

**Challenges of Families with Relatives Living with Mental Illness: A
Case of Thulamela Municipality, Vhembe District in Limpopo Province**

BY

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Dissertation

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DECLARATION

I, **Konanani Constance Matambela** hereby declare that this dissertation is my own work and all references and borrowed ideas have been duly acknowledged. This work has not been previously submitted for a degree at this or any other university or Technikon

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DEDICATION

I would like to dedicate this dissertation to all participants of this study and over and above every family living with a family member who has mental illness. I hope through this study adjustments will be made for mental health care services to be provided holistically.

ABSTRACT

The aim of the study was to investigate the challenges faced by families living with mentally ill relatives in Thulamela municipality in the Vhembe district, Limpopo province. The objectives of the study were to investigate the impact that caring for a mentally ill person had on the family members; to explore the strategies adopted by families to enable them to cope better with the challenges they faced when caring for their mentally ill relatives; and to understand the support services that were provided to families by health care professionals to enable them to cope with such challenges. A Non-probability sampling, in particular its subtype convenience samplings was used to select five families who participated in the study. A semi-structured interview schedule was used to collect data from the main care givers and a focus group discussion took place to gather more in-depth information from at least three members of each family. Those selected to participate in the study were all family members who were involved in the care giving responsibility. All participants were caring for mentally ill relatives diagnosed with schizophrenia, substance induced psychosis or bipolar affective. The care recipient had to be admitted at Hayani psychiatry hospital. Data extracted from the participants was analysed thematically following the six stages of thematic data analysis. The research findings obtained from family caregivers from Thulamela municipality found in the Vhembe district within the Limpopo province, highlighted that taking care of a family members with mental illness comes with a number of challenges. The impact was experienced by all members of the family irrespective of the age, social or financial status. The impact was experienced emotionally, physically, socially and financially. All participants also reported to be experiencing burnout. They prefer their loved ones to remain living in mental institution as it gives them a chance to live normal lives.

Key words: Challenges, Families, Mental illness, Reintegration, Relatives, Care recipient.

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LIST OF ACRONYMS

MHCU	Mental Health Care User
LOA	Leave Of Absence
WHO	World Health Organization
AIDS	Acquired Immunodeficiency Syndrome
HIV	Human-Immune Virus

CHAPTER 1

STUDY BACKGROUND

1. 1 INTRODUCTION

This chapter was about introduction and background of the study. The chapter consists of the background of the study, aims and objectives of the study, relevance of the study, motivation of the study, research methodology, limitation of the study, definition of the concepts and division of the study.

“Mental illness is not a personal failure. In fact, if there is failure, it is to be found in the way we have responded to people with mental and brain disorders”
Dr Gro Herlmen, Director-General of WHO (2009).

According to the World Health Organization report (2009), one in four people in the world will be affected by mental disorders at some point in their lives. It is also reported that 450 million people presently suffer from mental illnesses. More than 17 million people in South Africa are living with mental illness, Limpopo province is one of the four provinces with the largest number of people living with mental illness and it makes a percentage of 30.8 following North West (34%), Free State (37.5%) and Western Cape (39.4%). In the Vhembe district 1.9% of people are living with mental illness and across its sub-districts Thulamela municipality has 2.1% of people living with mental illness, followed by Makhado (2.0%), Mutale (1.2%) and Musina (0.4%).

According to Pearlin Mullan, Semple and Skaff (1990), mental illness is not only demanding for patients, but also for family members. Thomas, Stainton, Jackson et al (2003) further argue that taking care of a relative who has a serious mental illness, can place substantial strain not only on the primary carer but also on friends and other members of the family. These groups of people suffer from significant stresses and experience high levels of burden.

The frequency, impact and consequences of mental health are well-known and documented. What is less known and appreciated however is the remarkable but often unseen role that family members play within the mental health of their relatives and the impact of mental illness on families (Family Mental Care Alliance, 2006). According to Friesen and Koroloff (1990:16), the perspective and notion of family support, as well as actual resources and services for families, are developing more slowly for mental health care than for other disabilities. Families feel neglected and overwhelmed, and there comes a point where they develop burnout and are forced to institutionalise their loved ones in mental institutions in order to escape their ordeal. This problem is likely to result in crisis situations similar to the 2016 life Esidimeni tragedy. The overflow of families wanting their loved ones to be institutionalised as they can no longer cope with them is still high.

As the parable cited by the WHO (2009), goes; *“where there is neglect, there is little or no understanding. Where there is no understanding there is neglect.”*

In light of the above, the aim of the study was to investigate the challenges faced by families of relatives living with mental illness in Thulamela municipality in the Vhembe district, Limpopo province.

1.2 PROBLEM STATEMENT

In South Africa, the family is now placed at the centre of mental health care because of a limited supply of suitable facilities to care for the mentally ill. In the Thulamela municipality, in Vhembe district, Limpopo province there is only one mental institution, one psychiatric doctor and three general hospitals with very small acute mental health care units. The result is that mentally ill relatives are prematurely discharged back to their homes because of limited accommodation and a high inflow of sick or psychotic patients. This results in families having to bear the burden of caring for their relatives who are not yet fully stable.

The fully congested hospitals, with a limited number of staff, also have a great impact on the support given to the families of mentally relatives. The limited support that is available is mostly patient-focused. Only few families are provided psychosocial support

so that they can cope better with their situations. Most families do not receive psycho education to handle the illnesses of their loved ones. The families are overwhelmed and do not know what to do, how to act and when to act. This is, however, because of the little or no psychosocial support provided to these devastated families.

In the six years the researcher has worked in a mental institution as a social worker, the researcher come to understand the great impact caring for a mentally ill relative had on the family. A large number of families applied to social workers claiming that they can no longer provide proper care for their mentally ill relatives because of the overwhelming stress they always have to deal with (emotionally, financially and deteriorating health). Some of the families of relatives who were institutionalised even refused to take them back even when they had been declared rehabilitated or fit for leave of absence (LOA). In light of the above context, this research investigated the challenges faced by families of relatives living with mental illness in Thulamela municipality in the Vhembe district, Limpopo province.

1.3 SIGNIFICANCE OF THE STUDY

More focus is put on problems faced by mental health care users (MHCU) and there are also policies that have been devised to help the mental health care users to cope with whichever challenges they might face with. However, little has been done to help address those challenges faced by family members who are subjected to the tribulation that comes with mental illness. Mental illness is very demanding on those living in the proximity of the mentally ill person. One needs to be emotionally ready and willing to keep a good composure in order to keep the family as normal as possible for the sake of the significant others. There are services available to help the family cope with these stressors.

This study addressed the gap in literature by investigating the problems faced by South African families particularly those found in the Thulamela municipality in Vhembe district, Limpopo province. It also gave mental health care practitioner insight on some of the shortcomings in the service they are rendering to families caring for their mentally ill relatives. The research study made recommendations that will help health

practitioners to make strategic interventions and policy decisions and choices which will bring about lasting solutions to the problems faced by families of the mentally ill.

1.4 AIM, OBJECTIVES OF THE STUDY AND RESEARCH QUESTIONS

1.4.1 THE AIM OF THE STUDY

The aim of the study was to investigate the challenges faced by families of relatives living with mental illness in Thulamela municipality in the Vhembe district, Limpopo province.

1.4.2 THE OBJECTIVES OF THE STUDY WERE:

- I. To investigate the impact that caring for a mental ill person has on the family members;
- II. To explore the strategies adopted by families to cope better with the challenges they face when caring for their mentally ill relatives; and
- III. To gain insight on the support services provided to families by the health care professionals.

1.4.3 THE KEY RESEARCH QUESTIONS THAT INFORMED THE STUDY WERE:

- I. How has the families been impacted by caring for a mentally ill relative?
- II. Which strategies are adopted by families to enable them to cope with the challenges they face when caring for their mentally ill relatives?
- III. What type of support services do families receive from health care professionals when they are unable to cope with their challenges?

1.5 DEFINITIONS OF MAJOR CONCEPTS

I. Challenges

The Oxford Dictionary (2010) defines challenges as something that needs great mental or physical effort in order to be done successfully and therefore tests a person's ability. for the purpose of this research study, the term challenges refers to any stressors that are brought about by of the mental illness of the relative and which are experienced by other family members.

II. Family members

According to L'Abate, (1994) a family is defined as a structure or system which consists of two or more people, living together in the same household, who are related by blood, marriage, or adoption. For the purpose of this research study, this term refers to family members in a family who are playing a care giving role for the mental ill relative.

III. Mental illness

The World Health Organization (2009) defines mental health as a state of well being in which the individual realizes his or her own abilities, can cope with normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community. According to the Mental Health Care Act 17 of 2002, mental illness is defined as a positive diagnosis of mental health related illness in terms of the accepted diagnostic criteria made by a mental health care practitioner authorized to make such diagnosis. Some authors also define mental illness as mental conditions involving changes in thinking, emotions and behavior. For the purpose of this research study, mental illness refers to mental conditions that have been declared by a medical practitioner following the DSM5 criterion.

IV. Reintegration

According to the Oxford Dictionary (2010), reintegration refers to the restoration of an element that was once considered disparate back to unity. An offender can be reintegrated from prison and back to the community for a second chance. For the purpose of this study, the term reintegration refers to the process of reunifying mentally ill relatives who have been institutionalized with their families

V. Care recipient

According to the Oxford Dictionary (2010), a care recipient means a person who is receiving care or for whom care is proposed by a care provider. For the purpose of this research study, this term refers to the mentally ill person in a family who is receiving care from his family members.

1.6 STRUCTURE OF DISSERTATION / THESIS CHAPTERS

This dissertation covers 5 chapters; chapter one is as an introduction of the background of the study and it provides an overview of the challenges experienced by families when caring for their relatives living with mental illness. The chapter also covers the problem statement of the research, the aim of the research, the objectives, the questions used to give light to the research question and definition of major concepts.

Chapter two will be a detailed literature review which will interrogate both international and local literature on the experiences of families that are caring for relatives with mental health problems. Furthermore, a theoretical framework underpinning this study will be presented.

Chapter three will be the research design, which involves the methods, techniques and instrument to be used to conduct the research. The data analysis procedure and the ethical consideration will also be outlined.

Chapter four will be presentation of data that was obtained through interview schedule and focus group

Chapter five will present the data analysis and interpretation based on the empirical findings.

1.7 CONCLUSION

This chapter introduced the background of the study and provided an overview of the challenges experienced by families when caring for their relatives living with mental illness. The chapter also covered the problem statement of the research, the aim of the research, the objectives, the questions used to give light to the research question and definition of major concepts. It also highlighted the significance of undertaking this research study. The three objectives were the main themes that guided the entire research study. The outcomes of all these three themes will potentially bring about change in the lives of family care givers, the mentally ill relatives as well as the community at large.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter comprises of a literature review from different books and journals in order to show how the current research is related to previous research conducted by different researchers on the topic of mental health care. The literature reviewed is based on three themes: impact experienced by families caring for mentally ill relatives, strategies adopted by families to cope better with the challenges they face when caring for their mentally ill relatives and the support services provided to families by the health care professionals.

2.1.1 OVERVIEW OF FAMILIES LIVING WITH RELATIVES WITH MENTAL ILLNESS

The incidence, impact and consequences of mental health are well known and documented. What is less well known and appreciated is the tremendous but often invisible role that family members have within the mental health environment and the impact of mental health illnesses on families (Family Mental Care Alliance, 2006). Evavold (2003:14), states that the philosophy and concept of family support, as well as actual resources and services for families, are developing more slowly for mental health care than for other disabilities. Magliano, Mcdaid, Kirkwood, et al. (2007), note that it is not surprising that the family is now placed at the center of mental health care, because even globally, mental health care institutions have adopted a trend towards community care and the de-institutionalization of psychiatric patients.

The debate on the impact of caring for a relative with a mental health problem has been raging over time. Dincin, Selleck and Streicker's (1978), study discovered that parents of mentally ill persons often bear the burden of guilt and feelings of responsibility for their child's mental condition. Chapman (1997), states aptly that families who are caring

for a relative with a mental health problem are regarded as the main role players who holds the mental health care system together. Hence, this study intended to investigate whether the families who are caring for relatives with mental health problem are coping with the caring burden.

Mental illness is a disease that affects millions of people each year (Mental Health, Disability and Work, 2010). Experts estimate that one of four people in the world will develop a mental disorder in his or her lifetime (Bourdon, Rae, Locke, et al., 1992). Leskosek (2009), states that mental illness is not only stressful for patients, but also for family members. His view is shared by Hughes (2005) who highlighted that family members who take care of a mentally-ill family member might experience immense difficulties.

2.2 ROLE PLAYED BY FAMILIES CARING FOR RELATIVES WITH A MENTAL PROBLEM

Young (2001) argued that taking care of a relative who has a serious mental illness can place considerable strain not only on the primary caregiver, but also on friends and other members of the family. Mokguthu (2015) also affirms that families who cope with caring for a mentally-ill family member are involved in several support activities. Firstly, they recognize the mental illness and take the mentally-ill family member to the hospital or clinic (Fadden, Bebbington, and Kuipers, 1987). Secondly, they monitor compliance when it comes to medication and follow-up appointments (Corrigan, Liberman and Engel, 1990).

It has been found through numerous studies that family caregivers of persons with mental illness suffer from significant stresses and experiences high levels of burden (Saunders, 2003). Mccubbin and Figley (1983), explain two types of stressors that are experienced when coping with mental illness, namely, normative and catastrophic stressors. The main stressor is a catastrophic stressor (Lefley, 1989). It occurs as a result of stressors which suddenly attack the family and leave the members overwhelmed and unable to cope (Van Der Kolk and Mcfarlane, 2012).

2.3 THEME 1: IMPACT EXPERIENCED BY FAMILIES CARING FOR MENTALLY ILL RELATIVES

Family caregivers of persons with mental illnesses are a key support system in our country as well as in most of the developing countries (Arun, Inbakamal and Premkumar, 2018). Family caregivers take multiple roles at providing care for loved ones with mental illnesses. The family caregivers suffer substantial burdens as a result of the care giving role and need help from the mental health professionals. It is very important for the mental health professionals to identify the needs of the family caregivers, the stresses faced by them and introduce suitable interventions, so as to reduce the burden, as well as help in developing healthy coping strategies (Lefley, 1996).

Mental illness has a significant impact, not just to the mentally ill person, but also on those in his proximity. Mental illness is often characterized by a lot of troubling symptoms that are very stressful, namely; hallucinations and delusions, violent behavior, suicidal thoughts, self-neglect and lawlessness (Marsh, Lefley, Evans-Rhodes et al., 1996). The illness is viewed as a distressing and disruptive period during which minimization of anguish and the accomplishment of comfort becomes principal (Ross, 2017).

We all have different capacities and skills to deal with stressful situations; some are able to face the problem immediately and effectively, while others get so frustrated they are unable to cope. When it comes to mental illness, this factor plays an important role in how the mentally ill relative recovers or copes with the illness (Linda and Gwyther, 2003). It has been found that there are other factors that determine how the entire family will cope with the mental illness of a loved one; emotional reaction, the pre-existing relationship between the family and the member suffering from mental illness, the nature and severity of the mental disorder, and the family's existing stressful situation, the family's coping mechanisms, interaction patterns that exist within the family, the family's support system (Brodar and Donkin, 2009)

Most families have little or no information about the mental health disorder they are dealing with. Caring for a mentally ill person can be very demanding, it requires the care givers to supervise the care recipient daily treatment, the care giver might sometimes take time off work to take the care recipient to attend clinic or doctor's appointments and it is also financially strenuous (Addo, Agyemang and Tozan et al, 2018). The family can also be afraid of the brutal stigma attached to mental illness by the community. The family may also fear whether or not they will get support from their families and friends (Alfakhri, Alshudukhi and Alqahtani, 2018).

Everyone in the family system with a loved one who is suffering from mental illness will be affected in one way or another, from the oldest members of the family to the youngest. There is usually disruption of the family's normal social and leisure activities, because all the focus is directed to the sick family member (Iseselo, Kajula and Yahya-Malima, 2016). This challenge affects almost all spheres of a person's functionality; emotionally, physically, and financially (Albers, 2012). The family members may react differently when they learn that their loved one has a mental illness, they may experience shock, fear, guilt, anxiety, confusion, compassion, understanding, or anger.

2.3.1 DISCOVERING THE LOVED ONES MENTAL ILLNESS

2.3.1.1 THE FIVE-STAGE GRIEF MODEL

According to Kübler-Ross, as cited by Sandler, Tein and Cham, et al. (2016), people go through five stages of grief as soon as they learn that their family member has a chronic illness. The five-stage grief model includes denial, anger, bargaining, depression and acceptance which are describe below. It was however highlighted after a series of criticisms, that grief is not necessarily experienced in the order of the stages presented. Some people may not even experience any of the five stages, some might only experience one or two. The grieving individuals might also move back and forth between the stages, or go through the stages simultaneously.

Table 1: GRIEF MODEL

A Family of a Mentally ill Member Goes Through these Stages of Grief.	Possible Experience
1. Denial	<p>In this stage the family members might feel that nothing makes sense. When they receive the news that their loved one has mental illness they might think that the doctor might have made a mistake (Sandler, Tein, Cham et al., 2016). They might go to different mental health care practitioners to get what they believe is the correct diagnosis (preferable reality). The family members are in a state of shock, failing to believe the fact that their lives as well as their loved ones changed in an instant (Blandin and Pepin, 2016). This stage is however believed to help the grieving person to cope with the overwhelming situation. It is regarded as a defense mechanism that allows the grieving person to deal with the situation in their own time. It is only when the denial starts fading that the family starts facing the real problem.</p>
2. Anger	<p>Once the family comes to terms with the devastating reality of their loved one having to live with a mental illness for the rest of his or her life, a feeling of anger starts to set in (Blandin and Pepin, 2016). The family starts to feel that the world has mistreated them, they start to ask questions such as, "why me?", "why did it have to be one of ours and not someone else?" For those who are religious, they might start to question whether the god they believe in really exists; they might start to question why their god abandoned them (Sandler, et al., 2016). Some people tend to find</p>

	<p>someone to blame for their situation. Anger can lead a person to disconnect from reality and seem un-grounded. They redirect their anger mostly towards close family members and friends. Although this stage has the potential of destroying relationships in the process, it is significant and encouraged because the more the family feel anger, the quicker the anger goes away (Maciejewski, Zhang, Block et al., 2007)</p>
3. Bargaining	<p>Guilt goes hand-in-hand with bargaining. In this stage the family might start to feel somehow responsible for the mental illness of their loved one. They might find themselves making negotiations with their god/s to change their loved ones' situation and promise to be better parents if it's their child who was diagnosed with the mental illness, or better wives to their husbands. In this stage, the family still has hope that their situation might take a turn back to how things used to be (Blandin and Pepin, 2016). The family thinks that they could avoid grief through some sort of negotiation. The family might be having a lot of problems before the diagnosis, but at this stage they would sacrifice everything to have their old lives with its problems back. The family starts to regret not appreciating what they used to be, what they used to have and the time they wasted not appreciating one another. They long for a do over and to be spared from the torture (Sandler, Tein, Cham et al., 2016).</p>
4. Depression	<p>In this stage, the family starts to realize that indeed their lives as well as their loved one's life have changed forever (Kübler-Ross and Kessler, 2005). They start feeling empty; some even withdraw from life, feeling numb and feeling like they are living in a dark fog. Some members might feel that they have lost the purpose to live and they may not even</p>

	<p>want to get out of bed. The family members are overwhelmed with the feeling of hopelessness and of not knowing what to do to help their situation. Some family members might start experiencing suicidal thoughts. Most people stop taking care of themselves, by not eating, not bathing and neglecting their overall health (Sandler, et al., 2016).</p>
<p>5. Acceptance</p>	<p>This is the final stage, and this is where the family re-enter their new reality. In this stage, emotions have begun to stabilize and people are starting to think more clearly. The family starts to accept that their loved one is living with a mental illness and they start strategizing on how to adjust and readjust their new lives (Spuij, Prinzie, Dekovic, et al., 2013). It does not mean that the family will not experience a rollercoaster of sad and depressing emotions, but this time they are able to get up again and move on (Spuij, et al., 2013). They come to understand that their loved one can never be replaced, so they learn to love them again as they are and grow with them (Blandin and Pepin, 2016).</p>

2.3.1.2 THE ILLNESS CONSTELLATION MODEL

According to Angel and Thoits (1987), people go through four stages of the illness constellation model as soon as they learn that they might be suffering from an illness. The four stages of the illness constellation model include the stage of uncertainty, the stage of disruption, striving for recovery, and the stage of restoration. This model views illness as an experience that affects the sick person and his or her significant others. From this perspective, the consequences of the individual's illness experience causes intense changes in the interactions, roles, and relationships of those involved in the illness experience, and result in a loss of normality. The four stages of the illness constellation model are briefly/ discussed below.

