling data that belonged to each category from which the theme emerged.
- Existing data was re-coded.

4.8 TRUSTWORTHINESS

Trustworthiness, according to Brink *et al*. (2012: 172) is based on the 1995 model of Lincoln and Guba. It is a way of ensuring data quality or rigour in qualitative research. The model identifies four criteria for developing trustworthiness in qualitative research namely: credibility, dependability, confirmability and transferability.

4.8.1 Credibility

Polit and Beck (2012: 239) define credibility as confidence in the truth of the data. To ensure credibility of the study, the same interview guide was used throughout the study. The researcher maintained credibility of the study by taking sufficient time to collect the data. This helped the researcher to build trust and rapport with the participants. The participants for this study were purposively chosen and the information was collected until data saturation was achieved. Credibility was ensured through space triangulation which was achieved by interviewing participants from different types of households to ensure their privacy and comfort.

4.8.2 Dependability

Dependability refers to the provision of evidence such that if the study were to be repeated with the same or similar participants in the same or similar context, its findings would be similar (Polit and Beck (2012: 239). The researcher ensured dependability of the study by requesting the supervisors to review the data and by developing an audit trail of all original audio records of interviews and discussions on a disc. Original written and summarized interviews and those translated into isiZulu and all correspondence regarding the study, such as consent forms, were kept under lock and key. This was done so that they could be produced, if required for audit purposes.

4.8.3 Transferability

According to Polit and Beck (2012: 239), transferability is the ability to apply the findings of the study in other contexts or to other participants. The researcher ensured that the context of the study and the participants are adequately described so that the findings can be applied to other settings similar to the one researched. It will also assist in conducting further research. A comprehensive research report was provided so that other researchers could evaluate and test the applicability of the data in other research contexts.

4.8.4 Confirmability

Confirmability refers to accurate reporting of the real meaning of data as provided by the participants (Brink, van der Walt and van Rensburg 2012: 171). The interviews for this study were audio recorded to ensure that the information provided by the participants were accurate and truthful. The researcher interpreted and analysed the data through identifying themes and sub-themes which were supported by the use of direct quotations from the interviews in order to eliminate subjectivity and bias.

4.9 ETHICAL CONSIDERATIONS

Ethics refers to a system of moral values that is concerned with the degree to which research procedures adhere to professional, legal and social obligations to the study participants (Polit and Beck 2012: 727). The study commenced after the ethics clearance (IREC 196/18) was granted by the Institutional Research Ethics Committee (IREC) (Appendix 1). Certain ethical principles must be maintained to ensure that the rights of participants are upheld. Polit and Beck (2012:752) identify four principles namely, beneficence, justice, informed consent and confidentiality that are crucial for researchers that allow them to adhere to the professional, legal and social obligations towards participants of a study.

4.9.1 Beneficence

Beneficence outlines the researcher’s responsibility to minimise harm or increase benefits for the participants (Polit and Beck 2012: 748). The participants in this study were informed that they had a right to be protected from any type of harm such as physical, psychological, emotional, social or legal. If participants show signs of distress during data collection, the researcher will conduct debriefing, offer counselling services or suggest appropriate referrals (Brink *et al*. 2012: 36). The researcher ensured that participants understand the benefits of the study by providing detailed explanations before obtaining consent.

4.9.2 Justice

According to Brink *et al*. (2012: 20), participants should be treated fairly and should be provided with an information leaflet that details the study. There should be no intervention beyond what is described in the leaflet. Data must be collected with the explicit permission of the participant. The participant’s right to privacy must be respected in deciding how much information should be made available to others (Botma *et al*. 2010: 20). The researcher ensured that participants are provided with relevant information about the study (Appendix 3a and 3b). The names of participants were coded and not made accessible to any other party.

4.9.3 Informed consent

The researcher must also ensure that information is understood by the participant and that participation in the study is voluntary. Participants should also be provided with a written consent form that includes the purpose of the study, expectations of the participants, the time involved and the potential costs and benefits (Polit and Beck 2012: 93). According to Brink *et al.* (2012: 38), informed consent also includes giving the participant a choice to participate in the study. Before data collection, each participant was given an information letter that details the relevant areas of the study. Written, voluntary consent was obtained from each participant, with the right to withdraw from the study at any time. This is to ensure that no participant was coerced into taking part in the study.

4.9.4 Confidentiality

This ethical principle refers to the management of personal information that ensures that only the researchers that are directly involved with the study are able to access the information. The participant has a right to choose who he or she wants to share personal information with and the researcher needs to respect this (Botma *et al*. 2010: 16). Measures need to be taken by researchers to ensure that confidentiality is maintained and in order to maintain anonymity, participant's names should not be recorded on data collection tools, rather identification numbers should be used on study records (Polit and Beck 2012: 95). Therefore, in this study, codes, instead of the participant's names were used on the data collection sheets. This ensured that participants remained anonymous and that their responses could not be linked to individual names or families.

4.10 SUMMARY OF THE CHAPTER

The research design, setting and recruitment of participants has been clearly detailed in this chapter and the data collection process was outlined and followed. Trustworthiness of the study was guaranteed. Ethical considerations and the rights of participants were explained and applied in context of the study. Chapter 5 will present the results of qualitative data using a thematic approach. Tesch's method was utilised to analyse the data and further categorise the data into themes and sub themes.

CHAPTER 5: PRESENTATION OF FINDINGS

5.1 INTRODUCTION

This chapter will present the results of the study. The aim of the study was to explore family members' experiences of mental illness and identify their coping strategies and their needs of caring for their mentally ill relatives in the uMsunduzi Municipality in Northern KZN. After analysis of the in-depth interviews with the family members, a thematic framework was used to categorize findings as they emerged and organize them into themes and sub-themes. The researcher was able to get both objective and subjective responses from the participants who provided their personal reflections on caring for their mentally ill relatives. Adhering to the principles of a qualitative research approach, the researcher set aside any preconceived expectations or experiences and allowed the participants to tell their stories. This meant that the interview discussion was not subjected to researcher bias or influence. An interview guide (Appendices 4a and 4b) was used to guide the interview discussion, taking into consideration the participants' demographic information as indicated in Table 5.1.

