EXPERIENCES OF FAMILY MEMBERS LIVING WITH A FAMILY MEMBER SUFFERING FROM CHRONIC SCHIZOPHRENIA IN LOBATSE

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Dissertation

submitted in fulfilment of the

Masters Curation

in

Psychiatric Nursing

Faculty of Health Sciences

UNIVERSITY OF JOHANNESBURG

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May 2007
And hope does not disappoint Romans 5:5
DEDICATION

To the families living with a member suffering from chronic schizophrenia.
ACKNOWLEDGEMENT

I wish to express my thanks and heartfelt appreciation to the following for contributing towards the completion of this study.

My supervisor Professor M. Poggenpoel and co-supervisor Professor C.P.H. Myburgh for their exceptional guidance, patience and unwavering support.

Annie Temane, the independent coder, thank you Mam.

Dr Paul Sedandi, the psychiatric consultant at Lobatse Mental Hospital; The matron, mss Maphorisa also at Lobatse Mental Hospital, for their unwavering support; ms Keipope Mosupi and mrs Loeto for helping me with the purposive sampling.

All the families that participated in the study for their invaluable input thank you ladies and gentlemen.

My husband, Kgotla Moahi for financial assistance, love and support.

My family of origin for their prayers, faith in me and immeasurable support.

Mr Stanley Kazima for making the hard copy of this study, thank you Sir.

Above all I thank my Creator, my Father, the Lord God for His providences.
ABSTRACT

Schizophrenia is a devastating mental illness and probably the most distressing and disabling mental disorder. It is not the condition of the ill person alone but also of the family which is placed in a crucial and pivotal role and which must take care of the ill relative with schizophrenia. This is so because of the disillusional thinking, altered thought process and distractions of internal stimuli that may interfere with the planning, commitment and rationale for actions, making it difficult for everyone involved. The effects of the illness may be confusing and shocking to families. Parents suffer from great disruptions to their lives and children can struggle with the implications of having a parent suffering from schizophrenia. Siblings of the ill person suffering from chronic schizophrenia are not spared, they even suffer because issues of their own survivorship. The family becomes case managers and primary carers. Family caregivers are vulnerable to emotional manipulation by their mentally ill relative. They are rarely trained/helped to manage difficult circumstances. The family members are called upon for provision of psychological and social therapies, occupational and recreational therapy and attendant care for which they are not trained.

The family is also seriously affected and distressed because of the effect schizophrenia has on their relative and the burden of caring. Coping with schizophrenia can especially be difficult for relatives who remember their relative before he or she became ill, giving rise to chronic grieving and sorrow and because of the cyclic nature of schizophrenia giving no definite end point or lengthy respite to complete mourning. The reminders of the “might have been” can be distressing.

There is an obvious need for research on the family’s experience. It is essential to understand their emotional tones and specific needs in relation to living with a member suffering from chronic schizophrenia as well as to formulate guidelines.
The purpose of the study was to explore and describe family member’s experiences and to formulate guidelines of care for families living with a member with chronic schizophrenia.

The research design was based on qualitative research because of its explorative descriptive and contextual nature. Data were collected by means of indepth phenomenological interviews and naïve sketches. Field notes were written for reflecting upon methods used and the personal notes for the researcher’s personal inflections. Literature was used to compare and complement the results. Guba’s model on trustworthiness ensured the trustworthiness of the research.

The results of the fieldwork indicated the following themes and categories:

- Self-awareness about feelings experienced
- Recognition of varying emotions
- Shock because of the schizophrenia diagnosis
- Denial about the existence of mental illness
- Fear because of the symptoms for example, thought disturbances
- Anger directed at patient’s family and others
- Shame and embarrassment, uncomfortability with living with a member suffering from schizophrenia during exacerbation
- Pain associated with embarrassment in the social faux
- Blame because of wrong doings in the family
- Sadness and grief because of loss of the an ideal family member
- Powerlessness because of lack of control over the family member with schizophrenia’s behaviour during the exacerbation period
- Stigma and rejection because of having a member suffering from mental illness
- Hope and need for divine intervention for curing a family member suffering from chronic schizophrenia
- Acceptance of the presence of mental illness and its chronicity
Uncertainty about the practical care of a member suffering from chronic schizophrenia

Role shift related to a disintegrated thought process

Sustained motivation not succumbing to ridicule, rejection and stigma

Recognition of psychological, behavioural, cognitive and physical changes. Recognition of positive changes like treatment compliance, calm and corporative behaviour and doing activities of daily living.

Recognition of negative changes: bizarre behaviour, wandering, neglect of nutritional needs, violence and aggression and thought disturbances

Empowerment of families living with a member suffering from chronic schizophrenia

Feelings of appreciation of intervention received at the hospital

Increased knowledge on treatment regime leading to improved quality of life

Family members express their concerns and specific needs

Inadequate family support and over-burdening for example, enduring day-to-day hassles

A need for food security because of family's inability to avail food adequately

Need for extended support in the family

Based on these findings, guidelines were presented for care of the families living with a member suffering from chronic schizophrenia. The families seemed to subscribe to the idea brought about by the Theory of Health Promotion (UJ 2006), the individuals, who in this case are the individual family members, managed to use the psychological process, in an interactive manner to think, reflect, associate, analyse and judge their experience on living with a member suffering from chronic schizophrenia. Their sound judgement brought about an invaluable contribution in the formulation of guidelines for families in a similar situation.
Bolwetsi ja tlhaloganyo jo bo bidiwang “schizophrenia” ke bolwetse jo bo lereng bohutsana jo bo mahehe ebile gape bo baya motho mo seemong sa bothhoka boitiro. Ga se bolwetse fela ja molwetse a e le ese mme ke ja ba lelwapa. Balelwapa ke bone pinagare ya tlhokomelo molwetsi yo o amilweng ke “schizophrenia.” Ba lelwapa ba dirilwe e seng hela pinagare e leng tshoso e relweng mo kokong e, ka mabaka a gore bolwetse o bo tisa dikakanyo le dikgopolelo tse di sa twa elegang tse di sa tshimologo mo boteng jwa tlhaloganyo. Megopol o e e sa twaelegang ee bileng e le sekgoreletsi mo ditogamaanong, le mo maikarabelong a ditseta dingwe tsa botshelo ka jalo di lere bothata go botlhe ba ba amegang. Ditamorago tsa bolwetse jo, di lere ketsaketsego e elele dihakgamatsa ba lelwapa.

Botsadi jo bonaleng ngwana yoo amilweng ke “schizophrenia” bo ne ja nna le go itemogela thakakanyo mo matshelong a jone, bana ba banaleng motsadi yoo amilweng ke bolwetsi jo, le bo ne ban e ba kopana le dikgwetlho mmogo le barwarra ba molwetsi.

Balewapa ba amilwe thata ebile ba ngomoga pelo ka ntata ya maduo a bolwetsi mo go wa lelwapa la bone e bila gape ba imelwa ke morwalo wa tlhokomelo. Maitemogelo long a ba lelwapa mo go tsheleng le wa lelwapa yoo amilelweng ke “schizophrenia” go nnile bokete, go phatola pelo ka ntata ya kgakologelwa ya molwetse pele ga a nna le bokoa, maiphithelo a, a nnile le go rokotsa bohutsana le mangomo a a senang bokhotlo, a tsweletseng ka ntata ya mokgwa wa bolwetsi go boa seboaboane mo molwetsing, bo sena kalafi e e bo hudisetsang ruri, mme gape bon ale go kgobola ntho legogo. Ba lelwapa ba nnile le go kgoberwa maikutlo go gaisa ke mangomo a go tshela ka go ja “nkabo”, nkabo molwetsi wa rona a ntse jaana le jaana ... fa ene e se ka twadi ya “schizophrenia”.

Morago ga maiphithelo, a a begilweng a, mmantlisisi one a gwetlhega go batlisisa ka maiphithelo a ba lelwapa lele tshelang le molwetsi yoo lwalang bolwetse ja tlhaganyo “schizophrenia”, a bo a dire maiteko a go tswa ka ditseta tsa tlhokomelo.
Moono wa dipatlisiso ke go huputsa le go kaya maiphithelo, ditlhoko, go tlhaloganya le go dira ditseta tsa tlhokomelo ya bone ba molwapa a a nale mongwe wa lelwapa yo lwalang bolwetsi ja tlhalonganyo jo bo bidiwang “schizophrenia”.

Dipatlisiso di ne tswa dirwa ka mokwa wa go huputsa le go kaya mo lefelong le le rileng. (Explorative, descriptive, contextual). Patlo maiphethlho e ne ya dirwa ka mokgwa wa puisanyo e e gatisitswang mo sekapeng mantswe (indepth phenomenological interview). Polelo ya botshelo (naïve sketches) dipego tsa mokgwa wa go dira diphiitlhelelo tsa mmatlisisi (personal inflections). Thurifaso le netefatso ya patliso e e dirilwe go ya fa disetla tse di kwadilweng ke Guba (Guba’s Model of trustworthiness).

Tse di latelang ke maduo a neng a fitihelwa mo pegong, le dikarolo le dikarolwana .(Themes and categories):

- Kgakgamalo ka ntata ya twadi ya “schizophrenia”
- Tatofatso yo boleng teng jwa bolwetse ja “schizophrenia”
- Poifo ka ntata ya dikai tsa bolwetsi
- Go shakgalela molwetsi, balelwapa ka bongwe ka bongwe le bangwe fela
- Ditlhong le maswabi mmogo le go kokonelwa ke go nna le molwetsi wa tlholaganyo a amilwe ke “schizophrenia”
- Tshupano ka monwana mo dilong tse di sa tsamayeng sentle mo iwapeng
- Bohutsana le go phatoga pelo ka go lathegelwa ke “motho wa pele”
- Botlhoka boitiro fa ka ntata ya go palelwa ke go laola boitshwaro ja molwetsi fa a gateletswe
- Kgethelolo le thophego ya balelwapa ka ntata ya go nna le molwetsi wa schizophrenia
- Tsholofelo le lelhoko la Modimo mo phodisong ya molwetse yoo amilweng ke “schizophrenia”.
- Kamogelo ya boleng teng le go kora mo twading ya “schizophrenia”
- Go rola maikarabelo ka ntata ya tlhaloganyo ee bokoa.
- Ketsaatsego ka tlhokomelo molwetsi

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➢ Go gagamaletsa thamo lekgobo, tshotlo le tlhophego
➢ Itemogelo ya phetogo ya maitsholo a a eletsegang
➢ Itemogelo ya maitsholo a a sa eletsegeng
➢ Kgothalo ya go nna mooko oo thata
➢ Maikutlo a tebogo go ba booki, bo ngaka la badiredi ja bookelo
➢ Phetogo ya boleng ja botshelo, e fetogela botokeng
➢ Ditlhoko le matshwenyego di akaretsa:-
  ➢ Letlhoko la kemo nokeng mo lwapeng
  ➢ Letlhoko la dijo ka ntata ya itsholelo ee kwa tlase
  ➢ Letlhoko la kemo-nokeng e e sa tsweng go ba lapa, letlhoko la kamogelo
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CHAPTER ONE

OVERVIEW AND RATIONALE

1.1 INTRODUCTION

Of all the mental illnesses responsible for suffering in society, schizophrenia probably causes lengthier hospitalisation, more chaos in the family, more exorbitant costs to individuals and governments, and more fears than any other. Because it is such an enormous threat to life and happiness and because its causes are an unresolved puzzle, it has been studied more than any other mental disorder (Townsend, 2002:449).

According to the Lobatse Mental Hospital, one third of persons with schizophrenia are estimated to recover completely, one-third are in and out of the hospital, with the remaining one third running a chronic course (Sedandi, 2002:LMH Annual report)

1.1.1 Myths about schizophrenia – an illness not understood

Several myths surrounding schizophrenia exist. The following are some of such myths:

- Schizophrenia is confused with split a personality or multiple personality. People believe that people with schizophrenia are violent and dangerous. A limited number are violent, but this perception of people with schizophrenia (believed to be violent, particularly bizarre, frightening and committing crimes) has been brought about by the media and publicity. This has left the public with the impression that people with schizophrenia are violent.
- Schizophrenia is a result of bad parenting and a lack of will power.
- Some religious groups hold the view that the illness is one of God’s punishment
- Some people believe that people with schizophrenia have weak personalities and have chosen their madness.
- In the 1950’s it was believed that schizophrenia results from a form of psychic trauma inflicted on the individual in early life.
Mothers of those with schizophrenia were believed to be over-anxious, obsessive, domineering and were labelled schizophrenogic.

Any antisocial behaviour shown by a person with schizophrenia is usually not wilful but rather a result of brain disorder (www.sfnsw.org).

Schizophrenia is a severe, chronic and often disabling mental disease. It causes severe mental disturbances that disrupt normal thought, speech and behaviour. Studies have revealed that schizophrenia impairs a person's ability to think clearly, make decisions and relate to others (Townsend, 2002: 926).

The causes of schizophrenia are unknown, however, several theories do exist. Such theories include genetics, which suggest that schizophrenia runs in families. Family studies have shown that schizophrenia is more common in relatives of people suffering schizophrenia than the general population where lifetime risk is approximately one percent. The risk is ten to fifteen percent in siblings of people suffering from schizophrenia, among children of one parent with schizophrenia is ten to fifteen percent, and among children of two parents with schizophrenia the risk is about forty percent. Twin studies indicate that for the major part, familial loading is likely to be genetic rather than environmental. Adoption studies confirm the importance of genetic factors among children who have been separated from parents at birth and brought up by adoptive parents without schizophrenia, the likelihood of developing it is no less than that of children brought up by their own parents with a schizophrenia genetic inclination (Geddis Mayou & Gelder 2005:126). Other theorists talk of the biochemical, theoretical role in the cause of schizophrenia. Nevid, Rathmus and Green (2006:418) say that contemporary investigations of schizophrenia have focussed on the role of neurotransmitter dopamine. The studies suggest the likelihood of imbalance in dopamine, serotonin and norepinephrine in the neurotransmission process. The anti-psychotic action of neuroleptic drugs probably results from blockage of dopamine receptors. Related studies have focused on possible dysfunction of endocrine glands. Prolactin and growth hormone secretion or both may be controlled by the same neurotransmitter that implicates the cause of schizophrenia (Rawlings 1993:332). In addition to the brain abnormalities, both structural and cellular changes in the brain have been noted in people with schizophrenia. Other scientists are currently investigating viral infections that occur in
early life and mild brain damage from complications during birth as contributing to the development of schizophrenia.

Studies have revealed that schizophrenia affects between one and two percent of people. The illness occurs all over the world and the incidence is similar in different countries and different cultures. Men and women are at equal risk of developing the illness. Whereas in men the illness tends to surface between ages the 16 and 25, most females develop symptoms between the ages of 25 and 30.

Schizophrenia may develop so gradually that the family and even the person with the disease may not realise that anything is wrong for a long period of time. The slow deterioration is referred to as a gradual onset or insidious schizophrenia. A gradual built up of symptoms may occur or may not lead to an acute episode or crisis episode of schizophrenia. An acute episode is short and intense and involves hallucinations, delusions, thought disorders and an altered sense of self. Sometimes schizophrenia has a rapid or sudden onset. Very dramatic changes in behaviour take place over a few days. Sudden onset usually leads fairly quickly to an acute episode.

In some cases, the illness may develop into what is known as chronic schizophrenia. This is said to be a severe, long-lasting disability characterised by social withdrawal, lack of motivation, depression and blunted feelings. In addition, the patient may have moderate versions of acute symptoms such as delusions and thought disorders(www.mentalhealth.com). In this study the researcher will concentrate on exploring the experiences of family members living with a family member suffering from chronic schizophrenia.

Schizophrenia is believed to have two categories of symptoms, the positive and the negative. Positive symptoms include those symptoms which are present and should be absent and negative symptoms are those that are absent but should be present (Shives & Isaacs, 2002: 266).

Symptoms of schizophrenia involve disturbances and many areas of functioning. These include positive and negative symptoms.
1.1.2 Positive symptoms

Positive symptoms are the behavioural excesses. They can affect how somebody suffering from schizophrenia thinks, speaks and perceives. Positive symptoms do not mean good or favourable. This may include delusions and hallucinations.

*Hallucinations* are thought to be a result of over sharpening of senses and brain inability to interpret and respond appropriately to incoming messages. This includes an experience of hearing voices or seeing visions that are not there, or an experience unusual of sensations on or in his body. Auditory hallucinations are thought to be most common. The patient can furthermore experience delusions.

*Delusions* which are said to be strange and steadfast beliefs that are held only by the observer and remains despite obvious evidence to the contrary. One can further say delusions are fixed, unchallengeable beliefs. In addition to this, the person suffering from schizophrenia may experience thought disorders.

*Thought disorders* are basically the way a person with schizophrenia processes and organises thought. Moreover the patient suffering from schizophrenia may experience an altered sense of self.

*Altered sense of self.* This a term describing a blurring of all the ill person’s feeling of who he or she is. It may be a sensation of being bodiless or non-existent as a person.

1.1.3 Negative symptoms

Negative symptoms consist of deficits such as inability to express a normal range of emotions. Negative symptoms are less immediately troubling to others but are none the less troubling to the disturbed individual and may appear less noticeable (Neal, Davison & Haga, 1996:218).
Earlier on in was discussed that negative symptoms are those symptoms that are absent but should be present. Negative symptoms are a great source of confusion for relatives, who rarely recognise them as part of illness. The point is worth emphasising, since the relatives find emotional and behavioural deficits of schizophrenia very difficult to understand and cope with. Relatives frequently feel the sufferers are in control or acting on their own volition, hence lack of activity, conversation, or emotion is attributed to the sufferers rather than the illness and become a focus of criticism and dissatisfaction (Barrow Clough & Tarrier, 1992:8). Basically the list includes:

*Lack of motivation or apathy* is lack of energy or interest in life that is often confused with laziness. Life for the person with schizophrenia can be experienced as devoid of interest. The person suffering from schizophrenia would also present with blunted feelings or blunted affect.

*Blunted feelings or blunted affect* is basically a situation whereby there is flattening of emotions, the sufferer is devoid of emotions. One can further describe the situation as poverty of emotions. One other symptom is depression.

*Depression* involves feelings of helplessness and hopelessness and may stem in the past from realising that schizophrenia has changed one’s life from realising that the “special feeling” experienced in the psychotic state is a delusion and that the future looks bleak. Amongst the list of negative symptoms is social withdrawal.

*Social withdrawal* - may occur as a result of depression, as a result of feelings of relative safety in being alone or as a result of being caught up in one’s own feelings and fearing that one cannot manage the company of others. (www.mentalhealth.com).

Schizophrenia is a life changing condition that does not only impact upon the patient but also on the family and circle of friends and significant others that must care and support the members suffering from schizophrenia. Schizophrenia is not an illness of the client alone but of the family as well. It is believed that even when the families appear to be coping well, there is a notable impact on the mental health status of the relatives (Baker, 2003:26).
Chronic mental illness impacts upon the family in a significant manner. Although it is impossible to objectively rate the degree of stress, loss and handicap resulting from any chronic illness, the impact of family members suffering from cyclic psychosis is particularly devastating for the ill individual and his/her family (Valfre, 2001:373).

Owing to the nature of the disease, its chronicity and tendency to persist overtime with remissions and recurrences of severe and disabling symptoms in the form of altered thought processes and perception, the condition is more crippling and has far-reaching consequences in the social and occupational functioning.

Any episode of illness may involve a lasting change in a person’s level of functioning. A person who is seriously ill is more likely to have problems living productively in the community (Stuart & Larai, 2001:246). In this case, the mentally ill person with chronic schizophrenia may be rendered incapable of attaining the status of a fully functioning being owing to the altered thought process and altered perception. It therefore follows that the family as the caregivers have to step in. The family is particularly charged with the responsibility of creating an environment that is conducive to the chronically ill person suffering from schizophrenia.