I Stage of uncertainty

This is the first stage, where the individual become aware of signs of illness and tries to make sense of these symptoms by determining their severity and meaning. The family members and friends might also observe that the person is in poor health. In some cases, the sick relative might report the illness to the family or friends. In the case of mental illness, those closest to the sick person are the ones who first notice that there is a change in the behavior of the loved one (Morse, 1997).

II Stage of disruption

This is the second stage, and it begins when the sick individual and the family makes a decision that the illness is serious, and opt to look for help in order to make sense of the irrational behavior. The family's main goal to seek help is get confirmation of a medical diagnosis. When a loved one has a mental illness, the family takes over control and makes almost all the decisions on the sick person's behalf. At this point, the sick person becomes totally dependent on health care professionals and family members (Morse, 1997).

III Striving for recovery

In this stage, the sick person strives for recovery from the illness by attempting to gain control over the illness. The family find themselves supporting, working and assisting with treatments and day-to-day tasks. The family invests their energy in the sick person; while significant others try to protect the sick person from stressors. The mentally ill individual might want to prove to him or herself and to others that he or she is well enough to resume tasks and responsibilities that have been assumed by others. The family might be hesitant to let the sick loved one to regain such responsibilities; this might however cause a strain between the caregiver and the care recipient (Jarrett, 2000).

IV Stage of restoration

This is the stage in which the sick person gains more insight into his or her illness and starts to regain former relationships and control of him or herself. During this stage, the sick person determines when he or she is feeling better. Family and friends help the sick person in making it through, providing support and allowing the ill person to gradually regain control of his or her life. The ill person focuses on taking charge, learning to trust his or her body, to recognize and monitor symptoms closely, and to live within the new limits set by the illness (Morse, 1997).

2.3.1.4 SUCHMAN'S FIVE STAGES OF ILLNESS BEHAVIOR

A similar model is the illness behavior model by Suchman (1996). Illness behavior is a coping mechanism when people become ill. He describes the five stages of illness behavior, namely: symptoms, sick role, medical care contact, dependent sick person role, and recovery. Not all patients' progress through each stage, it may depend on the severity of the illness (Young, 2004).

I Symptom Experience

At this stage, the sick person is aware that there is something wrong by any means, either someone significant mentions that the sick person looks unwell, or they experience some symptoms such as pain, rash, cough, fever, or bleeding. During this stage, the un-well sick person usually consults others about the symptoms of feelings, validating with a spouse or support people that the symptoms are real. In some cases, the sick person denies the symptoms or just ignores it, while others try to self-medicate. This Stage has three aspects: the physical experience of symptoms, the cognitive aspect or the interpretation of the symptoms in terms that have some meaning to the person, and the emotional response like fear or anxiety (Young, 2004).

II Assumption of the Sick Role

This stage is the acknowledgement of the presence of health disturbance. The sick person is now accepts the sick role and seeks confirmation from family and friends. Often people continue with self-treatment and delay contact with health care professionals for as long as possible. During this stage, people may be excused from normal duties and role expectations. Emotional responses such as withdrawal, anxiety, fear and depression are not uncommon depending on the severity of the illness, perceived degree of disability, and anticipated duration of the illness. When symptoms of illness persist or increase, the person is motivated to seek professional help (Young, 2004).

III Medical Care Contact

The sick person now seeks for professional help either on their own initiative, or at the urging of significant others. When the sick person seeks professional advice, they are commonly asking for the confirmation of real illness, the explanation of the symptoms in understandable terms and reassurance that they will be alright or what that outcome will be. The health professional may determine that the sick person does not have an illness or that an illness is present, and may even be life threatening. The sick person may accept or deny the diagnosis. If the diagnosis is accepted, the sick person usually

follows through with the prescribed treatment plan. If diagnosis is not accepted, the sick person may seek the advice of other health care professionals or consult alternative health care providers (Young, 2004).

IV Dependent person sick role

After accepting the illness and seeking treatment, the sick person becomes dependent on the professional. In short, this stage is the dependence on health care professionals. People vary greatly in the degree of ease with which they can give up their independence, particularly in relation to life and death. Most sick persons accept their dependence on the physician, although they retain varying degrees of control over their own lives. For example, some sick persons request precise information about their disease, their treatment and they delay the decision to accept treatment until they have all this information. Others prefer that the physician proceed with treatment and do not request additional information (Young, 2004).

V Recovery and Rehabilitation

During this stage, the sick person is expected to give up the dependent role and resume former roles and responsibilities. For sick person with acute illness, the time is generally short and recovery is usually rapid. Thus, most find it relatively easy to return to their former lifestyles. Those sick persons with long-term illnesses and who must adjust their lifestyles may find recovery more difficult. For those sick persons with a permanent disability, this final stage may require therapy to learn how to make major adjustments in functioning (Young, 2004).

2.3.2 IMPACT OF MENTAL ILLNESS ON PARENTS

2.3.2.1 Parental role change

It is every parent's nature to protect their offspring, providing them with basic needs, such as food, medical care, shelter, and clothing, as well as love, attention, understanding, acceptance and support. The parental role is more structured when the children are not yet matured enough to take on life's responsibility on their own (Dalui, et al., 2014). Mental illness has a potential of stealing away the independence one has acquired and the person may need more assistance from his or her family system. When this happens, the parents often find themselves having to take on the structured parental role on a full-time basis again (Copeland and Heilemann, 2008).

They find themselves having to supervise their day to day activities. the mentally ill child might move back home, the parents may have to take care of them financially and make sure that there is food for them every day (Ingersoll-Dayton, Dunkle, Chadiha et al., 2011). The parents take on these responsibilities hoping that they will help their mentally ill child readjust, learn to live with their illness and eventually get back up on their feet again. The living arrangement can be long term or short term depending on how well the family and the mentally ill family member copes with this life changing illness.

2.3.2.2 Parents' concern for the future of their mentally ill adult children

The parents cannot help but worry about their mentally ill child and they also wonder if he or she will ever be the same person. The parents feel defeated and powerless when they are unable to change their child's situation. They also experience grief because they feel that they have lost their loved ones to the illness, all their hopes and wishes diminish. They feel that their loved one has lost his or her chance to a fruitful and successful life (Wilcox, Kuramoto, Lichtenstein et al., 2010). They may need to deal with the awareness that their child will not progress as other children do, and the milestones celebrated by other parents may be spells of unhappiness for them. They face the additional concern of who will take care for their child when they are no longer able to (Ingersoll-Dayton, Dunkle, Chadiha et al., 2011). At the same time; they find themselves

also having to worry about their other children. They wonder how the situation is affecting them. Parents are forced to redirect more attention to the mentally ill child. They worry that this drastic change in the home circumstances might also mentally affect the other children (Copeland and Heilemann, 2008).

2.3.2.4 Financial problems

Parents, who are employed, often skip work or take on unplanned or unpaid leave to take care of their mentally ill child. They often find themselves having to tap into their savings so that they can provide the best medical treatment for their mentally ill child. Those who are not employed or who are financially unstable find the stress excruciating because they sometimes fail to provide to their children the care they would have like to provide for them (Addo, et al., 2018). They often find themselves having to ask for money from other family relatives or bury themselves in more of debts. The parents find themselves in a predicament situation failing both the mentally ill child, as well as the other siblings. They lack basic needs such as food for the other siblings because the little money they were able to raise goes to the mental ill child (Addo, Agyemang, Tozan et al., 2018).

2.3.3 IMPACT OF MENTAL ILLNESS ON SIBLINGS

2.3.3.1 Sudden shift of attention and social dynamics

The experience of having a sibling suffering from mental illness can have negative consequences on the sibling's quality of life and mental health. It brings about feelings of confusion, stress, sadness, hopelessness, anger, and fear that their sibling's life will never be the same (Dalui, Guha, De et al., 2014). Siblings are often overwhelmed with the sudden shift of attention and the social dynamics in the family. More attention is directed to the ill relative and they often feel left out. Siblings find themselves having to take on greater responsibility within the family unit, because the parents are too preoccupied taking care of the sick sibling. The siblings have to assume supportive roles to their sick sibling, often having to sacrifice some of the social activities that they participated in before the onset of the illness.

Siblings need opportunities to learn effective coping skills including strategies for coping with disruptive behaviors, questions from friends, and their own feelings. Siblings' experiences are unique and differ greatly depending on numerous factors, such as the sibling's closeness prior to the onset of the illness, the birth order of the siblings, and the ill sibling's readiness to engage in treatment. How other members of the family cater to and deal with the situation will also influence how the siblings deal with their brother's or sister's illness (Manning and Gregoire, 2006).

2.3.4 STIGMA EXPERIENCED BY FAMILIES

Stigma is one of the problems that families of a person with mental illness are faced with (Schulze and Angermeyer, 2003). Individuals who seem to deviate to what seems normal or common are likely to be stigmatized or judged. Lack of knowledge or insight has been found to be the most contributing factor. A lot of awareness campaigns to address stigma have been done all over through all forms of social channels, however, change in the community remains minimal. The degree of stigma varies from setting to setting, from disability to disability and from person to person. Conditions that pose more fear to the community are the ones that have more stigmas attached to them, mental illness happens to fall under such conditions. The stigma unfortunately results in discrimination, isolation, disregard, depreciation, devaluation and threat for their safety and well-being (Kuemmel, 2016).

Families often find themselves afraid to talk to those within their inner-circle about what they are really experiencing, because they do not know if they will receive support or they will be shunned or discriminated based on their relative's condition. Family members might eventually develop resentment toward their mentally ill relative, blaming themselves for not being empathetic enough and grow increasingly detached. The impact of mental illness on the family members, however, depends on a number of factors, such as age. The younger the family member, the less the impact is, because it may be difficult for him or her to comprehend the extent of the existing problem as compared to the older family member (Mullis and Chapman, 2000).

Every individual is however likely to react differently; some may choose to become involved in supporting and caring for their loved ones. Others may totally withdraw and refuse to be involved whatsoever. While others may want to maintain life as they knew it prior the diagnosis by trying to normalize life at home, trying not to add on the burden their parents are faced with from the community (Spuij, et al, 2013).

2.3.4 THE CAREGIVER BURDEN HAS BEEN DESCRIBED AS HAVING TWO DIMENSIONS: OBJECTIVE AND SUBJECTIVE.

The objective burden refers to the physical and evident effects of the care giving on the family such as disrupted family routines, constraints on family's social and leisure activities and financial costs (Addo, et al., 2018). The caregivers feel cut off from the society, both due to restraint of their social and leisure activities, as well as the social discrimination and stigma attached to the mental illnesses (Jeyagurunathan, Sagayadevan, Abdin et al., 2017). The subjective burden includes the caregiver's negative consideration of circumstances such as feelings of loss, guilt, shame, and anger. The caregivers caring for their family members with mental illness feel stressed and anxious, since the illness tends to be chronic and demanding. In the long run, the care giver may develop burnout and emotional exhaustion (Schene, Tessler and Gamache, 1994).

2.3.5 THREE STAGES OF CARE GIVING BURNOUT

Care giving is considered to be one of the most rewarding things to do, especially for someone you care and love. The caregivers try, by all means, to provide support to the care receiver in order to alleviate the difficulties the ill family member might be experiencing. This means that the caregiver spends the majority of his or her time giving to others and neglecting him or herself in the process. As time goes on, this process can become more and more frustrating, impacting on the caregiver's wellbeing, and eventually leading to burnout (Lindgren, 1993).

2.3.5.1 The following are some of the signs and symptoms of the stages of caregiver burnout:

I. Stage 1: Caregiver stress

Stress is the first sign that people who are overwhelmed and tired present with. This might be because the caregivers are not getting enough formal or informal support. At this stage the caregivers are frustrated by the lack of progress or improvement of their loved one's mental illness (Yates, Tennstedt and Chang, 1999). The hope and beliefs that the caregivers had that their loved one might eventually get better, often gets shattered. The caregivers start to believe that the quality of their care and their efforts are not enough. This frustration quickly leads to stress arousal. The caregivers might start presenting with frequent headaches, bodily pain, trouble concentrating, heart palpitations, insomnia, high blood pressure and getting easily irritated or angered (Pearlin, et al., (1990).

II. Stage 2: Burnout

Burnout is a state of mental, physical and emotional exhaustion that occurs as a result of lengthened exposure to overwhelming stress. The caregivers lose the sense of purpose after realizing that their hard work is yielding nothing (Pinquart and Sørensen, 2003). The caregivers usually get criticized by other family members for fruitless efforts, and start feeling unappreciated and unsupported. The caregivers are at the stage where they are incapable of taking care of anyone they feel they also need to be cared for as well. Caregivers develop feelings of loneliness and starts isolating themselves. The caregiver also starts experiencing boredom, feeling resentful, postponement and neglecting responsibilities (Yates, Tennstedt and Chang, 1999).

III. Stage 3: Compassion fatigue

This stage is known to be the tremendous state of tension. The caregiver is preoccupied with the suffering of their loved one and the guilt of not being able to help them out of the torment caused by their illness. Research has showed that the stress level can be traumatic and can even lead to the development of mental health disorders (Day and Anderson, 2011). The fact that most families playing the care giving role have no

access to preventative measures is what makes them more susceptible to these disorders. The caregivers start to feel little or no empathy for the care receiver, they start having no patience and tolerance for the care recipients. They also start having outbursts of anger and rage, and might also start presenting with some of these symptoms; chronic headaches, chronic bowel problems, exhaustion, withdrawal, hopelessness and even suicidal thoughts (Lee, Brennan and Daly, 2001).

2.4 THEME 2: STRATEGIES ADOPTED BY FAMILIES TO COPE BETTER WITH THE CHALLENGES THEY FACE WHEN CARING FOR THEIR MENTALLY ILL RELATIVES

According to Folkman, et al. (1986), coping refers to cognitive and behavioural efforts to master, reduce or tolerate the internal and external demands that are created by the stressful transaction.

2.4.1 ALTERNATIVE HEALTH CARE

Several research studies have indicated that most South African have poor access to mental health care units, only a quarter of South African living with mental are receiving treatment. Another reason for this result is South Africans strong belief on their cultural ways. According to Cockerham (2005), society and its members tend to respond to health related problems by conforming to their cultural norms and values. Most South Africans hold the viewpoint that some of the illnesses, particularly, mental illness are due to punishment from their gods or ancestors or bewitchment.

Sorsdahl, et al. (2009), claim that South Africans believe that it is only through traditional healer and faith healers that the mentally ill person can get rid of the illness. It is believed that mental illness can be completely cured through these interventions. Studies have shown that there is an estimated number of 200 000 traditional healers in South Africa. This number proves that this is a widely used approach by South Africans. Traditional healers use divination which gives them power to discover the actual cause of the illness, they also provide herbal medicines as part of the treatment. Faith or spiritual healers integrates Christian rituals and traditional practices in helping those in need of healing. Research has also indicated that 61% of people living with mental

illness in South Africa have consulted a traditional healer or faith healer (Freeman and Motsei, 1992).

2.4.2 SETTING LIMITATIONS

There is a saying that states that in order to take care of others, we need to take care of ourselves first. The main reason for this is because we need to be emotionally, physically and spiritually ready to take on the care giving responsibility. The care giving role is often accompanied by a lot of challenges and stressors that most people find unbearable (Pinqart and Sørensen, 2007). Family members confronted with the reality of mental illness quickly learn that without constructing proper restrictions, they risk becoming engulfed and potentially consumed by the family member's illness. It is important to have some kind of backup or assistance from professionals. People who take on this demanding role without any kind of assistance are likely to become irritated, short tempered, and resentful or develop burn out and simply withdraw from the care giving role (Schulz and Sherwood, 2008).

2.4.3 SEEKING PROFESSIONAL ASSISTANCE

It is imperative for the caregivers to take care of their mental health; they should know where to go or who to talk to when feeling overwhelmed. Speaking to someone who knows what they are going through is very significant. Through counseling, a caregiver can be equipped on helpful problem solving skills that this will allow the caregivers to tackle future problems that they might experience during the care giving process (Deeken, et al., 2003).

When caregivers are placed in a care giving role, they every so often want to do as ample as possible to support the mentally ill person. In undertaking this, they run the risk of exceeding their limits, responding to the needs of others at the expense of their own needs. Caregivers may either feel compelled to assist out of guilt, out of authentic desire, out of the fear of hurting the person or out of their own need for approval by others (Ohaeri, 2003). For caregivers need to understand that considering their own needs and desires is not egotistical. In order to be of the best help to a mentally ill family member, caregivers need to find some time to sit down and evaluate how and what they

can realistically do to help out the mentally family members. They also need to communicate the boundaries of the support they can deliver (Deeken, Taylor and Mangan, 2003).

Most caregivers take on the caring role with deficiency of any substantial understanding about the chronic illness. The caregivers' perception on the illness determines how the caregivers will respond to the situation. The caregivers have broadened diverse coping strategies to deal with the challenges of the care giving responsibility (Walsh, 2015). The following are the two strategies employed by different people depending on the insight they have on the situation they are faced with.

2.4.3 COPING STRATEGIES EMPLOYED BY CARE GIVERS

- I. Emotion focused coping strategy: The emotion focused coping strategy has been reported to be connected with perceptions of higher burdens. The individual tries to gain control over their emotions by altering the meaning of distressing situation and focusing on positive aspects of an event. The emotion focused strategy aims to lessen the negative emotional impact of the stressors, and it includes avoidance, denial, fatalism, or looking to religion (Goldenberg and Goldenberg, 2012).
- II. Problem focused coping strategy: The problem focused coping strategy refers to direct actions, which the individual undertakes to modify the circumstances. These comprise of problem solving or seeking social support to resolve the stress of care giving. It is imperative to be aware of caregivers' coping mechanisms for tackling his or her own problems, because it affects caregivers' every day performance (Baker and Berenbaum, 2007). Ben-Zur (2009) attests that problem focused coping is actions or efforts that are aimed at managing future threats. It is expressed in the active efforts of an individual that actually changes his or her interaction with the environment. Individuals try to gain control over the troubled person-environment relationship through various techniques.

Problem focused and a little emotion focused coping strategies lead to reduced perception of burdens. A caregiver's positive evaluation of their coping strategies is associated with reduced distress levels and positive attitude toward the patient. Problem solving coping has been reported to be associated with better functioning (Baker and Berenbaum, 2007).

2.5 THEME 3: SUPPORT SERVICES PROVIDED TO FAMILIES BY THE HEALTH CARE PROFESSIONALS.

Clinical observation and early empirical research showed that assuming a care giving role can be stressful and burdensome. Care giving has all the features of a chronic stress experience: it creates physical and psychological strain over extended periods of time. It is accompanied by high levels of unpredictability and uncontrollability. It also has the capacity to make secondary stress in various life domains such as work and family relationships as it requires high levels of attention (Montgomery, Gonyea and Hooyman, 1985).

Research has shown that the family caregiver has remained neglected a lot, and often ignored by the mental health professionals. The family caregivers take care of the daily needs of the patients, monitoring the mental state, identify the early signs of illness, relapse and deterioration, and help the patient in accessing services. The family caregiver also supervises treatment and provides emotional support to the patient (Saunders, 2003).

The family caregivers put up with the behavioral disturbances of the ill family members and can fall victim to the patient's abusive or violent behavior. They also have to restraints on their social and entertainment activities. Researchers have also found evidence of impaired health behaviors, such as neglecting their own health care appointments and eating a poor-quality diet (Schulz and Sherwood, 2008).