5.2 DEMOGRAPHIC DATA OF THE PARTICIPANTS

This study considered age group, gender, marital status, education and occupational class to profile the demographic characteristics of the respondents as depicted in Table 5.1.

5.2.1 Gender

Table 5.1 illustrates that, from a sample of family members living with mentally ill relatives, 35% were males while 65% were females. This indicates that predominantly females take care, treat and rehabilitate their mentally ill relatives in the uMsunduzi Municipality.

5.2.2 Age group

Table 5.1 presents an age analysis of the family members living with mentally ill relatives. As illustrated in Table 5.1, family members range between the ages of 20-70 years.

5.2.3 Marital status

Regarding marital status, Table 5.1 indicates that 45% were single and 35% were married, whilst 20% were widowed.

5.2.4 The level of education

The level of education illustrated as per participants noted that they were apparently educated, with an understanding of mental health issues.

5.2.5 Occupational class

The study revealed as per Table 5.1 that 50% of the participants were fully employed or had professional careers.

5.2.6 Relationship to mentally ill relative

All participants that were interviewed indicated a close relationship with the mentally ill family members.

Table 5.1: Demographic data of the participants = 20

DEMOGRAPHIC DATA FOR FAMILY MEMBERS									
1	**Gender**		**No of participants interviewed**	**%**	**4**	**Level of Education**		**No of participants interviewed**	**%**
	1.1	Male	7	65		4.1	Secondary	9	45
	1.2	Female	13	35		4.2	College Diploma	7	35
						4.3	University Degree	4	20
2	**Age Group**				**5**	**Occupational Class**			
	2.1	20-30	5	25		5.1	Unemployed	10	50
	2.2	31-40	7	35		5.2	Teacher	4	20
	2.3	41-50	4	20		5.3	Clerk	2	10
	2.4	51-60	2	10		5.4	Engineer	2	10
	2.5	61-70	2	10		5.5	Sangoma	2	10
3	**Marital Status**				**6**	**Relationship to mentally ill relative**			
	3.1	Single	9	45		6.1	Brother	4	20
	3.2	Married	7	35		6.2	Sister	4	20
	3.3	Widow	3	15		6.3	Aunt	5	25
	3.4	Widower	1	5		6.4	Mother	3	15
						6.5	Father	1	5
						6.6	Son	1	5
						6.7	Daughter	1	5
						6.8	Uncle	1	5

5.3 THE OVERVIEW OF THEMES AND SUB-THEMES

In this empirical inquiry, three broad themes identified the lived experiences of family members living with mentally ill relatives. A summary of the emerged themes and sub-themes is outlined in Table 5.2. The emergence of these themes and sub-themes have been discussed in detail with direct quotations from the transcripts.

Table 5.2: Themes and sub-themes

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

Relevant to this study is Table 5.2 which depicts main themes and sub-themes related to the experiences of family members living with their mentally ill relatives.

5.4 THEME 1: CARING FOR A MENTALLY ILL RELATIVE

The burden of mental illness lies with the father, mother, brother, sister, among others, as family members living with mentally ill relatives. This theme is the thrust of this study and warranted intensive empirical inquiry. Participants reported that they felt uncomfortable when caring for a mentally ill relative. They experienced or were confronted with a multitude of challenges, inter alia, lack of skills, knowledge and capacity, lack of support, lack of mental illness awareness, lack of mental health information and programmes, nurses' attitudes, skills, knowledge and capacity to care, treat and rehabilitate and the lack of mental health facilities and infrastructure which proved to be major issues of concern. According to Evalvold (2003:8), these challenges contributed to the negative experiences of family members caring for mentally ill relatives.

5.4.1 Sub-theme 1: Coping strategies when caring for a mentally ill relative

The majority of participants remained unclear and confused of how they should care for someone who has a mental illness. This confusion is characterised by the lack of skills, knowledge and capacity to care, treat and rehabilitate their relatives living with mental illness. This is evident in the following statements:

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

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

Some family members were young and inexperienced to handle the challenging role of a caregiver. Following excerpts from participants verify this:

"Being young plays a less significant role in caring for my mentally ill relative." (Participant #6)

"Most of us are in the thirties to forties and we don't have matured personality to handle this kind of stress." (Participant #13)

5.4.2 Sub-theme 2: Support systems for families living with mentally ill relatives

Mental illness was viewed as a family and not a community problem and family members often looked for support systems to aid them in caring for mentally ill relatives. Often a lack of knowledge and skills related to mental illness and having little knowledge on how to handle a mentally ill individual increased their frustration. The participants in this study revealed the following:

“I shout on her because…. I thought she is an adolescent and is just behaving like one.” (Participant #20)

Other participant reported similar experiences at home as noted in quote below:

“It was for the first time my son reacted violently……. and I did not know how to handle this….” (Participant #6)

5.4.3 Sub-theme 3: Knowledge deficiencies related to mental illness management

Despite the lack of support, participants felt that they are also unaware of their relatives’ state of mental illness. Both participants shared similar sentiments encapsulated in the following quotation:

“….The mental condition of my daughter was unknown to me.” (Participant #4)

“I had no clue that my brother was mentally ill…..” (Participant #16)

To re-affirm the above assertion, participants responded by stating that:

“I was so desperate to know my sister’s illness.” (Participant #18)

*“I want to be involved in my mother’s illness.” (*Participant #7)

A lack of awareness and being uninformed of the dangers of missing out on treatment and appointments is another challenge that family members battle with, as stated by the following participant:

“I always miss my brother’s dosage as prescribed by the psychiatrist.” (Participant #10)

5.4.4 Sub-theme 4: Nurses’ attitude, skills, knowledge and capacity to care for mentally ill patients

There were growing concerns regarding nurses’ attitude, skills, knowledge when attending to patients as participants remarked in the excerpts below:

“I always felt uncomfortable with the nurses’ attitude towards my mentally ill mother.” Especially during my husband’s relapse…. (Participant #12)

“A psychiatric nurse refused to counsel my brother after treatment….” (Participant #1)

“I took us the whole to receive my father’s medication. (Participant #4)

“The nurses’ capacity has been out-weighed by the patients’ workload” (Participant #13*)*

5.4.5 Sub-theme 5: Inadequate resources and infrastructure for mentally ill patients

Due to psychiatric institutions being structurally over-burdened, overcrowded and inaccessible, family caregivers expressed a concern with finding support. The participants described these challenges:

“For the past two days, I have slept on the hospital’s floor due to space constraints.” (Participant #5)

“…I have been angered and frustrated by the lack of medication for a psychiatric treatment at the hospital” (Participant #15)

“A psychiatric nurse refused to screen my husband for this mental illness” (Participant #9)

Some participants complained that understaffed clinics placed unnecessary burden on nursing staff. These statements were echoed by the participants in this study as follows:

“There is only one psychiatrist at the hospital and this constrains the capacity of the nurses…” (Participant #2)

“The nurses’ capacity to care, treat and rehabilitate hampers by staff shortages” (Participant #10)

5.5 THEME 2: CHALLENGES ARISING FROM CARING FOR A MENTALLY ILL RELATIVE

The effects of psychiatric illnesses on patients are often displayed as symptoms of poor cognition, stressful behaviour and anger and other related dangerous and unpredictable behaviour. Family members, when asked how they handled these challenges, had different views and different ways of coping with such challenges.

5.5.1 Sub-theme 1: Overcoming the challenges of caring for mentally ill relatives

Some family members said that it was not stressful whilst others stated that they resorted to locking away their mentally ill relatives when they had visitors. The following responses allude to the above:

“My sister’s illness cause me to loss concentration at work” (Participant #19)

“Some health professionals don’t give us relevant information towards stressful environment” (Participant #16)

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

“If visitors are around I always locked my father in his room…” (Participant #2)

5.5.2 Sub-theme 2: Mental illness stigmatization in the community

The study found that stress and stigma about mental illness issues have a great impact on mental health. One participant responded as follows:

“There is unco-ordinated and broken consultation for mental illness….” (Participant #13)

The findings of the study revealed that stigmatisation could worsen the family member’s burden due to a lack of adequate health information and contribute to further stress. Societal stigma with the formal health services was also prevalent, resulting in the perception that mentally ill patients are dangerous people. Family members also stated that shame and embarrassment were closely associated with stigma. This is evident in the following statements:

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

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

“Since my brother became mentally ill, my fellow worshippers always doubt my presence in church meetings” (Participant #6)

5.6 THEME 3: FAMILY MEMBERS COPING MECHANISMS WITH CARING FOR A MENTALLY ILL RELATIVE

The study revealed that participants employed diverse means of coping with relatives’ mental ill health. This study provided evidence that the burden of managing mentally ill relatives and coping with the consequences of a psychiatric disorder lies with family members. Whilst family members develop different kinds of coping strategies to deal with the burden of caring for a mentally ill relative, some coping mechanisms could adversely affect the family member.

5.6.1 Sub-theme 1: Multi-disciplinary approach

Family members also resort to multi-disciplinary approaches to cope with the care, treatment and rehabilitation of their mentally ill relatives. One participant responded by saying:

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

Participants felt that there should be constant consultation between nurses and doctors treating mentally ill patients and appropriate referrals should be made.

"Both the doctor and nurse consult on matter affecting my mentally ill cousin" (Participant #19)

"There is always a consistent consultation on mental health by health professionals" (Participant #3)

5.6.2 Sub-theme 2: Governmental commitment

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

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

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

Family members also believed an increase in the social grant will assist in supporting their family and bring relief. The excerpts below indicate some of these challenges:
"*Sometimes we ran out of food to care for my sister*"... (Participant #7)

"My brother's illness affect us financially as a family" … (Participant #3)

5.6.3 Sub-theme 3: Traditional, spiritual and cultural role in managing mentally ill relatives

With inherent traditional, spiritual and cultural convictions, this study found that there were a number of beliefs influencing caregivers of mentally ill patients. In order to cope with a mentally ill family member; some family members prayed to God the Almighty to help them. They reported that they believed in prayer, and got their strength through prayer. One participant related how they used to pray as a family and they totally relied on 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. The participants responded by saying:

"Due to my religious conviction my first encounter was my Reverend to ease the evil spirit of mental illness" (Participant #5)

I have looked for help from my Pastor through prayers" (Participant #17)

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

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

5.7 CHAPTER SUMMARY

Chapter 5 presented the results of qualitative data using thematic analysis. Tesch’s method was utilised to analyse the information derived from the interviews with the selected participants so that certain themes could be identified. Chapter 6 will discuss the findings of the study in relation to the mentally ill patient and those caring for him/her by reviewing and interpreting data obtained. The relevance of the theoretical framework that was used to guide the study will also be discussed.

CHAPTER 6: DISCUSSION OF THE FINDINGS

6.1 INTRODUCTION

Whilst caring for a relative, who has a mental illness, is a very personal experience, it rarely happens in isolation. Mental illness as a phenomenon encompasses cultural, ethnic, spiritual, social components and caregivers often have to consider these factors when trying to understand the very nature of the illness and its effects on the person and their loved ones. The previous chapter presented the findings of the study. This chapter will discuss these findings in relation to the aim mentioned in Chapter one and themes identified in Chapter 5 as well as the relevance of the Theoretical framework that was used to guide the study. The main aim study was to explore and describe family members' experiences of mental illness and identify their coping strategies and their needs of caring for the mentally ill relative in the uMsunduzi Municipality in Northern KZN. The identified themes of the study were:

1) Caring for a mentally ill relative.
2) Challenges arising from caring for a mentally ill relative
3) Family members coping mechanisms with caring for a mentally ill relative.

6.2 DISCUSSION OF THEMES

6.2.1 Caring for a mentally ill relative

Based on the analysis of the findings, this study observed that family members lacked experience to care, treat and rehabilitate their mentally ill relative. This is possibly due to a lack of skills, knowledge and capacity to care, treat and rehabilitate their relatives with mental illnesses, having negative bearing on the family members' coping experience when caring for their mentally ill relative. Koen, Ryke, Walson and Eeden (2017:316) agree and states lack of skills, knowledge and capacity to care for the sick and needy in a society can be detrimental to the well-being of the community. Results also allude to family members being unable to participate in their relatives' care, treatment and rehabilitation for mental illness. Mokoena-Mvandaba (2013: 7) noted that a lack of knowledge and skills of mental illness and its repercussions, causes failure to attend follow-up appointments which in turn can negatively impact on the family members' illness causing a relapse in their condition (Bergund,Vahlane and Edman: 2003).It is further evident that mental health education or health education programmes failed to support the experiences of family members caring for mentally ill relatives. The decreased presence of health care staff and unavailability of proper health care programmes raised huge concerns for the promotion of the caregiver and patient alike. This is consistent with Mafuru and Maboe (2017: 232) who revealed that the challenge of lack of information and programmes is a barrier to mental healthcare.