Schizophrenia impacts not simply on individual sufferers, but also on the family, friends, colleagues, neighbours and the wider social network. This is certainly true because the disease process has the tendency to incapacitate the individual, more especially during periods of remissions and recurrence. Pivotal to the care of schizophrenia is the family who is placed in a pivotal, crucial role in the provision of after-care of a family member suffering from chronic schizophrenia.

1.2 PROBLEM STATEMENT

Schizophrenia is a disease that is not well understood and is greatly feared. It is a life-changing event not only for patients but for the family and friends who must care and support the affected members (MacFarland & Thomas, 1990:549). The family members are said to experience considerable stress owing to the fact that patients with
chronic mental illness have severe and persistent emotional disorders that interfere with the ability to live and function independently.

Perhaps no psychological disorder is more crippling than schizophrenia. Characteristically, disturbances in thought processes, perception and affect result in a severe deterioration of social and occupational functioning (Townsend, 2002:449). The nature of the disease, burdens the family with having to keep record of what type of symptoms may have appeared, what medication and dosage thereof have been taken and what effect the various treatments have on the patient. The parent has to take care of a defaulting patient who has become psychotic to a degree that he/she cannot provide his/her own basic needs including food, clothing and shelter. Owing also to the illness process the patient's rights may be temporary reduced or permanently reduced and every time patients are reviewed they have to be in a company of someone acting as a legal guardian. The family is often able to provide important diagnostic clues otherwise not available to the admission team. Stuart & Larai,(2001:266) further elaborates that informed family members who see the patient on a daily basis can provide professionals with information to supplement their own observation and sometimes can be more reliable informants than the patient. The members suffering from schizophrenia are also said to have limited skills in coping with problems of day-to-day living, lacking skills in communicating their thoughts and emotions. Schizophrenia is one of the most devastating illnesses one can have. The seriousness of impairment and the fact that the patients are at home for the greater part of their illness, place an enormous burden on the family. The family has been seen as a critical factor in successful management of the problem rather than its cause (Reder, McClaire, & Jolly 2000:214). The unanticipated task of caring for a mentally ill person often totally disrupts and dominates the lives of persons of parents and even siblings (Uys & Middleton, 2004:384). This is probably so because when a person develops mental illness, there is often an accompanying inability to relate to his or her peers, the group of friends that gives life much meaning. For many mentally ill people, parents and siblings are the only people who feel they should provide a social network, despite the varying interest of ageing parents as opposed to that of young adults.
The patient cannot function independently. The family as a group plays an important role in the functioning of a family member suffering from schizophrenia. They plan their activities around him/her. Much of the challenges of these families as caregivers is due to involvement with their patient and/or exaggerated self-sacrifice. The family as caregivers is under enormous stress everyday. Personal stress is something that often goes unacknowledged. The mental ill person becomes a priority and the family neglects its own needs. Johnson (1997:590) says that, recently families of people with mental illnesses have begun to be recognised as people with strengths and resources, who are instrumental in their ill member’s care and recovery.

In view of the assertion made by the mentioned authors, the researcher is interested in exploring the experiences of families who are known to be playing a crucial role in the care of family members suffering from chronic schizophrenia hence the topic “Experiences of family living with a family member suffering from chronic schizophrenia”.

The society values health and fully functioning individuals who are physically attractive. When children are found to be having a chronic condition that limits their ability to functioning fully in their environment, they deviate from the social norm. Families with children with chronic conditions are confronted to having a child who is less perfect by society standards (Fawcett, 1993:29). The family system of a member with schizophrenia has a demanding amount of input with which to deal with. Obviously, even before the illness recognition, the family is bombarded with unusual and incessant input that requires constant system modification. This barrage of input does not decline after adjustment to diagnosis and initial treatment, rather the family must continue to deal with changes, rule, role and task structures. The demand for flexibility and adaptability is overwhelming (Fawcett, 1993:344) In view of assertions made by the author, the family’s coping process, resources and understanding of the condition remain important in the care of people suffering from chronic schizophrenia.

Nationally guidelines for families who live with members suffering from schizophrenia do not exist. This has invoked a desire in the researcher to formulate guidelines of care that is not only suitable nationally but for the Lobatse population to
be precise and specific to schizophrenia and hence the second objective of the study is to formulate guidelines of care for families living with a member suffering from chronic schizophrenia.

The following research questions are posed: How is it for a family to live with a member suffering from chronic mental illness? What can be done to care for a family living with a family member suffering from chronic schizophrenia?

1.3 OBJECTIVES

The objectives of the study are to:
- Explore and describe the experiences of family members living with a family member suffering from chronic schizophrenia in Lobatse; and
- Describe guidelines of care for a family living with a family member suffering from chronic schizophrenia.

1.4 PARADIGMATIC PERSPECTIVE

The Theory of Health Promotion in Nursing (Department of Nursing 2006:4, University of Johannesburg) is taken as the paradigm for this study.

1.5 METATHEORETICAL ASSUMPTIONS

Metatheoretical assumptions are core beliefs that the researcher has about a human, his/her environment and society. These assumptions are philosophical in their origin and are value laden (Botes, 1991:12). They have no epistemic foundations and therefore they provide a frame of reference for guiding important research decisions. The Theory of Health Promotion in Nursing, University of Johannesburg (2006:4) is taken as a paradigm for this research study. The researcher’s assumptions will be described below.
1.5.1 Individual

In this study an individual is a member of a family living with a family member suffering from chronic schizophrenia who has this psychiatric disorder persisting over time with remission and recurrence of severe and disabling symptoms (Fortinash & Holoday-Worret, 2000: 72).

*Individual* – The individual embodies dimensions of body, mind and spirit. The individual functions in an interactive manner with the environment. In this respect the family members living with a member suffering from chronic schizophrenia are in fact individuals with bodies that are inclusive of anatomical structures and psychological processes. To the researcher, these individuals will use these God-given processes like the psyche to think, reflect, associate, analyse and judge the experience of living with a member suffering from chronic schizophrenia and come out with sound judgement and worthwhile contributions so that guidelines of care for families living with a member suffering from chronic schizophrenia can be made as well as recommendations. This will be made possible through their integrated, interactive functioning with the environment.

1.5.2 Environment

This includes the internal and external environment. The internal environment consists of the body, mind and spiritual dimensions and the external environment consists of the physical, social and spiritual dimensions. The researcher believes that families living with a member suffering from chronic schizophrenia will use both the internal and external environment to narrate their lived experience, and not only do that but will employ the resources in the external environment like the physical, social and spiritual dimensions to come out with guidelines of care that will be for the betterment of their welfare.

1.5.3 Health

The theory of Health Promotion in Nursing, University of Johannesburg (2006:5) defines health as a dynamic interactive process in the patient’s environment. These
interactions in the patient’s environment reflect the relative health status of the patient. The theory seems to emphasise one’s environment as having an impact on the health status. The researcher in this study’s focus is on exploring the experiences of family members living with a member suffering from chronic schizophrenia. The environment both internally and externally will be borne in mind.

1.5.4 Nursing

Nursing is a profession focused on assisting individuals, families and communities in attaining, maintaining and recovering optimal health (en.wikipedia.org).

In this study the nursing process will be adopted as laid out in the Theory for Health Promotion in Nursing (2006:4 University of Johannesburg, School of Nursing). To facilitate the promotion of health promotion, the individual, the family, the group and the community, the nurse engages in the nursing process, a methodology in which nursing is provided. It includes assessment, planning, implementation and evaluation as continuous and integrated activity.

1.6 Theoretical assumptions

The following constitute the theoretical assumptions for conducting the study.

1.6.1 Theory

The theory aims to recognise the potential and ability of individuals, who in this study are family members living with a family member suffering from chronic schizophrenia, to think, reflect, associate, analyse and judge their experiences and to come out with guidelines of care and recommendations. The researcher will use the Theory for Health Promotion in Nursing, University of Johannesburg (2006:4), as the basis for the whole study. The researcher will enter into the field without pre-empted ideas about experiences of families living with a schizophrenic member. After the data analysis a literature control will be conducted.
1.6.2 Methodological assumptions

These are assumptions about the researcher's view about the nature of the research process. These include opportunities of selected methods (Mouton, 1996:12). The assumptions ought to be related to the researcher’s preferred paradigm guiding the study. Compatibility in this regard is an essential component, this is based on it as well (Mouton & Marais, 1990:14-17).

In reality the methodological assumptions gain capacity through explaining the life story, beliefs and values of the researcher. This includes her views about the social world (Mouton, 1996:37-38). The researcher takes methodological assumptions as fundamental in the study and it provides an overall guideline to the researcher. Particular reference is made towards respecting research participants throughout all the stages of the research process. In reality, assumptions regarding the methodology have moral and ethical implications. It is through them that the research purpose can be scientifically realised. The researcher will comply with the general standards stated above as well as measures of attaining trustworthiness so that this study is acceptable and be counted as a scientific study. A functional approach to research is followed, that is research is conducted to improve practice. The principles in conducting research will be applied, such as, logic and justification.

1.7 CLARIFICATION OF CONCEPTS

1.7.1 Experiences

Experience is an event or occurrence that leaves an impression on one, an encounter or undergoing a feeling or emotion (Pearsall, 2001:501). In this study experience pertains to the feelings and emotions surrounding living with a family member suffering from chronic schizophrenia.
1.7.2 Family members living with a family member suffering from chronic schizophrenia

A family is a social system composed of two or more people living together who may be related by blood, marriage or adoption, or who stay together by mutual agreement. (Clark, 1996:365). In this study the family means those with whom one lives with and are related to.

1.7.3 Chronic schizophrenia

This is when the psychiatric disorder persists overtime with remissions and recurrences of severe disabling symptoms (Fortinash & Holoday-Worret, 2001:727).

1.7.4 Ill relative

This is the significant other in the family suffering from schizophrenia.

1.7.5 Mental illness

Mental illness is a psychological or mental disorder (Nevid, Rathus & Green, 2006:5). In this study it refers to chronic schizophrenia.

1.8 RESEARCH DESIGN

The design that will be used is qualitative, explorative, descriptive and contextual (Mouton, 1996:103). A qualitative design will utilise the experiences, beliefs and values related to the phenomenon under investigation. Exploration attempts to investigate whether the phenomenon has greater meaning whereas the descriptive part of it is the method that will be used to collect data in a qualitative study through description and clarification. The contextual part of design will use a dense description of research phenomenon. Full description will be given in Chapter Two.
1.9 RESEARCH METHOD

This research will be conducted in two phases. In Phase 1 family members’ experience of living with a family member who suffers from schizophrenia will be explored and described. In-depth individual interviews will be used. The central question is “How is it for you to live with a family member who suffers from a chronic mental illness”? Facilitative communication skills will be utilised to conduct the individual interviews. Data will also be collected by means of naïve sketches (Giorgi, 1985:57). Naïve sketches will be used in this study on the basis that the guiding theme in phenomenology is to go “back to the things themselves”, which means to visit the everyday world where people are living. Data will be analysed using Tesch method in (Creswell, 1994: 256) open coding method. Thereafter the results will be recontextualised in the literature. In phase 2 guidelines will be formulated, for the care of a family with a member suffering from schizophrenia, based on the findings of phase 1.

1.10 ETHICAL MEASURES

Permission from the Health Research Unit and the Faculty of Health Ethics Committee at the University of Johannesburg will be sought. Ethical measures centre around the protection of families with a member suffering from schizophrenia from any harm, be it emotional, psychological, spiritual or physiological. The following ethical measures will be observed.

Informed consent – The prospective participants will have the right to choose whether or not to participate in the research. Participants may withdraw from the research at any time without any negative consequences. They ought to be persons who have legal capacity to give consent and should be able to exercise free power of choice without elements of force, fraud, deceit, distress or ulterior motive. See annexure C.

Provision of essential information – Essential information will be given pertaining to the activities of the study such as the need to do in-depth individual interviews, writing of naïve sketches and the need for the researcher to write field notes. The
The purpose of the study will be explained. The research objective will also be given that it is to explore and describe experiences of family members living with a family member suffering from chronic schizophrenia, so that guidelines of care can be formulated and recommendations made.

*Duration of participation* will be explained, namely, that the researcher shall require forty-five minutes to one hour of their time, either for the interview or for the naïve sketches.

*Description of procedures* that will be done, what is expected of the participants during interviews or writing of naïve sketches.

*Risks and benefits* – The researcher will inform participants of foreseeable risks and discomforts involved, be it emotional, social, physical or economic. In this case the benefits are not directly personal but one can have an emotionally fulfilling experience of helping in formulation of guidelines of care for family members living with a family member suffering from chronic schizophrenia. The discomforts involved include having to relive the experiences of the past, which might be considered to be psychological harm. The researcher will explain how the risk will be minimised, this is to say that, in the event of unintentional psychological harm through self-exposure counselling will be provided or the researcher will be proactive enough to refer the participants to other counsellors. The prospective participants are encouraged to consult with a trusted advisor such as a friend, family member or another nurse to serve as a consultant to help in decision-making of whether to participate or not.

*Assurance of anonymity and confidentiality* – The prospective participants must know that their responses and the information from the records obtained during the study will be kept confidential. They must be assured that their identity will remain anonymous in presentation, reports and publications. This will be made possible through the use of codes instead of names, putting of raw data under lock and key and assurance that only the researcher, her supervisors and independent co-coder will have access to raw data.
Compensation for participation – No compensation will be promised. In this study: “Experiences of family living with a family member suffering from chronic schizophrenia” no remuneration in cash or in any kind is promised.

Offer to answer questions – The researcher will offer to answer any questions by families living with a member suffering from chronic schizophrenia.

Feedback – The participants will be given information on the results of the study. In this case the researcher intends to give a summary of the study written either in Setswana or English to all those who would like to have a copy.

Non-coercive disclaimer – Participants will be informed that participation is voluntary, refusal to participate will involve no penalty or loss of benefits to which the participants are entitled.

Option to withdraw – The participants will be informed of the option to withdraw from the study anytime without penalty.

Moreover, a trusting relationship, based on positive regard will be maintained throughout the process. The participants will be met prior to data collection to build rapport, to explain the purpose of study, duration, and method to be used and to allow for questions from the participants. Permission to use audiotapes and notes will be sought (Burns & Grove, 2001:208).

Measures to ensure trustworthiness are truth value, applicability, consistency and neutrality. The application of these criteria will be discussed in Chapter Two.

1.11 DIVISION OF CHAPTERS

Chapter One: Overview and rationale.

Chapter Two: Research design and method.

Chapter Three: Results: experiences of families with a member suffering from schizophrenia.
Chapter Four: Guidelines for care of a family with a member suffering from Schizophrenia.

Chapter Five: Conclusions, limitations and recommendations.

1.12 SUMMARY OF CHAPTER ONE

In this chapter, important factors in executing the research study were stated, that is: the rationale and overview, the problem of study, paradigmatic perspective for guiding the study, including the design and method. In Chapter Two, the design and method appropriate for the study will be discussed.
CHAPTER TWO

RESEARCH DESIGN AND METHOD

2.1 INTRODUCTION

A general overview and rationale for understanding this research has been given in Chapter One. As stated earlier the study plans to explore and describe experiences of families living with a chronic schizophrenic member and to formulate nursing care guidelines.

2.2 RESEARCH OBJECTIVES

The main objective of this study is to explore and describe experiences of family members living with a family member suffering from chronic schizophrenia in Lobatse and to describe guidelines of care for a family living with a member suffering from chronic schizophrenia. This will be done from contributions of families with chronic schizophrenia members.

2.3 RESEARCH DESIGN

The design that will be used in this research study is qualitative, explorative, descriptive and contextual in nature. The family’s experience will be explored and described and then used as a basis for formulating guidelines to support them as they live with a member suffering from schizophrenia.

2.4 QUALITATIVE DESIGN

A qualitative design utilises the experiences, beliefs and values related to the phenomenon under investigation (De Vos, 1998:241). The purpose for doing this is to allow the participants share their experiences (Mouton & Prozsky : 1998:28). It is them, who above any other persons have the authority to raise viewpoints. It therefore
follows that the researcher derives real meaning from data presented by the families. The researcher must avoid imposing her pre-existing knowledge of the phenomenon (Mouton & Marais 1990). In this study the participants will narrate their lived experience. They will talk with the researcher. The researcher will use facilitatory interactive skills trying to get the real meaning through clarifying and summarising.

2.5 EXPLORATIVE DESIGN

An explorative design attempts to investigate whether the phenomenon has greater meaning, rather than evaluate it (Mouton & Prozesky, 2007: 28). What is to be explored in this study is experiences of families in living with a member suffering from chronic schizophrenia. An explorative design will thus be particularly used in this study for purposes of making an intensive investigation during fieldwork and when formulating nursing guidelines in the care of families living with a member suffering from chronic schizophrenia. During this process the researcher will be cautious and remain open to any new ideas as they emerge in order that a meaningful explorative process is facilitated. Noteworthy suggestions from (Burns & Grove, 2001:596) will be used during individual interviews She will do this by using open-ended questions and becoming less verbal so that participants become the main contributors to the discussion held.

2.6 DESCRIPTIVE APPROACH

A descriptive approach is a method used to collect data in qualitative studies. In this study, which is qualitative in nature, the approach will be used for clarifying experiences of families living with a member suffering from chronic schizophrenia. Mouton & Marais (1990:43-44) verbalised that data collected ought to be accurate. This will be done by observing, describing and documenting the situation as it naturally occurs(Polit & Hungler, 1999 :195 ).
2.7 CONTEXTUAL DESIGN

The researcher's goal is not to generalise the results to a larger population but rather to give a dense description of the research phenomenon, which in this context is experiences of families living with a member suffering from schizophrenia in Lobatse. By understanding the meaning of a phenomenon in a particular context, it is easier to understand phenomena in other similar situations (Burns & Grove, 2001:674). Based on the outcomes of the study effective guidelines can be formulated to care for family members in their experience.

Contextualising the study means allowing important characteristics of what is often unclear in the study to come clear for everyone to understand. These characteristics are described by Mouton (1996:35) as intrinsic and immediate features pertaining to the phenomenon. In this study what is of interest is to explore and describe the experiences of family members living with a family member suffering from chronic schizophrenia and to formulate guidelines on the care of family members living with a member suffering from chronic schizophrenia.

2.8 RESEARCH METHOD

The research will be conducted in two phases. In phase one an in-depth study of the experiences of families living with a member suffering from chronic schizophrenia will be conducted. In phase two formulation of guidelines for care of families living with a member suffering from chronic schizophrenia will be done. These guidelines will be derived from the results of phase one.

2.9 SAMPLE

Purposive sampling is a selection of those individuals or objects that will yield the most information about the topic under investigation (Leedy & Omrod, 2005:39). These are the people who are expected to give a typical perception and perspective.

Purposive sampling will be used in this study, which means a conscious and intentional selection of individuals will be hand-picked continually until data are
saturated as demonstrated in repeating themes. Selection will be based on participants relevant to selection criteria (Polit & Hungler, 1999:284).

2.9.1 Sample criteria

A sample is the subset of the target population. In this study sampling criteria will be used to assist the researcher in determining the target population for the study (Burns & Grove, 1993:403) and this is based among other things, on the research problem and experiences. In this research, therefore, individuals who display the following characteristics will be selected:

- Family members living with a family member suffering from chronic schizophrenia who has had at least three admissions.
- Initial diagnosis should date three years back to ascertain chronicity.
- The member suffering from schizophrenia should be aged between 18 and 35 as is the age group which is thought to be at a prime time for career development and the family is supposed to have high hopes about the individual.
- The family should speak either Setswana or English as the interview and naive sketches will be in both languages.
- They should be residents of Lobatse.
- The family member who wishes to participate in the study should be a blood relative, and should have stayed with a member suffering from chronic schizophrenia during periods of remissions and recurrences.
- The family member who wishes to participate should be aged between 18 and above and those below 21 should have an affirmation letters from their parents/guardians.