2.5.1 SUPPORT FOR FAMILY CAREGIVERS BY THE HEALTH CARE PROFESSIONALS

It is essential for the mental health professionals to identify the problem faced by family caregivers, so that they are not adversely affected by it (Schulz, Visintainer and Williams, 1990). Early identification and suitable interventions would help in keeping this support base intact, healthy and effective (Gaugler, Roth and Mittelman, 2008). The mental health professionals need to take timely care of the needs of the caregivers and provide necessary support and interventions, as per indication. This would help the caregivers to deal effectively with the burden of care giving using healthy coping strategies and also improve their care giving capability. Social workers also play a critical role in providing care and support to caregivers of people living with mental illness (Schulz and Martire, 2004).

2.5.1.1 Before recommending the most suitable support for the caregiver it is important to assess the following factors.

The relationship that existed between the caregiver and the mentally ill relative, preceding the diagnosis. The quality of the relationship between caregiver and care receiver appears to be important also. Intimacy and love in the relationship between caregiver and care recipient have been associated with lower levels of minor psychiatric symptoms and burden (Braithwaite, 2000).

The willingness of the caregiver, to take on the care giving role. Depressive symptoms, anger and resentment may be experienced by caregivers in very close or enmeshed families if they have taken on the care giving role to conform to family rules (Karp, Tanarug and Sachock, 2000).

Another factor to consider is the severity of the mental illness. Caring for someone with more severe symptoms can be very stressful for the family, especially if they are not given the chance to develop the skills needed to cope with mental illness (Jeon, Brodaty and Chesterson, 2005). It can be exhausting, especially for families with young children who still need structured care as well.

The existence of behavioral problems in the care recipient with mental illness is associated with increased depression in the caregiver (Saunders, 2003). Whether or not the caregiver lives with the mentally ill relative, Baronet (1999) found that living with a relative with a mental illness increased the experience of burden.

How long caregivers have been in the care giving role needs to be taken into account when providing services to caregivers.

The coping strategies that the caregiver employs when faced with challenges should be assessed as well.

The coping resources that are available at the caregiver's grasp, for example, financial status. Financial instability may exacerbate the negative impact of caring on the mental health of caregivers. Financial stability, significantly increase the coping options available to any person (Addo, et al., 2018)

The social support system available either formally (by professionals and agencies) or informally (by family and friends). Research has shown that caregivers who stated having greater informal support systems reported greater life gratification, greater perceived support from family and friends, and less resentment and anger than did caregivers reporting smaller informal support systems. There are, however, conflicts in this fact because some research findings have indicated that it is the quality of social support rather than the quantity offered that is most important (Schulz and Martire, 2004).

2.5.2 SUPPORT GROUP

A range of research has proven that support groups are significant for caregivers of people living with chronic illness. The support groups are led by professional, paraprofessional, nonprofessional or collaboration (Sherman, 2003). The main objectives of a support group are emotional support, education, social networking and advocacy. Through support groups the caregivers are given a chance for disclosure, empathic connection, sharing of goals and psychological adjustments to life challenges. The benefits that can be gained from participating in support groups are directly related

to the perceived needs of care giver (Cook, Heller and Pickett-Schenk, 1999). If attendance is timely, then benefits can be gained on both the objective and subjective levels, that is, information and coping skills can be developed, as well as emotional support given and received.

Direct outcomes that assist with the objective burdens of caring for someone with mental illness essentially include the stipulation of education, information and improvement of the problem-solving capacity of caregivers (Biegel, Shafran and Johnsen, 2004). Useful recommendations and suggestions for coping with difficult or irrational behaviors are provided: new ways to think, to feel and to deal with life experiences are established. When it comes to subjective burdens, the families can be able to compare their problems, decreasing negative emotions and establish new relations with people who understand exactly what they are going through. The families get to understand that they are not the only ones faced with the care giving burden and, as a result, they renew their hope (Biegel, Shafran and Johnsen, 2004). This kind of peer support is often the only resource available to family members experiencing the emotional distress that accompany the care giving role.

The research into caring together: families as partners in the mental health and addiction system suggests that the problem that really lets down our mental ill patients, occurs after the mentally ill patient has been treated and rehabilitated, when they have to go back to the community (Family Mental Health Centre, 2006). The community is where they spend most of their time, so a comprehensive and integrated system of community based services should be available to the outpatients as well as their families. These service centers are responsible for providing support to the entire family (Mcfarlane, Hornby and Cimett, 2001). Families are assisted to deal with either emotional or financial challenges they face when taking care for mentally ill members. There are also family support groups that advocates for these families, these groups also tries to intervene on all the problems the families are encountering and also educate them on what mental illness is about and how to manage their ill family members (Addo, et al., 2018)

The research into caregivers and people living with mental illness, particularly schizophrenia suggests that the following are the roles of these family groups (Family Mental Health Centre , 2006).

- I. They create an environment where the needs of the families can easily be addressed.
- II. The families are also empowered in how to deal with the ill member's residual symptoms.
- III. They are also educated in how to recognize symptoms of relapse.
- IV. And how to cope with family conflicts, negative and depressive feelings.
- V. The families are encouraged to be part of the treatment support system to make sure that the mental ill relatives comply with their treatment at all times.
- VI. They also play the role of a care taker to the families involved.
- VII. The families also get to know exactly what mental illness is all about and what to expect.

2.5.3 PSYCHO-EDUCATION

Hagger, et al. (2004), state that individuals who did not get any kind of education about a certain illness tend to develop their own illness model or mental representation that gives them lay understanding of their illness and also gives them guidelines regarding coping and adaptation in the context of illness. The source that moulds this mental representation might be through social interaction, cultural beliefs about the illness and individual's experience with the illness. So, it is very important for caregivers to receive education on the illness of their loved ones.

Psycho-education sessions are very helpful for people who are about to embark on a care giving responsibility, especially when caring for people with chronic illness. Psycho-education is considered to be an essential aspect of all therapy programs (Mcfarlane, et al., 2001).The sessions may include a brief introduction to the illness, presenting symptoms, early signs of relapse, available treatments and their efficacy, safety of treatment, common side-effects, treatment related costs, identifying burden, and coping methods (Kakuma, Minas, Van Ginneken et al., 2011).

Those who have a thorough understanding of the challenges they are facing as well as knowledge of personal coping ability, internal and external resources, and their own areas of strength are often better able to address difficulties. The caregivers are assisted to feel more in control of the situation, and have a greater internal capacity to work toward mental and emotional well-being (Kakuma, et al., 2011). Studies have shown that when psycho-education is administered to families caring for their sick relatives, they reported a decline in both readmissions of their loved and the stress experienced by the caregiver (Nakigudde, Ehnvall, Mirembe, et al., 2013).

According to Xia, Merinder and Belgamwar (2011), the following may constitute psycho-education:

- A therapist explaining to a person in therapy the ways a mental health condition might impact function
- A psychiatrist describing how a prescribed medication can counteract symptoms of a mental health condition
- A psychiatric hospital providing support and education to family members of those receiving treatment
- Formal classes designed to educate the population about both specific mental health conditions and mental health in general
- Self-help and support groups designed to encourage caregivers of those diagnosed with mental illness to share strategies and information with one another (Biegel, Shafran and Johnsen, 2004).

2.5.4 INSTITUTIONALIZATION

There are a lot of programs that families can take their relatives to, so that they can learn new ways that might help them lead a productive life. Research has found that most caregivers still insist on institutionalization of their mental illness relatives as the best choice (Bitter, Roeg, Van Nieuwenhuizen et al., 2016). They believe that this approach relieves them and gives them a chance to progress with their lives without hindrance. The institutional inpatient care model states that institutionalization of

mentally ill patients is the most effective way of care that a mentally ill patient can be given (Zida, Lavis, Sewankambo et al., 2017). Institutionalization is also welcomed by families and communities struggling to care for a person living with mental illness. This approach might seem advantageous to the stressed, overwhelmed families but it is also stressful to the mentally ill family member. It has been found that most inpatients report feeling unappreciated and neglected by their families (Sayma, Tait, and Michail, 2015).

2.5.5 SPIRITUAL SUPPORT

According to Tom (2013), religious institutions play an important role in helping individuals and families that are faced with life burdens, it helps the family to regain hope and replaces defeating and negative feelings with expressions of comfort (Gallant, Spitzer and Grove, 2010). The spiritual advisors play a major role to the families as well as to the mentally ill member as they encourage and support them to be strong and positive. The church congregation encourages the ill members to stay off the streets and not engage in substances, such as dagga and alcohol.

Research has shown that pastors and family members concur that local churches have a responsibility to provide resources and support for individuals with mental illness and their families (Schulze and Angermeyer, 2003). Family members and persons who have attended church frequently as an adult point out that their churches have been supportive when they are faced with life challenges such as death, sickness and other tough times (Mantovani, Pizzolati and Edge, 2016). Most churches talk openly about mental illness to remove the stigma, improve people's understanding of what mental illness is and what to expect when living with a mentally ill person, either at home or in the community. They also host support groups and awareness campaigns such as the national alliance on mental illness which help those living with mental illness and those who are affected by mental illness (Jackson-Best and Edwards, 2018).

Research has shown that a larger percentage of families with a loved one who is showing signs of mental illness first go to their churches hoping for divine intervention, before even going to the hospital for diagnosis and treatment (Vasui, Pottick and Chen, 2017). Pastors' reactions to people struggling with mental illness however vary, some pastors do not encourage western medication stressing that the family should only

focus on prayer while others encourage the families to integrate the two means (Cheney, Sullivan et al, 2017).

2.6 THEORETICAL PERSPECTIVE

The family systems theory has emerged from a collection of theories focusing on different aspects of family relationships as the dominant theoretical model for developing and maintaining such a balance (Evavold 2003). This theory emphasises that everything in a system is constantly influencing everything else (Sawa, 1992). The behavior of individual members of the system influence or affect others positively or negatively.

This theory is relevant to this study, because the family of a relative living with mental illnesses is in very close proximity to the mentally ill relative (Mojtabai, Stuart, Hwang, 2017). When the relative is psychotic, they are the ones who are mostly affected by the illness. Their emotions, their physical health and their financial health will be affected by the relative's state. The patient's mental illness also affects the family's mental health; they often suffer an overwhelming amount of stress almost every day (Kisa, Baingana and Kajungu, 2016).

Family members are expected to play their part by ensuring that the ill relative receives superior care and support (Zegwaard, Aartsen and Grypdonck, 2015). People who are psychotic often present with aggression and conflict. Mental illness falls under the category of chronic illness. However, unlike HIV/AIDS or diabetes the patient is not bed-ridden; these patients are vigorous and unpredictable (Tomasetti, Lasevoli, Buonaguro et al., 2017). They are guided by their hallucinations and delusions and one can never know what they are thinking about or planning to do. As a result, the family constantly lives in fear of the unknown.

The theory of caregiver stress is a middle range theory that has been custom-made from the Roy adaptation model, in order to provide a superior relevant representation for caregivers of chronically ill relatives (Tsai, 2003). This theory is broken down in arrangement and identifies the objective burden as the most significant stimulus for

caregiver stress. The theory argues that, if the caregiver experiences high stress levels then the caregiver will experience fruitless responses in the four adaptive modes, namely: the physiologic mode, the self-concept mode, the role function mode and the interdependence mode. According to Lazarus (1998), depression can either be a direct product of a caregiver's stress, or may influence the stress in the four adaptive modes.

This theory is relevant to this study because it emphasizes that there are challenges that are brought by caring for people with chronic illness. However, it also highlights that there are various factors that help the caregivers to cope or adapt with the stressful situation. The factors are: self-concept, companionship, orientation and insight. All these factors are made possible or encouraged through the assistance of health care professionals. Tsai (2003) indicated that, without stability in all these modes, the caregiver is bound to respond fruitlessly. For caregivers to provide proper care for ill persons, they too need to receive some care and support, whether informally through friends and families or formally through consulting the health care providers.

2.7 CONCLUSION

The literature review brought to light the impression of families living with relatives with a mental illness, the role played by families caring for relatives with mental problems, challenges faced by families taking care of relatives within mental problems, support systems that help families taking care for people with mental problems and the coping strategies used by these families when they are faced with a problem. The literature also revealed the theoretical perspective that supports this study's challenges.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

The chapter's main intention is to outline the research design and methodology the researcher used when conducting the study. The content that was in this chapter was the following: nature of the study, population and sample, data collection instrument, validity and reliability of the measuring instrument, data analysis and conclusion. All the above mentioned methodology made it possible of an objective research to be conducted.

3.2 RESEARCH METHODOLOGY AND DESIGN

A research method is a detailed plan outlining how a research project will be conducted. For the purpose of this study, the researcher used the qualitative research approach. According to Babbie (1993), the qualitative research approach is an inquiry or a process of understanding which a researcher develops a complex of pictures, analysis and, words, as well as reports detailed views of informants and conducts a study in a natural setting. Qualitative research is conducted using a range of methods that use qualifying words and descriptions to record and investigate aspects of social reality (Monette, Sullivan and Dejong, 2008). The use of the qualitative research enquiry enabled the researcher to gain an in-depth understanding of the challenges faced by families of relatives with mental illness in Thulamela municipality in Vhembe district, Limpopo province.

The qualitative research usually involves just a few participants. The intention of qualitative research was to understand a particular social situation, event, role, group or interaction. It is largely an investigative process in which the researcher gradually makes sense of a social phenomenon by contrasting and comparing, replicating, cataloguing and classifying the object of the study (Van Maanen, 1979). In this study, the researcher conducted a semi-structured interview with the main caregivers and a focus group discussion with at least three family members from each family, in order to

gain an in-depth understanding of the challenges faced by families of relatives living with mental illness in Thulamela municipality in the Vhembe district, Limpopo province.

For the purpose of this study, the researcher used exploratory research design in order to investigate the challenges faced by families of relatives living with mental illness in Thulamela municipality in the Vhembe district, Limpopo province.

3.3 POPULATION AND SAMPLE

The location of the study was Thulamela municipality in Vhembe district, Limpopo province. Thulamela local municipality is one of the four local municipalities (Thulamela, Musina, Collin Chabane and Makhado) which fall under of the Vhembe district municipality. According to Babbie (2007:53), population refers to the aggregation of elements from which the sample is actually selected. Welman, Kruger and Mitchell (2005) also defines population as study objects consisting of individuals, groups, organizations, human products and events or the combinations to which they are exposed.

Samples of five families with relatives, who have been institutionalized in a local mental institution for rehabilitation called Hayani psychiatric hospital, were chosen. The sample was selected using the non-probability sampling technique, in particular convenience sampling. In convenience sampling subjects are selected because of their convenient accessibility and proximity (Babbie 2007).

Those included in the study were family members (siblings, parents, spouses, aunts and children) who are involved in the care of mentally ill relatives diagnosed as having schizophrenia or the bipolar affective disorder.

3.4 DATA COLLECTION

According to Gray (2009), data collection is the gathering of information for a research project through a variety of data sources. Babbie (2007) also defines data collection as a procedure specifying techniques to be employed, measuring instruments to be utilized and activities to be conducted in implementing a research study.

3.4.1 Interview schedule

An interview schedule (see Appendix 1) was used as a measuring instrument to collect qualitative data from family members. Creswell (2007:87) defines an interview schedule as a two way conversation in which the interviewer asks the participants questions to collect data and to learn about the ideas, views, options and behaviors of the participants. Interviews are valuable source of information provided they are used correctly. The aim was to obtain rich descriptive data that helped the researcher to understand the participants' construction of knowledge and social reality. The interview schedule was written in English and also translated into Venda to enable the participants to understand the questions.

3.4.2 Focus group discussion

A focus group is a formal discussion that is undertaken with a group of selected participants. It is usually conducted for the purpose of discussing a particular topic and is focused because it involves some collective activity (Wilkinson, 2004). Five focus group discussions with three participants from each of the five families were conducted. The focus group discussion enabled the researcher to triangulate the in-depth information the researcher obtained from the individual interviews. The researcher also got elicits new information from the interactions with group participants.

3.5 VALIDITY AND RELIABILITY OF THE MEASURING INSTRUMENT

The validity of the measuring instrument was addressed, in order to ensure that the measuring instrument measures the intended concept and answers the research question. As noted by Somkh and Lewin (2008), a measuring instrument can always be reliable and generate the same result but it might not be valid (not measure the intended concept). Neuendorf (2002) views validity as the standard of having "good" measurements that ensures that the researcher has followed reliable procedures and methods. The reliability was also be considered in assessing whether the instrument that was used will yield the same result when re-used in the same population (Maree 2007).

For the purpose of the study, the researcher conducted a pilot study, in order to evaluate the feasibility, the reliability and validity of the instrument, time, cost and adverse events and effective size in an attempt to predict an appropriate sample size and improve upon the study design prior to conducting the full scale research project.

3.6 DATA ANALYSIS

3.6.1 Six stages of thematic data analysis

Brawn and Clarke (2006) indicated that there are six stages in thematic analysis, which are as follows:

Stage 1: the researcher repeatedly read the participants' descriptions until the researcher was familiar with them.

Stage 2: the researcher re-read the collected data again, identify and highlighted meaningful phrases, statements or words that seemed to be important.

Stage 3: the researcher took each significant statement and gave it a code or number.

Stage 4: different statements were organized into clusters of themes.

Stage 5: common or similar themes or meanings were identified and grouped together.

Stage 6: the researcher then tried to find the links between the themes describe and then summarized them. Regularities and sets of similar ideas were grouped into categories and compared.

3.7 ETHICAL ISSUES

An ethical clearance was granted by the High Degree Committee, see appendices. A gatekeeper letter was sent to the department of Health in Vhembe district municipality to request permission to conduct the research in Thulamela local municipality

3.7.1 Confidentiality

According to Creswell (2007), confidentiality is when a research project guarantees the participants that their identity will not be openly publicized. In this study, the researcher informed participants that the information given to the researcher during the study

remained confidential. The researcher also ensured that the names and information given by the participants were not disclosed to anyone else. The researcher kept the information in a safe place, which was not easily accessible to everyone.

3.7.2 Reflexivity

The researcher did not allow her experience of working with families of the mentally ill to contaminate the research process. The researcher distanced herself from her role as a social worker and put more focus on exploring the family's perspective on the situation. The researcher was not biased when processing the research findings (Brawn and Clarke, 2006).

3.7.3 Informed Consent

Taylor (2002) defines informed consent as a norm in which subjects' voluntary participation in the research project is preceded by a full understanding of possible risks involved. In this study, the researcher informed the participants about the study before the actual study began. The researcher also informed participants about what to expect and also the purpose of the study. The researcher informed participants about the goals of the study, the benefits, the risks, the advantages and disadvantages of the study. Participants made an informed choice to take part in the study.

3.7.4 Voluntary Participation

Neuman (2011) argues that people should never participate in research unless they are clear about what the objective of the study is. In this study, the researcher allowed the participants to participate in the study voluntarily without forcing or blackmailing and/or bribing them.

3.7.4 Deception

According to Gray (2009), deception involves an intentional misrepresentation of facts related to the purpose, nature or consequences of the study. The researcher did not give any false information to the participants to make them agree to take part in the study.

3.8 CONCLUSION

This chapter has summarized and justified the research methodology employed in this dissertation. Guided by the nature of the research, the researcher decided on qualitative approach, bound by its ability to produce detailed findings. The key research tools were interview schedule, complemented by focus group interviews with five groups of families taking care of their mentally ill relatives. The participants were carefully targeted and recruited through non-probability sampling; in particular its subtype convenience sampling technique. The results analysed were thematically following the six stages of thematic data analysis. The key results and findings of this dissertation are discussed in the following chapter.

CHAPTER 4

DATA PRESENTATION

4.1 INTRODUCTION

This chapter presents the data collected from families of relatives living with mental illness. All the participants who took part in this study are situated among the Tshiombo, Makuya and Lambani villages, which fall within the Thulamela municipality in the Vhembe district, of the Limpopo province. An interview schedule and focus group was conducted with 20 family members caring for their relatives with mental illness. Five custodian or caregivers who have denied taking their mentally ill relatives, who are institutionalized at the Hayani psychiatric hospital for a leave of absence, participated in a semi-structured interview. Three family members other than the primary caregiver from each family took part in a focus group discussion which was aimed at finding more information on the challenges the entire family face when taking care of their mentally ill relative. The study was based on three research questions which focused on the impact faced by families caring for a mentally ill relative, strategies adopted by families to enable them to cope with the challenges they face when caring for their mentally ill relatives, and support services families received from health care professionals when the families are unable to cope with their challenges.