There are growing concerns regarding nurses' attitude, skills, knowledge in the medical and nursing fraternity (Meiring, Visser and Themistocleous, 2017: 307; Mntlangula, Khuzwayo and Taylor 2017: 53; Sibiya 2012: 39). Naidoo and Sibiya (2013: 78) point out that, although nursing is a caring profession, the attitudes of certain nursing staff can deter patients from seeking treatment. (Meiring, Visser and Themistocleous 2017: 307) agree with the KZN Department of Health that practicing health care professionals such as nurses are not fully equipped with the adequate knowledge, skills and relevant qualifications to manage and treat relevant diseases and conditions (KZN Department of Health 2015). These challenges coincide with the findings of this study. Understaffing and increased patient volumes are other reasons that place unnecessary burden on nursing staff (Meiring, Visser and Themistocleous 2017: 307). The participants in this study have agreed that failure to address these challenges resulted in negative experiences by family members caring for mentally ill relatives.

The operational inefficiency that has resulted in KZN not being equipped with an adequate number of psychiatric beds have concurred with participants' responses that the family caregivers' burden, with inadequate psychological support, stems from inadequate resources (Seloilwe 2006: 262; Sibiya *et al*. 2018:1). Bhengu (2016: 44), agrees that psychiatric institutions are structurally over-burdened, overcrowded and inaccessible creating barriers to effective psychiatric care, treatment and rehabilitation.

6.2.2 Challenges arising from caring for a mentally ill relative

The study also found that the stresses and stigmatization of mental illnesses are contributory factors to the ineffective coping skills of the caregiver. Lorenzo, Matiwane, Cois and Nwanze (2013) and Magadla and Magadla (2014 suggest that the effects of psychiatric illnesses often caused patients to display symptoms of poor cognition, stressful behaviour and anger towards each other and their family members and are, sometimes, viewed as dangerous people in society. It was noted that, while caring for their mentally ill relatives, the attitude of family members towards mental illness contributed to the feeling of shame and embarrassment. As this feeling is closely associated and linked to stigmatization, embarrassment is often seen as a source of disgrace (Tlhowe, Du Plessis and Koen 2017: 32). This led to an element of social exclusion towards a mentally ill patient and their relatives for fear of unnecessary problems and disruption. In addition, this guilt and humiliation together with embarrassment of the symptoms and the behaviour of the patient cause family members to live an isolated life.

6.2.3 Family members coping mechanisms with caring for a mentally ill relative.

This study revealed that participants employed diverse means of coping with caring for their mentally ill relatives. Findings of the study clearly indicate that the burden of managing and coping with such relatives lie with family members. It was evident that, through a multi-disciplinary approach and adequate referral systems, family members were able to cope with the care, treatment and rehabilitation of their mentally ill relatives. Trying to find alternatives in an attempt to find solutions and seeking information from family members caring for mentally ill patients were deemed vital during the consultative process of a patient(Marimbe-Dube2013:32).This was consistent with study findings from Dowing, Pogenpoel and Myburgh(2017: 319) who revealed that, when individuals with mental health challenges engage in a partnership with other health professionals, they become empowered, appreciated and motivated to overcome their own challenges. This suggests that holistic community care approach such as teamwork and partnership from all members of the multidisciplinary team, for the promotion of care and rehabilitation of the mentally ill patient. Koen, Ryke, Watson and Van Eeden (2017: 319) agree that engaged community involvement gives society a sense of responsibility. Although social grant payments assisted and alleviated the financial caregiving burden of family members, participants indicated the need for additional income in the form of an increase in social grants to adequately support their mentally ill relatives. Sspiritual, traditional and cultural coping strategies, appeared to dictate the way family members rendered care and coped with a mentally ill relative. Sibiya *et al*. (2018: 5) states that there are a number of cultural issues experienced by family members caring for mentally ill relatives in the uMsunduzi Municipality and tradition and beliefs do play an insightful role. In order to cope, while living with a mentally ill family member, some family members prayed to God the Almighty to help them. They reported that they believed in prayer, and got their strength through constantly praying to God.

6.3 RELEVANCE OF THE THEORETICAL FRAMEWORK USED TO GUIDE THE STUDY

Theoretical frameworks guide the researcher through the research process and provide a frame of reference for the interpretation of results. The frame of reference also forms the basis for observations, definition of concepts, research designs, interpretations and generalizations (LoBiondo-Wood and Haber 2010: 141). To gain a deeper understanding of the problem, the researcher adopted Pearlin’s Caregiving Stress Process Model (Figure 3.1). Within the context of this study, this theoretical model was applied to examine the experiences of family members caring for their mentally challenged relative, how they make meaning of their situation and how they manage the stress symptoms that arise from the situation as depicted in Figure 3.1. According to this model, caregiver stress can occur because of a process, which comprises of a set of interrelated conditions, including the socio-economic characteristics and resources of caregivers as well as the primary and secondary stressors to which they are exposed.

The theoretical grounding of this model can also be applied in a South African context, such as the setting of the current study, in Northern KZN where the uMsunduzi Municipality is located. Relevant to this study, primary stressors identified were hardships and problems such as lack of skills, knowledge and support to care for the mentally ill. These challenges contributed to family members' negative experiences in the uMsunduzi Municipality. Consistent with the model, the findings in this study also confirm that stress and stigma contributed to the negative experiences of family members. Family members developed different kinds of coping strategies to deal with the burden of caring for mentally ill relatives and challenges arising from unhealthy coping styles adversely affected them.

The following three main themes emerged during data analysis and became the core factors related to Pearlin's Caregiving Stress Process Model:

- Caring for a mentally ill relative.
- Challenges arising from caring for a mentally ill relative
- Family members coping mechanisms with caring for a mentally ill relative.