2.9.2 Sampling size

In a qualitative research study as this one, the researcher is committed to obtain a clear understanding of experiences rather than a stipulated sample size. What determines the sample size is therefore, development of rich and dense description (Streubert & Carpenter, 1995:24) of experiences of families living with a family
member suffering from chronic schizophrenia. The size of the sample will thus be
determined by the factor of saturation which Morse (1994:104) and Streubert &
Carpenter, (1995:24) describe as a point where no new information is generated. At
this point there will be no purpose in pursuing interviews.

2.9.3 Pilot study

A pilot study is a miniature of the main study. Before launching the main study, the
person carrying out the pilot study tries to duplicate, on a similar scale, all procedures
that have been planned for the main study that is to follow (Knapp, 1998:209). A pilot
study will be carried out with a family with a member suffering from chronic
schizophrenia who has similar characteristics as other participants in the main
research sample. This will also help to orientate the researcher to the project (De Vos,
1998:178). The participant in the pilot study will like others be exposed to individual
in-depth interview.

2.10 DATA COLLECTION

As soon as families living with a family member suffering from chronic schizophrenia
have given permission to participate, data collection will commence. Throughout the
data collection process, the researcher suspends any preconceived notions or personal
experience that may unduly influence what the researcher “hears” the participant
saying. This is essential for allowing the researcher gain an understanding of typical
experiences that people have had (Leedy & Omrod, 2005:139). Since experiences of
families living with a family member suffering from chronic schizophrenia is the
focus of the study, the phase of the data collection is intended to gain access into their
experiences. Phenomenological in-depth individual interviews, observation and naïve
sketches would be used. Naïve sketches are when the participants are asked to write a
composition about their experiences. The central question that the researcher will ask
is “How is it for you to live with a family member who suffers from a chronic mental
illness?” To facilitate the process, facilitatory/interactive skills will be used. Probing
will be used to obtain information in specific areas. Summarising will be used to
ensure mutual understanding of participants and the researcher. Clarification will be
used for the same purposes.
Observation will be employed, paying attention to non-verbal cues, for example, gestures, movements, tone of voice, repetition and stammering. The researcher needs to pay attention to body language as well as to presenting affect of participants at the time of the interview (Burns & Grove, 2001:594). Observations carried out while watching and listening is valuable to qualitative-oriented research because what is being observed is actually what the participant experiences (Wilson, 1989:343).

2.11 PHASE ONE: EXPLORATION OF THE EXPERIENCES OF FAMILIES LIVING WITH A MEMBER SUFFERING FROM CHRONIC SCHIZOPHRENIA

A phenomenological interview is an in-depth, semi-unstructured interview in which the researcher and the participants work together to “arrive at the heart of the matter.” The researcher listens closely as participants describe their everyday experiences related to the phenomenon and must be alert for subtle yet meaningful cues to the participants’ expressions, questions and occasional sidetracks. A typical interview looks more like an informal conversation with the participants doing most of the talking and the researcher listening (Leedy & Omrod, 2005:139). An in-depth individual interview is communication between the researcher and the family member living with a member suffering from chronic schizophrenia. It is a process in which both interviewer and interviewee are constructors of knowledge (Burns & Grove, 2001:420). The in-depth semi-structured interview fits well in qualitative circles where acquiring meaning is central. Furthermore in-depth interviews that will be used in this study are regarded as the most relevant for acquiring input in this study. Naïve sketches will also be used, they are thought to be the basis of guiding themes in the phenomenology in this study, that is “going back to things themselves” (Giorgi, 1985:57) That means to visit the everyday world where people are living. Families living with a member suffering from chronic schizophrenia will be encouraged to write their lived experience in an unbiased atmosphere.

The interviews will be audio taped throughout and then transcribed for purposes of reflecting and understanding. Each of the participants will be asked to speak loudly so that information is not lost. Consent forms will be made available at this meeting for
participants and their parents/guardians as is the case with minors. A free and non-threatening environment that affords privacy will be availed. The environment is to be pleasant, free from noise and interruptions. A note reading, "Please do not disturb" will be put on the door. Every participant will be greeted in the traditional way. The researcher will be careful not to display negative non-verbal communication.

Initially a working relationship with participants will be established at face level to explain the purpose of the study and how it will be conducted. All participants will be assured of confidentiality and respect and informed of their right to participate or not to participate. The researcher needs to maintain a rapport by using clear communication in the language families living with a member suffering from chronic schizophrenia understand, so that they can speak with ease and without inhibition (Giorgi, 1985:56).

On completion of the interviews and written life experience, the researcher will select a few participants from those who participated and do follow up interviews. This is done in order to validate or clarify certain themes (Streubert & Carpenter, 1995:46). The participants who will be followed up are those who have availed a dense description of their experience and have displayed unwavering commitment towards participation in the study.

For purposes of obtaining supportive information, field notes will be recorded (Marshall & Rossman 1985:108) during the interview. These field notes are important in qualitative research because they help the researcher to remember observations made during the interview process (Wilson, 1989:434) and more importantly they can be retrieved and analysed.

*Theoretical notes* are notes as described by Wilson (1989:435) that the researcher makes with the intention of deriving meaning from observational notes following the interview. The notes will be used to interpret and conjure on which analytical scheme can be built.

*Methodological notes* will be kept for the researcher's self-critique in respect of tactics used as they are valuable in representing instructions about the methodological approaches which might be beneficial.
Personal notes are notes about one’s own reaction, inflections and experiences and they are complimentary to phenomenological interviews. On gaining access to the field, the suitability of identified areas and envisaged participants will be checked according to De Vos (1998:158).

Suitability of the area is assessing several characteristics; one of them will be accessibility of the participants to the researcher. In this regard Lobatse is thought to be appropriate; it is within reach of the researcher and will enable the researcher and participants to communicate when the need arises.

2.12 DATA ANALYSIS

Analysis starts after few steps in data collection have been taken, the emerging ideas guide the analysis (Holloway & Wheeler, 1996:102). There is a need to listen, observe and take notes during interviews so that sense can be made out of all the collected data (Wilson, 1989:15). Wilson (1989:15) is of the opinion that, when one puts data in relation to the research question, the meaning of the research objective emerges. In the process of data analysis, all records kept will be reviewed to discover any additional themes related to the findings of observations or interviews. Data analysis will be done as suggested by Tesch in De Vos (1998:343-344) where she describes eight steps to consider in data analysis.

2.12.1 Data assembling and organising

All data will be collected from transcripts of audiotapes in in-depth interviews, field notes and observation through naïve sketches. It will then be sorted into themes and categories.
2.12.2 Method of data analysis

Data obtained from interviewed family members living with a member suffering from chronic schizophrenia will be first be analysed in the language that it was collected. The purpose is to facilitate interpreting and to explain it in meaningful way. The findings will have to be categorised in an orderly manner. During the process, the researcher will have to become immersed in what the data "speak", so that she can fully understand it (Streubert & Carpenter, 1995:24). It is suggested that in order to have a fruitful analysis, one will need some degree of dedication to reading, intuiting, synthesising and reporting of what is discovered. In this study, the analysis will follow the method described by Tesch in (Creswell 1994:155).

2.12.3 Tesch’s approach

Tesch’s approach(1994:155) consists of the following;

a) The researcher ought to get sense of the whole information, reading through all the transcriptions carefully. She can then jot down some ideas as they come to mind.

b) The researcher selects one interview for example, the most interesting, the shortest, the one at the top of the pile and goes through it, asking “What is this about?” and thinking about the underlying meaning in the information. She writes thoughts that come up in the margin.

c) When the researcher has completed this task for several participants, a list is made of all points. Similar topics are clustered together and formed into columns that might be arranged into major topics and leftovers.

d) The researcher has a list and returns to the data. The topics are abbreviated as codes written to the appropriate segments of the text. The researcher tries out this preliminary organising scheme to see whether new categories and codes emerge.

e) The researcher finds the most descriptive wording for topics and turns them into categories. She endeavours to reduce the total list of categories by grouping together topics that relate to each other. Lines are drawn between the categories to show interrelationships.
f) The researcher makes a final decision on abbreviations for each category and alphabetised codes.
g) The data material belonging to each category is assembled in one place and a preliminary analysis is performed.
h) The researcher records existing data.

Following completion of data analysis, consensus discussions on the results will be held between the researcher and independent coder to affirm the authenticity of the findings.

2.13 LITERATURE CONTROL

Once data have been analysed, an evaluation of its significance and meaning will be done by comparing the results with similar research (Wilson, 1989:64). Direct quotations from naïve sketches and in-depth individual discussions will be utilised during discussions in order to ground the findings with previous researchers.

2.14 MEASURES TO ENSURE TRUSTWORTHINESS

Trustworthiness measures the quality of research. The purpose for ensuring trustworthiness in qualitative studies is to ensure that the study is valid and reliable (Streubert & Carpenter, 1995:318). Guba’s model (Guba & Lincoln, 1985:290-327) strategies will be employed.

2.14.1 Truth value ensured by the strategy of credibility

This is all about whether the researcher has established confidence in the truth of the truth of findings for the subjects and the context in which the study was undertaken (Guba & Lincoln, 1985:290-327). In qualitative research like this one, the truth value is usually deduced from the human experience as lived and perceived by informants. Truth value is ensured by the strategy of credibility through the following actions.

➢ *Prolonged Engagement.* This is a strategy which allows the participants to become accustomed to the researcher. This extended period of time is
important for enhancing rapport and helps participants to open up and give information that they would never give in the first instance or before they become familiar with the researcher. The researcher by virtue of being a community mental health nurse has worked and lived with the family members living with a family member suffering from chronic schizophrenia and other psychiatric disorders. Owing to her exposure, the researcher considers herself to be a person whom family members living with a family member suffering from chronic schizophrenia can safely confide their feelings and ask questions related to the study.

- Reflexivity encompasses the researcher’s awareness of her own influence on the data. One can further say, reflexivity refers to the assessment of influence of the investigator’s own background, perception and interests on qualitative study (Krefting, 1991:218). To meet reflexivity in this study, the researcher will be able to describe and interpret her behaviours and experiences by making use of field journal that will be kept throughout the research process (Lincon & Guba, 1985:290-327). This will include:
  - the daily schedule logistics of the study and the methods log in which decisions about methods and rationale are described.
  - field journal which is important for auditing purposes,
  - personal diary that reflects thoughts, feelings, ideas and hypotheses generated by contact with participants. It will also contain questions, problems and frustration concerning the overall research process.

- Triangulation. In research terms it means being able to show that more than one source has been used (Sapsford & Abbott, 1992:132) Triangulation is a powerful strategy for enhancing the quality of the research, particularly credibility. It is based on the idea of convergence of multiple perspectives for mutual confirmation of data to ensure that all aspects of phenomena have been investigated (Krefting, 1991:219). Furthermore, triangulated data are assessed against one another to cross check data and interpretation.
A number of types of triangulation exist, the most common being triangulation of data methods, which basically involves comparison of data in which various means are collected. In this study this triangulation will be met by use of research methods such as in-depth phenomenological interviews, observational notes and description of literature and naïve sketches. Various methods will bring their unique contributions and therefore compliment one another.

- **Peer review** - This will be achieved through discussing the research process and findings with impartial colleagues who have the experience with qualitative methods. Insights are discussed and problems presented as a form of debriefing. The objective behind peer review is to keep the researcher honest and may aid in the development of deeper reflexive analysis by the researcher owing to the fact that colleagues may help in increasing credibility by checking categories developed by the researcher out of data and identify disconfirming or negative cases.

- **Member checking** - It is thought that central to the credibility of qualitative research is the ability of informants to recognise their experiences in research findings. Member checking is a technique that consists of continually testing with informants the researcher’s data, analytic categories, interpretation and conclusion (Polit & Hungler, 1999 :429). In this study member checking will be done by playing summaries of taped interviews to participants for their responses and through interweaving of participants contact hours so that information from one interview is checked with other information before the subsequent interview with the first. The researcher will however be mindful of the ethical aspect of this strategy. This will be achieved through diligent selection of participants involved in member checking.

- **Authority of the researcher** - Miles & Huberman (1984) Identified four characteristics that are necessary to access trustworthiness of human instruments;
a) the degree of familiarity with the phenomenon and setting under study setting.
b) strong interest in conceptual or theoretical knowledge and ability to conceptualise large amounts of qualitative data.
c) ability to take responsibility of multidisciplinary approach; and
d) good investigative skills.

Examination of investigative skills or technical competence involves examination of researcher’s background for any special training he/she has received that is relevant to this project. In this study, the researcher is a qualified psychiatric mental health nurse with experience of interviewing and observational technique.

Structural coherence - This is about ensuring that there are no unexplained inconsistencies between the data and interpretation (Lincon & Guba, 1981). To attain this, the researcher in this study will interpret the apparent contradictions, account for rival explanations so that data are not necessarily consistent but are in fact credible if described and interpreted correctly.

2.14.2 Applicability ensured by the strategy of transferability

Transferability refers to the degree to which findings will be transferred to the other groups, contents and settings (Krefting, 1991:22). Transferability will be facilitated through purposive sampling of families living with a member who suffers from chronic schizophrenia and dense description of data, demographics and the results from direct quotations from the participants.

2.14.3 Consistency ensured by the strategy of dependability

This implies traceable variability, this is to say variability will be ascribed to identified sources. This criterion will assess the extent to which this study, when applied by using family members living with a family member suffering from chronic schizophrenia in a similar context will not provide the same results but rather increase
insight on parts of the research (Krefting, 1991:26). Dependability will be ensured by implementing the following strategies:

- Step-wise replication of data collection and data analysis.
- Code-recode method.
- Dense description of the research methodology.

2.14.4 Neutrality ensured by the strategy of conformability

Neutrality refers to the degree to which findings are solely of the informants and conditions of the research and not of other biases, motivations and perspectives (Guba, 1981). This will be met by relying on the above in this study. This is to say findings will be exclusively derived from data that were presented by families with a member suffering from chronic schizophrenia. The researcher having entered the field with a "blank state" or without any pre-empted ideas, moving from a point of not knowing to knowing to avoid biases. The researcher will stick to the objective of the study. Neutrality will be ensured by the strategy of conformability that the result will not be biased and techniques described above are reliable.

2.15 PHASE 2: FORMULATION OF GUIDELINES FOR CARE OF FAMILIES OF A MEMBER SUFFERING FROM CHRONIC SCHIZOPHRENIA

Guidelines will be derived from the results of phase one and a literature control will be included.

2.16 SUMMARY OF CHAPTER TWO

This chapter covered the research design and method in the process of the study. The methods of ensuring trustworthiness were also discussed. The next chapter will deal with the results from in-depth phenomenological interviews and naïve sketches of family members living with a member suffering from chronic schizophrenia.
CHAPTER 3

EXPERIENCES OF FAMILIES LIVING WITH A MEMBER SUFFERING FROM CHRONIC SCHIZOPHRENIA

3.1 INTRODUCTION

In Chapter Two, the research design and method for this study were discussed. The results will be presented based on identified themes and categories and obtained from in-depth individual interviews and naïve sketches of families living with a member suffering from chronic schizophrenia. The field notes that were made after the interviews will be incorporated into the analysis of data. Based on these findings, the support of relevant literature, guidelines of nursing care will be formulated.

This section will handle the discussion of results obtained from the individual interviews and results from naïve sketches written by participants.

Tables will be used for maintaining clarity. A Literature control will be integrated with the discussion of results to facilitate credibility, whilst direct quotations from the interviews will be utilised during the discussion. An example of this interview will be found in the annexure.

A data analysis protocol and all transcribed interview scripts will be sent to independent coder with knowledge and experience in qualitative research.

Analysis of scripts was conducted by using Tesch in Creswell (1994:154 – 155).

3.2 DESCRIPTION OF SAMPLE

Individual in-depth interviews were conducted with eight family members aged between 21 and 60, three males and five females, one male was a career person while the other two were unemployed. One woman was a professional, two of them were business women and the other two were unemployed. Naïve sketches were done by four people, all of them were females, two of the females were professionals, one a
nurse, another student for chartered accounting, and one was self-employed while the other one was un-employed. All the participants were blood relatives of persons suffering from chronic schizophrenia, of the twelve families interviewed, only two were parents, the rest were siblings, except for one who was a spouse and one who was a niece to the ill relative suffering from chronic schizophrenia. The participants met sample criteria of living with a family member suffering from chronic schizophrenia aged between 18 – 35 as it was the prime time for career development. Initial diagnosis of the family member suffering from chronic schizophrenia dated three years back. They all spoke Setswana or English or both. All the participants were aged above 21 years. And their place of abode was Lobatse except for one who abode in Gaborone and was chosen for pilot study purposes at the onset of interviews to satisfy the researcher about the feasibility and correctness of the study and was incorporated into other participants.

3.3 RESULTS

Table 3 reflects the major themes, categories and subcategories of experiences of families living with a member suffering from chronic schizophrenia in Lobatse:
Table 3.1: **Major themes and categories: experiences of families living with a member suffering from chronic schizophrenia**

<table>
<thead>
<tr>
<th>Major Theme</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-awareness about feelings experienced</td>
<td>Recognition of varying emotions:</td>
</tr>
<tr>
<td></td>
<td>• Shock because of schizophrenia diagnosis</td>
</tr>
<tr>
<td></td>
<td>• Denial about existence of mental illness</td>
</tr>
<tr>
<td></td>
<td>• Fear because of symptoms like thought disturbances</td>
</tr>
<tr>
<td></td>
<td>• Anger directed at the patient, family members and others</td>
</tr>
<tr>
<td></td>
<td>• Shame and uncomfortability with relative during exacerbation</td>
</tr>
<tr>
<td></td>
<td>• Pain associated with embarrassment in the social faux</td>
</tr>
<tr>
<td></td>
<td>• Blame because of wrong doings in the family</td>
</tr>
<tr>
<td></td>
<td>• Sadness and grief because of loss of ideal person</td>
</tr>
<tr>
<td></td>
<td>• Powerlessness because of lack of control over the relative's behaviour during exacerbation</td>
</tr>
<tr>
<td></td>
<td>• Stigma and rejection because of having a member suffering from chronic schizophrenia</td>
</tr>
<tr>
<td></td>
<td>• Hope and need for divine intervention for curing a family member suffering from chronic schizophrenia</td>
</tr>
<tr>
<td></td>
<td>• Acceptance to presence and chronicity of mental illness</td>
</tr>
<tr>
<td></td>
<td>• Uncertainty about practical care of a member suffering from schizophrenia</td>
</tr>
<tr>
<td>Role shift because of disturbed thought processes of a member suffering from chronic schizophrenia</td>
<td>• Sustained motivation: not succumbing to ridicule, rejection and stigma</td>
</tr>
<tr>
<td></td>
<td>• Recognition of psychological, behavioural, cognitive and physical changes: Recognition of positive changes like treatment compliance, calm, cooperative, and doing activities of daily living</td>
</tr>
</tbody>
</table>
3.3.1 Discussion of results

The discussion is based on themes and categories in Table 3.1. In order to facilitate clarity, the discussion will, where relevant, be sustained by appropriate direct quotes from the transcription and the literature. The main themes identified in this research are: self-awareness about feelings experienced, role shift because of disintegrated thought processes of family members suffering from chronic schizophrenia, empowerment of families living with a member suffering from chronic schizophrenia and expressed concerns and specific needs.