The content of this chapter includes the demographic information of each participant who took part in this study, as well as the diagnosis of their mentally ill relative. The findings are presented according to the research questions which guided the research interviews and the focus group discussions.

4.2 DEMOGRAPHIC INFORMATION PARTICIPANTS

Table 2: DEMOGRAPHIC INFORMATION PARTICIPANTS

Participant Number	Age	Gender	Relationship To The Patient	Occupation
1	76	Female	Mother	Pensioner
2	74	Female	Mother	Pensioner
3	47	Female	Mother	Store manager
4	32	Female	Sister	Unemployed
5	45	Female	Mother	Unemployed
6	31	Male	Brother	Teacher
7	29	Male	Brother	Data capturer
8	32	Female	Sister	Unemployed
9	34	Female	Sister	Cashier
10	26	Female	Aunt	Unemployed
11	21	Male	Nephew	Student
12	18	Female	Niece	Student
13	33	Female	Sister	Domestic worker
14	31	Female	Sister in-Law	Unemployed
15	19	Female	Niece	Student
16	28	Male	Brother	Gardener
17	22	Male	Nephew	Unemployed
18	22	Female	Sister	Unemployed
19	36	Female	Aunt	Unemployed
20	18	Male	Brother	Student

Note: Participants no. 1 – 5 participated in a semi structure interview and participants no. 6-20 are those relatives who participated in focus group discussions.

Table 3: Profile of the relatives living with mental illness

Relative to participant no#	Age and gender	Fit or not fit for a leave of absence(LOA)	Diagnosis	Reason for admission
1	33 years male	Fit for LOA	Schizophrenia	Attempted murder
2	36 years male	Fit for LOA	Schizophrenia	Assault with intent to cause severe bodily harm.
3	26 years Male	Fit for LOA	Substance induced psychosis	Murder
4	44 years Male	Fit for LOA	Schizophrenia	Murder
5	25 years Male	Fit for LOA	Substance induced psychosis	Assault with intent to cause bodily harm

Note: Attempts to convince the primary caregiver or custodian to take the patients for a LOA have been made by the hospital social workers, with no success.

4.3 THEMES AND SUB-THEMES

THEME 1: The impact experienced by families caring for a mentally ill relative

- Emotional Impacts
- Physical Impacts
- Financial impacts
- Social impacts

THEME 2: Strategies adopted by families to enable them to cope with the challenges they face when caring for their mentally ill relatives

- Seeking family support
- Seeking spiritual support
- Seeking professional intervention

THEME 3:
Support services families received from health care professionals when the families were unable to cope with their challenges.

- Counselling
- Psycho-education
- Support groups
- Institutionalisation

4.3.1 THEME: 1 THE IMPACT EXPERIENCED BY FAMILIES CARING FOR A MENTALLY ILL RELATIVE

The following research findings give an indication that caring for a relative who suffers from mental illness has a potential of impacting on every member of the family; emotionally, physically, financially, as well as socially.

4.3.1.1 DISCOVERING THE LOVED ONES MENTAL ILLNESS

According to Kübler-Ross (cited by Sandler, Tein, Cham et al., 2016), here are five stages of grief. It was evident from the participants' responses that they experienced these stages of grieving. Some participants experienced more than one stage at the same time, and some participants went through the stages simultaneously.

The participants' indicated that they noticed that their relatives were acting in a strange way but they never thought the diagnosis that the doctor would come with would be mental illness. They indicated that when they heard what the diagnosis was, they felt that the doctor must have made a mistake. Some believed that it must be the work of the devil or evil spirits, such as witchcraft, and they also believed that the doctor was being used by these evil spirits to come with such a diagnosis. Some members of the family indicated that they even took their loved one to different hospitals to at least get a second opinion, and when the diagnosis came back the same, they indicated that they were devastated and they still did not believe what they were being told. Most participants indicated that they even went to traditional healers to find out from their gods what might be causing their loved one's behavior. They indicated that they also went to different churches all over the country seeking for divine intervention. Some of their responses are given below:

Participant no: 1

I still do not believe that my son is indeed mentally ill; I believe that people in my village are somehow responsible for what he has become. The doctors told me that he has mental illness and I never believed it for a minute. They told me that his mental illness was caused by substances.

Our forefathers used substances all the time and nothing like this never ever happened to them. My children are all educated and the real reason why he is like this is because they did not want to see him also succeed like my other children. I still remember that moment as if it was yesterday; I felt my world turning upside-down. I did not have the energy to talk to anyone about what was happening because if I start talking about it would be like I was accepting the diagnosis. I always prayed for my son's situation would just go away, I still pray for a miracle.

Participant no: 2

When the doctors told me that my son's behavior was caused by his heavy use of substances, I was not surprised. It has been long that I was trying to make him stop using substances ever since he was still in his tender age. What I never accepted is that he had mental illness. A lot was going on in my mind, I have never heard of such thing and the fact that my son was being declared mentally ill did not sit well with me. I believed that they must be another explanation to the doctor's diagnosis. All the doctors I went to were saying the same thing, at the back of my mind as they were all telling me their diagnosis was a strong belief that witchcraft might be at play. I believe that my enemies might have learned of my son's weakness and used it to give him mental illness in order to get to me. My life has never been the same ever since my son's "life" was taken away, I still find myself not sleeping thinking about what my family must have done to deserve such a never-ending punishment. My family felt defeated because we tried by all means to find other ways like taking him to church, in order to help him. However, nothing seemed to bring any change and that the reason we opted to accepting the doctor's diagnosis and let them put him in their medications.

Participant no 3

With me everything just moved very quickly, my family did not even get a chance to comprehend what was going on. One minute our lives were very normal, my children were happy and no one could suspect that life would turn in to the hell we are living in today. Out of nowhere my younger son brutally attacked his brother without being provoked, the next thing everyone was shouting; police were all over the place and before I knew it the court suspected that he might be mentally ill, because nothing made sense to anyone. I still remember the date 12/02/2013 when the psychiatrist told me that indeed my son was mentally ill. I still feel up until today as though this is just a bad nightmare and I will eventually wake up from it. I can't believe I lost my two sons' that day and I still ask myself, why God allowed such a thing to happen to me.

Participant no 4

I grew up knowing that my brother has a mental illness, everyone even in the community knew it. He never bothered anyone; all he did was just to roam around aimlessly or sometimes asking people for money. Everyone in the family accepted his mental illness and we were also aware of the fact that in order for him to be stable he needed to be on treatment and we all took turns to remind him.

Participant no 5

It took me everything to raise my children alone since I was tired of letting them watch their father who was a heavy substance abuser physically abuse me every time he felt like it. I had hopes that my children, particularly my son would one day make me live a deserving life again as he is the eldest of three children. We were very close and talked about everything. I was shocked when he out of the blue just started axing the man he knew I was seeing at that time, claiming that he feels he wants to replace his absent father. Police were called and he got arrested. When he went for trial the court noticed that he was talking senseless

things, he was referred for observation and the psychiatrist final recommendation was that he was not fit to stand trial because he has a mental illness. I still remember telling the psychiatrist that she was wrong and that she is incompetent. We got in an argument that let the team calling the security personnel to escort me out of the room. I still do not believe that my son is really mentally ill. I know for a fact that my ex husband is a wicked man and he might have caused the mental illness on my son because he heard people telling him that I found an honest, hardworking man who was willing to put food on the table to feed the family he failed to feed. Now my son is trapped with the mental illness curse because of him jealousy.

4.3.1.2. IMPACT OF MENTAL ILLNESS ON PARENTS

4.3.1.2.1 Parental role change

All parents indicated that when their son's mental illness started they were already independent and were able to care for themselves. Some indicated that they were living on their own, but as soon as the mental illness started they indicated that they saw a drastic change in their behaviors. Some indicated that they started not bathing and not eating. They also noticed that the always roamed around aimlessly, collecting waste and storing it at home. They indicated that they had no choice but to resume supervising them as though they were supervising young depended children; they had to force them to bath, eat, and take their treatment. All parents also reported that they also had to support them financial as well and those parents who are unemployed and those who only depended on social grant indicated that they were very strained. They also had to wash their dirty clothes as they could not afford to get someone to do all these chores for them.

Participant no 1

My son had a career and he stayed at his own stand, but when he was psychotic he broke all the windows of his five roomed house and the house needed a lot of repairmen. The family decided that he stayed with me as his mother. He was in

no condition to take care of him, I had to make sure that I cook for him, give him his medication and force him to bath because at that time he grooming was very poor. I felt as thou I was talking care of a little child.

Participant no 2

My son was very independent and loved nicer things in life way before the illness started, but as soon as the illness started all this went through the drain. It seemed as though he did not have a purpose in life and he roamed around the streets dirty. I was touched as a parent because no parent wants to see their child deteriorate like that without doing anything about it. I forced him to move in with me and I at least forced him to eat and wash his himself. I also washed his cloths and when I was successful in forcing him to bath I would take his dirty cloths and replace them with cleans, but this would always cause a fight between us.

Participant no 5

My son was a teenager when the illness started, though he was still living with me, he was able to take care of himself without full supervision. When the illness started, he moved from being an independent young adult to a baby. I felt as though I was taking care of a child, he didn't bath, he didn't wash his cloths and he would go for days without eating. I had to force him all the time to do all these things.

Parents indicated that they had to force their loved ones to go for their monthly checkups and this always led to anger and aggression by their mentally ill children, especially when they were still in denial of the fact that they are mental health care user. Most parents who are in their old age indicated that the process was very stressful and they would sometimes be physically and emotionally violated in the process. They indicated that they would secede in convincing them to go for their checkup but as soon as they come back from the clinic or hospital they would discard the pills.

Participant no 1

At my age I found myself having to force him to go to his monthly review at the clinic. We always fought because he always claimed that he is not mentally ill and he would sometimes become verbally and physically aggressive. I would sometimes succeed in forcing him to go to the clinic but he would come back with the pills and flush them down the toilet. He never complied with his treatment and this always made me feel defeated because this means that all my efforts of me helping him would all be in vain, he would always remain psychotic and would also make life for me and other family members difficult.

Participant no 5

I used to remind him of the appointments dates and he would go alone, but after two to three months I got a message from the clinic that he was not coming to the clinic. So I made it point that I go with him at every appointment. This way always a burden because this meant that everything had to stop that day.

4.3.1.2.2 Parents' concern for the future of their mentally ill adult children.

All parents reported always feeling sad when they thought back to the days before their children became mentally ill. They indicated that they were full of life and had so much potential. Some of them were pursuing their studies; one of the patients was studying to become an Engineer when the illness started, and another one was studying mining and Geology. The parents were tearing up as they were talking about this, they indicated that they felt like they were robbed of a chance to see their sons flourish and become something better in life. They also indicated that they tried everything possible to help their son's situation without success.

Participant no 1

I used to cry all the time when the I first learned that my son has mental illness, the thing that hurt me the most was the fact that my son led a very good life. People used to always say that he is well mannered and respectful; his studies

were progressing very well. He was doing his final year of Electrical engineering when all this started. I watched when my son's life all went to waste, months went by and I hoped that he would someday wake up well and would resume his life again. It has now been plus-minus seven year and things are still the same. My son has been robbed of his promising life and he has now amounted to nothing.

Participant no 3

My son has always been an A student ever since he started schooling; he even passed his matric with a distinction. When all this started, he was doing his first year in Mining and Geology; he even had a scholarship that he was awarded because of the good grades he got in his metric results. I used to proud myself a lot of him and expected only good outcome from him. So, when his mental illness started out of the blue I felt as though it was just a bad dream I would eventually wake up from. I couldn't believe it, I still do not believe it. I will never see my son graduate; I will never see my son be what he was meant to be. I always find myself crying even when I am in public places when I think about what life has dealt my son.

Participants reported that they sometimes find themselves wondering who will take care of their mentally ill child if something were to happen to them. They indicated that their other children have grown to resent their mentally ill siblings. Parents worry because they see that no one in the family even bother to visit them at mental institution and they believe that when the pass away, they too will be simply forgotten. They also highlighted that they do not blame their other children for acting the way they did, because they know for a fact that they were subjected to a lot of abuse by the mentally ill sibling and there was a point when attention was shifted from them to the sick relative in an unhealthy manner. For their safety and a better life, the parents indicated that they would prefer their mentally ill children to remain institutionalized with their other children always keeping in touch with them.

Participant no 1

My son is currently institutionalized, but I often wonder what will happen to him when I pass from this world. I say this because even when I talk to my other children about taking him for festive seasons or long holidays they do not want to hear about it. They still do not forgive him of the things he did to me and other family members when he was psychotic. They also do not go to pay him visits at the hospital. So, I often ask myself what will happen when I'm gone, I fear he will be neglected.

Participant no 2

My son has hurt me a lot, he was physically abused me and when he is at home he makes sure that he makes life for me very difficult. To tell you the truth I do not even miss him, I prefer for him to stay at the institution. I love him very much but I hate the person he has become. The only thing we will do for him is to pay him visits, but I think it will be for everyone's best interest if he stays there until he is responsible enough to come back home and move out to his own stand.

Participant no 5

I will be at peace if I know that the hospital will take care of my son until God decides to take him. I'm afraid that if he comes back to the community people would kill him or he would commit an even bigger crime like actually killing someone. I tried supervising his treatment but failed, I am sure that no one in his father's side wants anything to do with him. So, if I failed I know for a fact that no other person would be able to bear him destructive behavior.

4.3.1.2.3 Financial problems

Participants who are employed indicated that they had problems at work when their loved ones were psychotic; they indicated that they had to disclose what they were going through at home hoping for some kind of kindness and compassion. They were advised to apply for a leave but the problem occurred when the leave occurred when the leave days got exhausted while the situation at home still demanded them to be

available. The employer wanted them to come back and some even indicated that they were even getting ultimatums of losing their jobs if they were not back by the stipulated dates. Participants who depended on odd jobs to survive indicated that they found themselves not able to go out and look for jobs because they had to stay home and look after their sick loved ones. They indicated that things became so bad that they felt there was no longer food to feed the family.

Participants indicated that they found themselves having to use up all of their life saving so that they could get their loved ones better services. Those who has insufficient fund also went to loan sharks to burry themselves in more debts. Some participants indicated that they also went to close relatives to request for assistance and when they were unable to repay them it led to conflict between them, conflict which still exist today.

Participant no 2

I am a pensioner and the time when my son got ill I had a little money that I had set aside for the improvement of my house. I had to use all my savings on him; we went to several doctors including Psychologists trying to understand what was really going on with him. The situation was very stressful, the money got exhausted and I also had to tap on my other children's savings when the money was not adding up. My other children complained all the time and it also caused them to resent him.

Participant no 3

It was a very difficult time for me, I found myself having to skip work for several weeks because I had to attend the court sessions as I was the main witness. My supervisor was also putting extra pressure on me threatening that I will wouldn't get paid for the days I was absent from work. I was so surprised as to how my colleagues were not being understanding of the predicament I was facing. I was so traumatized because apart from being questioned by the police and being crossed examined at the court, I also had to plan my son's funeral. I spent a lot of

money and I was also forced to take a loan from the bank as the money was not enough.

Participant no 5

I remember using all my saving and I was forced to go to “vhomatshonise” (illegal loan sharks) so that I can take my son to traditional healers to get more information on what was happening to him. I was a very bad time because I was only relying on the child support grant of my last born. I couldn’t even go out and look for piece jobs as I had to give full attention to my sick child. There were days when we would go without eating properly, there was no money and no one in my family was willing to assist us.

4.3.1.3 IMPACT OF MENTAL ILLNESS ON SIBLINGS.

4.3.1.3.1 SUDDEN SHIFT OF ATTENTION AND SOCIAL DYNAMICS.

Siblings indicated that taking care of their mentally ill siblings has had negative consequences on the quality of their life and mental health. They indicated that they often found themselves experiencing feeling confusion not knowing how they could help their mentally ill sibling. They indicated that there were a number of times when they lost hope of their sibling ever getting better because nothing they were doing seemed to be helping. Some indicated that they often felt sad and angry that they had been robbed of a normal life. Some siblings indicated that they watched as the entire attention was being directed to just the mentally ill relatives by their overwhelmed parents and this feel made them feel left out. Older siblings complained of having to take on more responsibility when it came to taking care of their mentally ill sibling and having to take care of their younger siblings when their parents were too stressed to take care of them. All participants indicated that their social lives were disrupted as they had to spend most of their time on the mentally ill sibling.

Participant no 4

When we were growing up my mom used to tell us that we need to take care of our brother as he has no one else than his family to care for him. We used to make sure that our mother sees that we indeed taking care of him like she told us to. we sometimes used to grumble behind our mother's back saying things like, we are tired of taking care of our brother like he is a baby, cooking for him, washing his cloths etcetera. It was, however, after her tragic passing, that we got to realize that the lessons she was teaching us will help us deal better with future tribulations. After my brother assaulted our mother to death I was forced to grow up fast and take care of my siblings. it was very painful having to take on the parental role to my siblings, nevertheless, I feel having to take care of my brother who was mentally ill trained me to be the strong person I am today.

Participant no 18

I became a mother to my youngest brother as my mother was too stressed to function. My mother would always go out to look for assistance from different churches and prophets. She was too stressed I would be afraid that she would also develop mental illness. So, someone had to see that the household is running, and unfortunately I was that person. I had to make sure that there was food at the table for everyone to eat and I had to make sure that the house is clean. i was forced to stop going to school because there was a lot for me to do. I started looking for odd jobs so that I would be able to support my mother. I am now a 22 years unemployed adult, with two children. To tell you the truth I blame my brother for what my life turned out to be.

Some participants indicated that they felt that they were expected by their families to take more responsibility of caring for their mentally ill siblings because of their position of being the eldest child in the family. They indicated that their younger siblings did not have to bear the same burden as they did. It was also highlighted that the relationship that existed before and after the sibling got ill also determined the willingness of the sibling to care for the mentally ill sibling. Siblings who had poor relationship with the ill

relative chose to escape the stressful situation by either moving out of the household or getting married prematurely by female siblings. It was clear that siblings react differently to the siblings living with mental illness.

Participant no 4

I am the eldest and I was forced to take over the responsibility when our mother passed away. I had to be strong for both my mentally ill brother as well as my younger siblings. It was very difficult at first but I found it easier as time goes by. I was the one whom my brother could get along with even when our mother was still alive. When my mother passed on it was left being a child headed household and I headed it the best way I could. My younger siblings were left unable to cope and hopeless, I had to be strong for everyone.

Participant no 13

I did not like my brother ever since we were very young, he used to bully us a lot. So, when he eventually murdered my mother who was also the bread winner at home, I felt my life coming to an end. I was unable to see how the future will turn out to be. I lost all possible hope, and only resentment grew more. My sister encouraged us to remain supportive to our brother but the anger that I had towards him wouldn't let me. So, to escape it all I got pregnant at a very young age, I got married and ended up dropping out of school.

Participant no 16

I used to think of killing myself to escape the way life was like when living with my brother. He did not want to see our mother doing something nice for other children. He would accuse her of bewitching him. He would even go to an extent of hurting the person he thinks mom is caring more for. He made life very difficult. I hated being home, I hated him. I swear you could say he was possessed by a demon that does not want to see happiness.

4.3.1.4 Stigma experienced by the family

Most participants indicated that their children's mental illness has had an impact on how their relationship has turned out to be with the rest of the community members. They indicated that they saw little or no support whatsoever from the community members. They indicated that this was mainly as a result of their children's irrational behaviour. Participants indicated that their families were well respected before the mental illness, but, they feel judged and stigmatised against as they walk in the streets. They indicated that people no longer communicate as often as they used to.

Participant no 2

After my son attempted to kill a neighbour's child, my family went to apologise and they indicated at first that they do not hold any grudge against us. They indicated that they understand he committed the crime because of his unstable mental condition; we were the ones who encouraged them to open a case at the police station. And now to my surprise, the family no longer speaks with my family; they blame everyone as if we sent him to do the crime. This is so disheartening; we now have to pay for my son's crimes. I understand their pain but why does the rest of my family have to be crucified. My niece once told me that when she is out people no longer call him by her name, they referred to her as 'mashaka a houla wa toda u vhulaya nwana wa vhathu' meaning; the relative of that guy who almost killed that poor child. I feel that our identity have been ripped away from us, we are now called 'mashaka a mupengo', the relative of the crazy guy.