The findings in this study were in keeping with this model and noted that primary stressors were hardships and problems directly inherent in caregiving, while secondary stressors were the strains experienced in roles and activities outside of caregiving, which included the lack of infrastructure and resources. All these stressors contributed significantly to the burden of caregiving. The study also concurred with the model in showing that effective coping strategies of social and societal support and eradication of stigmatization can potentially be used at multiple points along the stress process, thereby avoiding the escalation of problems.

6.4 SUMMARY OF THE CHAPTER

Chapter 6 discussed the findings of the study in relation to family members' responses on their experiences in caring for their mentally ill relatives. This chapter also detailed the application of the chosen theoretical model to the findings. The following chapter will highlight the study's strengths, limitations and recommendations and present the conclusions.

CHAPTER 7: CONCLUSION, LIMITATIONS AND RECOMMENDATIONS OF THE STUDY

7.1 INTRODUCTION

In the previous chapter, the study findings were discussed in relation to the theoretical framework of the study. In this final chapter the conclusions, limitations and recommendations will be presented.

7.2 CONCLUSION OF THE STUDY

The three (3) broad themes and ten (10) sub-themes that have emerged from data analysis in this study, as discussed in chapter 6, were factors that influenced the experiences of family members living with their mentally ill relatives.

This study showed that the research setting, a rural area in the uMsunduzi Municipality needs assistance with resources to support family members living with their mentally ill relatives. Family members' lack of experience emerged as a major factor that influenced the care, treatment and rehabilitation of their mentally ill relatives. This current situation at uMsunduzi Municipality contravenes the Constitution of Republic of South Africa (Act No. 108 of 1996), Mental Health Act (Act No. 12 of 2002), National Health Act (Act No. 61 of 2003) and National Health Policy Guidelines (NHPG) for Improved Mental Health (South Africa 1996: 29; South Africa, 2002; South Africa, 2003; South Africa 2004). The implications of the poor enforcement and non-implementation of the acts, policies, processes and procedures in the mental health discourse are evident in the uMsunduzi Municipality. It is concluded that the underlying causes of the inexperience of family members are lack of skills, knowledge and capacity, lack of support for mental health, lack of awareness, lack of mental health information and programmes. Nurses' attitudes, skills, knowledge and capacity to care, treat and rehabilitate mentally ill patients as well as inadequate mental health facilities and infrastructure also affected the care of the mentally ill patients by their families. The aforementioned factors necessitate an urgent call for intervention in the mental health sector, particularly in the uMsunduzi Municipality. Stemming from participant's responses in this study, the multidisciplinary approach in caring for the mentally ill person from diagnosis to rehabilitation was found to be lacking in the uMsunduzi Municipality. Participants suggested that, in addition to a proper health service infrastructure, there was a need for a team approach from health care personnel such as referral mechanisms, health education programmes and other services to support those with mental illnesses. Traditional and cultural beliefs featured dominantly in participants' responses, which indicated how society and family members handled issues of mental illness. Irrespective of the area or the vicinity where mentally ill persons reside, the actual caregiving experiences takes an emotional toll on all persons caring for the mentally ill. Therefore, family members need to have support networks in place, not only to assist in providing care, but also for their own emotional wellbeing.

7.3 LIMITATIONS OF THE STUDY

According to Botma *et al.* (2010: 107), limitations are barriers or constraints that weaken or decrease the credibility of the study results and these could be the research design, sample of the study or research methods. The sample in this study was limited to the uMsunduzi Municipality and limited to family members who care for individuals affected by a mental illness. Inherent findings of this study cannot be generalised to other settings, regionally provincially, nationally or globally or to individuals diagnosed with any other illness.

7.4 RECOMMENDATIONS OF THE STUDY

Based on the findings of this study, the following recommendations are made with special reference to nursing and community education, institutional management and practice, policy development and implementation and further research.

7.4.1 Legislation, development and implementation of policy

A post-apartheid South Africa has laid a firm foundation for various laudable acts, policies, procedures and processes for the public health sector. These legislative and policy frameworks are not limited to the Constitution of Republic of South Africa, Mental Health Act and the National Health Act. Therefore, policy frameworks, such as the National Health Policy Guidelines for Improved Mental Health should be subject to ongoing independent review boards to review mental disorder treatment regimens and management. This study proposes and calls for intervention in the coping strategies for mental illness management and references should be made to multi-disciplinary approaches, assistance from Non-Governmental Organisations and community services. Provision should be made for the inclusion of traditional and cultural stakeholders to assist in health education and the formation of support networks.

7.4.2 Institutional management and practice

This research has explored family members’ experiences of mental illness and reported needs of family members with mentally ill relatives to determine their coping strategies. Area managers and operational managers need to track and manage progress in the implementation of acts, policies, guidelines and procedures, to be proactive in improving the family members’ capacity to care, treat and rehabilitate their mentally ill relatives and thereby counteract the negative experiences resulting from the lack of skills, knowledge and capacity to treat and rehabilitate mentally ill relatives. Both the area managers and operational managers must engage with family members, on a regular basis with a view towards a shared decision-making process. It is incumbent for area managers and operational managers to be proactive in strategizing coping styles to improve the family members’ experience of caregiving.

7.4.3 Community education and healthcare professional's education

Since this study has been conducted in the diverse rural environment and setting of the uMsunduzi Municipality, information through ongoing community education is of paramount importance. Although extensive health literature is necessary for mental health education, health promotion programmes and healthcare awareness are equally important. This study recommends the need to enhance community education of all health professionals, providing relevant training in mental illness management. Family members caring for mentally ill relatives should be included in a shared decision-making process so that a collaborative partnership between family members and health professionals across KZN is established, enhancing the lived experience of family members and patients alike.

7.4.4 Nursing research

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

7.5 SUMMARY

The unique character of this study is the chosen site, the rural setting of the uMsunduzi Municipality in the province of KZN, which is home to about 600 000 people from different cultural groupings and comprises rural areas that are governed by municipal by-laws and common laws. Notably, this area has only two provincial hospitals specializing in mental ill health, namely, Townhill and Fort Napier provincial hospitals. With an estimated population of over half a million, it poses a huge service delivery problem for mentally ill patients who are seeking treatment. Consequently, the burden of managing mentally ill relatives and coping with the consequences of psychiatric disorders lies with family members. The study further contributed to the holistic management of caregivers as well as patients afflicted with mental illnesses. The findings can be generalised to other settings, outside the uMsunduzi area and KZN and can be extended to exploring family members’ experiences of caring for individuals afflicted with other physiological illnesses.