3.3.2 Self-awareness about feelings experienced

Self-awareness implies that one can focus attention on a particular experience and promote individual “knowing” of that experience. Awareness is a kind of turning inwards and willingness to recognise what is currently significant. As people begin to have this awareness, they can recognise the reality of their life situations. Only then
can they identify their contributions to life events, acknowledge the choice they make, and fully assume responsibility for themselves (Rawlins, Williams & Beck, 1993:30).

Self-awareness involves having at least a notion of how other people perceive one, how one come across to them (Thompson, 2000:85). Self-awareness as a major theme in the study was developed owing to the fact that the participants were aware of their feelings. Thompson, (2005:85) in describing self-awareness in his book says: “Self-awareness is keeping in touch with our feelings”. The participants displayed the following: shock, anger, fear and shame.

3.3.3 Shock because of the schizophrenia diagnosis

The initial period of illness for a patient and family who receive the diagnosis of schizophrenia is an extra ordinary difficult one. The patient and family may experience extreme fear, confusion, shock and anxiety. One woman verbalised shock and disbelief so much that she ended up believing that it is a curse from God that he allows her daughter to become mentally ill. This participant had this to say:

*Bolwetsi jo ke petso e e tswang mo Modimong, Modimo o nale dipetso tse di ntsi, bolwetsi jo ja ngwanake e ka tswa e le nngwe ya tsone!* (This illness is curse from God. God has so many curses and my daughter’s illness could be on of them!)

Another participant said

*Re hakgamaditswe ke bolwetsi ja ngwana yo! Rona mo lesikeng la rona g arena twadi e.* (We are all shocked about this disease! We don’t have this kind of ailment in our family).

Yet another participant said

*Re nnile le diemo tse di gwentlhang mo lwapeng lame, nako le nako fa re nna le kgothang nna le mosadi wame, kene ke tle ke bitse botsadi gore rarabolodisa kgang ka setswana, mme re ne re tle re tshwarwe ke kgakge ka maitsholo a mosadi wame!* (I have had devastating life situation in my marriage,
so much that whenever my wife and I had conflict and consulted with our parents to help in ironing out the problems traditionally, we were all shocked and marvelled at the way my wife conducted herself!).

As the family learns more of the severity of the diagnosis and long-term care and extensive rehabilitation, anger and shock abounds (Boyd & Nihart, 1998: 365).

3.3.4 Denial about the existence of mental illness

Denial is a defence mechanism that is described by the psychologist Sigmund Freud as an unconscious refusal to acknowledge certain distressing aspects of reality. This mechanism is mostly employed when one wishes to run away from the harsh and cruel realities of life. Denial is refusal to acknowledge some aspect of objective reality or subjective experience (Barlow & Durand, 2005: 19). The mechanism is fleeting and would only last when one in denial has not consciously chosen it. Denial when it is consciously chosen ceases to be genuine, for people cannot fool themselves into something that exists. Denial was expressed by some of the participants in both the naïve sketches and the interviews.

*Ke ne ke sa bolelela ka bolwetsi ja mosadi wame, ke ne ke bona gore sengwe ga se ya siama, mme ka seka ka dumela, ka kene ke foofaditswe ke lorato.* (I was not told about my wife's illness, I could see something was not right but was in denial because of the blinding effect of love).

Another participant had this to say in describing the shock she experienced.

*Golo mo ga ngwana yo, ke mewa ee sa itumelang ya badimo, go no go batlile go alashwa setswana, jaanong mathata ke tumelo ya boora nnake!* (*Our relative is not mentally ill as such, this is not mental illness, rather the gods are not happy with this child and have given her plenty of sprit, it is just that the parents do not want the child to be treated traditionally!*).
Stuart & Larai, (2001:858) has this to say about denial. It is avoidance of disagreeable realities by refusing to recognise them. This is certainly so, because of their cruel realisation that the situation is unpleasant to face and the mind engages in temporary escape, refusing to acknowledge that the undesired reality exists. This is done because when the families cannot tolerate the pain of acknowledging what reality would produce, they resort to denial. (Smith, Hoeskema, Fredrickson & Loftus, 2002:463)

Families dismiss the first indications that the family member may be mentally unstable, facing the situation as pointed out, as stressful and painful. Families deny, ignore and minimise the patient’s idiosyncrasies to maintain the family status quo. Although this coping choice delays intervention, it can provide a needed respite during which families can develop alternative strengths to deal with this chronic crisis (Fawcett, 1993:348).

Denial as a defence mechanism is used by the ego to fend off anxiety by preventing recognition of the nature of the threat (Nevid, Rathmus & Green, 2006:47).

Literature indicates that difficulty in accepting a chronic, severe illness is normal and that the first feeling is generally disbelief.

### 3.3.5 Fear because of the symptoms of thought disturbances

Fear is an emotional response to immediate, known, exaggerated external, definite or perceived dangers threatening. Fear is an emotion that is characterised by being afraid of specific danger or threat or harm focused on a particular object or experience (Stenrberg, 2001: 411). Fear was rife in all 12 participants. They verbalized feelings of fear secondary to patients’ disturbed thought processes, disruption in emotional responses and unpredictable behaviour, their wandering tendencies and bouts of aggression and violence. During the initial phase of the diagnosis and early stages, the signs and symptoms may both be confusing and frightening to the patient and family. Few families have had the experience with mental illness to help them deal with such behaviours. They do not know how to comfort their disturbed family.
member and may find themselves becoming fearful of his/her behaviour (Boyd & Nihart, 1998: 361).

One woman had this to say about her daughter during a relapse:

_Kene ke sa robale nako tseo, ke sa itse gore ao thudilwe ke koloi, ao bolailwe ke batho kana ba mmeditse._ (I never used to sleep during those days, I used to wonder whether she has been hit by a car, killed by people or beaten by people.)

Another participant said:

_Sometimes my brother really becomes aggressive, sometimes he beats us but sometimes he becomes exceedingly prayerful, sometimes is insulting and wanders about naked or wears underwear only. I become really fearful and shameful._

Swanson (1994:101-136) has suggested that people with a diagnosis of schizophrenia are more likely to have been violent than individuals without mental illness, albeit marginally. She says that people with schizophrenia account for three percent of total violence.

Others like Wesly (1997:8-11) cites a number of studies in which it is suggested that offending and violent behaviour among mentally ill people are related to the relatively high rates of pervert and poorer family history. In addition the existence of previous offending history before the onset of mental illness has also been identified as a factor in subsequent offending and violence.

What the authors have suggested is indeed a fear producing situation, more so when the family members do not have skills to comfort and pacify the ill relative with bouts of aggression and violence.
In addition to that, another participant in a naïve sketch said she is fearful for the patient's spouse and children and other people. He has paranoid delusions about people having an affair with his wife. She said she is afraid he might kill them.

Nevid, Rathmus & Green, (2000: 577) said fear is experienced when there is perception of specific danger or threat and tendencies to avoid threat of the feared objects. Such behaviours are tantamount to helplessness and powerlessness.

Families with a member suffering from chronic schizophrenia experience considerable stress. There is often pain and puzzlement about the vulnerable relative's behaviour and obvious distress, grief over lost hopes and fear for future possibilities, anger, guilt and self-blame (Baker, 2003: 267). What seemed to heighten fear in this study were the positive symptoms more than any other things. The family members feared for their own safety and that of other people as well as the patient's safety Fawcett (1993: 343) says, with recurring symptomatology, delusions, inappropriate affect and defective abilities to interpret language and perceive reality, schizophrenia tends to frighten and offend society.

People with a mental disorder (psychiatric diagnosis) are perceived or feared because they are thought to be dangerous, violent and aggressive (Fortinash & Holoday-Worret, 2000:13). This is sometimes not merely a perception but rather a reality. The family member has disturbed thought processes. His or her disturbed perceptions accompanied by bouts of aggression and violence, may prove to be a fear-inducing situation coupled with knowledge deficit in practical care of such behaviours. In addition, one woman in a naïve sketch wrote that she is fearful of her brother because he beats them, and she fears him when he adorns himself with underwear and wanders at night. This probably in keeping with what Hick (2005:121) says when he describes man's avoidance of danger as a normal human emotion. When aggressive bouts appear fear becomes rife because danger lurks in aggressions.
3.3.6 Anger directed at the patient's family and others

Anger is considered to be an inner feeling that people do not necessarily express in overt behaviour. Anger is a mask to cover other feelings that are more difficult to express. It is not easy for the family members to admit that they are hurting or afraid as this would acknowledge their vulnerability. In fact expressing anger is much easier than admitting helplessness (www.c.sulb.edu.ut).

In this study a participant displayed anger and directed it towards his spouse who locked him up in the house. He said:

I was very angry and sweaty, what annoyed me was that she was giggling without any remorse for what she had done.

People with schizophrenia are likely to assault those they live with or the mental health professionals who work with the, particularly the nurses (Ryan 1999:63). This is certainly so because people with schizophrenia may have difficulty in forming lasting relationships and may have a tendency toward isolation, resulting in increased dependency on close family members. In this circumstance, conflicts within the family, coupled with increased delusional and persecutory thinking can provide a trigger which may lead to violent acts. Ryan, (1999:63) further says that for some time random acts of violence against strangers are rare. The family by virtue of being with the ill relative suffering from chronic schizophrenia are vulnerable to violence from onset of the disordered thought processes that start in the home. Such behaviours may involve feelings of anger towards the perpetrators who in this case is the ill member suffering from chronic schizophrenia.

People can be especially uncomfortable with the parenting aspect of caring for a spouse with schizophrenia. Anger is disruptive of emotions indicative of displeasure, frustration and conflict. It is a compensatory assertive response by an individual to prevent feelings of utter helplessness and hopelessness from becoming overwhelming. The expression of these feeling is manifested in a variety of ways. Some are subtle and some measurably overt, covert or indirect. The transition through periods of limit
setting and behavioural controls is difficult and an ambiguous time for marital relationships (Fawcett, 1993: 343). The very same participant mentioned above said he was also angry when his wife removed her clothes to show her pregnancy to the visitor who had come to study the Bible with him. He says:

*I was very annoyed, my mouth went dry, and I was sweating and shaking.*

Another participant verbalised feelings of anger directed at the community that beats up their family member suffering from schizophrenia when she wanders away, and when she uses insulting language. She said

*Ke ikuthwa ke tlalelwa, ke sa itse gore ke ka dira eng, ka gore ba mmetsa mme ba itse gore ke molwetsi. (I feel very angry, I do not know what to do because they beat her up yet they know that she is mentally sick.)*

Anger is directed at the patient, but is more often felt toward family members, mental health care providers or entire the system (Stuart & Larai, 2001: 253)

Coping and adjusting often results in anger as family members try to avoid their fear. Although anger can be used to temporarily avoid dispiriting emotions, it can also undermine other sensitive family relations when channelled into blame and conflict.

### 3.3.7 Shame and embarrassment, uncomfortability with living with a member suffering from schizophrenia during exacerbation

The family is embarrassed and uncomfortable with a member suffering from schizophrenia during the exacerbation cycle. It is equally understandable when they try to withdraw from social situations. In this study one woman said “I was ashamed when my brother went to a wedding wearing a blanket and underwear” while the other one was ashamed by his wife sleeping with another man. He had this to say:
Ke matlhabisa ditlhong a a sa kaleng ka a bolela ope, kene ka didimala jaaka lesolę. (It is a situation that is shameful and I never told anyone about it, I kept quiet like a soldier).

Clients with chronic schizophrenia have little insight into their illness and suffer impaired judgement (Fortinash & Holoday-Worret, 2000:311). Owing to this, they may do things that are out of keeping with societal norms, and they lack inhibition and may do things that are uncalled for in the social milieu bringing embarrassment and shame to their family members. It does not just end with this only, this shame has given birth to pain. This was verbalised by the participants.

The participant who verbalised shame on grandiose delusions had this to say:

O nlhabisa ditlhong fa fosa are o godisitse bagolo bangwe mo motsing. (He makes me ashamed when he claims that he has brought up important people in the village).

Another participant had this to say about ill relative’s delusion bringing shame:

Sometimes he (the ill relative) ha a heightened sense of importance. This brings shame to the family as those who do not understand his disease, have their tongues wagging, destroying the name as they do.

Although the intensity and difficulties of chronic mental illness in any context would elicit social support and sympathy, the very nature and oddities of illness elicit stares, avoidance and embarrassment (Fawcett, 1993:343).

The adult person suffering from schizophrenia wants to be respected and self-directed, however delusional thinking and disturbances/distractions from internal stimuli may interfere with planning, commitment and rationale for his/her actions. This has in many instances invoked feelings of shame when the patient is let to
choose his own plans during periods of exacerbation. Family members may be embarrassed about the illness or fear that the family member with the mental illness will behave inappropriately in the presence of others. In this study two participants verbalised shame when the mentally ill people exhibited their bodies. Two participants verbalised shame about grandiose delusions while one verbalised shame on revelation of family secrets.

3.3.8 Pain associated with embarrassment in the social faux

Pain is an emotional phenomenon of the mind and as such it is a highly individualised subjective experience. Pain is real. Pain is hurt and pain is suffering, anguish and agony. It can be experienced emotionally, physically, psychologically and spiritually. There is excruciating pain, throbbing pain, tormenting pain, searing pain and pain associated with embarrassment as in the social faux. Rawlings, Williams & Beck, (1993:412) defines pain as a universal human experience. They say in the broadest terms that pain is personal, private sensation of hurt.

One participant in describing his pain said:

Ke ne ka nna le gone go tsena mo dinakong tse thata, ka dilo tse di thata go tlhaloswa, di ama kgang ya maikutlo, ka utlwa bothoko, ka utlwa ke nyenyefaditswe, ke lebetswe ko tlace, ke sena boleng, ke tletse boitlhobogo e bile ke sena tokololo ya go tswelela le seemo. (I have had an emotional turmoil, it is difficult to explain, it involves feelings. I felt pain, I felt despised, looked down, worthless, hopeless and unable to continue with the situation.)

This same participant further said in describing the situation:

Seemo sa go nna le molwetsi wa thaganyo se bokete, jaaka mokeresete o lebile Modimo, o batla go itshwara, mme go bothoko ka fa teng, ke seemo sa matlhabisa ditlhong, a ke sa kakeng kaa bolela ope gore mosadi wame o robetse le monna yo mongwe. (It is a difficult situation,
as a Christian you look up to God and you appear strong outside whereas you are paining and hurting very much inside, it is a situation that is shameful and I never told anyone that my wife is sleeping with another man.)

Another participant had this to say:

Fa o thokometse molwesi, o dira ka tsholofelo ya gore Modimo o tlaa go thusa, fela mme go utlwisa bothloko, go ama sebete o bona morwatwa a itshola ka maitholo a sa siamang, a bua mafoko a bosula, a dira duo tse a sa tshwanelang go di ra. (When you take care of the sick, you do it with hope that one day God will intervene but all the same its hurting and painful to see your loved one behaving abnormally and saying nasty words or doing things that he is not supposed to do.)

The words uttered by this participant are keeping with Saddock and Saddock (2003: 490) whereby they purport that seeing the deterioration in their children and siblings has caused excruciating pain to the family.

Pain in this study is psychological, based on countless cases of trauma and sadness following loss through schizophrenia. This help to explain why an individual is hurting, sad and grieving.

3.3.9 Blame because of wrong doings in the family

Blame is placing the responsibility of doing something wrong on another. Blame was rife in this study, directed at God, at the family members living with a mentally ill person and among family members. One said:

At first my daughter used to wander, sleep anywhere she pleases, eating what, I do not know and it pained me because people used to accuse me of letting her to wander.
Another said:

_Morago ga loso ga ntate bolwetsi bo bo etse morago, go nale kagiso le thitibalo_ (After my father’s death, the relapses are few, there is peace and order).

Blame here is directed at the late father. In a family system framework, it is neither helpful nor constructive to assessment or intervention to blame one member or one dyad. Another one said:

_Modimo o nale dipetso tse ditsi. Bolwetsi jo e ka tswa e le nngwe ya dipetso_ (God has several curses, and this illness is one of them.)

Blame here is directed at God. Another participant said:

_Ngwanake o seretse fela, o boitseme, o bodutu, ga a battle go dira sepe._

(My daughter is “mud like”, she is lazy, has poverty of speech and does not want to do anything!).

Blame here is directed at the ill relative, although blame may be warranted in the family situation, in most it is not. Blame in a family leads to alienation between the family and not only them but the treatment as well. Families, particularly mothers, often have been blamed for problems of persons with schizophrenia. Once a family member becomes disruptive, there is a high probability that it will have a negative effect on the family (Keltner, Schweke & Boston, 1995:369). In this study, the blame comes from all directions, owing to perceptions people have about the persons suffering from schizophrenia and their families.

Fortinash & Holoday-Worret, (2000:13) say that people with a mental disorder (psychiatric diagnosis) are feared or perceived as dangerous, violent and aggressive and are blamed for their illness. The following participant verbalised:
Contemporary views recognise mental illness as a phenomenon of the family system as opposed to past views which associated schizophrenia with deficiencies in early parenting, learning and communicating. These views later led to the concepts of the schizophrenic mother and later the father’s role in the illness process, no wonder were blamed or scapegoated for the pathology of their offspring and the identified patient viewed as victim. The current speculation however is that individuals get in families, they also work through illness process and get well in the families. (Joe & Collins, 1998:259).

For decades parents have been blamed inappropriately for the illness of their children. This has caused parents to be wary of psychiatrists and other mental health professionals. Blaming parents for the illness of their children is totally inappropriate (Saddock & Saddock, 2003:484).

3.3.10 Sadness and grief because of the loss of the ideal family member

Grief is a universal experience that may come with or without warning and occurs many times with varying intensity throughout life (Fortinash & Holoday-Worret, 2000:685). It is an emotional state experienced by an individual following a loss or prolonged deprivation. It occurs when an individual experiences loss of a person, treasured object or part of the physical self. In schizophrenia there is grief in terms of the loss of a person that was known before the illness and owing to recurrent patterns or cyclical appearance of the mental illness, the grief itself becomes recurrent, receding during remissions and returning again at exacerbation. One of the participants had this to say:

*Maitemogelo a mangwe a ke naleng one ke gore molwetsi wa lwapa la rona o tsaya dikgwedi tse 5 – 6 a tsogile sentle. Fa a tla go lwala ke bo ke tla go utlwa bothoko gape sesha, ke eletsa e kete mongwe o ka tla go*
mo nthusa. (One other experience I would like to share with you is that our family member with mental illness takes 5 – 6 months without relapsing, so normally when the condition recurs I feel so sad and sick from having to undergo the painful grieving experience again and wish someone can come and help me to take care of him).

Family members who value success and upward movement would likely have more subjective burden related to this situation than members who are comfortable with nurturing and supporting someone. In one of the naïve sketches one participant expressed grief and hurt over the lost opportunities for promotion for their relative owing to his recurrent relapses. She had this to say:

*My cousin drinks but complies with treatment. Generally, he gets relapses something like every two years or so. This has been a deterrent in his professional life and does not get promoted; this grieves me because I believe he has potential.*

These grief like reactions are secondary to the idealised expectation for the child (Baker, 2003: 268). One participant in verbalising grief said:

*Ke amega fela thata, ka gore ke a itse gore kgaitsadike o nale bokgoni jwa go ka itshetsa, e seng ene fela, one a ka kgona go nthusa mmogo le ba lelwapa, jaanong bolwetse jo ke sekgoreletsi mo go fitlheleleng seo. (I am very sad and grieve for I know that my brother has the potential of becoming self-sufficient, not only that but could also help me and the family and this disease is proving to be deterrent.)*

The very same participant talking of sadness and grief, said:

*I personally have feelings of grief, frustration, pity and annoyance at the same time. I feel frustrated when he continues to drink. I pity him because has married someone he did not fancy, but because she was tolerant to his condition. He married a cleaner but has always fancied professional ladies. I*
also pity him because he has become a comedy in the
neighbourhood and in the workplace in addition to the fact that
he is over-sensitive to gossip whether perceived or real,
compromising his quality of life.