Participant no 3

People are so heartless, you wouldn't believe what people are capable of doing, after my son murdered his brother I thought people would try to understand the predicament I was in. They started coming up with many theories of how the death might have happen, one of the theory was that I loved one son more than the other and that's why he felt threatened and killed his brother. I feel as though

people are happy that this happened to me, as I move around my street I feel people staring at me with judgemental eyes.

Most participants indicated that some of the community members treat them as though the mental illness of their relatives is contagious. They indicated that most people withdraw and distanced themselves from them. They indicated that they noticed that they were not being involved in community activities, such as women stokvel, clubs as well as parties and other deluxe activities. They indicated that people no longer take them seriously; they feel that nothing they say or do is taken seriously. They feel that their community members do not understand impact their loved one mental illness has on them and that they do very little to ease their burden.

Participant no 5

People knew me for my good deeds; I supported each and every family who I felt needed my help, especially when they are faced with challenges such as funerals, or if they needed an extra hand when they were hosting fun family activities. Everyone knew me for that, I was very active in women gatherings, I was part of the committee of our women's stokvel and I was good at what I did. When my son started getting ill the women from my stokvel group started as if they were very concerned about what I was experiencing. We had a meeting and the agenda was about alleviating me of my "demanding" duties in the stokvel, they indicated at that time that they felt I should focus more on getting help for my mentally ill son. I felt supported and cared for. They even suggested prophets and priests they knew who can be able to heal my son's mental illness. This however did not last long, I started seeing people pulling back from me, they no longer called me in simple stokvel meetings, and they never updated me of anything. The stokvel was a good way for me to save the little I earned from my children's support grant, but as I'm speaking now no one wants me at their stokvels. This really hurts me; it makes me feel unwanted, sidelined and betrayed.

Some participants indicated that community members started acting violently to the mentally ill relative as well as to the entire family. They also indicated that they would hear reports that their loved ones have committed a crime which they very well know that they didn't. Their loved ones would be the first suspect in any crime that happens in their community. They also indicated that there are incidences where angry community members would come to their homes shouting and cursing wanting to beat their mentally ill relatives up, claiming he did something to their family or to their property.

Participant no 2

I was receiving a lot of reports from community members; whenever there was someone robbed my son was the first suspect. I used to literally hold my breath when I see someone entering my yard; I would always think that he or she might be coming to report that my son did something. I would also fear that the community might gang up on him and attack him.

Participant no 5

False allegations were made that my son stole from homes and shops and he was beaten a lot by the community members. I used to tell him not to go out, but he never listened to me. It was every community member's wish to see my son arrested. People were getting away with their crimes because they knew that everything was being blamed on my son.

Most siblings indicated that people stigmatize against people with mental illness as well as their family. They indicated that community members treated them as if they are not human beings who just happened to go through such predicament without choice. They indicated that they couldn't even talk to their friend about the problem they are facing at home because they were afraid of being ridiculed about their relatives' mental illness. Some siblings indicated that they even grew resentful toward their mentally ill sibling for making them go through the stigmatization. Some participants also indicated that they even detached themselves from their loved siblings as a way of preventing being associated to them.

Participant no 12

My friends used to make fun of me and my family, this used to make me very sad because I did not ask to have a mentally ill relative. I was ashamed of him and resented him. I avoided being seen in public with him and it would pain me to hear people saying all kinds of awful things about him.

Participant no 20

When my brother got ill I was still very young, I did not understand what was going on with him, what I noticed is that my mother was not around as much and household chores were being neglected. I still remember coming back from school very hungry and I did not find any food at home, which rarely occurred. That was the point I told myself how to cook. When my mom was not around I did all the possible chores. My friends also used to make fun of me saying nasty things, such as, 'mukomana wanu u a khada zwisusu' meaning your brother is mad. It became so bad that I preferred not going out with friends anymore because there was not a day where my family's situation was not made fun of. This made me resent my brother for the suffering I was going through.

4.3.1.4 THREE STAGES OF CARE GIVING BURNOUT

Signs and Symptoms of the Stages of Caregiver Burnout:

I. Caregiver stress

This is the first of the care giver burn out stages which is known as the caregiver stress. At this stage the caregivers are frustrated and long for support from their friends and families (Yates, Tennstedt and Chang, 1999). The participants indicated that the care giving role quickly started weighing on them. The constant stress brought about by their loved ones absurd behavior led them to a feeling of uneasiness and loss of sleep. Most participants indicated they started developing frequent headaches and heart problems. They also indicated that they became easily irritated and angered by simple things and lost a lot of friends because of it.

Participant no 5

I remember not being able to sleep because I feared that my son would wake up and hurt my other children. As a result of not sleeping I started feeling physically sick. I always had excruciating headaches and my heart would always beat very fast. I also made sure that I avoided being in the company of other people as I would easily get irritated and start fights without being provoked.

Participant no 17

I sometimes felt like running away and live in the streets; there was no more peace at home and all we did was to think of ways we can care better for him. Everything was about him and this left me very stress. He was also violent most of the time and he made the care giving process very stressful. I couldn't concentrate at school my teachers were even surprised to see my grades dropping.

II. Burnout

This is the second stage of the caregiver burnout stages. On this stage the caregivers experience a state of mental, physical and emotional fatigue as a result of prolonged exposure to great amount stress (Pinguart and Sørensen, 2003). Participants indicated that they saw that their efforts were not yielding any results; they indicated that there was poor improvement on their loved ones condition. They indicated that this really demotivated them and they began to see that they were the ones who were losing a chance to live a life they would have loved to live. Participants indicated to feeling exhausted in such a way that they felt that they also need to be cared for by someone.

Participant no 13

It was hard on the first time our mother passed away, I tried visiting him while he was in the hospital and even took him one or two times for LOA. I feel that we must not forget that I am just a sibling to him, I didn't ask for this. I developed chronic illness because of him; I saw that I was putting my brother's needs way in front of me and my children's needs. I am tired of feeling this way all the time, he took my mother away from me and I suffered a great deal to get to where I am

now. I will only be able to help him where I see I can, but other than that, I'm afraid I won't, believe me when I say I am tired.

Participant no 17

I sometimes wish my uncle had a different chronic illness but mental illness. I felt that no matter how much we try as a family to support him he always relapses. I even took an initiative to help him take his daily treatments, he would be fine for the first three weeks of the month but on the fourth week he would start acting out and being verbally aggressive and sometimes physically aggressive. I sometimes felt that maybe I was not doing enough to help him, however when I evaluated all my efforts I saw that I was doing more than enough. A mental health care user is impossible to care for especially when you are not educated much on the illness.

III. Compassion fatigue

The third stage is known as Compassion Fatigue and the caregiver presents with a immense tension. The participants indicated that they started feeling little or no empathy for the mentally ill relatives. They also indicated that they started having no endurance and patience for the ill family member. They also start having outbursts of anger and rage, number of participants indicated that taking for care of their loved ones was very stressful in such a way that they even develop some physical ailments; there were participants who reported to have developed hypertension because of the stress they were facing and some indicated that the developed bowl problems because of the constant stress they were facing.

Participant no 2

I am 100% sure that I developed hypertension because of my son. He hates me and he makes it his life mission to torment me and his siblings. Sorry that I have to say this aloud, but I wish I never gave birth to him. I no longer want to live in the same place with him. We are better off when he is at the mental institution.

Participant no 6

I have nothing against my brother but what frustrated the family the most is whenever we tried to give him absolute support and supervision, he always managed to let everyone down by going back to his old habits. We felt as if we are not having any progress with him. At the end of the day we are the ones who are suffering because, we know we lead a poor quality life and some of the family members even developed chronic illness. And I feel that I am speaking for everyone in the family when I say we are tired and I think it's for the best interest of everyone for him to remain institutionalized for a longer period of time.

Participant no 11

I was so afraid of my uncle because he would always beat us for no reason, so whenever he would start talking to me I would for some reason feel that I need to go to the toilet. I always have a bowel movement, that's how scared I was of him.

4.3.2 THEME 2: STRATEGIES ADOPTED BY FAMILIES TO COPE BETTER WITH THE CHALLENGES THEY FACE WHEN CARING FOR THEIR MENTALLY ILL RELATIVES

4.3.2.1 SETTING LIMITATIONS

Helping a loved one to deal with life challenges such as illness often comes naturally among family members. However family members run the risk of exceeding their capabilities putting their own well-being on the line. Some people, however, feel obliged to assist out of guilt and fear of hurting the person (Ohaeri, 2003). Most participants indicated that they felt obliged to take on the care giving responsibility because they had no alternative choice. Some indicated that they did not want to be judged by their family relative and community members for not taking care for their mentally ill relative. Most participants indicated that they quickly felt the burden of taking care of their relatives weighing on their shoulders. They found themselves stuck in their situation and the stress unbearable to live with. They indicated that their quality of life deteriorated drastically; some indicated that they felt that their lives were not worth living, they lack sleep, lost appetite and lost a lot of weight did not bath. Younger members of the family

also indicated that they were taking on a lot of responsibility that was too much for their age. The younger care givers indicated that they often do not want to take on this responsibility but they were forced as they saw that this burden was too much to be taken by just one person in their families. They felt that they were being robbed of their social life because of this. And to make matters worse it was also impacting on their future. There were participants who indicated that their grades were affected a lot in such a way that their teachers even noticed the plunge.

Participant no 5

When my son was diagnosed with mental illness I had no knowledge of what the illness was really about. I was never told what to do except that I have to bring him to his monthly checkups. Everything I was doing was experimental and I was preoccupied with trying to ease his burden. I found myself losing touch with reality, I felt like I did not exist. There was a time I didn't even bath, eat or sleep. The illness kept him up most of the nights and I would keep watch of him. I was always stressed and as a result I lost a lot of weight. I was failing him because he was never getting better as well as my other children because I was tired and unable to care for them. This depressed me even more.

Participant no 17

My uncle's condition was very stressful, it literally consumed my life. I would find my mind drifting away whilst I'm in class because I would be thinking of what I should do to give him effective care so that I would ease the burden my family was experiencing because of him. My grades dropped as I was unable to concentrate whilst in class or read at home. I sometimes felt like the burden I'm faced with exceeded my age and my capability. I was responsible of giving him his treatment when my mother was away and accompanying him to the hospital for his reviews. I would sometimes be expected to go and look for him when my mother saw that it was getting late and he was not coming back home. I lost my social life; everything was basically going down the drain for me. When I tried to

communicate how I was feeling my family members would always say something to make me feel guilty.

4.3.2.2 SEEKING PROFESSIONAL ASSISTANCE

Family members caring for relatives with mental illness experience a lot of tension and they quickly realize that they learn that without developing proper boundaries they risk becoming engulfed and potentially consumed by the family member's illness. They need to frequently consult health care professionals so that they can be also assisted with the challenges they face as they take care for their loved ones (Schulz and Sherwood, 2008). However, none of the participants have taken the initiative of consulting a health care practitioner for assistance with challenges they face as caregivers. There are a number of participants who indicated that they feared being judged by the health care providers as not wanting to take responsibility of their relative. Some believe that as the health care practitioners review the patient, they should also focus on how the caregiver is coping because the stress faced by caregivers is continuous. They believe that the health care professionals are the ones who are letting them down.

Participant no 3

I was once referred to a psychologist by my Doctor for counselling, I attended a series of counselling sessions that really helped me a lot. I finally got into terms with what had happened to me and my family. I still feel like I need to go.

Participant no 4

I never went to any professional to get counselling and I have been trying by all means to do what I can to care for my brother. The reason why I haven't gone to talk to professionals about the difficulties I facing is the fear of being judged and being labelled to be what I am not.

Participant no 5

The social workers used to come to my home all the time to check on my son and to motivate him to take his treatment. The problem was when they did not

concentrate on what the family experience and challenges were. I have never asked for help or share with them the burden that I face when taking care of my son. I feel that it's my responsibility as a mother to take care of my son and I do not have to complain to anyone about my children.

Participant no 17

I never went to speak to any professional about the problems me and my family were facing. It never came to my mind and I was not aware that there are services available for caregivers of people living with mental illness.

Participant no 20

I always thought that the health care professionals only focus on helping people living with mental illness and not their caregivers. Every time I accompanied him to the hospital it never crossed my mind to go and consult someone about the difficulties I was facing while taking care of my brother.

4.3.2.3 COPING STRATEGIES EMPLOYED BY CARE GIVERS

People are likely to look at one or both of these two coping strategies in order to deal with the challenges they face with. The first strategy of coping is known as emotional focused: this strategy aims to rid of any negative emotional stressors; however the strategies employed are less effective. The stressed person might chose to avoid the situation all together or look to other alternatives such as religion (Goldenberg and Goldenberg, 2012). The second coping strategy is problem focused and it looks at employing unswerving actions to solve the problem one is facing. People who use this coping strategy are not easily weighed down, they do not look at their situation with defeat, they usually present with optimism and eagerness to pull through (Baker and Berenbaum, 2007). Most, if not all participants indicated that they were overwhelmed with their relative's condition in such a way that they did not know how to help their circumstances. They indicated that they were in denial and thought that their loved one's situation will soon go our through divine intervention. None of the participant seemed to possess the problem focused strategy of coping.

Participant no 1

My son's situation crippled me, I couldn't even think straight or let alone make an informed decision. The burden was too much for me to handle.

Participant no 3

I lost my two sons' the day mental illness entered my household. So, to ease my pain I avoid being face-to-face with now mentally ill/murderer son. I have chosen to forget about him and I tell myself that I lost my two sons' that fateful day.

Participant no 5

I think it's better for everyone for my son to remain institutionalized at Hayani hospital for a longer period. He is too much for me to handle and I have accepted that only a controlled institution is best for him.

4.3.2.4 SPIRITUAL SUPPORT

Spiritual support can be very helpful and it also plays an important role in helping individuals and families that are faced with life's burdens, it helps the family to replace defeating and depressing emotion with hope and comfort (Gallant, Spitze and Grove, 2010). Most participants indicated that when they first found out that their loved ones were acting in an absurd manner, the first thing they did was to take them to churches and faith healers in order to take out the evil spirits they thought was causing the behavior. A number of participants indicated that they are still consulting their faith healers up until today believing that their loved ones will be set free from the spirits that are tormenting them. Participants indicated that keeping in touch with their faith healers keeps them sane. Those who go to church indicated that their church members comfort them and assure them that they will someday receive their miracle.

Participant no 2

When my son started acting psychotic we took him to Zion Christian church where he was prayed for and he also stayed at Moria for three month.

Participant no 5

When my son started acting strange I saw it in his eyes that he was possessed by something, so I took him to several prophets in order for my son to be delivered from the evil spirits that has possessed him. I still go once in a while to ask for prayer and I will continue to go until something happens.

4.3.3.5 FAMILY SUPPORT

Most participants indicated that support from the extended family is the most important thing to have when dealing with a family member suffering from mental illness. They indicated that it eased the burden one feels in a daily basis; it gives one a sense of belonging and security. The participants however indicated that with time they feel that their family support eventually burns out. They indicated that that this is mostly because of the relative's disruptive behaviour as well as the pressure they get from the community.

Participant no 1

At first my brother in law was very supportive; he used to come all the time to speak to him encouraging him to take his medication and to go to his review dates. He started being troublesome, at home and in the community. People started complaining to him since he is also the village chief; he, and my other two sons made all efforts to make sure that people open cases of assault against him so that he goes to prison, saying that he had had enough of him and didn't want to account for his behaviour anymore. He got his wish my son got arrested for assault and ended up being referred to a mental institution for treatment. He told me that if I take him back he will no longer get involved in anything that has to do with my son. I feel that I have been given an ultimatum, he is my son, I still want to see him fulfil his life, I believe that he is now rehabilitated and I would have

loved it for him to be given a chance to prove himself but at the same time I am afraid that he might relapse and I won't be able to control him since I am just an old lady.

Participant no 3

After my son murdered his younger brother my family especially the paternal side want nothing to do with him. I feel so torn, I cannot turn my back away from my own flesh and blood. Yes, he is the perpetrator but I feel he is also a victim in this entire predicament. My heart hurts a lot because at the end of the day I lost two of my sons that day. I would like to someday, although I do not know when, give him a chance and see if is rehabilitated enough to move on with his life.

4.3.3THEME 3: SUPPORT SERVICES PROVIDED TO FAMILIES BY THE HEALTH CARE PROFESSIONALS.

4.3.3.1PREPARING THE FAMILY FOR THE CARE GIVING ROLE

It is vital for mental health professionals to recognize the burden experienced by the caregivers, so that they are not adversely affected by it (Schulz, Visintainer and Williams, 1990). Early recognition and appropriate interventions would help in keeping this support foundation in one piece, enthusiastic and successful (Gaugler, Roth and Mittelman, 2008). The mental health professionals need to take timely care of the needs of the caregivers and provide necessary support and interventions. However, this is not the case according to the participants; because most participants indicated that they did not see any efforts by the health care practitioners in preparing them on what they were yet to experience. They indicated that the practitioner did not help them with anything even when they were complaining that they are finding the care giving burden too much to bear. Participant indicated that they feel neglected and judged, as a result, they fail to ask for assistance when they really need it. Most participants indicated that they end up doing a very poor job as caregivers because they did not receive enough support when they took over such responsibility.

Participant no 2

I never saw any efforts from the health care professionals. When they were explaining to me about my son's condition it was procedural and they did not even empathized with me. No one was concerned about my feeling or how I was coping with the situation.

Participant no 3

Something really needs to be done to at least re-educate these professional on proper ways to treat sick persons. I was traumatized, I felt like I was being interrogated and no one seemed to care about how the situation was treating me. I thought that I would perhaps be referred to a psychologist for counseling, but nothing like that happened. I went left the hospital feeling even worse.

Participant no 5

I do not remember being asked by a health care professional how I was coping with the care giving burden. I feel like all they care about is whether or not I'm doing what is expected as a care giver. They are very quick to judge when you are doing things wrong, but never ask what might be causing me fail.

4.3.3.2 BEFORE RECOMMENDING THE MOST SUITABLE SUPPORT FOR THE CAREGIVER IT IS IMPORTANT TO ASSESS THE FOLLOWING FACTORS.

4.3.3.2.1 Relationship between the caregiver and the mental health care user.

The healthcare professionals should look at the following when assessing a suitable caregiver; the relationship that existed between the caregiver and the mentally ill relative, Intimacy and love in the relationship between caregiver and relative as well as the willingness of the caregiver to take on the care giving role. It has been identified that most caregivers take on the care giving role to conform to family rules or expectation by the health care providers (Karp, Tanarug and Sachock, 2000). This was extremely evident on the participant response; most participants indicated that no assessment was done by the health care professional to find suitable caregivers in the family. Some

indicated that conflicts among family members took place as no one wanted to take the responsibility. Participants indicated that they feel that if the health care professionals were involved in choosing the right caregivers at the first place, families were going to work as a unit since the election was organized and agreed upon.

Participant no 1

I do not remember anyone from the hospital asking me of who is going to be a care giver. They never cared to ask, all they told us was that he should come back for his regular reviews with a relative. When we got home everyone was running away from the responsibility and I was forced to be the primary caregiver as old as I am. I still blame the health care practitioner for failing to do their jobs.

Participant no 13

They told us that the family should sit on its own to talk about who will be a suitable caregiver. They never participated on the discussion; however, I wish they did because no one in the family was willing to take over the responsibility.

There were, however, some participants who indicated that the health care practitioners do assess the home circumstances as well as they suitability of care givers. The participants indicated that they felt that the practitioner managed to do a proper assessment with empathy. This made them happy because they were not forced to take on the responsibility which they were not only afraid of taking but which would not be best for neither the family nor the mentally ill relative.

Participant no 3

When my son was due for LOA social workers did come to my home to find out about the home circumstances, focusing, particularly, on the relationship that existed between their patient and his family members. They found out that the family was still bitter about the murder he committed and his stay at the hospital was extended. I was happy they did not force the family to take him back because I was 100 percent sure that hell was going to break lose.