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APPENDICES

Appendix 1: DUT Ethics clearance certificate

DUT
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Institutional Research Ethics Committee
Research and Postgraduate Support Directorate
2nd Floor, Berwyn Court
Gate 1, Steve Biko Campus
Durban University of Technology

P O Box 1334, Durban, South Africa, 4001

Tel: 031 373 2375
Email: lavishad@dut.ac.za
http://www.dut.ac.za/research/institutional_research_ethics

www.dut.ac.za

6 December 2018

Mr A Mjajubana
34 Mbolompo Street
Ikhwezi Township
Mthatha
5100

Dear Mr Mjajubana

Experiences of family members caring for mentally ill relatives at uMsunduzi Municipality in the province of KwaZulu-Natal.

I am pleased to inform you that Full Approval has been granted to your proposal.

The Proposal has been allocated the following Ethical Clearance number **IREC 196/18**. Please use this number in all communication with this office.

Approval has been granted for a period of two years, before the expiry of which you are required to apply for safety monitoring and annual recertification. Please use the Safety Monitoring and Annual Recertification Report form which can be found in the Standard Operating Procedures [SOP's] of the IREC. This form must be submitted to the IREC at least 3 months before the ethics approval for the study expires.

Any adverse events [serious or minor] which occur in connection with this study and/or which may alter its ethical consideration must be reported to the IREC according to the IREC SOP's.

Please note that any deviations from the approved proposal require the approval of the IREC as outlined in the IREC SOP's.

Yours Sincerely

Professor J K Adam
Chairperson: IREC

DUT DURBAN UNIVERSITY OF TECHNOLOGY
2018 -12- 06
INSTITUTIONAL RESEARCH ETHICS COMMITTEE
P O BOX 1334 DURBAN 4000 SOUTH AFRICA

Appendix 2a: Letter of information for participants (English)

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Thank you for agreeing to participate in this study.

Title of the Research Study: Experience of family members caring for a mentally ill relative in uMsunduzi Municipality, in the KwaZulu-Natal province.

Principal Investigator/s/researcher Mr. A Mjajubana, MHSc: Nursing.

Supervisor/co-supervisor: Prof M.N. Sibiya, D Tech: Nursing (Supervisor); Dr V Naidoo, D Nursing (Co-supervisor).

Brief Introduction and Purpose of the Study: The proposed study aims at describing the experiences of family members living with mentally ill patients at uMsunduzi Municipality in the province of KwaZulu-Natal.

Outline of the Procedures: You are kindly requested to participate in an interview. The interview questions focus on your experiences in caring for a relative who has been diagnosed with a mental illness. The interview will be conducted by the researcher, in both English and IsiZulu. The interviews would be under taken at your home to ensure privacy and comfort. The interview session will take between 20 minutes to 30 minutes. Permission is sought to record the interview for record purposes.

Risks or Discomforts to the Participant: The study does not involve any physical risk or cause physical discomfort to participants.

Benefits: The proposed study intends making recommendations to improve support systems to families living with mentally ill patients. It aims to also improve the body of knowledge in public health domain discourse to improve mental health service delivery to benefit users, decision-makers, policy-makers and practitioners.

Reason/s why the Participant May Be Withdrawn from the Study: Contribution will be voluntary and as a participant you can withdraw at any given time without any opposing consequences and will be not required to give a reason.

Remuneration: There is no remuneration for participating in the study.

Costs of the Study: There are no costs involved by participating in this study.

Confidentiality: The information provided will be kept strictly confidential and will remain anonymous. The interview does not comprise names and any personal identification details; instead codes will be used.

Research-related Injury: There are no identified or foreseen risks and discomforts related to you in this study, nevertheless, if so, no compensation will be presented.

Persons to Contact in the Event of Any Problems or Queries:
Please contact the researcher Avela Mjajubana on 078 253 8406, my supervisor, Prof MN. Sibiya on 031-373 2704 or the Institutional Research Ethics Administrator on 031 373 2375. Complaints can be reported to the Director: Research and Postgraduate Support, Prof C. Napier on 031 373 2577 or carinn@dut.ac.za

Appendix 2b: Letter of information for participants (isiZulu)

Ngiyabonga ngokuba uvume ukubamba iqhaza kulesisifundo.

Siyabonga ngokuthi uvume ukubandakanyeke kulolucwaningo.

Isihloko salolucwaningo: Imizwa yalabo abahlala nabantu abagulayo ngokomqondo endaweni yase Msunduzi kwisifundazwe sakwaKwaZulu-Natali.

Umcwaningi: Mr. Avela Mjajubana, umfundi wemastazi kwezobuhlengikazi.

Abahloli bocwaningo: Prof M.N. Sibiya (Umhloli), uneziqu zobudokotela, Dr V. Naidoo (isekela Mhloli), uneziqu zobudokotela.

Isithulo yalolucwaningo kanye nenhloso yalo: Inhloso esinayo mgalomubono ukuthi sikwazi ukuthi sihlakaze izimo imindeni ebhekene nezinkinga yalabo abagula ngokomu mqondo ebhekana nayo kulabo abahlala kumasipala uMsunduzi kwisifundazwe sakwaZulu-Natali. Sizophinda sibheke namasu abawasebenzisayo ngenhloso yokuthi sikwazi ukuthuthuka izindlela ababhekana nazo nezimo abaphila kuzo. Izimo zabagula ngokomuqondo ziyathuthuka eMzansi Afrika kodwa mincane imindeni efuna ukuxoxa ngalezizigameko.

Uhlelo lokuzokwenzeka: Ngakhoke siyakucela ukuba ubandakanyeke kulolu hlelo elubheka imindeni enalabo abaphazamesekile ngokomu mqondo. Imubuzo kulolu cwaningo igxile kwizimo obhekene nazo ngesizathu sokuhlala nomuntu ongaphilanga ngolomuqondo. Lolucwaningo luzo qhutshwa ngesiZulu kanye nesiNgisi. Ukuqinisekisa ukuphepha nokunethezeka kwakho, lolucwaningo luzokwenzelwa ekhaya lakho. Lolucwaningo luzothatha imizuzu engama shumi amablili kuya kuma shumi amathathu. Ngisacela imvume youkuqopha ingxoxo ukuze ngigcine imiphumela yengxoxo.