Severe mental disorders like schizophrenia in the family entail a host of
responsibilities and burdens associated with care-giving but also severe emotional
strain, associated with loss, grief, chronic sorrow and living on an emotional roller

Grief is common and is related to the loss of a person the family knew before the
illness, as well as the loss of future that they expected to share with the ill member
(Stuart & Larai, 2001:253). Young clients who are just beginning the transition to
adulthood with plans for career and success, as well as their families must accept that
these goals may be unattainable. The family may experience chronic grieving and
sorrow, because the cyclic nature of schizophrenia gives no definite end point or
lengthy respite to complete mourning. This loss is enormous and perhaps stronger
than death. Certainly the remainders of "might have been" can be vivid, a distressing
part of family life (Fawcett, 1993:346).

3.3.11 Powerlessness because of lack of control over family member with
schizophrenia's behaviour during exacerbation period

Powerlessness is a perception that one's actions will not significantly affect an
outcome, a perceived lack of control over the current situation or immediate
happening.

Powerlessness normally goes hand in glove with fear and often results from families'
realisation that they are dealing with long-term recurrent illness. Most people believe
that a health care system will cure illness. When this is impossible they feel powerless
and frustrated (Stuart & Larai, 2001:253). This powerlessness compounds feelings of
uncertainty and fear because some members fear that the patient may be dangerous
because of the symptoms of the illness. The statement reading:
I rely on God and mental hospital for care of my daughter.

does not only depict uncertainty about practical care, but displays powerlessness as well.

Individuals who have led lives characterised by helplessness believe that their own action cannot significantly influence an outcome. This is related to their constant dependence on others to meet their needs and a resulting perception of lack of control. They come to doubt their abilities and may be criticised by others for their passivity (Wilson & Kneisl, 1996:333).

One woman had this to say:

_Batho ba motse ba betsa mme, ga ba ele tlhoko gore o lwala tlhaloganyo. Ga ke rate dititeo tseo, ke ikutlwa ke kgopegile, ke sena thata, ke feletswe, morago ke rapelela seemo._ (The villagers beat my mother; they do not take note of the fact that she is sick. I don’t condone to the beatings, I become emotionally overwhelmed, annoyed, angry, helpless and powerless and I later pray about it).

One participant verbalised powerlessness in living with a spouse suffering from chronic schizophrenia:

_I was just there in the relationship passively because there was nothing I could do. I no longer had the love that gives one strength to carry on with the relationship._

Society often devalues people with schizophrenia. People with severe mental problems are twice to be harassed in public as compared with people without schizophrenia (Berzins, Petch, & Arkinson, 2003:526-533).

Chronic illness by virtue of its unpredictable nature and concomitant losses precipitates powerlessness. When powerlessness was not contained hopelessness can
result. This is certainly true in this study for the family members who witnesses relapses after relapses and for some families, 3 out of 12 had two members suffering from chronic schizophrenia in the same family, same home.

3.3.12 Stigma and rejection because of having a member suffering from mental illness

Stigma is a shameful mark of difference and one that works as a partially effective sanction (Clinton & Nelson, 1999:5). Stigma has been described as an attribute or trait deemed by the social environment as unfavourable. Rejection and stigma go hand in hand, one cannot be separated from the other. Society values healthy, fully functioning individuals who are physically attractive. When children are found to be having a chronic physical condition that limits their ability to function fully in the environment they deviate from the social norms. Families of children with chronic conditions are confronted with adapting to having a child who is less perfect by society standards.

The stigma for those suffering from mental conditions results from the way people are branded with different labels. Dehumanisation through stereotyping and labelling is inflicted on those groups of individuals perceived as threatening to physical and emotional stability (Clinton & Nelson, 1999:4).

With recurring symptomatology of delusions, hallucinations, inappropriate affects and defective abilities to interpret language and perceive reality, schizophrenia tends to distance, frighten and offend society (Fawcett, 1993:343).

Stigma and rejection is a problem for relatives, the families cite stigma on the ill relative and themselves. One participant said:

Ke nale mathata a batho ba ba shemang nkonne fa a kgwa mathe kana itumile leleme fa ke mo isitse sepatea. (I have a problem with people who give my brother a dirty look when I take him to the hospital especially when he is spitting saliva or has bitten his tongue.)
Another one in a naïve sketch wrote that:

*Ke utlwiswa botlhoko ke batho ba ba sa bueng sentle ka molwetse wa rona ebile bare raya mafoko a a botlhoko.* (I am hurting because of words of rejection and stigma that are uttered by our neighbours about our mentally ill person and us.)

From the literature (Fawcett, 1993:297) it appears that regardless of the type of chronic condition, there are many similarities in this grief process which families undergo in their response and subsequent adaptation to the condition.

Stigma also presents major obstacles to developing relationships and adversely affects quality of life. Stigma which literally means shame is a major cause of social isolation of people with schizophrenia. Stigma often spreads to the whole family who may be having their own schizophrenia related problems stemming from embarrassment about having an illness in the family (Stuart & Larai, 2001: 412). The impact of stigma can be profound. It actually promotes "illness" by adding stress. It certainly adds unnecessary pressure to the lives of those who may be already experiencing unbearable strain.

Fawcett (1993:47-8) says that the mass media has made a concerted effort to improve the understanding and acceptance of those suffering from Acquired Immuno Deficiency Syndrome (AIDS). However, the same source has dramatised and incorrectly portrayed mental illness as flamboyant and unmanageable, with none of the sympathy accorded in other chronic situations. It is no wonder that families are embarrassed and uncomfortable with schizophrenia during the exacerbation cycle and it is equally understandable when they withdraw from social situations (Fawcett, 1993: 47-8).

3.3.13 Hope and need for divine intervention for curing a family member suffering from chronic schizophrenia

Hope is anticipated of a continued good state, and an improved state or release from perceived entrapment. It gives an incentive to keep going (Clinton & Nelson,
Hope is a desire for something to happen, combined with the expectation that it will happen. Hope does not disappoint (Romans 5:5). All the participants verbalised hope for the divine intervention that the Lord God would cure their loved ones. This hope was coupled with total surrender to God. They all relied on God for support, sustenance and provision of cure and this seemed to give them peace, strength and hope to carry on living with a member suffering from chronic schizophrenia. One of the participants said:

Ke ikantse Modimo gore a dire dikgakgamatso tse di tlaa hakgamatsang nna le batho ka go fodisa nnake, bolwetsi jo, ya nna fela dikgang tsa bogologolo jaaka a kite a fodisa batho bangwe. (I always pray to God, I lean on God that he should perform a miracle that will astonish myself and the people at large and cure my brother, so that his sickness becomes a story of the past as God once did for others).

Another participant said:

Fa o tihokomela molwetsi o dire ka tsholofelo ya gore Modimo o tlaa go thusa. (When you take care of the sick, you do it with hope that God will intervene).

Hope gives one an encouragement to try, change and trust which are essential in the recovery form major illness (Johnson, 1997:973). The families are demonstrating hope and trust in the divine being, and this for some reason has sustained encouragement in their care giving role. When a person acts and moves he/she achieves. Hope defends against a feeling of hopelessness, It enables an individual to tolerate a difficult situation and maintain motivation.

A participant said:

Ke neetse Morena tsotlhe ke botsogo ja ngwanake, mme ke a dumela ebile ke nale tsholofelo gore Modimo otlaa mo fodise (I have surrendered my daughter's ill health unto the Lord and have hope that the Lord will heal her).
Hope is an important concept in recovery literature. Some first accounts of schizophrenia describe hope as a turning point in recovery. Hope is experienced in the present but linked with the past and the future (Clinton & Nelson, 1999:26). The statement in simple terms is narrating, that the hope that the families living with a member suffering from chronic schizophrenia are displaying, is the one that gives them an incentive to keep carrying the burden of care in the present time and upon reflection of their past experience. They are motivated that things are becoming better and they hope for a continued good state or improved state. In other words it is the one that gives them a desire for something positive to happen to their ill member and expectations that it will happen. The Bible in Romans (5:5) says hope does not disappoint. Hope has been defined as a multidimensional construct that provides comfort while enduring threats and personal challenges (Fortinash & Holoday - Worret, 2001:718). It is force that gives the family members “a push” and inner strength to transcend the seemingly difficult challenges of living with a member suffering from chronic schizophrenia.

The need for divine intervention was coupled with hope in the study, these two were inseparable. The need for divine intervention has a firm and deep-rooted seat in one’s spirituality. It is this spirituality that allowed one to cope with feelings, fear, death and loss by providing a sense of meaning to experiences that would otherwise be crippling. Having a spiritual understanding that one’s connection with creation is more than merely physical, helps to ease fear, pain and loss. In this study the perceived loss is about the “ideal person” who has been lost to schizophrenia. The family’s connection and need for divine intervention eased feelings of grief, alienation as well as strengthened hope. Fortinash & Holoday – Worret, (2000:769) asserts that spirituality is a key component in the healing process.

Insights into ways in which spiritual beliefs have become a survival system of black people and their manifestation in the treatment have been expressed during the initial interviews. The most commonly expressed clues by the leader of spirituality or divinity consist of

a) “God will solve my problems”.

b) “God is punishing me for having sinned”.

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c) “The church is my salvation”.

The notion highlights the inner strength of a person and the power of his/her faith and belief system (Boyd-Franklin 2003:127). This was in line with what the participants in the study verbalised. Their need for divine intervention and hope is the one that sustain them to survive difficult situations laden with uncertainty.

3.3.14 Acceptance of the presence of mental illness and its chronicity

Acceptance involves an acknowledgement of dysfunctional change of agendas and an active process of experiencing feelings as feelings. Acceptance is affirming people as they a (Fontaine & Fletcher, 1999:94). Statements depicting acceptance were ones like this:

Ke ithobogile, Keamogetsa, ke neetse gotlhla Modimo botsogo ja ngwanake. (I have given up, I have accepted my daughter’s conditions and surrendered her health unto the Lord.)

Another participant said:

Ke amogetse bolwetse ja ngwanake, ke itshwantswantshanya le mosadi yoo naleng ngwana yoo naleng bogole. Ke ngwanake, o golafetse, ke taa tswelela ke ntse ke nna nae. (I have accepted my daughter’s mental illness, I liken myself with any other woman who has a child with a physical disability. She is my child, she is handicapped, i will continue to live with her).

3.3.15 Uncertainty about the practical care of a member suffering from schizophrenia

All participants verbalised feelings of uncertainty coupled with fear. Uncertainty is a cognitive state created when an event occurs that cannot be adequately defined or categorised due to lack of information. The degree of uncertainty is influenced by the
complexity of the event, the amount of ambiguity surrounding the event and other situational factors, such as previous experience (Johnson, 1997:927). In schizophrenia there is disturbed thought patterns, delusions, the hallucinations, and aggressive bouts and all the cardinal features bring about uncertainty on how to care for the patient and relatives living with him/her. The family is very important to the successful rehabilitation of a person with mental illness. The mental illness of a member is often a shock and a source of great stress. The impact of mental illness is shattering traumatic in the life of a family and as such, family members are ideal candidates for secondary intervention strategies. When the family is not equipped with intervention strategies then the uncertainty is likely to be more profound in relation to:

- a relationship between the family members and the mentally ill suffering from schizophrenia; and
- uncertainty about practical care for the patient. The families seemed to be having uncertainty with regard to how to relate with their members suffering from chronic mental illness. This was made clear by the way they talked about their relations during relapse. One had to lie and entice the mentally ill person when the other one relied on strangers and passers-by.

Fa nkonne o lwala ke a mo koketsa ke bo ke mo fora kere reye dishopong gore a tle a dumele go palama taxi, ke bo ke mo isa sepatela. (When my brother has relapsed I entice him and lie to him telling him that we are going to the shops when in reality I am taking him to the hospital).

One said:

Ke atle ke mo thusiwe ke ba feta ka tsela, ke ba kope gore ba mo kope gore o nwe dipilisi. (I normally ask for help from passers-by asking them to beg him to take treatment).
One gentleman said:

\[ Nna\ ke\ thusiwa\ fela\ ke\ Modimo\ le\ mental\ hospital.\ (I\ only\ rely\ on\ God\ and\ the\ mental\ hospital\ for\ care\ of\ my\ daughter). \]

When it comes to practical care of patients the family were found to be lacking in knowledge and skill and therefore uncertain about certain measures of care. The experience of uncertainty can range from a vague sense of feeling unsettled to being completely overwhelmed and unable to cope with the situation. All the participants knew that a calm and non-threatening environment was ideal. Patience, respect, love, ensuring food supply and compliance were necessary, nothing beyond that. They were uncertain about how to handle other features or symptomatology present in schizophrenia and relied on the health workers for such.

### 3.4.1 Role shift related to disturbed thought process

A role is a pattern of behaviour experienced by a person who occupies a certain position in a social system. It is a relationship with one or more individuals interacting in specific situations for a purpose (Sladen & Toit, 2000:21) A mentally ill person in the family similarly has a role to play, first by his/her virtue of being a family member and secondly as a worker or professional where there are dual roles. Each person has a certain role expectation congruent with societal norms as determined by the individual’s position or status in a group or relation. This has not always been possible owing to the nature of the chronic schizophrenia disease where there is delusional thinking, distraction of internal stimuli that interfere with planning, and commitment and rationale for actions.

Behaviours such as lack of motivation, poor handling of money, difficulty in completing tasks, non-compliance with medication renders one to become less functional. Younger siblings or the spouse have to take over from the mental ill person despite of him or her being older, more educated or having a better social standing. Any episode of illness may involve lasting changes in a person’s level of functioning. A person who has been seriously ill is more likely to have more
problems living productively in the community (Stuart & Larai, 2001: 246). One participant said;

*Ngwanake o seretse fela.* (My daughter is mud like).

On probing on exactly what she meant, she had this to say:

*Oa itsapa, o palelelwa ke go dira tiro tsa lelwapa, o setshwakga, o bodutu.* (My daughter is lethargic, lazy and reluctant to carry household chores and has poverty of speech).

The participant despite her age, the late fifties had a role, shift. She was cooking for her daughter and even playing surrogate mother for the mentally ill person’s child.

Another participant aged 21 said in a naïve sketch:

*I have been told by my grandfather many times from an early age that my aunt ‘ke segole’ meaning that she is handicapped and should be looked after despite the fact that she is six years older than me.*

Role reversal or shift in chronic illness and other necessary changes a family might make to adjust to demands of illness assume a more permanent character. A family becomes increasingly incompetent in stabilising the system and performing new roles in the family, the patient is seen as increasingly incompetent. Less is expected of the patient. Others are unavailable to fulfil the needed task (Joel & Collins, 1998:312).

According to the traditional concept of family roles the parents form a primal unit. They are authority figures in the family, making rules for behaviour and decisions for survival. The parents are seen as a unit and the children as dependents and are given less authority in decision-making. As children go of age, judgement and decision-making ability, they are granted more independence and participation in the decision-making process.
Contrary to all the above the mental ill person suffering from chronic schizophrenia did not graduate to the level of maturity of having to make their own judgement or being 100% independent because their decision-making abilities were sometimes grossly affected by the schizophrenia and hence the need for a role shift. The ill member becomes increasingly incompetent in performing roles and less is expected of him/her (Joel & Collins, 1998:312). It is the family in this study, who are negotiating a tenuous and sensitive balance between the need for protection and the need for independence.

Chronic mental illness can interfere with a person’s ability to parent his/her children effectively. As the illness worsens and a person’s ability to attend to personal responsibilities and care diminishes so does his or her ability to meet his/her child’s needs. The needs, therefore are, met by someone else, and role shift comes in. This was experienced by participants in the study.

3.4.2 Sustained motivation not succumbing to ridicule, rejection and stigma

Motivation is to act in a particular way, to create a state of intense desire, to inspire, stimulate an interest over something. In this study families living with a member suffering from chronic schizophrenia demonstrated sustained motivation and unwavering support to their members on the use of psychotropics. Maslow, the Psychologist who developed the hierarchical “Pyramid of needs” proposed that the utmost fundamental level we are totally driven by the need for physiological survival (Booyens 1993:460). We must eat, drink, exercise, keep warm and so forth. If these are denied, they ultimately take precedence over anything else. The family’s sustained motivation for treatment compliance, support and love can be equated to the need for physiological survival. One participant said:

Even though we suffer from stigma and rejection at the hands of our neighbours, we will continue to support our cousin in treatment taking, loving him and caring for him.
These families are not succumbing to ridicule, rejection and stigma.

One participant narrated that:

_Sometimes when you take the patient to the hospital, there are patients who look down upon the chronically ill patients but health workers always attend to the patient in a prompt and satisfying way._

This participant when asked how he feels about such people that he thinks they look down upon the patient, said:

_I try not to think too much about them and concentrate on my patient, whether he is loud, spitting saliva or biting his tongue. They (meaning the public) do not understand, and after all, they have and ailment of the same kind too._

Families who are involved with their children are tremendous assets to rehabilitation. They are of invaluable support for the patient that is difficult to replicate. Many families have done and will continue to do all in their power to help the ill member of the family (Sadock & Sadock, 2003: 500).

Goldman (2000: 248) says that most patients with schizophrenia benefit from prudent use of antipsychotic medication in combination with supportive psychotherapy and working with the patient’s family and significant others. This suggests that with the support of the family and antipsychotic medication, the wellness of the mentally ill is enhanced.

Motivation is a process that involves the purposiveness of behaviour, the process is brought about by factors that activate behaviour and influence direction and preservation, that is sustained effort of behaviour (Bergh & Theron, 2003:150). This is certainly true because amidst the stigma, rejection and blame, family members made a resolve to take care of their member suffering from schizophrenia.
3.4.3 Recognition of psychological behavioural, cognitive and physical changes: recognition of positive changes like treatment compliance, calm and corporative behaviour and doing activities of daily living

The family is the primary caregiver and by virtue of the fact that they have known and stayed with the relative for a prolonged period of time, they are always the first to notice any change in behaviour, either positive or negative. All the participants were able to tell when their significant other, being the member suffering from chronic schizophrenia was well. They cited calmness, cooperativeness, staying at home and helping with activities of daily living such as household chores. They have a need for food, water, rest and proper compliance to treatment, to cite but a few as positive behaviours.

One mother had this to say about her daughter:

*She eats, takes treatment, and stays at home, if ever she forgets treatment it will be like any other person.*

3.4.4 Recognition of negative changes: bizarre behaviour, wandering, neglect of nutritional needs, violence and aggression and thought disturbances

The participants cited wandering tendencies, violence, undressing or exhibition of body parts, thought disturbances, neglect of nutritional needs and rest, lethargy, poverty of speech, laziness as negative behavioural change. To demonstrate this one participant said;

*When my relative is unwell she normally wanders, talks a lot and reveals family secrets.*

While another recognised relapses by verbalizing that

*Nkonne oa tsamaya tsamaya, o huela ko godimo, gongwe a bitse maina a batho ba ba tona, a fose a re o godisetse batho bangwe, a*
*bue puo e re sa itseng.* (My brother will pace up and down, speaks loudly, calls out ministers’ names, and has heightened feeling of importance, lying that he brought up certain important people in society, speak a language that we do not understand).

Another participant said:

*Sometimes he (ill relative) will have very low mood and we would really get afraid because many times this has preceded a relapse.*

Another participant said;

*O nna mo gae, a leke-leke tiro tsa lwapa, a bue-bue le rona, a bo a ye kerekeng.* (She stays home, she talks a bit, helps a bit with household chores and agrees to go to church).