4.3.3.2.2 The severity of the mental illness.

Taking care for someone with severe symptoms can be very demanding for the family, especially if they are not given the opportunity to develop the skills needed to deal with mental illness (Jeon, Brodaty and Chesterson, 2005). It can be very tiring, particularly for families with younger children who still need structured care as well because more care is likely to be directed to the mentally ill relative. Most participants indicated that they were forced to care for their relative with severe symptoms because the health care practitioner failed to help them with finding out if there was any one in the family who could take on such responsibility. They indicated that they were subjected to all kinds of abuse and life for the whole family was unbearable. Most participants indicated that their mentally ill relative would assault them for no reason. They indicated that the health care professionals should also take into account the severity of the crimes they committed as well as their diagnosis when they release them for LOA.

Participant no 1

When my son started getting sick he was very aggressive and he did not mind to hit me for no reason. I couldn't control him and he wouldn't listen to anyone in the family. I tried to voice my concerns to the hospital staff when he was getting discharged from the hospital, but the issue was never entertained. I had to stay with him bearing all the suffering until the incident that led him to be taken to a mental institution.

Participant no 4

My brother was diagnosed with schizophrenia from a very tender age. We grew up with him abusing us and blaming it on the mental illness. His aggression also led him to kill our mother, nevertheless, the social workers from the mental institution he is currently in expect us to take him back. I do not want to stay with him again because of his behavior and I expect the social workers to accept it, because I am the only one who knows how it's like to stay with this person.

Participant no 15

Living with my uncle was very exhausting and when we tried to raise the issue at the clinic I felt like the health care providers judged us. They would say something like 'he is one of you, whom do you want to care of him, if not you?' They would just end by saying that and did not help us with other available alternatives, or even just provide us with counseling.

4.3.3.2.3 The caregiver's occupation.

Caregivers who are employed, who have a good financial status are more likely to cope better with taking care of a mentally relative than those with financial problems. The financial unsteadiness may aggravate the negative impact experienced by caregivers, whereas, financial stability; significantly increase the coping options available. (Addo, Agyemang and Tozan, 2018). Most participants indicated that they have financial problems but the health care professional did not note that fact as a hindrance. They went in to the care giving role with no escape; they failed to consider other alternatives that might have helped them cope better with the situation that faced them. Some participants indicated that they if they had stable financial status, they would have taken their loved ones to nice mental institutions where they were going to get the best care. Some indicated that they would remove their younger children from the unhealthy environment so that they would not have to be exposed to abuse and constant stress, some indicated that they would have move out and escape the torture of caring for a mentally ill relative.

Participant no 1

I am a pensioner and ever since my son got sick I am the one who has been taking care of his financial needs. The health care professional did ask about the family financial circumstances when they were filling their forms. They later on helped him with a disability grant and this was before he got institutionalized. He would always misuse his grant and demand money from me and when I tell him that I did not have the money he would become more and more aggressive. I would beg my other children to raise money for him so that they can take him to

private placement institution for people living with mental illness, so that I would get a break.

Participant no 5

I am unemployed and I only rely on odd jobs for income. Not working and not being able to work made my life unbearable. I would have sent my other children to boarding school so that they would not have to be subjected to the pain of watching their brother's irrational behaviors. It would kill me inside to hear them cry or watch them being attacked for no reason. When I asked for my son to be assisted with a disability he did not qualify.

Participant no 16

I'm not ashamed to say this but if my family was well to do, I would have moved out when I still got the chance. Watching my brother suffering from mental illness broke me inside and I feel like some of the bad choices I made in my life were a result of that. If moved out and escape that torture I would have turned out to be something better than gardener today.

4.3.3.2.4 Support system.

Caregivers often find themselves stress and unable to cope, especially without support from friends and family. It is vital for the health care professionals to determine the potential care giver support system, before assigning them the care giving responsibility (Schulz and Martire, 2004). This is why it is important for the health care professional to determine this factor. The research findings, however, indicate that the health care practitioners did not take it upon themselves to assess whether the families had a good support system or not. Most participants indicated that the health care practitioner never bothered to ask about the availability of support. The participants indicated that it would be helpful if the health care practitioner set down with their family to motivate unity and support.

Participant no 2

The health care professional only emphasized that I should make sure that I bring the patient for his monthly reviews and did not bother to ask me if I have any family support. I would like it if they arranged an appointment to encourage my family to show a little bit of support.

Participant no 14

I never heard the health care professionals talking about the importance of family support in caring for a mental health care user. I suppose they just assume that everyone who was there during the review would participate in caring for our relative, however, that was not the case some of the relatives who were there that day were just spectators.

4.3.3.3 SUPPORT GROUP

Support groups are very important particularly for people who are faced with a very stressful situation because they provide them with emotional support, education, social networking and advocacy. Participants of support groups gain more information on the situation they are faced with, therefore, improving their problem solving skills (Biegel, Shafran and Johnsen, 2004). Unfortunately, all participants indicated that they have no knowledge of support groups for care givers of people living with mental illness, in their communities or in their nearest clinics and hospital. They all indicated that they think that would be very helpful because speaking to people who know exactly what you are experiencing is better than speaking to someone who just has knowledge from the text. They however indicated that the only support group they know of is patient focused.

Participant no 1

I have no knowledge of support groups that focuses on care givers of people living with mental illness. It would be very helpful if our hospital did this for us.

Participant no 3

I am not sure if there is a support group or not but I have never been told about one existing.

Participant no 4

We have been going to our local hospital and clinic for ages and we have never heard of that kind of service.

Participant no 17

There are no support groups for people living with mental health care users.

4.3.3.4 PSYCHO-EDUCATION

Psycho education sessions help to equip the care givers with knowledge about their loved ones condition, the care givers gain more insight on early signs and symptoms of relapse, available treatments and their effectiveness, safety of treatment, common side-effects, identifying burden, and coping methods (Kakuma, Minas and Van Ginneken et al, 2011). Participants indicated that they lack adequate knowledge about their loved ones condition. They indicated that they only pick up little information about the illness as the doctor and other multi-disciplinary teams review the patient (self taught). They also highlighted that they would like for the health care practitioners to formally educate them about mental illness and their roles as caregivers. Most participants emphasized that they think that this knowledge can be simply passed to the caregivers through a continuous support group program and not just a once of session.

Participant no 11

During review the health care professionals do talk about a thing or two about mental illness, but, it was going to be very helpful if there was some kind of class or session where they call families caring for mentally ill relatives so that we can get more information about the illness.

Participant no 16

We were once referred to a clinical psychologist by the Doctor and he tried by all means, to explain to us about what was going on with my brother and ways we can help him, but it was just one session.

Participant no 19

I have little information about mental illness and it is very difficult to care for someone with a condition you do not understand.

4.3.3.5 INSTITUTIONALIZATION

There comes a time when mentally ill patients need to be institutionalized in a health care facility for various reasons. The stay depending on the reason might be long term or short term. Families of those who are institutionalized are encouraged to participate in the rehabilitation process. The participation can be through frequent visits and taking their loved ones home for LOAs. However there are some instances where some families withdraw from the process insisting their loved ones to be kept in the institution for eternity. Some families claim that institutionalization is the best decision for both the patient as well as the family member (Bitter, Roeg, Van Nieuwenhuizen et al., 2016). This was also evident on the response by all caregivers; they believe that it's for everyone's best interest for their loved ones to remain in a mental institution. They indicated that it has given them a chance to progress with their lives without difficulty. They also indicated that it has given them a chance to mend their relationship with fellow community members. They also feel that their loved ones are in a safer environment where in the community can not retaliate and mobilize against them for their destructive behavior. None of the caregivers were willing to remove their loved ones from the institution, nevertheless, they only reassured that their will continue to show them support by frequently visiting them.

Participant no 2

To tell you the truth I am happy that my son is in an institution, because knowing how he behaves he might have been killed by the community by now.

Participant no 5

Life has been so much better with him living in an institution and I hope they keep him longer for the sake of my other children.

Participant no 6

I hope he remains institutionalized for a very long time for what he did to my mother.

4.4 CONCLUSION

This chapter covered the presentation of the data collected from families of relatives living with a mental illness. The data was collected through an interview schedule and focus group from 20 family members caring for their relatives with mental illness. The study was based on three research questions relating to the impact experienced by families caring for a mentally ill relative, strategies adopted by families to enable them to cope with the challenges they face when caring for their mentally ill relatives, and support services families received from health care professionals when the families are unable to cope with their challenges. In this chapter, the experiences and views of all research participants were presented.

CHAPTER 5

DATA ANALYSIS AND INTERPRETATION

5.1 INTRODUCTION

This chapter presents the discussion of the study findings from the themes that were developed during the data analysis. The researcher gained insight on the tremendous amount of challenges experienced by families caring for relatives living with mental illness experience in their daily lives. Caring for someone with a mental disorder can be traumatic and can affect the dynamics of a family in an immense way. Families experience the effect and burden of mental health problems in their roles as caregivers, as well as simply by virtue of being a family member. Parents, partners, siblings and children react, and cope in different ways (Barker and Skinner, 2005; Cochrane, et al., 1997; Roberts, 1999; Andrews, et al., 2004). The experiences of 20 family members in the Thulamela municipality in the Vhembe district, within the Limpopo province, in taking care of their mentally ill relatives, are typical examples of what families playing this role go through. They usually have to take on difficult responsibilities that usually strip away a fruitful and fulfilling life.

The limitations of the study are also discussed here, and recommendations for future research are made, based on the results from the empirical study. The aim of the study was to investigate the challenges faced by families of relatives living with mental illness in the Thulamela municipality in the Vhembe district, of the Limpopo province. The objectives of the study were:

- I. To investigate the impact that caring for a mental ill person has on the family members;
- II. To explore the strategies adopted by families to cope with the challenges they face when caring for their mentally ill relatives; and

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- III. To gain insight in the support services provided to families by the health care professionals.

5.2 INTERPRETATION OF DATA

5.2.1 THEME 1: THE IMPACT EXPERIENCED BY FAMILIES CARING FOR THEIR MENTALLY ILL RELATIVES.

5.2.1.1 DISCOVERING THE LOVED ONE'S ILLNESS

Research findings
Participants indicated that, when they saw their relative acting unusual they thought that their relative was going through a phase and that it will all soon come to pass. Families went to the health care professional to seek for an explanation why their loved one was acting the way they were, hoping to be told that everything will be fine soon. Participants indicated that when the doctors diagnosed their loved ones to be suffering from mental illness, they felt that the doctor must have made a mistake. They even took their loved one to different doctors to get a second and third opinion. Participants indicated that they never expected to hear that one of their family members is diagnosed with mental illness. Some chose to deny the diagnosis, taking their loved ones to traditional healers to get a different explanation about their loved ones sudden change of behavior. They also indicated that they went to different churches seeking for divine intervention.
Consulted literature
According to Kübler-Ross (in Blandin and Pepin, 2016), families are aggrieved when they come to learn that their one of their family member has chronic illness. The families are likely to go through some or all stages of grief, namely; denial, anger, bargaining, depression and acceptance. Cockerham (2009), however, indicated that different societies respond to health-related problems by conforming to their cultural norms and values. Suchman (in Young, 2004), further argued on the third stage of his illness behavior model, that sick person and his family can chose not to accept the diagnosis and opt to seek the advice of other professionals or other alternative health practitioners.

Interpretation

The research findings attested to what the literature said about individuals moving through the grieving stages differently, however, most of the caregivers seemed to be trapped between the denial and anger stage. The research findings also found that most caregivers believe that their loved ones' mental illness was caused by evil spirits. The evil spirits are believed to have been sent by those who do not want to see their families to succeed. This belief prevents them from moving on through acceptance stage because they believe that their loved ones will someday be set free and goes back to be what they once were. Not accepting the sick role also means that the sick person will not comply with treatment.

5.2.1.2 IMPACT OF MENTAL ILLNESS ON PARENTS

5.2.1.2.1 Parental role change

Research findings

All parents indicated that when their son's mental illness started they were already independent and were able to take care for themselves. Some indicated that they were living on their own, but as soon as the mental illness started they indicated that they saw a drastic change in their behaviors. Some indicated that they started not bathing and not eating. They also noticed that the always roamed around aimlessly, collecting waste and storing it at home. They indicated that they had no choice but to resume supervising them as though they were supervising young depended children; they had to force them to bath, eat, and take their treatment. All parents reported that they also had to support them financially as well, and those parents who are unemployed and those who only depended on social grant indicated that they were very strained. They also had to wash their dirty clothes as they could not afford to get someone to do all these chores for them.

Consulted literature
<p>The third stage of the illness constellation model known as striving for recovery, states that families try, by all means, to minimize the stress the sick person might be experiencing by taking over most of the stressful responsibilities the person might be having (Morse, 1997). Mental illness has the potential of robbing ones' independence and the person might require more help from those in his or her close proximity. The parents are the ones who are likely to take on such responsibilities, they often find themselves having to take on the structured parental role in a full time basis again (Copeland and Heilemann, 2008). Parents have to make sure that their mentally ill children are well taken care for, their finances are on point, and they are eating well and are taking their daily treatment. Parents usually find these responsibilities frustrating and tiring on their side. Factors such as the caregivers' age as well as the sick child age can put more strain on the care giving relationship. Parents who are at their old age may find it physically challenging to deal with a mentally ill person, while, the mentally ill children who were once independent and self reliant might show aggression when the parents have to step in to help them with things they used to do on their own. (Ingersoll-Dayton, et al., 2011).</p>
Interpretation
<p>The literature consulted indicated that the parental role is more structured when the children are young, however, when the adult children are faced with a chronic condition the parents are forced to resume the structure parental role. The research findings also attested to this when the parents had to let their mentally ill children to move in back to their house. They had to do simple tasks such as cooking for them, encouraging them to eat and bath, washing their cloths and making them take their medication. However, the research findings also highlight that that these roles were accompanied by a lot of challenges because of the nature of the illness (emotional and verbal aggression). The parents invested most of their time trying to help their children get back on their feet. Fatigue was the main problem they experience; they indicated that they were used to living a lay back life without a lot of stressors. The parents have to stretch their</p>

insufficient funds to cover their children who were once financially independent. The financial problem also adds to the pile of problems they are faced with, as parents or caregivers.

5.2.1.2.2 Parents' concern for the future of their mentally ill adult children.

Research findings

Parents indicated that before the mental illness started, they had all kinds of dreams and hopes for their children. Their children were busy making a good life for themselves and had a lot of potential. There were parents who indicated that their sons were students at one of the best universities in South Africa, but in a matter of seconds their lives and dreams came crashing in front of them. The parents were very emotional when they were talking about how mental illness ruined their children's future. The parents also indicated that they have a lot of fear about how their children will thrive moving forward, especially, when they have passed from this world. They have concerns of whether their children will ever be able to complete their degrees or find stability in their lives again. They wonder if they will ever marry and have families of their own like they were supposed to. They indicated that they feel like they were robbed of a chance to see their children flourish and become something better in life. They also indicated that they tried everything possible to help their children's situation without success.

Consulted literature

Morse (1997) indicated that parents feel defeated, helpless and hopeless when they are unable to help their mentally ill children. They watch as the illness completely transforms the child they used to know, into someone they find difficult to accept and understand. Parents often worry about their mentally ill children and wonder if they will ever live normal lives. They experience grief because they feel that they have lost their loved ones to the illness. All their hopes and wishes diminish as they realize that their loved ones have lost their chance to a fruitful and successful life (Coopeland and Heilemann, 2008). Parents of children with disabilities may need to deal with the fact

that their children lives will never be the same again, they should also be assisted with letting go of the high expectations they once had on their children, because chances are that they will not progress as other children do, and the milestones celebrated by other parents may bring misery on them. (Wilcox, Kuramoto, Lichtenstein et al., 2010).

Interpretation

The literature consulted indicated that it is very difficult for parents to accept that their children have mental illness or any other chronic condition. They watched their children future and potential go down the drain and they are always hurt when they see other children who are of the same age group with their children succeeding in life. The research findings attested to this as all the interviewed parents shared the same feelings; they indicated that they still cannot believe that this is what life has turned out to be for their children. Parents are more devastated when they think about the progress their children had already made before the onset of their mental illness, this was all in vain.

5.2.1.3 IMPACT OF MENTAL ILLNESS ON SIBLINGS

5.2.1.3.1 Sudden shift of attention and social dynamics

Research findings

It was reported that, finding out that a sibling is suffering from mental illness can bring about confusion and frustration among other siblings. They indicated that for them, it was as if they were in a never ending bad dream. Most siblings indicated to be mostly bothered by the sudden change of the home environment. They indicated that, although they had problem before, such as small sibling rivalry they were happy and they enjoyed each other's company. They indicated that their siblings had become aggressive and made their lives very difficult. They watched as their parents were being consumed by their sibling's mental illness, all the attention was directed in finding ways to help the mentally ill sibling to get better. The siblings indicated that they always felt guilty because they wanted their parents to also attend to their needs, just like they used to before their sick sibling took all their attention. Older siblings complained of

having to take on more responsibilities to make sure that things still run smoothly in the household. They were also expected to play their part in taking care for their mentally ill siblings, as well as their younger siblings when their parents were too stressed to take care for them. The siblings also indicated that their social lives were disrupted as they spent most of their free time focusing on trying to ease the burden weighing on their family members.

Consulted literature

Manning and Gregoire (2009) state that the experience of having a sibling who is suffering from mental illness can have negative consequences on the other siblings. They are impacted mentally because of the constant exposure to the overwhelming stress. The siblings are weighed down with feelings of confusion, stress, sadness, hopelessness, anger and fear. The sibling's mental illness also impacts on their social lives, they may feel reluctant to go out and have fun with their friends while their loved ones are not well. They usually experience fear of being next in line to develop mental illness just like their siblings. They also fear that their sibling might never get better, which also means that they will be stuck in a stressed filled life for eternity (Dalui, Guha, De et al., 2014). Parents move all their attention to the sick relative and the other siblings often feel left out and deserted. The parents sometimes get to a point of feeling crippled by their children's situation and the siblings are forced to come in and help out with some of the responsibilities within the family unit (Alui, et al., 2014).

Interpretation

The research findings support the consulted literature on the fact that, the mental illness of one sibling can have a negative impact on the quality of life of other siblings. The research findings highlighted that this negativity was brought mainly because the siblings experienced a sudden change in the life they were used to living. Similarity between the consulted literature and the research findings was also on the fact that their sibling's mental illness made their parents attention towards them to be redirected to their sibling. Just like on the consulted literature, the research findings attested to the fact that mental illness of one sibling can make other siblings to lose out on their social lives as they have to play their care giving role. Sibling rivalry is bound to occur among

siblings and at a later stage the resentment might also be directed towards the parents for not protecting the other siblings from the circumstances.

5.2.1.3.2 The burden experienced by siblings

Research findings

Older siblings reported feeling obliged to help their parents with some of the major responsibilities that they are failing to carry out. They indicated that they had to take care of their siblings when their parents were unable to; they found themselves taking over majority of the chores at home. They indicated that they would sometimes feel resentment towards their sick siblings for causing their lives to be complicated. They also resented their parents for expecting too much from them, robbing them of their youthful life. The older siblings also indicated always feeling anger towards their younger siblings as they did not bear the same burden as they did. Some siblings indicated that the relationship they had with the sick sibling before they got sick, determined their involvement in the care giving role. Siblings who had poor relationship with the sick relative indicated that they did not bother to put themselves in a stressful situation for someone whom does not help them with anything in life. Some indicated that they saw moving out of the household as the easiest way to escape the torture they were being subjected to. Most siblings indicated that they only took this responsibility because they did not want to hurt their parent's feelings and worsen the stress they were already experiencing.

Consulted literature

The literature has indicated that there are different factors that determine how siblings may respond to their siblings who have been diagnosed with having mental illness. It has also been found that experiences are unique and differ depending on a number of factors, such as the relationship that existed between the siblings before the illness started, the birth order and the insight of the sick relative on the demands and implications of their condition (Spuij, Prinzie, Dekovic et al., 2013). Some siblings may choose to become involved in supporting and caring for their brother or sister, while

others may completely pull out and refuse to be involved in the care giving role. There are some sibling who would want to maintain life as they knew it prior the diagnosis by trying to normalize life at home, trying not to add to the burden their parents are faced with regardless of the above mentioned factors (relationship prior the diagnosis, birth order and the sick sibling's insight) (Spuij, et al., 2013). Taking part on the care giving role for someone with mental illness requires one to learn effective coping skills. The entire family needs to be in sync and work together to care for their sick relative, because if there are other family members who are not willing to carry the burden, this will have a great influence on how the other family members will respond to the sick relative (Manning and Gregoire, 2006). It has been found that younger family members are likely to quickly develop burnout when they do not get support from the family.