Ukuphepha kulabo abazodlala indima kulolucwaningo: Sinesiqiniseko sokuthi lolucwaningo ngeke lukuhlukumeze emoyeni kanyenasenyameni.

Usizo lwalolucwaningo: Lolucwaningo luzonika ulwazi olumanyelana nezimo amalunga omndeni abhekana nazo njengoba behlala nabantu abagula ngokomqondo. Lolu cwaningo luzohlumulisa izinhlelo uhu;umeni avumelene ngazo nalabo ekumele baqale lezinhlelo kumphakathi wonke,

Izizathu ezingengza kuhoxe labo abalekelelayo kulolucwaningo: Ukubamba iqhaza kulolucwaningo akuphoqelekile futhi ungahoxisa noma ingasiphi isikhathi. Loko ngeke kube nemithelela emibi kuwe futhi awuphoqelekanga ukuthi udalule izizathu ezikwenza uhoxe.

Umhlomulo: Angeke uhlomule ngokubamba iqhaza kulolucwaningo.

Izindleko zocwaningo; AAkukho zindleko ozobhekana nazo ngokubamba iqhaza kulolucwaningo.

Ukudalulwa kwakho: Ulwazi nemininingwane ebhekene nalolu cwaningo ngeke ixhumaniswe nenigi futhi izohlala ingaziwa umthombo wayo. Lolucwaningo ngeke lubalule imininingwane yakho. Ikhodi izosetshenziswa.

Izingozi ezibhekene nocwaningo: Azikho izingqinamba nemibuzo nokunga thuliseki ezobhekana nawe ngenxa yalolucwaningo.

Ongaxhumana nabo uma unemibuzo yilaba: Sicela ukuba uxhumane nomcwaningi uAvela Mjajubana inombolo yocingo 071 875 2224/0782538406 nalabo abamuhlolayo uDokotela V Naidoo inombolo yakhe yocingo 031-373 2748, email; vasanthrien@dut.ac.za noSolwazi M.N Sibiya inombolo yocingo 031-373 2704). Uma ungagculisekile ungaxhumana nalemini niningwane engenhla Ungaxhumana noMabhalane obhekelele ucwaningo kulenombolo 031-373 2375. Izikhalazo zingadluliselwa naku Mqondisi wocwaningo, uSolwazi C. Napier kulenombolo 031-373 2577.

Appendix 3a: Consent in English

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Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, Mr A. Mjajubana about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number: ____________,
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

______________________	___________	_______	________________
Full Name of Participant	**Date**	**Time**	**Signature / Right Thumbprint**

I, Avela Mjajubana herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

___________________	___________	_____________________
Full Name of Researcher	**Date**	**Signature**
___________________	___________	_____________________
Full Name of Witness (If applicable)	**Date**	**Signature**
___________________	___________	_____________________
Full Name of Legal Guardian (If applicable)	**Date**	**Signature**

Appendix 3b: Consent in isiZulu

Isitatimende sesivumelwano sokuba yingxenye yocwaningo:

- Ngiyaqinisekisa ukuthi ngazisiwe ngumcwaningi, Mnuz A Mjajubana ngobunjalo ukuphathwa, inzuzo nokungaba yingozi ngalolucwaningo-inombolo ye Research Ethics Clearance_____________.
- Ngiyitholile, ngayifunda ngaqonda ngokubhalwe ngenhla (Encwadini yolwazi) maqondana nocwaningo.
- Ngiyazi ukuthi imiphumela yocwaningo neminingwane yami mayelana nobulili, ubudala, usuku lokuzalwa, iziqalo zamagama ami nesifo esingiphethe angeke kuvezwe kumbiko wocwaningo.
- Ngenxa yezidingo zocwaningo, ngiyavuma ukuthi ulwazi oluqoqwe ngumcwaningi kulolucwaningo angalusebenzisa nge computer.
- Ngingayihoxisa imvume nokuba yingxenye yokuba yingxenye yalolucwaningo ngaphandle kokucwaswa.
- Ngibe nethuba elanele ukubuza imibuzo ngakho ke ngiyavuma ukuthi ngikulungele ukuba yingxenye yalolucwaningo.
- Ngiyaqonda ukuthi ngiyokwaziswa ngokusha okutholakele kulolucwaningo ngenxa yokuzimbandakanya kwami nalo.

______________________	__________	________
Igama eliphelele loyingxenye yocwaningo **Sayina/ Isithupha sangasokudla**	**Usuku**	**Isikhathi**

Mina Avela Mjajubana ngiyaqinisekisa ukuthi lona obhalwe ngasenhla oyingxenye yocwaningo wazisiwe ngobunjalo, ukuphatha nokungaba yingozi obuphathelene nalolu- cwaningo.

____________________	_______________	_________
Igama lomcwaningi	**Usuku**	**Sayina**
____________________	____________	______________________
Igama lofakazi **(Uma kusesidingo)**	**Usuku**	**Sayina**

Appendix 4a: Interview guide (English)

Participant Code: ☐

Date of interview: ………………………..

SECTION A: DEMOGRAPHIC DATA

1. Age: ………………………………..
2. Gender:……………………….
3. Marital Status: ……………………
4. Level of education: ………………
5. Occupation ……………………….

SECTION B: INTERVIEW QUESTIONS

Grand tour question

- What are your experiences regarding caring for a mentally ill relative?

Probing questions

- What are your needs as a family member caring for a mentally ill relative?
- What is the extent of your psychological distress caring for a mentally ill relative?
- How do you see yourself in the community caring for a mentally ill relative?
- Which strategies do you use to cope with caring for your mentally ill relative?

Appendix 4b: Interview guide (IsiZulu)

Ikhodi yomuntu obamba iqhaza: ☐

Usuku locwaningo: ………………………..