Stuart & Larai (2001:266-7) has revealed that family members are the first to realise that something is wrong with their relative, and owing to the fact that the diagnosis of mental illness has been done in retrospect, they are always more informed when it comes to notice of behaviour change.

One woman shares her thoughts in knowing her ill relative in a poem:

I know you are well, when you tell me a different story  
When I call this time,  
And you remember the stories you told me yesterday  
And the day before  
And you remember my responses to you  
And you ask me why

I know you are well when  
You laugh at a joke because you think it’s funny  
And not because of hidden implications  
You recognise the need for a hospital
And you realise that it is not the result of a political misstep
Or that the psychiatric wants to kill you
And you don’t second guess the dosage of the latest round of medications

(Dr Deen A. A. Nard July 2005).

3.5 Empowerment of families living with a member suffering from chronic schizophrenia

Empowerment is the process of assisting others to uncover their own inherent abilities, strength, vigor, wholeness and sprit (Smith & Maurer, 2000:7). The relatives displayed knowledge on the importance of compliance and the treatment regime and positive behaviours for caring for the mentally ill person such as being calm, being quiet, respectful, loving, patient and tolerant. Such behaviours may be associated with expressed emotion. Low expressed emotions are family factors that may protect against relapse, such as warmth and positive comments (Johnson 1997:573). The participants were able to identify potential problems and encouraged patients’ compliance with the treatment plan.

One participant said this concerning an unfavourable home environment:

_Rrarona o ne a re kgopa-kgopotsa ka mafoko, o ne a re buisa fela ka fa ratang ka teng, mafoko a lekgobo le kilo._ (My father was verbally abusive, he used to speak to us in any way, and was not just demeaning but hateful as well).

Two critical factors appear to be, family support and exposure to stressful living conditions. Studies of families of people with schizophrenia have found that the quality of communication and interactions may be either encouraging of discouraging the onset of schizophrenia in people who are genetically at high risk. The quality of family interactions may also influence whether future episodes of psychosis are triggered (Pastorino, & Doyle- Portillo, 2006:689).
The suggestion brought about by the authors is that communication patterns that are harsh, hyper-critical and intrusive make a high risk person more prone to the disorder.

The very same participant had earlier said:

_Rre o ne a swabisitswe ke kgaitsadike, one a mmitsa maina, a mo sotla, a mo kgokgontsha ka ditsela tsothle tse di kgonafalang gore a helele a le ko mental hospital._ (My father was disappointed by my brother, he used to call him names, ostracise him and ridicule him in every way possible until he was admitted in the mental hospital).

From what the participant described, one could tell that she knows that hostile behaviour could have a negative impact on one's health. She certainly did not condone to such behaviours and was blaming her late father for the non-therapeutic environment. Barraclough and Gill (1996:36) say that abnormal family relationships are no longer believed to be primary aetiological factors. If present they are probably consequences rather than causes of disease. However, they affirm to say patients living with critical over involved parents who display expressed emotions, are known to be at increased risks of relapse. This expressed emotion has been defined as a measure of relatives expressed attitude about the ill relative (Johnson 1997:573)

Another participant said this concerning favourable a home atmosphere:

_Barata difatlhogo tse di nyenyang, go retwa le go tlotlwa_ (The mentally ill person needs love, needs to be called by endearing names like happy, smiling faces and like to be respected).

3.5.1 Feelings of appreciation of intervention received at the hospital

Appreciation was prevalent in nine participants who participated in the study. Appreciation was directed at the health workers and the government for provision of psychotropics. One participant had this to say;
Ke leboga baoki ba re etelang ba bile ba re ema nokeng. (I thank the nurses for their support and visits).

Another participant said:

Ke Itumelela thuso e e bonako go tswa mo booking le bongaka. (I thank the doctors and nurses for the prompt and efficient service that they provide.)

Another one said:

Ke eletsa gore badiri ba botsogo ba ka tswelela ba re etela, ba re rutuntssha gore re nonohaletsa dikgwetho tse re kopanag le tsone me kokong ya botlhoko ja tlaloganyo. (I wish the health workers could continue visiting us and empower us and see to it that we are meeting the demands of caring for the sick.

One participant said:

I remember one time my brother had relapsed and I took him to the hospital, the nurse who attended him was patient and respectful towards the ill relative. The nurse came to visit us at the home one day, the ill relative who happens to be my brother was very excited and during the visit, he kept on saying, so I am somebody who can be visited by people who are not my relatives. This gave him peace and I was happy about the interventions we received.

Families are hungry for information about diseases that affect their members. A psychiatrist must be able to educate the family in groups, or in any way possible such as speeches, individual meetings, written material or telephone conversations (Saddock & Saddock, 1999: 3194). The participant above is really demonstrating the hunger for information of the disease that has affected their member.
Families require detailed education about serious mental health problems and those families need to acquire the ability to recognise symptoms of relapse. Furthermore families need skills in stress management and coping responses because the burden of trying to look after someone with serious mental illness can obviously overwhelm the family and other carers (Sanford, Gourney & Hancock, 1996:43). This is only possible when the health workers are proactive enough to bring in the interventions that the families are seeking for and appreciate.

3.5.2 Increased knowledge on the treatment regime leading to improved quality of life

The participants demonstrated that with good compliance the quality of life is improved, the relapses are few and functional levels increase. This was verified by this statement:

*Ngwanake o botoka, ga a tshwane le pele, dipilisi di mo thusitse, onna mo lwapeng.* (My daughter is much better, the medication she is taking has made a vast improvement, she stays home)

Another lady said:

*Treatment helps to keep in touch with reality for quite some time and if she does not comply she normally relapses.*

Non-compliance with psychotropics is the primary reason for in-patient hospitalisation (Stuart & Larai, 2001:251). The families in this study seem to subscribe to this idea as evidenced by their resolve to help the ill relative to take treatment.

3.6 Family members express their concerns and specific needs

An analysis of the data reveals that families living with a member suffering from chronic schizophrenia have concerns and specific needs.
The family is defined as a social system composed of two or more people living together that may be related by blood or marriage, or adoption (Clark, 1999; 364). In this study family means those with whom one lives and is related to. The families expressed varying needs and concerns. Among the list were a concern for empowerment, a need to be supported emotionally and a need for food security.

One participant verbalised this:

*I wish the health workers could continue visiting us and empower us and see to it that we are meeting the demands of caring for the sick, this disease is brought thoughts and nothing else.*

The family is believed to offer a supportive screen between family members and the rest of the world. Among shared responsibilities that appear in families are displaying acceptance of their members even with shortcomings, feeling a sense of belonging and connectedness, showing a caring attitude and compassion. The family is believed to care for itself.

Healthy and functional families have clear set boundaries that are permeable and this boils down to say that family members are free to take different roles. Having said this, there is a need to gain insight into the family’s personal relationship with a member suffering from chronic mental illness.

### 3.6.1 Inadequate family support and over-burdening example enduring day-to-day hassles

A family burden is defined as an overall level of distress experienced by the family in response to the illness. There is an objective burden that refers to practical problems such as paying medical bills and enduring day-to-day hassles and a subjective burden, which refers to family’s responses to the illness. It refers to the cascade of powerful feelings that families experience in response to illness (Valfre, 2001:373). In this study the families experienced both objective and subjective burdens. The varying emotions expressed like fear, anger, uncertainty, rejection and shame are a result of
the subjective burden, whereas, the need for food security is a cry for help in sharing the burden of caring are a result of an experience of objective burden.

Family members are stressed by burdens of caring for an unwell member or economic distress and need support to manage responsibilities, resolve concerns and prevent further functional deterioration (Baker, 2003:267). The most disturbing things associated with schizophrenia are the burden of caring and a role shift. One participant said:

\[ Mokgwelo \ wa \ tlhokomelo \ o \ tshwanetse \ go \ rwadisanngwa. \ Nako \ tse \ dingwe \ molwetse \ o \ kgopiswa \ e \ go \ bona \ motho \ a \ le \ mongwe \ fela \ nako \ tsothe \ a \ bo \ a \ gopole \ gore \ motho \ wa \ go \ na \ jalo \ o \ le \ tshwenyo. \ (The \ burden \ of \ care \ ought \ to \ be \ shared, \ the \ patient \ sometimes \ gets \ annoyed \ from \ seeing \ one \ person \ and \ think \ you \ are \ troublesome) \]

One participant said:

\[ Ke \ imetswe \ ke \ thokomelo, \ ke \ eletsa \ e \ kete \ mme \ o \ ka \ bo \ a \ tshela \ gore \ a \ thuse \ go \ mo \ tlhokomela. \ (I \ am \ overburdened \ by \ caring \ for \ him \ and \ wish \ my \ mother \ was \ alive \ to \ help \ in \ caring \ for \ him) \]

Another participant said:

\[ Ha \ e \ sale \ batsadi \ ba \ rona \ ba \ tlhokafala, \ ke \ nosi \ mo \ go \ tlhokomeleng kgaisadiake \ ere \ ntswa \ ke \ nale \ bo \ morwarre \ ba \ berekang \ mme \ ebile \ ba \ rutegile \ go \ mpheta, \ ga \ ba \ nthuse \ ka \ sepe. \ (Ever \ since \ the \ passing \ away \ of \ our \ parents, \ I \ am \ alone \ in \ taking \ care \ of \ my \ brother \ and \ yet \ I \ have \ other \ siblings \ who \ are \ working \ and \ more \ educated \ than \ myself, \ they \ are \ not \ helping \ in \ any \ way) \]

This is a typical example of an objective burden.

Most families with a member suffering from schizophrenia report that caring for an ill member places a burden on the family unit. The family burdens reported most often
are financial strain, disruption in family routines, worry about the future and feeling overwhelmed or unable to cope (Wilson & Kneisl, 1996:309). Other authors say that these families are operating at altered family functioning because of being burdened with a long-term responsibility of caring for a member suffering from schizophrenia. They are thought to be suffering from disruption in household routine, work, social interaction and physical well-being. It is further said that the family may bend to the client’s wishes fearing an increase in anxiety, possible fighting or shouting and this suffering can extend to work because of the emotional strain of living with a mental ill person. The family members as caretakers may be overburdened by the need to curtail social and occupational activities to attend to the behavioural and observable needs of the client bringing about isolation from others and eliminating sources of stress reduction and support, fuelling burnout and exacerbating family tension and conflict (Fawcett, 1993:345).

3.6.2 A need for food security because of the family’s inability to avail food adequately

Maslow, a giant psychologist who made a pyramid of needs has this to states the following concerning physiological needs. He said that at most fundamental level people are totally driven by the need for physiological survival. People must eat, drink, exercise and keep warm. If these are denied they will take precedence over anything else (Booyens, 1993: 460).

Almost all the participants the in in-depth interview verbalised the need for food or the inadequacy of food at home. One participant said:

_My brother wanders away in search of food in the neighbourhood and afar._

Another one said:

_Kgaitsadiake o atle a boele morago fa a jetse nala ko masikeng a a seng tlhaga le go apaya kana ba seno tsone dijo ka gore, a re dipilisi di a mo hekeetsa fa a sa ja. (My brother relapses whenever he visits relatives_
who are not keen to cook or who do not have food as he suffers from severe side-effects when he takes medication on empty stomach).

Another respondent said:

> I wish to say something, am not saying the government should spoon-feed us but we need to be assisted with food because this medication needs to be taken on a full stomach. In absence of food, compliance becomes poor because even the patients say they cannot kill themselves by taking treatment when hungry.

The environment plays an active role in determining stress factors and the ability to cope. There is also a definite correlation between socio-economic levels and health. A low socio-economic level leads to poor nutrition, crowded living conditions, maternal deprivation and a lack of self-esteem. The poor are at high risk for mental health problems because they are exposed to more stressors than the average person (Waughfield 1997:371).

3.6.3 Need for acceptance in the social milieu and extended support in the family

Acceptance is willingness to participate in life in an active and open manner (Eifert, Forsyth & Hayes 2005:69). Acceptance involves willingness to experience anxious thoughts, memories and feelings without acting to avoid or escape from the experience and circumstances that may give rise to them and without acting on the basis of what the mind may say and the meaning of events. Acceptance is accepting what it is together with responding to what it is in an appropriate way (Linehan, 1993:121). This certainly is in keeping with what the participants experienced regarding their acceptive behaviour and help them to experience the pain of living with a member suffering from chronic schizophrenia as it is without trying to escape
the harsh reality. This in a way has created a way forward of how best they can live with this mishap of chronic grieving secondary to schizophrenia.

One of the participants had this to say about the non-acceptive behaviour of their neighbours.

*Ke utlwa bothoko ka batho ba ba sa bueng sentle ka molwetse wa rona ebile ba re kgokgontsha ka mafoko* (I feel sad about the people who ridicule our ill relative and ostracise us as a family).

One participant said:

*I have come to realise that God has several curses and may give one to your family. I will just accept it and treat myself as a woman who has a disabled or handicapped child.*

The families have verbalised needs for acceptance following the experience of rejection and stigma that is displayed towards them, heightening the subjective burden. People live their entire lives in social situations. It is almost impossible to think of them without reference to the context in which they live, particularly their relationships with other individuals or groups. Social acceptance, therefore, is a very important aspect of life (Wright & Giddy, 1997). From assertions made by Wright and Giddy (1997) one can deduce that those who are not socially accepted are having a difficult time.

**3.6.4 Need for extended support**

Family members are stressed by burdens for example, caring for unwell members or economic distress and need support to manage responsibilities, resolve conflict or prevent functional deterioration (Baker, 2003:267). The family system does not operate as effectively as it might be and consequently individual members are subject to a stressful interactive process. Owing to this role of a family as a supportive screen between the health setting and society, it therefore follows that their need for support is funded. This was evidenced by responses such as these:
I wish my mother was alive to help me in caring for this mental ill person. My siblings do not help me in any way to care for our brother.

All the participants in the in-depth interviews verbalised the need to be visited by health workers often and appreciate when they did visit:

I wish the health workers could visit us often.

Parents, children and siblings of those with serious mental illness have demonstrated a need for education and support to reduce family burdens, prevent problems and promote adaptive coping skills (Stuart & Larai, 2001: 270). This statement affirms their need.

3.7 DISCUSSION OF FIELD NOTES

Observational, theoretical, methodological and personal notes were made as a method to collect data in addition to in-depth interviews and naïve sketches. The following themes were derived from data the collected, that is, self-awareness about feelings experienced, role shift because disturbed thought processes of family member suffering from chronic schizophrenia, empowerment of families living with a member suffering from chronic schizophrenia and expressed concerns and specific needs. Initially the atmosphere that prevailed during the interviews was formal, later family members became free and trusted the researcher and expressed their emotions freely and keenly.

As the interviews progressed, physical manifestation of inner distress were displayed as experienced by the participants such as clasping and unclasping hands, voices becoming louder or charged with emotion, narrowing of eyes, clearing of throat repeatedly, and shifting in the chair, starring into space and uneasy chuckling. It appeared to the researcher that the families just needed someone who would just listen without prejudice, they even verbalised that they wish the researcher would come quite often.
3.8 SUMMARY

The main themes that describe experiences (see Figure 3.1) of family members living with a member suffering from chronic schizophrenia were identified based on the analysis of data gathered during in-depth interviews. A literature control was made to verify the findings. The theme and categories and specific needs will be used in chapter four to infer and guidelines for nursing care will be formulated. Limitations and recommendations of the research study will be discussed.
CHAPTER FOUR
GUIDELINES OF CARE FOR A FAMILY MEMBER LIVING WITH A MEMBER SUFFERING FROM CHRONIC SCHIZOPHRENIA

4.1 INTRODUCTION

Chapter Four discusses the results of the study, which were derived from dense description of data through usage of in-depth phenomenological interviews and naïve sketches, field notes, observations and literature control.

See Table 4.1: Overview of identified themes, categories and guidelines

4.2 ADJUSTING TO A VARIETY OF EMOTIONS STEMMING FROM LIVING WITH A FAMILY MEMBER SUFFERING FROM SCHIZOPHRENIA

The family system of a person with schizophrenia has a demanding amount of input with which to deal with. Obviously, even before the illness recognition, the family is bombarded with unusual and incessant input that requires constant system modification. The barrage of input does not decline after adjustment to a diagnosis and initial treatment, rather the family must continue to deal with changes in rule, role and task structures. There is a demand for flexibility and adaptability from this stressful variability (Fawcett, 1993:343). The family undergoes varying emotions, a subjective burden which is a cascade of powerful feelings that the family operates in response to the illness. The families would try to normalise their relative's emerging symptoms for as long as possible, but eventually something happens to dissolves the illusion. Once tragedy is acknowledged, anger sets in, fear becomes an inescapable emotion. The subjective burden list includes grief, sadness, pain, shame and uncertainty. The list is endless. This is certainly in keeping with the Theory of Health Promotion (UJ 2006:5) assumption which purports that the person who embodies dimension of body, mind, and spirit functions in an integrated, interactive manner with the environment. In this study the researcher visualised the interplay of emotions and environment, with the psych that includes all the intellectual, emotional and
volitional processes of the individual, family and group taking a leading role in the process involved. In this case it is a variety of emotions experienced by the family members living with a member suffering from schizophrenia that present with an unusual and incessant input from the environment.
Table 4.1 Overview of identified themes in families living with a member suffering from chronic schizophrenia

<table>
<thead>
<tr>
<th>Identified themes and categories</th>
<th>Guidelines</th>
</tr>
</thead>
</table>
| **Self-awareness about feelings experienced** | ➢ Adjusting to a variety of emotions stemming from chronic schizophrenia.  
➢ Therapeutic supportive counselling |
| **Role shift because of disturbed thought process of family member suffering from chronic schizophrenia** | ➢ Practical care  
➢ at home  
➢ for coping  
➢ with regard to medication  
➢ for embarrassing behaviour  
➢ for things to remember  
➢ Acknowledge with the family members that their ill relative will not return home ready to resume his/her role and expect a continuation of recovery  
➢ Psycho-educate about the disease process |
| **Empowerment of families living with a member suffering from schizophrenia** | ➢ Provide skill and stress management  
➢ Diagnosis and treatment information  
➢ Behaviour management in the home milieu |
| **Expressed concerns and specific needs: inadequate family support leading to overburdening, need for food security, need for extended support** | ➢ Family consultation as opposed to family therapy  
➢ Form support groups  
➢ Liaise with social workers |
Regarding these emotions, the following can be taught to family members living with a member suffering from chronic schizophrenia:

- It is natural to experience these specific natural emotions.
- As a psychological being a person must experience emotion and express it. It is important to allow expression of family frustration and anger, even if it is directed to the mental health system although it may be difficult for the psychiatric mental health nurse to remain undefensive, remembering that anger is not personal but instead universally focussed may help the psychiatric mental health nurse to respond to these intense feelings with support and guidance, acknowledging the families pain from powerlessness to grief.

- Let the family members know that feelings are not controlled by holding them inside.
- Feelings are not controlled by pretending that they do not exist.
- Feelings are controlled by accepting them as personal and expressing them.
- Let them happen.
- Do not fight emotions or hold them back.
- Be aware of these emotions.
- It will be alright if these emotions take a natural course.
- It is often helpful to feel them more. The most important thing is to allow these emotions to exist and to be appropriately expressed (Johnson, 1977).