Interpretation

The research findings attested to what the literature indicated on the fact that siblings of siblings living with mental illness are expected to assume some kind of responsibility depending on their place in the family's birth order. It was found that older siblings do not just have to take care of their mentally ill relative but they also have to take care and supervise their younger siblings as well. The research findings also added that the siblings feel that they take on this responsibility out of their parent's expectation and not out of their free. The research findings also endorse the fact that the nature of relationship between the siblings prior the illness is a determining factor on the involvement of siblings on the care giving role. Most siblings who had poor relationships with their mentally ill siblings indicated that they did not want to complicate their lives with taking on such a demanding responsibility. However, the research uncovered that the mentally ill siblings' destructive behavior can also sour up the relationship with the siblings with whom they had a good relationship with prior the illness in such a way that the siblings withdraw from the role all together.

5.2.1.4 STIGMA EXPERIENCED BY FAMILIES

Research findings
<p>The participants indicated that they experienced a lot of cruelty from their community members. Their close friends started distancing themselves and they had no one to support them. They indicated that before their loved ones became mentally ill they would participate in all kind of social activities in their communities and they used to feel accepted and appreciated. Most participants indicated that they started to notice that they no longer received invitation to parties and other social gatherings. Other participants also indicated that they would be called names like “<i>vha pengo</i>” which means the crazies and this made them feel very upset. Some indicated that they would hear people talking about their mentally ill relative as if they were not there. Some participants indicated that other community members would gang up on them and come to their homes threatening to hurt their mentally ill relatives, claiming that they have wronged them. Participants indicated that if there was a robbery in one of their community member’s home, their mentally ill relative would always be the first suspect. The participants indicated that the ill-treatment by their community member always hurt them emotionally. The participants indicated that they could not even talk to their friends about the problems they were facing at home because they were afraid of being ridiculed about their relatives’ mental illness. They started distancing themselves from their loved ones as a way of avoiding being associated with them.</p>
Consulted literature
<p>Stigma has been found to be one of the main problems that have contributed to the development of early burnout by the caregivers who provide care for people living with mental illness. It takes the entire community working together to turn mental illness into mental wellness. A lot of campaigns have been conducted to provide knowledge about mental illness in different communities, in order to address the issue of stigma. A lack of knowledge is the number one factor that causes stigma. Caregivers who receive support from a friends and families have reported to find the care giving burden easy to carry out (Schulze and Angermeyer, 2003). Families who are subjected to stigma often</p>

isolate themselves as a mechanism to protect themselves and their loved ones from the torture and brutality by their own community members. This problem consequently causes them to feel depressed and at a later stage it also impact on the quality of care they provide for their sick relatives. Stigma usually brings about a lot of feeling in those who are subjected, the families may feel betrayed, disappointed and let down by those who were once their fellow community members. Caregivers feel alone with no one to talk to; because they do not know if they will receive support or they will be rejected or discriminated against. Family members might ultimately develop bitterness toward their mentally ill relatives, blaming themselves for not being empathetic enough and grow increasingly detached (Mullis and Chapman, 2000).

Interpretation

Just as the consulted literature pointed out that stigma is the core problem that makes life difficult for caregivers and families of people living with mental illness, the research findings as well indicated the same point. Instead of the community members, supporting and working together with the families of people living with mental illness and turning mental illness into mental wellness they continue to make these families find the load unbearable. As a result, the families have no one to assist them when they are finding life to tough to handle. This usually led the family members to withdraw from the community social activity. At the end, they resent their mentally ill relative more and more for placing them in the horrendous position.

5.2.1.5 STAGES OF CARE GIVING BURNOUT

5.2.1.5.1 Caregiver stress

Research findings

Most participants indicated that it didn't take them too long to realize that taking care for someone who is suffering from mental illness was very stressful to the entire family. They indicated that experienced constant stress mostly due to their loved one's disruptive behavior. They indicated that they were always alert as they didn't know what triggered their aggressive behaviors. Participants indicated that they would always

suffer from headaches and heart problems. They also indicated that they would easily be irritated by simple things and as a result, they lost a lot of friends.

Consulted literature

The first stage of the care giving burnout is known as stress. The main objective of every caregiver is to bring about change in the lives of the care recipient. When the care givers starts to realize that there is little or no progress occurring in the quality of life of the care recipient, they are likely to feel frustrated and overwhelmed. The frustration quickly leads to stress arousal. These feelings rapidly build up when the care giver is not receiving any kind of support, either, formal or informal support (Yates, Tennstedt and Chang, 1999). The overwhelming amount of stress can also induce all kinds of physical symptoms, such as frequent headaches, bodily pain, trouble concentrating, heart palpitations, insomnia, high blood pressure and getting easily irritated or angered (Pearlin, Mullan, Semple et al., (1990).

Interpretation

As indicated in the literature, when care givers notice that there is no or little improvement on the care recipients, they are likely to become angered and frustrated. Care givers indicate that the psychotic behavior is the main factor that triggered the feeling of stress; they feel that no matter how much they try to give the best care to them they always act irrationally. The stress makes them experience physiological symptoms such as headaches, insomnia and heart problems.

5.2.1.5.2 Burnout

Research findings

As the care recipients continued showing no improvement in their mental health, the participants indicated that they grew more and more depressed by the day. They started realizing that they had put their lives on hold to perform a task that never yielded any fruits. They indicated that they felt exhausted in such a way that they were incapable of taking care of anyone; meanwhile they also needed to be rescued from the stressful

situation.

Consulted literature

According to Pinguart and Sörensen(2003), the second stage is known as burnout and this stage starts when a caregiver experiences mental, physical and emotional exhaustion, due to the prolonged exposure to a stressful situation. At this stage the caregiver have tried all kinds of approach to help out the care recipient with no improvement. At this stage friends and families also notice the lack of progress and starts criticizing the caregiver for his or her fruitless efforts. The caregiver begins to feel lonely and start isolating themselves. The caregiver also starts experiencing boredom, feeling resentment, putting off and neglecting responsibilities (Yates, Tennstedt and Chang, 1999).

Interpretation

The literature defined burnout as a state of mental, physical and emotional overtiredness, and the research findings confirmed this definition. The caregiver's efforts that have been invested for a very long time to do whatever possible to help their loved ones without any long-term improvement, makes the caregivers to realize that they are not getting anywhere. They feel that they are trapped in a revolving door which is only taking them to a stressed filled life. The caregiver's feelings of emotional exhaustion are due to the constant stress they experience. They stress also induces some physical symptoms as well. These impacts might exacerbate the caregivers' burnout and give him or her reason to refrain from their responsibilities all together.

5.2.1.5.3 Compassion fatigue

Research findings

At this stage participants indicated that they started having no interest on caring out the care giving role. They indicated that they had reached a point where they saw their mentally ill relative more as a liability. They had little or no empathy for them, they wanted someone else to come and take over the care giving role. The participants indicated that they went to many social workers' offices, pleading with them to get

placement for their mentally ill loved ones. They indicated that they were not successful, since many institutions' did not allow people with mental illness. The two institutions that allow people who are living with mental illness were always full. Participants indicated that the main reason that drove them to the edge was their deteriorating health; there were participants who reported to have developed hypertension and frequent headaches because of the stress they were experiencing.

Consulted literature

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At this stage caregivers experience a tremendous state of tension. The caregiver is preoccupied with the suffering of their loved one and the guilt of not being able to bring about change into their lives. Research has showed that the stress level can be traumatic and can even lead to the development of mental health disorders (Day and Anderson, 2011). The fact that most families playing the care giving role have no access to defensive measures is what makes them more vulnerable to these disorders. The caregivers start to feel little or no empathy for the care recipient, they start having no patience and tolerance for the care recipients. They also start having outbursts of anger and rage. They might also start presenting with some of these symptoms; chronic headaches, chronic bowel problems, exhaustion, withdrawal, hopelessness and even suicidal thoughts (Lee, Brennan and Daly, 2001).

Interpretation

The research findings attested to what the literature supposed about this final stage of burnout. It was found that when family members have been in the care giving journey for a long period without any reward or satisfaction, they often start resenting the responsibility. The caregivers start feeling little or no empathy for their mentally ill relatives. The caregivers even develop chronic illnesses because of the constant stress they experience.

5.2.2 THEME 2: STRATEGIES ADOPTED BY FAMILIES TO COPE BETTER WITH THE CHALLENGES THEY FACE WHEN CARING FOR THEIR MENTALLY ILL RELATIVES

5.2.2.1 SETTING LIMITATION

Research findings

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Most participants indicated that when they found out that their relatives were suffering from mental illness, they felt sorry for them and vowed to themselves that they will do whatever possible to help them to cope better with their condition. Some indicated that they took the care giving responsibility out of guilty, they felt bad for having to enjoy a happy normal life while their loved ones are staying alone and unable to care for themselves like they used to. Some participants indicated that they felt obliged to take on the care giving responsibility because they had no alternative choice, while some took the role because they did not want to be judged by their relatives and community members for not taking care of their mentally ill relative. All participants indicated that they found the responsibility very demanding, and they had to put their lives on hold so that they can focus on their loved ones. Their social life became none existent; some indicated that they even stopped looking for work and those who were employed were sometimes unable to go to work. Parents indicated that they were failing to juggle all their responsibilities, responsibilities which also needed their full attention such as, being a parent to the other children, taking care of the household and even taking care of their own health and hygiene. Younger members of the family also indicated that they were taking on a lot of responsibility that seem to be too much for people their age. The younger caregivers indicated that they did not want to take on such responsibility but they were forced to, as they saw that this burden was too much to be taken by just few people in their families. They felt that they were being robbed of their social life because of this.

Consulted literature
<p>It is human nature to provide help to those who are less fortunate, however, it is also important for one to know how and when to offer that help. The problem begins when one starts exceeding their limits, responding to the needs of others at the cost of their own needs. People feel obligated to assist out of guilt, authentic desire, and fear of hurting the person or seeking for approval from others (Ohaeri, 2003). As time goes by, they learn that without constructing proper restrictions they risk becoming engulfed and potentially consumed by the family member's illness. It is important to have some kind of backup or assistance from professionals. People who take on this demanding role without any kind of assistance are likely to become aggravated, short tempered, and resentful (Schulz and Sherwood, 2008).</p>
Interpretation
<p>These research findings entirely support the literature on the idea which indicates that people lean to be more optimistic when taking on care giving responsibility and therefore end up taking on more than their physical and mental health can endure. This is usually done out of guilt or to get approval from those in their close proximity. They before long find it difficult to cope and soon develop burnout. The impact seems to be more on younger members of the family; they lose touch with their social lives and their school work.</p>

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5.2.2.2 SEEKING PROFESSIONAL ASSISTANCE

Research findings
<p>Participants indicated that they have had a bad experience with the way health care practitioner in their local hospital treat people. They indicated that when they try to explain about the difficulties they are experiencing as caregivers to their mentally ill relative, the health care practitioners are very harsh in the way they respond. Most caregivers indicated that they have been accused of trying to get rid of their relative. So,</p>

they have decided to keep to themselves and just endure suffering in silence because they know very well that they will not receive any assistance, but only judgments and hurtful words. Participants indicated that they feel that the health care professional don't empathize with them, they strongly believe that they have no idea of the ordeal they experience as care giver, other than what they have read in their fancy text books.

Consulted literature

Literature has showed that it is essential for family care givers to receive some kind of formal assistance, in order to address some of the challenges they face during the care giving process. Caring for a mentally ill person is very stressful, and the prolonged stress that the care givers found themselves in can also lead to the development of mental disorders. Care givers who have been engulfed by the care giving responsibility have been found to be easily annoyed, short tempered and resentful, particularly to the care recipient. Care givers can prefer to speak to a social worker, psychologist or even join a support group, because Speaking to someone who has an idea of what they are going through can be very helpful. Caregivers can be equipped with helpful problem solving skills that this will allow them to take on future problems that they might experience during the care giving process (Deeken, et al., 2003).

Interpretation

The consulted literature emphasized the importance of care giver to seek for professional assistance in order to cope better with challenges that comes with caring for a mentally ill relative. However, the research findings said otherwise, it has been found that most participants have never gone to a health care professional to seek for assistance. And the few who have been to a health care professional's office were somehow referred but they never continued with their sessions. The main reason that was indicated by these participants was the fear of being judged by the health care professional. Participants believe they are obligated to perform the care giving role to their loved ones and if they start complaining about it, the health care professional may get a wrong impression as if they are trying to neglect their relative. Some participants indicated that they find the health care professional hash and difficult to talk to, so they

end up suffering in silence. The health care professional seems to be not abiding by the core values of integrity and compassion when helping families of mentally ill patients. This is why the caregivers find it difficult to talk freely to them about their concerns and difficulties.

5.2.2.3 COPING STRATEGIES EMPLOYED BY CARE GIVERS.

Research findings

Most participants seem to be using the emotion coping strategy, in order to deal with their loved ones illness. They still believe that their loved ones mental illness will someday get healed through spiritual intervention. All participants indicated that they were overwhelmed with their relative's situation in such a way that they did not know how to help their loved ones to cope with the illness. Participants did not do any action to change their situation, but only hoped and prayed for their loved one's situation to somehow go back to normal, through divine interference.

Consulted literature

Goldenberg and Goldenberg (2012), indicated that they are two different coping strategies that are employed by people when they are faced with life challenges. These strategies include the emotion focused and problem focused coping strategies. The emotion focused strategies intends to minimize the harmful emotional stressors, through denial or looking to religion as means of intervention. The people who use emotion focused coping has been reported to put in little effort in solving their own problems. They usually perceive their problems to be too much to solve on their own. While people who use problem focused strategies, aims to look at reliable actions to bring change into their situation. People who use this coping strategy are usually not easily intimidated by life's challenges. They hold a belief that every challenge can be solved and usually approach their problems with an optimistic mind-set (Baker and Berenbaum, 2007).

Interpretation
<p>The literature consulted spoke of two coping strategies; the emotion focused coping strategy, as well as the problem focused coping strategy. The research findings indicated that all the participants found the fact that their loved one had to live with mental illness for the rest of their lives too devastating. Caregivers have not yet come into terms with this reality. They indicated that ever since finding out about this illness they still ask for their gods to intervene on their situation as they do not see themselves getting over this challenge on their own. They refuse to comply with westernized means to manage their mental illness, and yet they still insist that they remain institutionalized in the mental institutions.</p>

5.2.2.3.1 SPIRITUAL SUPPORT

Research findings
<p>Participants indicated that according to their culture, there are some illnesses that are known to be caused as a result of calling by their ancestor and some illnesses that occur as a result of being bewitched. So, most participants indicated that when they first discovered that their loved ones were acting psychotic, the first place they took them was to the traditional healers and faith healers in order to find out what might be causing the illness. Some participants indicated that they were told that their loved ones were being punished by their ancestor for ignoring their calling to be a traditional healer, while others were told that their loved ones were bewitched in order to hinder a success filled life that has been seen coming their way. All participants, however, indicated that they ended up taking their loved ones to the hospital for further assistance as they saw that there was no improvement in their loved ones condition. Nonetheless, participants are still consulting their faith healers up until today, hoping for a miracle.</p>

Consulted literature

According to Cockerham (2005) the way people respond to health related problems can be influenced by their cultural norms and values. Most South African hold the perspective that several illnesses, predominantly, mental illness is as a result of the punishment from gods or ancestors or bewitchment. According to Sorsdahl, et al. (2009), South Africans believe that it is only through traditional healer and faith healers that the mentally ill person can get liberated from the mental illness. These institutions play an imperative role in helping individuals to cope with the problems they are facing. These institutions also help individuals to defeat negative feelings with hope for a better outcome (Gallant, Spitze and Grove, 2010).

Interpretation

The research findings also attested to what the literature review alluded about the role of spiritual support on families caring for relatives living with mental illness. The research findings indicated that all participants went for spiritual support on an attempt to make sense of what was happening to their loved ones. The research findings also brought to light that most participants seem to have more confidence on faith healers than on western medication. They believe that their loved ones were somehow cursed and the only way they will be set free through spiritual intervention. This belief holds back the caregivers to help their loved ones to fully comply with their mental health treatments. They move back and forth between the two approaches- when their loved ones are psychotic and dangerous they take them to the hospital and when they come back stable and well they default treatment and take them back for spiritual healing.

5.2.3 THEME 3: SUPPORT SERVICES PROVIDED TO FAMILIES BY THE HEALTH CARE PROFESSIONALS

5.2.3.1 PREPARING THE FAMILY FOR THE CARE GIVING ROLE

Research findings

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Nearly every participant indicated that little was done by the health care practitioner to prepare them on what they will come across as they will be carrying out the care giving responsibility. Participants pointed out that they ended up doing an extremely poor job as caregivers, since they did not receive any direction and guidance when they took over the responsibility. They indicated that they later realized that they took more than they bargain for and when they complained about the difficulties they were experiencing, they did not receive any help.

Consulted literature

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Gaugler, Roth and Mittelman (2008) stated that, it is important for the health care practitioners to properly prepare the caregivers so that, they are equipped with the necessary knowledge about the conditions of their loved ones. This is to ensure that care givers are not taken by surprise when they encounter some of the challenges related to their relative's condition. Early identification of the challenges that the caregivers might be encountering and providing appropriate interventions would assist in keeping the support foundation strong and successful (Gaugler, Roth and Mittelman, 2008). It also helps to ensure that the caregivers are not negatively affected by the devastating care giving burden (Schulz, Visintainer and Williams, 1990).

Interpretation

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There is a contradiction between the literature review and the research findings about the expected role of health care professionals on supporting the care givers of people living with mental illness. The research findings indicated that the health care professionals are doing very little effort to help caregivers to cope with the care giving burden. This has been seen as one of the reasons why caregivers fail to give the utmost care to their loved ones.

5.2.3.2 FACTORS THAT HELP PROFESSIONALS TO DETERMINE THE MOST SUITABLE SUPPORT FOR A CAREGIVER

5.2.3.2.1 Relationship between the caregiver and the mental health care user.

Research findings
<p>The majority of participants indicated that the health care practitioners were not interested about the relationship that existed between the potential care givers and the patients. They pointed out that they had to discuss as a family, on who will take the most responsibility. Some indicated that there were a lot of conflicts amongst members of the family, as no one wanted to be nominated to be a care giver. Most participants believe that this chaos would have been avoided if the health care practitioners did their job.</p>
Consulted literature
<p>The relationship between the care giver and the care recipient can be a determining factor on the quality of care that will be provided. It has been recognized that the majority of caregivers take on the care giving responsibility in order to act in accordance to the family rules or expectations of the health care providers. Family members who had a poor relationship with the care recipient prior the illness easily develops burnout as compared to those who had a good relationship (Karp, Tanarug and Sachock, 2000).</p>
Interpretation
<p>There was a contradiction between the literature and the research findings on the procedure followed by the health care professional when determining the best caregiver for a mentally ill patient. The research findings indicted that the health care professional did not bother to assess the relationship that existed between the potential caregiver and the mentally ill relative, the caregiver indicated that it would have been proper if the health care professional did consider that factor, because it would have mean that the mentally ill relative would have been taken care for by someone who really cares about their wellbeing. The research findings endorsed the fact that some caregivers were forced to take on the care giving role out of the fear of what other family members and the community might say as they are the closest next of kin. It was highlighted that</p>

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being the closest next of kin doesn't automatically mean that someone is the best candidate to be the main caregiver.

5.2.3.2.2 The severity of the mental illness.

Research findings

The participants indicated that they felt that they had no choice but to accept the care giving responsibility to care for their loved ones who were diagnosed with severe mental illness, such as schizophrenia. The indicated that they found it very difficult to cope with them, when they try to ask for assistance with placing their loved ones in a mental institution, the health care practitioners were very judgmental and made them feel like they are rejecting their loved ones just because they are mental status. They indicated that they only got relief when the court referred them to a psychiatric institution for placement. They were arrested because they were very problematic at home and in the community. The participants indicated that they feel that the health care professional continue to fail them when they force them to take their loved ones back home on leave of absence, because the communities have had enough of their destructive behavior.