ISIGABA A: IMININGWANE

1. Iminyaka yakho ………………………………..
2. Ubulili:…………………………….
3. Isimo somshado: ……………………
4. Ibanga lemfundo: ………………
5. Umsebenzi owenzayo………………………

ISIGABA B: IMIBUZO NGOCWANINGO

Umbuzo omkhulu

Chaza uvo lwakho ngokuhlala nomuntu ohlukumezeke ngomqondo.

Imibuzo yokwengeza

- Yiziphi izidingo zakho njengomunto onakekela ohlukumezeke ngomqondo?
- Kukukhuba kangakanani ukuhlala nomuntu ohlukumezeke ngomqondo?
- Uzibuka kanjani emphakathini njengomuntu ohlala nomuntu ohlukumezeke ngomqondo?
- Yiziphi izindlela ozisebenzisayo ezikulekelelayo ukunakekela umuntu ohlukumezeke ngomqondo?

Appendix 6: Sample of a transcript

Date 17 November 2018 **Participant no**: **07**

SECTION A: DEMOGRAPHIC DATA

Age: 40

Religion: Muslim

Race: Indian

Marital status: Married

Gender: Female

Level of education: Certificate

Employment status: Unemployed

Interviewer: Good morning Mam and how are you?

Participant: Good morning Sir, I am well thanks except the tiredness and cold… eh… this weather.

Interviewer: I am well thanking you, the weather is really cold but hopefully it will end soon. Thank you for agreeing to participate in this study, are there any questions you would like to ask me before we start?

Participant: No Sir, we can start.

SECTION B: GRAND TOUR QUESTION

Interviewer: What are your experiences regarding caring for a mentally ill family relative?

Participant: Eh… caring for my mentally ill sister can be challenging and difficult experience…

Sir, I feel strongly that I need the basics on the care, treatment and rehabilitation of my mentally ill sister. I need to have the knowledge, skills and capacity as well as accurate on the mental illness *(Theme 1: Experiences of family members living with their mentally ill relatives, Sub-theme 1.3: Knowledge deficiencies related to mental illness management.). (Category: Skills, Knowledge and Capacity) and (Category: Mental health awareness)*.

Interviewer: What are your needs as a family member for caring with mentally ill relative? *(Probing Question).*

Participant: Sir, as I am not yet well prepared to care and treat for my mentally ill sister, this created a stressful environment due to the burden of this illness *(Theme 2: Family members handling of challenges arising from caring for a mentally ill relative, Sub-theme 1.2: Family members handling of coping challenges).*

Interviewer: What is the extent of your psychological distress caring for a mentally ill relative? *(Probing question)*.

Participant: Sir, as I am unprepared to care and treat for my mentally ill sister, as a young family member I felt ashamed and embarrassed since I took her illness for granted. *(Theme 2: Family members handling of challenges arising from caring for a mentally ill relative, Sub-theme 1.2: Family members handling of coping challenges) (Category: Shame and embarrassment)*.

Again, I won't tell my friends about my sister's mental illness. *(Theme 2: Family members handling of challenges arising from caring for a mentally ill relative, Sub-theme 1.2: Family members handling of coping challenges) (Category: Stress and Stigmatisation)*.

Interviewer: How do you see yourself in the community caring for a mentally ill relative? *(Probing question)*.

Participant: My sister's illness forced community members to drift away from me (*Theme 1: Experiences of family members living with their mentally ill relatives, Sub-theme 2.2: Support systems for families living with mentally ill relatives.)…most of my neighbour are in denial of my sister's mental condition (Theme 1: Experiences of family members living with their mentally ill relatives, Sub-theme 2.2: Support systems for families living with mentally ill relatives.)*.

Interviewer: Which strategies do you use to cope with caring for your mentally ill relative? *(Probing question)*.

Participant: To be honest Sir, I maintain a calm attitude towards my mentally ill sister as one of my coping strategies. *(Theme 3: Family members coping mechanisms with caring for a mentally ill relative, Sub-theme 3.1:* Multi-disciplinary approach*.). (Category: Community members' support)*.
I always attend my prayer session at our Church in order to receive word of courage and support from my Pastor. *(Theme 3: Family members coping mechanisms with caring for a mentally ill relative. Sub-theme 3.3: Spiritual and religious belief).*

Interviewer: Is there still other information you would like to add that I did not ask about male student nurses care in maternity? *(Probing question).*

Participant: Mhh… not really.

Interviewer: Ok…Mam…this brings us to the end of our interview session. Let me take this opportunity and thank you for taking part in this study and giving me the opportunity to interview you…. I really appreciate it, Thank you. I wish you well.

Participant: Thank you Sir.

Any other probing questions following the participants' responses will be used to facilitate the discussion.

Appendix 5: Certificate of proof reading from a professional editor

EDIT A SHAH (PTY) LTD

REG. N0. 2018/353171/07

10 MAGENTA PLACE
CLARE ESTATE
4091
DURBAN
Tel: 031-8295252
Cell: 0834637758
e-mail: tharadevishah@gmail.com

EDITING CERTIFICATE

EXPERIENCES OF FAMILY MEMBERS CARING FOR THEIR MENTALLY ILL RELATIVES AT UMSUNDUZI MUNICIPALITY - Avela Mjajubana (20935117)

I am a freelance editor specialising in proofreading and editing academic documents. I confirm that I have edited this dissertation and the references for clarity, language and layout. I used the track changes/review option in Microsoft Word. I returned the document to the author:

- Ensuring that spelling, grammar, punctuation, line spacing, and font is consistent and correct.
- Checking the List of References for consistency and style and checking entries against online databases to check accuracy of spelling and reference detail.
- Ensuring that all references in the text appear in the List of References and vice versa.

Resolving and accepting the changes in the text and references is the responsibility of the author.

My Qualifications and Experience:

- 30 years' experience as a research librarian at the University of KwaZulu-Natal and the Durban University of Technology.
- 16 years' experience in editing theses, research reports, teaching materials, journal articles, newsletters.
- Scribing, recording and transcriptions for workshops, seminars, debates.
- Facilitating and lecturing at Workers' College and Durban University of Technology.
- Masters in Library & Information Science, University of KwaZulu-Natal.
- B.Bibl.(Hons) in Library & Information Science, University of South Africa
- Higher Diploma in Education, University of South Africa.
- B.A. University of Durban-Westville

Thara Devi Shah (Director) 06 APRIL 2019