The nurse will avail herself for therapeutic purposes as depicted by the UJ (2006; 7) Health Promotion Model that reiterates that nursing is an interactive process where the nurse/midwife as a therapeutic professional, facilitates promotion of health through mobilisation of resources. In this case these resources are endowed within the families. The psychiatric mental health nurse will help the family members to unleash them for health promotion purposes.
4.2.1 Therapeutic supportive counselling

The psychiatric nurse's role here is to know that families seek assistance to overcome a flush of varying emotions. She should take a neutral stance, and offer positive warm regard in such a way that at the end of the day the families will perceive her as a real person in a real situation. Normally families present in disarray, its members are demotivated, frustrated, angry, helpless and with loss of control on initial meetings. Use therapeutic communication including open-ended questions, appropriate eye contact and supportive gestures to encourage venting of feelings and concerns. Listen with concern without being patronising or condescending (Gorman, Sultan & Raines 1996:93). This she will achieve by not becoming judgemental and not uttering negative remarks, conveying an attitude of reception and regard. Some outdated theories have blamed parenting styles for causing schizophrenia and as such it is imperative to convey acceptance throughout.

One approach to family therapy is based on a system theory. A family is seen as a system that will strive to maintain homeostasis or balance. A dysfunctional system cannot tolerate health in one member, the entire system must be made functional in order to restore health (Fortinash & Holday - Worret, 2000:532)

4.2.2 The initial phase

The essence of the initial phase is to hold the family to become full participants in the therapeutic process by developing trust and safety. This could be accomplished only if the psychiatric mental health nurse follows through agreements made on introduction, for instance demonstration of dependability, punctuality, willingness to discuss with the family, length of the meeting, location and confidentiality of information.

Therapeutic communication techniques as identified by Nevid et al,(2006:17) suggest listening for themes that run throughout the family stories using silence, to give the client time to collect and organise thoughts, think through a point, accepting, offering self, giving broad openings, offering general leads, making observations, encouraging description of perceptions, encouraging comparison, restating, reflecting, focusing, exploring, seeking clarification and validation, presenting reality, voicing doubts,
verbalising the implied, attempting to translate words into feelings and formulating a plan of action would be used.

To achieve this, rapport will be built at the outset. The communication technique is to be such that is not intrusive, being direct and not confrontational. The psychiatric nurse remains genuine as she becomes aware of the thoughts and feelings. The psychiatric mental health nurse tends to allow the families living with a member suffering from chronic schizophrenia a catharsis, which is the release of intense emotions (Nevid et al, 2006:17) with the nurse actively listening, observing the family, the relationship between them, the affect and demur, listening to what is not said, omission of feelings, reactions, thoughts, listening and identification of feelings. At the same time feelings are involved in relation with the family. Identify strengths and positive aspects of the family. The family is encouraged to bring out feelings and experiences into the open in the working phase.

4.2.3 The working phase

The objective is to relieve emotional distress. On attaining trust the psychiatric mental health nurse should observe cues and use direct words like “How is it for you to live with a member suffering from chronic mental illness?”

The main idea in the working phase is to understand the problem and to assist the family in translating this understanding to actions that work to their benefit. This would be made possible through unconditional positive regard, which is a process of accepting clients without preconditions, constituting an acceptance which is totally uncontaminated by judgement or evaluation or behaviour of clients (Clarke, 1999:35).

Unconditional acceptance will be demonstrated throughout, emphasising when the need arises. This will happen as the families share their experiences with the psychiatric mental health nurse listening to the cognitive and emotional experience in order to heighten trust and self-disclosure. Of utmost importance is the ability of the psychiatric mental health nurse’s attitude. Although the family is in therapy as a unit, occasionally the nurse may wish to work with one member on a particular issue.
The psychiatric mental health nurse in the therapeutic relationship acts as resource person, counsellor, surrogate and technical expert (Fortinash & Holoday - Worret, 2000:534). She/he has to be a genuine person. Genuiness, depicting absence of facade, a sense in which the counsellor allows his/her thoughts, feelings and attitude to flow freely within the relationship is of importance (Clarke, 1999:35). Her/his task is to work in the “here and now” and to reflect feelings that the family is experiencing and encourage them to verbalise them. Of critical importance are listening and non-judgemental responses, addressing the important themes that emanated from the experience of the family. The role of the psychiatric mental health nurse is to concentrate on the immediate experiences that take place, over the events in the current outside world to elicit catharsis and meaningful self-disclosure. At a later stage the psychiatric mental health nurse will look into the here and now that occurred in the therapeutic counselling session. The families are encouraged not to fight the emotions back or to hold them back, to be aware of the emotions and to express them. This will help to let go of the negative emotions instead of harbouring and internalising them. Problems related to roles are discussed with the nurse providing a perspective that they may lack. The psychiatric mental health nurse as resource person will improve the family with relaxation techniques, and diversional therapy as a way of dealing with the negative energy as appropriate for the family.

4.2.4 Termination phase

The termination phase is the final phase of the relationship. The termination phase is usually the gradual weaning off process when contact time with a helper is reduced. Ideally, termination should be done by mutual agreement (Reynolds & Cormack 1996:168).

The goal of the termination phase is to dissolve the therapeutic relationship while ensuring the family of improved ability to function independently. Preparation for termination takes time although it has been discussed on the onset of therapeutic relationship, it will occur when the family has accomplished the appropriately defined goals and has improved to a higher level of sufficiency.
Health adaptive behaviours are reinforced. The family members are informed that healing occurs outside the counselling therapy. The family is frequently encouraged to make changes in its routines, interact with the community, home assignments to complete the next session and a caring and encouraging attitude conveyed. Successful termination requires the psychiatric mental health nurse’s ability to resolve negative feelings of supportive counselling. The nurse continues to be non-judgemental with positive warm regard to the family even if they experience, apathy directed at the nurse of institution. The psychiatric mental health nurse will help the family to acknowledge the gains of the therapeutic alliance. This they will do together. The nurse will also share his or her perception of the work, what she/he has learnt from the family. The family members who failed to adjust positively during the working phase will be referred accordingly if they are willing for further management.

4.3 GUIDELINES TO UNCERTAINTY ABOUT PRACTICAL CARE

Schizophrenia strikes at the very heart of what we consider the essence of a person. Yet because its manifestations are so personal or social it elicits fear, misunderstanding and condemnation in society instead of sympathy and concern (Whitebourne & Halgin, 2000:324). Looking at the assertions made, one is not wrong to assume that uncertainty is rife in the world of families of members living with a member suffering from chronic schizophrenia. It therefore follows that guidelines for practical care are imperative.

**At home**

- Know how to behave towards the relative, what to say to ascertain that expectations are realistic.
- Aim to help your relative to become as independent as possible, consistent with the extent of disability.
- Recognise that moving towards independence involves much trial and error.
- Recognise that persons suffering from schizophrenia must learn to cope with new and demanding circumstances.
- Learn the most effective ways of speaking to and behaving towards the relative.
Try to understand gestures and facial expressions.
Speak directly in clear, short simple sentences in a supportive way.
Allow him/her to take time
Be prepared to listen for fairly long periods even if what the person is saying is not making sense.
Be patient.
Think ahead of time of discharge about safety measures, for example, consider putting locks in some doors.
In the early stages, discuss frankly the risks of drugs and alcohol and the question of sex. This should be consistent with the degree of the relative’s maturity.

Hygiene

With regard to hygiene, encourage responsibility for proper hygiene but lend a hand occasionally. The following is suggested:
- Run a bath
- At first you can put clean clothes in the room and eventually the person will get the idea and will do it himself/herself.
- Make him/her realise that laundry and keeping the room clean is part of hygiene.

Exercise

Most clients with chronic schizophrenia prefer to stay in bed, therefore there is a need to encourage exercise to invoke an interest in wellness.
- Encourage walks.
- Try to rekindle interest in sports.

Sex

This should be discussed factually and unemotionally.
- Direct questions should be answered with guidance as to where to get information.
- Advice on contraceptives needs to be given openly.
4.3.1 Suggestions for coping

The families of members suffering from chronic schizophrenia are hungry for information about the disease that affects their member. No opportunity to educate should be missed (Saddock & Saddock 2003). The following suggestions should be observed:

a) Speak with a slow paced and low tone of voice. Use short and simple sentences to avoid confusion.
b) Explain clearly what you are doing and why you are doing it, for example, I am putting your clean clothes in your closet.
c) Establish a structured and regular daily routine. Be predictable, be consistent. Do not say you will do something and then change your mind.
d) Offer praise continually. If a patient combs his/her hair after three days of not doing so, comment in how attractive he/she looks.
e) Avoid over-stimulation, reduce stress and tension, for example, eating meals with the family may be too overwhelming at first.
f) Persuade him or her but never force your relative to take his or her medications. Keep all medications appointments.
g) Try not to be overly involved or critical.
h) Try to enlist the support of other relatives and community support staff.

4.3.2 Guidelines to practical care with regard to medication

Most people with schizophrenia benefit from prudent use of antipsychotic medication. The family is highly instrumental in encouraging good compliance. It is advisable that the suggestions below are observed.

a) Know that initial medication must continuously be monitored. Therefore you should listen to your relative’s complaints about side-effects. Empathise with any distress about medication.
b) Know that bad symptoms will not appear immediately upon discontinuation of medication. They stay in the system in a period of six weeks to three months.
c) Explain to your relative that he or she may end up in hospital if medication is not taken. This should not be a threat.

d) If other people in family are on medication, turn pill taking into a ritual. Everyone takes his or her medications at the same time.

e) Never sneak pills into food, if paranoia exists, this will increase it. Trust will never be built up.

f) Do your best to be calm and reasonable about getting your relative to take medication. If you press too hard, you may make it more difficult for your relative to move to greater independence (www.worldofschizophrenia.org).

4.3.3 Embarrassing behaviour

Clearly outline and reach an agreement with your relative about what behaviour will be or will not be tolerated and examine your own attitude about why you are allowing yourself to be embarrassed.

➢ Be direct and honest
➢ Remember that some behaviour will take longer than others to correct. Much patience is needed.
➢ Assessing the relative without taking blame for embarrassing behaviour that may occur.
➢ Keep your sense of humour.
➢ Be polite to bystanders. Assume they are understanding and tolerant.
➢ If necessary, apologise and explain the situation to anyone involved in the embarrassing situation.

4.3.4 Things to remember

Keep a dairy on schizophrenia. One main reason for keeping a diary is to recall important information to share and discuss with mental health providers and others involved with the family. The diary will help the family to express themselves in more concrete and factual manners when under stress. Recordings should include medications used, their various side effect. This will come in a quite handy reference for informing the mental health providers of all drug related issues. Records include
day, time, and duration in a clear precise and point form. It will also enhance interest in your relative, helping you in reflecting and demonstrating the severity of the situation.

4.4 ROLE SHIFT

Guidelines for the recognition of role shift – Acknowledge with the family members that the member suffering from schizophrenia will not return ready to resume his role and expect a continuation of recovery.

Because of the person suffering from schizophrenia’s repeated exits and entries into the family system, role boundary is always a problem. Even if spouses or parents are physically absent for long periods, they still possess a psychological family presence. Families may modify roles and boundaries during absences, only to realign the structure when the client returns and expects his or her roles and rights to remain the same. Many a times an adult suffering from schizophrenia wants to live a self-directed and fulfilling life, yet this has not been possible at all times because of the disease process, hence the need for a role shift. The family should be given psycho-education so that they could learn to develop realistic expectations (Fawcett, 1993:347).

➢ The member will not return home ready to resume his or her place in the family and society. The family should expect a continuation of the recovery period and thus emphasise predictability and structure, encourage behavioural change and treatment compliance, and provide for gradual increases in autonomy and responsibility. This will certainly curb disappointment and anxiety as the client slowly progresses and recuperates (Fawcett, 1993:347).

➢ Negative symptoms are a source of confusion for relatives, who may rarely recognise them as part of the illness. This point is worth emphasising since relatives find emotional and behavioural deficits of schizophrenia very difficult to both understand and cope with. Relatives feel that the client is in control and acting on their own volition, hence lack of activity, conversation or emotion and dissatisfaction (Barrowclough & Tarrier, 1992:8).
4.5 GUIDELINES FOR SUSTAINED MOTIVATION

The family has been seen as a critical factor in successful management of the problem rather than its cause (Redder, McClue & Jolly 2000:214). For successful after-care programmes of ill members, the adaptive patterns and health functioning of family the guidelines for motivation are suggested below:

- Firstly identify the strategies that the family knows and is using and those that they do not know. Enhance motivation by teaching problem solving, assertiveness and positive self-talk, including stress and anger management.
- Avoid self-blame and destructive criticism.
- Try not to neglect other relationships, for instance in the family, parents should not neglect their children who are well.
- Realise that life must go on for others in the family.
- Never lose hope.
- Keep your religious beliefs.
- Recognise that successful treatment and workable after-care programmes require the coordinated effort of several groups of caregivers.
- Spend time with caring, supportive and optimistic people.
- Decrease unhealthy self-destructive behaviour.
- Be aware of your own health on day-to-day basis. Eat nutriously. Get enough sleep.
- Engage in hobbies.
- Positively reinforce behaviour.
- Give praise for adaptive behaviours.
- Encourage mutual support within the family.
- Challenge regressive behaviours.
- Challenge maladaptive behaviours.

4.6 RECOGNITION OF POSITIVE BEHAVIOURS

Capitalising on strengths: encourage, support and compliments.

With time the patient may show signs of being able to handle more responsibility.
The following should then to be done:

a) Discuss with your relative how she/he feels about doing more things.
b) Begin with mastery of self-care tasks, such as personal hygiene and getting dressed.
c) Encourage, but do not push, your relative to take part in social gatherings.
d) Assign household responsibilities.
e) Do not be too inquisitive; do not always ask your relative, “What are you thinking about?”
f) Understand that although it may be difficult for your relative to have conversation with you, she may enjoy your company in other ways. Consider television watching, listening to music, talk about childhood events.
g) Avoid constant petty criticism. Identify major behaviours and learn how to deal with them in an honest, direct manner.
h) Be forgetful. Say something like, “I forgot the sugar, can you please get it.”
i) Encourage your relative to take responsibility. Leave instructions about supper in case you are getting home late.
j) Try to be a friend, talk as a friend would, for example, “would you come with me tonight?”
k) If your relative is a church member, encourage someone from the church to be his or her friend. (Some of your relative’s age mate).
l) Always try to put yourself in your relative’s place, respect his/her feelings and do not say, “Don’t be silly”.
m) Respect wishes and concerns as much as possible
n) Respect your relative’s concern about the illness.

4.7 GUIDELINES THAT MAY HELP WHEN NEGATIVE CHANGES OF BEHAVIOUR ARE RECOGNISED

Providing information to family members regarding practical care of persons suffering from schizophrenia.

Serious mental illnesses such as schizophrenia have a major effect on behaviour, not least in common manifestation of apathy and poor motivation. Simple behavioural
techniques such as reinforcement may be used to great effect. Families need particular help in identifying behavioural goals and be advised regarding the use of appropriate methods of reinforcement, for example, simple activity schedules and time tables may be helpful in training both patient and relative in the use of behavioural diaries. It may give them considerable information about the patient’s condition.

- Remain as calm as possible, decrease destructions, turn off the television. If people are present ask them to leave the room.
- Talk one at a time. Try saying “Let’s sit down and talk or let’s sit down and be quiet”.
- Speak slowly in a normal voice.
- Make statements of behaviour you are observing. “You are afraid/angry/confused”.
- Avoid patronising authoritative statements like, “You are acting like a child”.
- Repeat questions and statements when necessary.
- Allow personal space.
- Do not stand over him/her or get too close.
- Too much emotion on your part can upset your relative.
- If it is possible to have your relative to go to the hospital voluntarily encourage that, provide choice of whom to accompany.

4.7.1 Don’ts

Certain behaviours are considered to be counterproductive in the ill relative, suffering schizophrenia’s milieu and such should be avoided.

- Do not shout, if your relative is not listening it could be because of your voice.
- Do not criticise. Your relative cannot be reasoned with at this point.
- Do not challenge your relative into acting out.
- Avoid continuous eye contact.
- Do not argue with other people about what to do.

Family crises are emotionally draining and may escalate into an event involving the police or mental health services. As time goes on, these families tend to become more
isolated and feel more frustrated, helpless and hopeless even though they care very much about the patient (Kelner, Schewke & Boston, 1995:371).

4.7.2 Homicidal – Do’s

One of the cardinal features of schizophrenia is disturbed content of thought presenting in delusion. The delusions being false beliefs that remain fixed in the person’s mind despite their illogical bases and lack of evidence to support them. The delusions may take an upper hand in controlling one’s mind leading to acts of homicide. In the event of the homicidal ideation, observe the following:

- Secure the person with schizophrenia in a room when you look for help.
- Call the police if the situation demands.
- Use your judgement about better chances of responding to tactics.

4.7.3 Suicidal

There will be times when people do not respond to medication in the community, when their families are no longer able to guarantee their safety, and when the future looks so bleak and hopeless to them that they speak of wanting to commit suicide.

Indirect threats to friends and family members include references to being better of dead, discussion of suicide methods, burial, statements such as “If I see you again ...” and dire predictions about the future. Whether direct or indirect, communication of suicidal intent usually represents a warning and cry for help (Carson, Butcher & Mineka, 2000:262).

When the relative talks of suicide or wish to die or get concerned about a will after his or her death and gives away his treasured possessions, expresses feelings of unworthiness and shows signs of hopelessness about the future, shows signs of hearing voices or seeing visions that may be instructing him/her to be harmful/dangerous do the following:

- Take this seriously
➢ Take him/her to the hospital or nearest emergency department if possible (McGovern & Whitcher 1994:115).

If there has been a suicidal attempt

➢ phone the police
➢ perform a Cardiac Pulmonary Resuscitation (CPR) if you know how to do it.
➢ do not try to handle the crisis alone
➢ contact support groups

4.7.4 Disappearance

Similarly, if the person suffering from chronic schizophrenia talks of leaving, or has wandering tendencies, do the following:

➢ If your relative says anything about places he or she is interested or would like to see or visit some time, jot it down. It could be a useful clue as to where to look should your relative disappear.
➢ If your relative decided to travel, try to think of some way of staying in touch. For example, arrange to keep the ill relative’s money, whenever the money is needed, the ill member will contact the family and not so much will be given. This will help in keeping contact.
➢ If the family has an idea where the relative has gone to, get in touch with the police and village elders.
➢ If the family has lost touch with the member suffering from chronic schizophrenia for a period of time, it is not wise to wait too long before you begin searching with the police, the neighbours and village elders.

4.7.5 Hospital admission

The bizarre behaviour of a deranged family member can produce an intolerable situation in which not only treatment but hospitalisation is a welcome respite (Cockerham 2003:272). In view of the assertions made by Cockerham, hospitalisation
is warranted and the best option. The hospital provides different types of rules and regulations that have to be followed for smooth operation. These regulations may differ according to the mental health treatment received, the degree of psychological problem and grounds for admission.

➢ Be conversant with various types of admissions (voluntary admissions, reception order and urgency order) and the Mental Health Act of Botswana concerning admission, when to apply and who is fit to apply for them.
➢ Familiarise yourself with the hospital set up. Know the assigned doctor, nurses and social worker.
➢ Know visiting times, activities, and familiarise self with routines of the ward
➢ Be polite and assertive when talking to hospital staff.
➢ Ask for clarification of all answers.
➢ Do not settle for a jargon or vague information.
➢ Ask for meetings with the assigned psychiatrist.
➢ Keep record of everything while you remember, list questions, names and number of attended meetings.

Consider your relatives' complaints realistically, act on complaints that appear real rather than imagined. If you feel that your relative is been badly treated or is not receiving adequate care, and polite approaches to the immediate care-givers fail to resolve your concerns, you may wish to raise the matter with the nurse-in-charge. Do all you can to make it clear to your relative that the period of hospitalisation is important.

4.7.6 Don’ts

Certain behaviours are repulsive and thwart the good intentions of the health professionals. The following should be observed.