Consulted literature

People with severe mental illness usually find it very difficult to co-operate, therefore, making it difficult for the caregivers to convince them to do simple tasks such as, taking their treatment or going for checkups. So, it is very important for the health care practitioner to put more effort on motivating the involvement of the whole family in the care giving role, the health care practitioner should also provide the caregivers with necessary skills that will ease their burden (Jeon, Brodaty and Chesterson, 2005). It can be exhausting, especially for families with young children who need to grow up in a healthy and protected environment. Young (2001) further argued that taking care of relatives with serious mental illness can place substantial impact on the primary caregiver as well as on the community at large.

Interpretation
<p>The research findings also indicated that the failure of the health care professional to assess a suitable caregiver resulted to people who were unfit physically and emotionally taking care of their relative with severe mental illness. Caregivers who are at their old age years found them enduring all kinds of abuse from their loved ones. The research finding also brought to light that the constant fear the caregivers experience cripple them to such an extent that they end up developing burnout. The more severe the mental illness, the harder it is to give the outmost care by a caregiver. A care giver who was never preparing for this amount of responsibility is likely to fail in the care giving role.</p>

5.2.3.2.3 The caregivers' occupation.

Research findings
<p>Participants indicated that their families suffered a great deal of stress when they were taking care of their mentally ill relatives. The indicated that they were subjected to all kinds of abuse, especially when their relatives had relapsed. Most participants' indicated that they always felt guilty as they were unable to protect their family members, especially the younger ones from the pain and constant stress. They indicated that they felt that it would have been better if the health care professionals encouraged the entire family to support whoever they chose as a suitable care giver, particularly, financially in order for the person to cope better with the care giving role. Most participants indicated that the health care practitioner did ask them about their occupation as they were filling down their forms, however, when they reported that they were unemployed, the health care practitioners did not comment further, it was as if they were only asking just to complete their forms.</p>

Consulted literature
According to Agyemeng and Tozan (2018) care givers with a more stable financial status are better able to cope with social stressors than those who are struggling financially. They have more options to look at, which can help them to ease the burden they are facing. They can hire someone to assist them with the care giving role and they can also afford to send their mentally ill relatives to a rehabilitation center when they are struggling with substance. Those caregivers with financial problem experience the full impact that comes with caring for mentally ill relatives. It is very much important for health care practitioners to consider this factor when assess for a suitable care giver (Addo, Agyemang and Tozan, 2018).
Interpretation
The literature consulted emphasized the caregiver's occupation as an important factor to consider when a health care professional is assessing a suitable care giver for someone with mental illness. However, the research findings indicated otherwise, it was found that the health care professional did not even ask if the potential care givers are financially stable or not. Most participants endured the full-blown experience of taking care for someone with mental illness without any form of escape such as taking them for temporary placement or to rehabilitation centers for people living with mental illness. Younger siblings were also negatively affected which showed clearly on their performance at school. Their parents who could not afford to take them to a boarding school in order to escape the stressful home environment. People who are more financially stable have many alternatives at their disposal that can health them cope better with life challenges that come their way, as compared to those who are financially unlucky.

5.2.3.2.4 Support system

Research findings
Most participants indicated that they have little or no support system; they indicated that most of their close friends and families have distanced themselves away from them and their families. As soon as they learned that their loved ones are suffering from mental illness the relationship and communication decreased drastically. The participants also indicated that the health care practitioner did not care that they will be faced with the care giving burden on their own, without support from others. Some participants indicated that they would have loved it if the health care practitioners tried to address this issue before they sent them back home to carry out the care giving role single handedly.
Consulted literature
It is essential for the health care practitioner to cheer families to work together as a unit, when caring for a family members suffering from mental illness. They can support each other, either emotionally, spiritually or financially. Caregivers with more friends and family backing them have reported to experience lesser burden as compared to caregivers without any support (Schulz and Martire, 2004).
Interpretation
There seem to be contradiction between what was indicated on the consulted literature and what has been attained from the research findings. The literature indicated that it is important for the health care professional to assess whether or not the potential caregivers have support from other family members backing them before assigning them of care giving role. However, based on the research findings none of this is being done by. The research findings also indicated that this bad move by the health care professionals also contributed to the splitting up of the families of those living with mental illness. Most caregivers have come to resent some family members for not supporting them to care for their mentally ill relatives.

5.2.3.3. SUPPORT GROUP

Research findings
None of the participants have ever attended a support group program. They all indicated that there are no support groups available that focus on caregivers of people living with mental illness in any of their communities. Some participant indicated that they are only aware of the support groups that focus mainly on people living with mental illness that are held at their clinics. Most participants seemed to be interested in the idea of being part of support groups that helps to address some of their unheard challenges as caregivers.
Consulted literature
According to Biegel, Shafranand Johnsen (2004) support groups are an essential tool that allows caregivers to obtain knowledge about an illness one is faced with. People with similar life challenges are grouped to talk about their concerns. The advantage of a support group is that people get to talk about their problems with people who know and understand exactly what they are going through. People learn effective problem solving skills from one another to tackle problems they are faced with. The other advantage of a support group is that group members can establish long term relations; as a result they no longer experience loneliness and isolation (Biegeletal., 2004).
Interpretation
It was quite evident from the research findings, that there are no centers that provide support group service to caregivers of people living with mental illness. The only support groups that the health care professionals conduct focus mainly on patients living with mental illness. This is the main reason the caregivers are besieged and always stressed because they have no one who truly understands what they are going through to talk to. The caregivers are losing out on knowledge that would have helped them to better handle some of the challenges that come with caring for a mentally ill relative.

5.2.3.4 PSYCHO-EDUCATION

Research findings
<p>Most participants indicated to have never received any kind of formal education about mental illness from the health care practitioner. They indicated that they took over the care giving responsibility without any idea of what they were about to face. They indicated that the lack of knowledge, made the process very difficult and within a period of time they had already developed burnout. They indicated that the only little information they had was from what they had observed as they were taking care of their loved ones and from what they hear people in their community say about the illness. There are some participants who indicated that they also searched the internet to get more information, but they also indicated that they found some of the terms used in the articles they read difficult to understand. The participants indicated that they would like the health care practitioners to provide continuous sessions of psycho education to all main caregivers so that they can educate their family member's correct ways on how to care for their mentally ill relative.</p>
Consulted literature
<p>It is a prerequisite for all caregivers to be engaged in some sort of psycho education session, in order to gain more insight about the condition of their loved ones. The psycho education sessions should at least include a concise introduction about the illness, presenting symptoms, early signs of relapse, available treatments and their effectiveness, safety of treatment, common side-effects, treatment related costs, identifying burden, and coping methods (Kakuma, Minas, Van Ginneken, et al., 2011). According to Hagger, et al. (2004), individuals tend to develop their own illness model or mental representation which gives them lay understanding of their illness and also gives them strategies regarding coping and adaptation in the context of illness. The source that moulds this mental representation might be through social interaction, cultural beliefs about the illness and individual's experience with the illness.</p>

Interpretation

There seem to be a great difference between what has been attained from the findings and what has been indicated in the consulted literature. Most participants never attended to any structure psycho education sessions with a health care professional. However, the little knowledge they have is from what they picked up as they were accompanying their loved ones for review. Every mental health care unit should make it a point that care giver are well informed through psycho education about the illness of the person they are about to care for. The health care workers negligent have had a great impact on the effectiveness of the caregivers in providing correct care for their mentally ill relatives.

5.2.3.5 INSTITUTIONALIZATION

Research findings

Most participants indicated that they have had enough with the constant stress that comes with caring for their mentally ill relative. They indicated that when their loved ones are institutionalized; their families get a chance to live normal lives, not worrying about being attacked or verbally abused all the time. They indicated that when their relatives are at the institution, they get to see their children laugh and smile, something they last saw a long time ago. They believe that when their loved ones are living in a mental institution, it does not only favor the family, but the patients as well. They indicated that their loved ones receive thorough medical attention by trained mental health care professionals at all times and they are also protected from their cruel communities. All participants indicated that, they would rather prefer visiting their loved ones frequently at the mental institution, than to take them back home to live full time.

Consulted literature

Patients are institutionalized in mental institution for a number of reasons, the main objective being to bring about good change, insight and empowerment to people living with mental illness. Bitter, Roeg, Van Niewenhuizen, et al (2016) indicated that a trend has developed among families with relatives living in these mental institution; it has been found that families fail to comply with the institution expectations. The families have been found not to visit their loved ones in the institutions and some fail to take their relatives back home once they have been deemed fit to be reintegrated back to their communities.

Interpretation

The research findings correlate to what has been eluded in the literature review about families institutionalizing mental health care users. All participants believe that it is for everyone's best interest for their relatives to remain in a mental institution. They see their relative's mental illness as a burden that hinders progress in their lives. They feel that the mental institutions give them a chance to escape from their reality. The families do understand the main objective of a mental institution as mentioned in the literature; however, they seem to be still holding grudges on what their relatives once did before they were institutionalized. Based on the participant's response, family members seem to be hesitant to give their relatives a chance to prove to their families as well as the community that they have changed. Once their relatives are institutionalized they see it an escape and believe that if they take them back they will experience the troubled life they were once subjected to.

5.3. RECOMMENDATIONS

Providing care for someone with mental illness brings the risks of mental ill health to the families in the form of emotional stress, depressive symptoms, or clinical depression. The caring course of action can be very costly and strenuous, particularly if the care recipient has a severe mental disorder. Providing such long-term care can be a source of significant stress. The behavioral tribulations coupled with mental disorders further augments the stress levels of these families and therefore impacts extensively on their mental health (Shat, et al, .2010).

Families face mental ill health as a direct consequence of their caring role and experience higher rates of mental ill health than the general population. This leads to negative effects on the quality of life of the family and the standard of care delivered. Efforts to recognize and treat caregiver psychological distress will need to be multidisciplinary, requiring consideration of the cultural context of the patient and the family, and center on multiple risk factors concurrently (Shat et al, 2010).

5.3.1 SUPPORT SERVICES BY LOCAL HOSPITALS

According to Cochrane, et al. (1997), being a care giver for a mentally ill family member can be emotionally, physically and financially drained, so these families who are playing the care giving role also deserves to receive care, support and enlightenment, as well as counseling to help them cope with the yoke that has disrupted their live. This support helps relieve the load they carry on their shoulders. Everyone in the family is besieged with making sure the ill member gets full attention so as to prevent the guilt and shame, and as a result their wishes often go unattended. These families often end up too stressed and needing support or even antidepressants to cope. So, it is important for both the family and the ill member to get support from close relatives, friends, and peers as well as professional support from mental health care professionals to at least show them that they are not alone and to give them a feeling of belonging and security.

5.3.2 AWARENESS CAMPAIGN

Research into family members of mentally ill and their experience with mental health professionals suggests that mental health unit has devised a team with the main purpose of giving comprehensive care and support to the mentally patients as well as their family members. The team is known as the multidisciplinary team, because it is made up of a variety of disciplines that have been well skilled to give the best service for the mental well-being of the patient and the family. The team is usually made up of a psychiatrist, psychologist, nurses, social workers, dieticians and occupational therapists (Evavold, 2003).

The services for all people who are distressed by any situation are obtainable; the problem might be that the government hospitals are not making their services known to the recipient. It is highly recommended that the government to organise awareness campaigns throughout the media so that everyone gets the information about the services. The awareness campaign should make public that that the services are not solely for the mentally ill people only but their care givers as well. Caregivers need to have opportunities to learn more effective ways of coping with stress and taking care of their mentally ill relatives. If they can learn new ways to cope, they can reduce their anxiety and reliance on treatments (Shat, et al., 2010).

5.3.3 HALFWAY HOUSE

A halfway house is form of dwelling where in people who have been kept in an institution for the purpose of rehabilitation are realized to. The purpose main function of a halfway house is to prepare the mentally ill patient to gain independence as they are reunited back to the outside world (community). A semi structured environment is created wherein patients are assisted in order to gain a better insight on their condition and how to avoid relapse. The patients are also equipped with necessary skills that they will need as they interact with people back in their communities. These residences have been seen to improve the lives of mental health care users as well as their families.

The government needs to establish more halfway houses in each and every province, particularly provinces dominated by rural areas. There is a serious challenge of halfway

house in Limpopo province. The mental institutions are parked by patients who are stable and would benefit a lot if they were to be discharged via a halfway house.

5.3.4 SUPPORT GROUP SERVICES AT PUBLIC HEALTH CARE (PHC) LEVEL/ CLINICS.

The research into caring together: families as partners in the mental health and addiction system suggests that the problem that really let down our mental ill patients occurs after the mentally ill patient has been treated and rehabilitated, when they have to go back to the community (FMHA,2006). The community is where they spend most of their time in so a comprehensive and integrated system of community based services should be available to the outpatients as well as their families. These service centers are responsible for providing support to the entire family. Families are assisted to deal with either emotional or financial challenges they face when taking care for mentally ill members. There are also family support groups that advocate for the families, these groups also try intervening on all the problems the families are encountering and also educate them on what mental illness is about and how to manage their ill members.

It is also recommended that the department of health should promote that in every clinic a support group for patients with mental illness as well as their caregivers are up and running. In these support groups the following should be met: formation of an atmosphere where the needs of the families can effortlessly address. The families should also be empowered on how to deal with the ill member residual symptoms. They should also be well-informed on how to be familiar with symptoms of relapse. The families should also be trained to handle family conflicts, negative and depressive feelings. The families should be encouraged to be part of the treatment support system to make sure that the mental ill always comply to their treatment, at all times. At the end of the day the families will get to know exactly what mental illness is all about and what to expect (FMHA, 2006).

5.3.5 FINANCIAL SUPPORT

In South Africa, most patients with chronic illness including people living with mental illness who meet the SASSA criterion received disability grant amounting to R1650.00, this money is however meant to assist the person with mental illness to supplement the little money he earns. The questions that remain unanswered is “What about those investing a lot of their time to make sure that their family members with mental illness are well taken care for?”, “What about those family members who lose a great deal as a result of staying with a family member with mental illness?” According to Wankiri (2013), people with relapse psychosis behave in an absurd or irrational way. Families complaining that their relatives often burn down their properties and repairing these damages cause them a lot of money, money which they do not even have.

The Department of Social Development, through SASSA, should provide a considerable amount of grant in aid or danger allowance to assist the families staying with their family members with mental illness. This grant will help the families bridge the income gap that was caused by their inability to work. The money will also help the families to repair all the damages that were caused when the family member had relapsed.

5.3.6 COLLABORATION BETWEEN THE COMMUNITY HEADMAN, CHURCHES AND THE GOVERNMENT DEPARTMENTS.

According to Tom (2013), religious institutions play an important role in helping individuals and families that are faced with life burdens, it helps the family to regain hope and replace defeating and negative feeling with words of comfort. The spiritual advisors play a major role to the families as well as to the mental ill member as they through their church congregation encourage the ill members to be off the streets.

Community headman and churches can work together with the department of health and the department social development to assist to ease the burden of families caring for relatives with mental illness. Working together with the government departments will provide a holistic support service to these families and avoid any contradictions, like churches telling the families to stop giving their mentally ill family members their treatments as a sign of faith. When they are working together they will be on the same

page following similar principles and policies. The community headman and the churches can also assist on eradicating the problem of stigma in the community. Families sometimes find it difficult to give proper care to their loved ones because they lack support from the communities they live in, so if the community works together in order to uplift these families' things would be a whole lot easier for them.

The above recommendations have all been emphasised by the cited authors. These recommendations are not idealistic in nature; they can be easily attained but only with the involvement of the government and through the encouragement of public servants to have the families' best interest at heart. Families who are the main treatment supporter when the patients are back in their communities need to be well taken care for, to avoid them from developing burnout.

5.4 CONCLUSION

This chapter discussed in detail the research outcome derived from the experience of families caring for relatives living with mental illness. Comparison between the research findings and the consulted literature were also made, in order to gain new perception on the experiences of families caring for loved ones living with mental illness. Recommendations were also made to address some of the challenges that the health care professionals and the government seem to be failing these families on. This is because it was discovered that more focus is placed only on the patients while the caregivers are not taken into consideration. The caregivers reported to suffer in silence not knowing where to go.

Family caregivers from the Thulamela municipality in the Vhembe district, in the Limpopo province reported that taking care of a family member with mental illness has a negative impact. It has affects all members of the family irrespective of the age, social or financial status. The impact is felt emotionally, physically, socially and financially.

Older care givers have developed chronic illness because of the constant stress they are always faced with, while younger caregivers lost out on their social lives and school work. The family members are subjected to all kinds of abuse; emotional and physical abuse by their care recipient. Families where affected greatly financially, some are still repaying up the loans they took while trying to get help for their mentally ill loved ones.

The lack of support by the health care professional seemed to be the root cause of most of the predicaments the families are in. The caregivers have no insight about mental illness and they do not have access to any support group in their communities. Caregivers developed burnout and are afraid to take back their loved ones from the institution they are placed in. No family seems willing to afford their loved ones a chance to prove that they have changes. Families believe that when a mentally ill family member is staying in an institution, it is not only benefiting the ill family member but the entire family members as well. Caregivers get a break; they get to catch up on what they were left out on while they were busy taking care of the mentally ill family members. Younger family members get a chance to live their lives in peace and get to finish their studies without stress.

Families chose to avoid their situation which indicated that they have a relay on emotional coping strategy. Health care professionals need to equip caregivers with necessary skills that will help them cope with their responsibilities and help to ease the stress they experience.

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7. APPENDICES

Appendix 1: Interview schedule



University of Venda

1. How has the families been impacted by caring for a mentally ill relative?
2. Which strategies are adopted by families to enable them to cope with the challenges they face when caring for their mentally ill relatives?
3. What type of support services do families receive from health care professionals when they are unable to cope with their challenges?

Appendix 2: Focus Group Discussion



University of Venda

1. How has the families been impacted by caring for a mentally ill relative?
2. Which strategies are adopted by families to enable them to cope with the challenges they face when caring for their mentally ill relatives?
3. What type of support services do families receive from health care professionals when they are unable to cope with their challenge

Appendix 3: Letter of request



University of Venda

School of Human and Social Sciences

Department of African Studies-Sociology

Date: 26/04/2018

Dear participant

LETTER OF REQUESTING INDIVIDUAL PARTICIATION

Title of the Research Study: Challenges of Families with Relatives Living with Mental Illness: A Case of Thulamela Municipality, Vhembe District in Limpopo Province

Student researcher: MatambelaKonanani Constance

Supervisor : Dr Tshifhumulo

Co-supervisor: Dr G.M Lekganyane

Co-supervisor: Mr N.J Budeli

Brief Introduction and Purpose of the Study:

The purpose of the study is to investigate the challenges faced by families of relatives living with mental illness in Thulamela Municipality in the Vhembe District, Limpopo Province. The researcher intends to investigate the impact that caring for a mentally ill person has on the family members; to explore the strategies adopted by families to enable them to cope better with the challenges they face when caring for their mentally

ill relatives; and to understand the support services that are provided to families by health care professionals to enable them to cope with such challenges.

Data will be collected by means of interviews and focus group discussions. Interviews should take about one hour to complete. There are no risks and direct benefits involved in participating in the study. If participants are uncomfortable about participating at any stage of the research, they should contact the researcher on:

Mobile no: 083 4573 897

Work no: 015 963 9200

Email: konieconnie@gmail.com

Alternatively, you can contact my research supervisor Dr Tshifhumulo on:

Mobile no: 084 589 5987

Work no: 015 962 8000

Email: Rendani.Tshifhumulo2@univen.ac.za

Appendix 4: Informed Consent



Consent

Project no: SHSS/18/AS/08/0307

Statement of Agreement to Participate in the Research Study:

I hereby confirm that I have been informed by the researcher Matambela Konanani Constance, 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, MatambelaKonanani Constance here with confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

MatambelaKonanani Constance _____

Full Name of Researcher Date Signature

Full Name of Witness (If applicable) Date Signature

Full Name of Legal Guardian (If applicable) Date Signature