➢ Do not be rude.
➢ Do not come late for appointments.
➢ Do not allow yourself to be intimidated.
➢ Do not intimidate staff and do not criticise specific staff members.
4.7.7 Treatment

Family interventions have been found to be effective as an adjunct to drug therapy in the management of schizophrenia (Gillam 2002:105).

➢ Treatment involves both medication and counselling depending on the severity of symptoms. It is important for you and your relative to understand what is involved in treatment and to take an active role in planning the most suitable cause.

➢ It is important to know about treatment and side-effects.

4.7.8 Discharge plan

Following the admission and intensive management of schizophrenia the ill relative may show signs of improvement and may be ready for the after-care program in the home environment. Preparations for this program should be undertaken prior to discharge. Observe the following:

➢ When your relative is in hospital, make the hospital aware that you would welcome assistance in planning for what should happen when your relative is released from hospital.

4.8 GUIDELINES FOR EMPOWERMENT OF FAMILIES LIVING WITH A MEMBER SUFFERING FROM CHRONIC SCHIZOPHRENIA

A guided family support and education group will facilitate individual family growth and understanding.

Empowerment is defined as a process of helping people to assert control over factors that affect their lives (Martin 1995:30). Enhance empowerment through psycho-education techniques in a group set up, the essence being to provide families time to express their feelings for the nurse to understand how to meet each group’s unique needs. Psycho-educate families, they require detailed education about serious mental health problems and also need to acquire the ability to recognise symptoms of relapse. Furthermore they need skills in stress management and coping responses.
because of trying to look after someone with serious mental illness can be overwhelming.

- Diagnosis and treatment information, for instance,
  - fact of illness and treatment
  - intricacies and vocabulary unique to psychiatric treatment
  - concentrate on explanation of the patient’s behaviour
- Purposes, actions, and side-effects of psychotropics
- Functional and dysfunctional copying strategies
- Diffusing family energy – focussing on each member’s needs
- Behaviour management in the home milieu
- Monitoring the patient’s progress, stress, symptoms and early warning signs
- Coping with stigma
- Stress management and relaxation techniques
- Problem solving skills
- Reinforce positive behaviours for care, for instance patience, love and provision of a calm environment
- Maintain or improve interventions appreciated by families of members living with a member suffering from schizophrenia.

When facing challenges of mental illness, family members tend to seek support from family members and close friends, they also turn to other with similar experiences. This involvement of other family members in care giving validate the care giver’s experience and provide a mutual supporting environment that encourage personal growth while meeting challenges in coping with mental illness. Families may also seek support from other families who are facing similar challenges. Participating in the social group also lessens social isolation and provides opportunities for family members to grow by gaining knowledge about mental illness, learning advocacy skills and becoming more confident in capacity for care giving (Saunders , 2003). This in is in line with facilitation as stipulated by the UJ’s (2006:5) Health Promotion Model. It reads: facilitation is a dynamic, interactive process for health promotion through the creation of a positive environment and mobilisation of resources as well as bringing of obstacles in health promotion. The guided family support groups are meant to create a positive environment through mutual support, mobilising of resources.
through strategies such as diffusing family energy, problem solving identification and
dealing away with obstacles in the promotion of health like stigma, stress, grief,
dysfunctional coping and mobility.

4.9 GUIDELINES FOR EXPRESSED CONCERNS AND SPECIFIC NEEDS

*Family consultation as opposed to family therapy offered on one time, intermittent or continuing basis.*

Family consultation as practiced by the mental health professional has much in common with the consultation offered by services offered by architects and financial planners. Just as the family consults architects about a dream house, or financial planners about egg nests, families consult a mental health professional functioning as a family consultant for help in creating a family action plan for dealing with mental illness. The objective of family consultation is to enhance coping, competence and heighten family satisfaction (Valfre, 2001:376). The theory of Health Promotion in Nursing, University of Johannesburg (2006:5) states that the sensitive, therapeutic professional demonstrates facilitative knowledge, skills, attitudes and values in promoting health. Gorman, Sultan & Rathmus (1996:20) is also of the same opinion when it comes to the therapeutic professional. She says therapeutic communication is the art of reaching a person by means of verbal or non-verbal messages. Acceptance, respect, honesty, trust, concern, protection and support must all be present for communication to be present. The researcher will try to observe this throughout her interaction with the family members. This will be made possible through:

- Intensive listening to the families under stress
- Communicating in a simple, clear language, maintaining humility to check frequently with the family to make sure that communication remains genuine to their self-defined needs or assistance
- Appreciation and knowledge of families’ cultural diversity
- Increase the family and individual’s self-confidence
- Effective use of functional coping strategies
➢ Increase understanding and acceptance of the member suffering from schizophrenia
➢ Provision of support and normalisation of feelings and experiences
➢ Improve behavioural management techniques and skill training
➢ Improve problem solving and stress management skills
➢ Increase the family’s efficiency in managing resources.
➢ Teach relaxation techniques
➢ Referral to the support and advocacy group.

4.9.1 Accommodation of needs for food security

The need for food security is a basic need and therefore ought to be regarded as an urgent matter for survival. It therefore follows that the following ought to be done:

➢ Liase with the area social worker for food security and refer accordingly.

4.9.2 Guidelines for the need for acceptance

Acceptance is all about demonstrating an interest in another person’s behaviour and feelings, communicating that he/she is valued. This is possible through community health education. Community health education is basically an application of a variety of methods that will result in the education and mobilisation of community members in action for resolving health issue and problems that affect them (Breckon, Harvey & Lancaster 1994). The following is suggested:

➢ Form support groups.
➢ Network with key workers in mental health like the District Commissioner, the police, other workers and the community. This will sensitise them on mental health issues and soften their attitude towards the mentally ill persons and their families.
➢ Give psycho-education in public places, print brochures and fliers in the local language and official language and leave them in public places.
➢ Recognise mental health day and give it the needed publicity.
4.9.3 Accommodating the need for extended support

The idea here is to reduce the burden of caring. Family education should target family members themselves as primary beneficiaries of intervention, aiming to provide education and support will increase the family members’ well-being and quality of life (Allen, 2000:367).

The following should be observed or done:

- Form support groups.
- Offer psycho-education on the concerns of the family.
- Allow the family members to say how best they can be supported.
- Refer when the need arises.
- Do home visits.
- Talk to the family at a level that is right for their emotional maturity.
- Do not give false hope or inaccurate information.

4.10 GUIDELINES FOR RECOGNITION OF POSITIVE BEHAVIOUR

- Positive behaviour will enhance health.
- Reinforce behaviour for care that is love and provision of a calm environment.
- Psycho-educate the family on positive behaviours. This will augmentate their knowledge base.

4.11 SUMMARY

In Chapter Four the discussion of the results and formulation of guidelines were done based on the major themes that were derived from the data collection on the experiences of families living with a member suffering chronic schizophrenia.
CHAPTER FIVE

5.1 CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

In Chapter Four the results of this study were discussed and a literature control was conducted. Chapter Five discusses the conclusions, limitations and recommendations.

5.2 OVERVIEW OF RESEARCH

The objective of the study is to explore and describe experiences of families living with a member suffering from chronic schizophrenia and to formulate guidelines of care. Attempts to meet this objective commenced by making use of a qualitative, explorative and contextual design. Fieldwork was done to collect input from family members living with a member suffering from chronic schizophrenia. In-depth phenomenological interviews and naive sketches were employed. The results were obtained, analysed and categorised. The results from all data were contextualised and a literature control was carried out. In this way, findings were validated. A full description of the research methodology was applied in Chapter Two.

Four main themes were identified that indicate how family experience living with a member suffering from chronic schizophrenia.

The first theme reflects self-awareness of the varying emotions the family experience. This subjective burden includes fear, anger, shock, grief, pain, powerlessness, blame, sadness, denial, hope and a need for divine intervention. According to this research study families living with schizophrenia experience these feelings in response to illness. Schizophrenia is distressing for everyone involved. Parents clearly suffer from great disruptions to their lives. Family and friends will also be seriously affected and distressed because of the effect of schizophrenia has on their relative and the burden of caring for the beloved one. Coping with schizophrenia can especially be difficult for relatives and friends who remember their loved one before the illness. (www.psychiatry24x7.com ).
A category of uncertainty with regard to practical care of the member suffering from chronic schizophrenia was also noted. The family living with a member suffering from chronic schizophrenia had little knowledge with practical care and as such the researcher capitalised on psycho-education.

The second theme is role shift, which was rife in almost all the family members. The role being a pattern of behaviour expected from a person who occupies a certain position is a social system having attachments and obligations. This traditional concept of family roles, with the parents forming the primal unit and the children as dependents was not always realised owing to the inability of members suffering from chronic schizophrenia's inability to fulfil their roles secondary to the crippling effect of mental illness. Similarly some parents experience role shift/reversal of having to take care of their grown up children and their offspring because schizophrenia has incapacitated them.

The category of sustained motivation and not succumbing to ridicule and stigma was noted. Mental illness remains a stigmatised and feared condition. Stigma is defined as a negative social reaction. It also reflects social devaluation and negative labelling of the individual (Moon & Gillispie, 1996). The bearer of the label is frequently viewed inferior. Contrary to speculations made by Moon & Gillispie (1996) the family members living with a member suffering from schizophrenia did not succumb to the pressures of stigma, ridicule, ostracism and rejection. They were fortified to take care of their ill member amidst this ridicule. They withstood the challenges.

The category of recognition of positive changes, behaviourally, cognitively, socially and physically. This was observed by the family members in their ill relative.

The category of recognition of negative behaviours like bizarre behaviour, wandering, neglect of nutritional needs, violence, aggression and thought disturbances was indicated by family members.

A major category of empowerment of families living with a member suffering from schizophrenia was demonstrated through increased knowledge on the treatment
regime leading to improved quality of life, positive behaviours for care as well as feelings of appreciation of intervention received at hospital.

A major category was identified for expressed needs and concerns. The family expressed the specific needs for support following inadequate family support which has lead to overburdening. A need for food security, for acceptance and for extended support was verbalised.

All the guidelines generated by the collection of data, inference and deduction later were discussed in accordance with the main themes and related categories that emerged from the data.

5.3 LIMITATIONS

The method of data collection was both phenomenological in-depth interviews and naïve sketches. Of the twelve participants, eight preferred the interview and as such information on the naïve sketch was comparatively smaller compared to the interviews.

The colleagues who were supposed to help the researcher with purposive sampling took their time and tossed the researcher between the management offices before helping her. Initially the sample had 13 participants, but one participant had to be dropped because she did not want to be audio taped nor write naïve sketches she just wanted to talk and talk with no field notes taking despite the explanations given to her.

Some people have shown interest participating in the study but did not honour appointments and the researcher had to make more appointments for later dates.

The colleagues who were supposed to help the researcher with purposive sampling tossed the researcher between management offices before helping her.
5.4 RECOMMENDATIONS

Recommendations will be done to the following fields: the psychiatry nursing practise, nursing education and research.

Recommendations stated here are based on their applicability to clinical procedures, nursing education and nursing research and to the research field.

- Firstly, the guidelines described in this research study suggest practical advice to support families living with a member suffering from chronic schizophrenia. The guidelines were formulated in relation to the major themes and categories that emerged from data collection on experiences of families living with a member suffering from chronic schizophrenia.

5.5 CONCLUSION

The summary in Chapter 5 concludes guidelines in care of family members living with a member suffering from chronic schizophrenia, for Clinical Practice, Nursing Research and Nursing Education.
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ANNEXURE I : ETHICAL CLEARANCE FROM UNIVERSITY OF JOHANNESBURG
TO WHOM IT MAY CONCERN

TITLE OF RESEARCH PROJECT: “Experiences of family members living with a family member suffering from chronic schizophrenia in Lobatse”.

RESEARCHER: Moahi S

SUPERVISOR: Prof M Poggenpoel

The Committee for Academic Ethics of the Faculty of Health Sciences of the University of Johannesburg evaluated the research proposal and consent letters of the above research project and confirms that it complies with the approved Ethical Research Standards of University of Johannesburg.

The study supervisor and researcher demonstrated their intent to comply with approved Ethical Research Standards during conduct of the research project.

The following recommendations are made by the committee which will improve the quality of your proposal and render it fully ethically compliant.

- How will it be established that patients with schizophrenia has been correctly diagnosed?
- 20% of the research will be done off campus – is this correct – see page 1 of the registration form.

The changes must be re-submitted to the supervisor/s to their satisfaction.

On behalf of the committee, I would like to wish you luck with your studies.

Kind Regards

Ms M H SELOLO
FACULTY RESEARCH ADMINISTRATOR
FACULTY OF HEALTH SCIENCES
HIGHER DEGREE COMMITTEE

31 July 2006

TO WHOM IT MAY CONCERN

TITLE OF RESEARCH PROJECT: "Experiences of family members with a family member suffering from chronic schizophrenia in Lobatse"

RESEARCHER: Moahi S
SUPERVISOR: Prof M Poggenpoel

The Faculty Higher Degree Committee scrutinised your proposals and confirm that it conditionally complies with the approved research standards of University of Johannesburg.

The following recommendations are made by the committee which will improve the quality of your proposal.

1. Executive summary poorly structured with lots of grammatical errors.
2. Information on methodology and design is limited, Procedure, interview structure is not stated. How is the research going to identify the appropriate households without an ethical breech?
3. Possible outcomes is not stated in the executive summary.

Wishing you all of the best with your studies.

PROF P'SINGH
CHAIRPERSON: HIGHER DEGREES COMMITTEE
ANNEXURE II: PERMISSION FROM HEALTH RESEARCH UNIT, MINISTRY OF HEALTH, BOTSWANA
Research Permit: “Experiences of family members living with a family member suffering from chronic schizophrenia in Lobatse”

Your application for a research permit for the above stated research protocol refers. We note that you have satisfactorily revised the protocol as per our suggestions. **Permission is therefore granted to conduct the above-mentioned study.** This approval is valid for a period of 1 year effective October 11, 2006.

This permit does not however give you authority to collect data from the selected households without prior approval from the head of the household. Similarly, consent should also be sought from all the participants.

The research should be conducted as outlined in the approved proposal. The title should be reflected as indicated above. Any changes to the approved proposal will need to be resubmitted to the Health Research Unit in the Ministry of Health.

Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research Unit, Ministry of Health within 3 months of completion of the study. Copies should also be sent to relevant authorities.

**Approval is for academic fulfillment only.**

Thank you,

S. El-Halabi

For Permanent Secretary Ministry of Health
ANNEXURE III: CONTRACT FORM IN ENGLISH
Dear prospective participant,

I am Sefentse Moahi, a M.Cur (Psychiatric Nursing) student at the University of Johannesburg. I invite you to participate in my research.

The central question is "How is it for you to live with a family member who suffers from chronic schizophrenia?"

The objective of the study is to explore and describe experiences families living with a family member suffering from chronic schizophrenia in Lobatse. The aim of the study is to elicit experiences from families living with a family member suffering from chronic schizophrenia so that guidelines of care and recommendations can be formulated. It will take between forty-five minutes and one hour for each participant for an in-depth interview. You are kindly requested to give permission to use a tape recorder and the need to write notes for reflexive purposes. These audio tapes will be kept under lock and key and after they have been transcribed will be destroyed. Alternatively, the participant may choose to write an essay of her/his lived experience on living with a family member suffering from chronic schizophrenia.

Your identification will be protected to ensure anonymity and confidentiality.

Please note that participation is voluntary, and that you opt to withdraw anytime from the study without penalty, and take cognisance of the fact that no remuneration in cash or in kind is promised.

The benefits of participating in this study are not directly personal but have a long term benefit of emotional fulfilment through contribution to the welfare of self and others when the results of the study are being put to use.

The researcher will offer herself to answer questions raised by the participants.
The possible risks of participating in the study are remembrance of painful experiences, and self-disclosure to unfamiliar persons. To minimise this risk counseling will be provided accordingly or referral done as the case may warrant.

You may reach me at Mobile No. 72856173 or email at sefmoahi@yahoo.co.uk if you have any questions.

The local person to be contacted about the participants rights is Mrs Shenaaz El-Halabi at the Health Research Unit, Telephone number 391 4467 / 363 2018.

Sefense Moahi (Reseacher)

Supervisor
Prof M. Poggenpoel

Co-supervisor
Prof C.P.H. Myburgh
I voluntarily give consent to participate in the study.

I understand that I am not obliged to continue to participate in the study and can terminate or withdraw from the study whenever I wish.

I understand that no form of remuneration is promised.

Signature of the participant .......................................

Date ..................................................................

Signature of the researcher .......................................

Date .................................................................
ANNEXURE IV: CONTRACT FORM IN SETSWANA
Go basupa kgatlhego,

Leina lame ke Sefentse Moahi, ke moithuti wa dithuto tse dikgolwane tsa botsogo ja thaloganyo (M. Cur psychiatric Nursing) kwa unibisithing ya Johannesburg. Ke le laletsa ba tsaya karolo mo dipatlisisong tsatsethogo se se reng "Maiphetlhelo a ba lelwapa le le tshelang le molwetse wa botlhoko ja thaloganyo jo bo boaboelang molwetse".

Potso ya konokono ke "Maiphetlhelo a gago ke a fe mo go tsheleng le molwetse yoo boelelwang ke botlhoko ja thaloganyo?"

Maikalelo a dipatlisiso ke go huputsa le go kaya iphetelo ya malwapa aa nneleng le go tshela le molwetse wa go go boaboelwa ke bolwetse ja thaloganyo mo Lobatse. Keletso ke go batlisisa maipithlelo a ba malwapa a a tshelang le molwetse yoo boeboaangelang ke bolwetse gore mmatlisisi a dire ditsetla tsa tlhokomelo ya balelwapa ba ba okang molwetsi yo.

- Puisanyo e tlaa tsaya selekanyo sa masome a mane go houra e le nngwe.
- O kopiwa go leta mmatlisisi go dirisa sekapa lentswe, le go ka kwala dintilha e le tsele ya go itsa go lebala.

Sekapa lentswe (tapes) se tlaa bewa fa go babalesegileng e bile se lotlolelwa.

- Batsaya karolo ba ka nna ba ithophela go kwala polelo ka maiphetlhelo a bone mo go tsheleng le molwetse wa botlhoko jo thaloganyo jo bo boaboelang.
- Bomang-mang ja motho bo tlaa serelediwa ka go tlhoka go dirisa maina, aterese kgotsa eng fela se se ka fang bokao ja gore o mang.
- Ela tlhoko se, dipatlisiso di tsenelelwa ka go rata ga motho nteng ga patiko, O ka nna wa lesa go tsaya karolo nako nngwe le nngwe.

- Ela tlhoko, ga o tshephisiwe tuelo epe.

- Maduo a go tsenelela dipatlisiso tse, ga a bonwe ka matlho, mme a a busesa mo moyeng ka go rokotsa maikutlo a go bo motho a nneile mosola mo go thuseng ene ka sebele le ba bangwe fa maduo a dipatlisiso a dule e bile a dirisiwa.

- Mmatlisisi o tlaa araba dipotsa tsa batsaya karolo.

- Tse di ka kaiwang disa jese diwelang mo dipatlisisong tse, di ka akaretsa, kgakologelo ya ditiragalo tse di seng monate, go ipua mo mmatlisising. Go fokotsa dintla tse, maikutlo a tla a thobiwa (counselling) ke mmatlisi kgotsa a go golaganye batsaya karolo le bathoba maikutlo ba ba ngwe.

Fa mo tsaya karolo a sa itumelela maitholo a mmatlisisi kgotsa a batla go bua ka ditswanelo tsa ba tsaya karolo, o ka bua le Mrs Shenaaz El-habi, Chief Research Officer ko nomoreng ya 391 4467 / 363 2018.

Mmatlisisi o a ka tshwarwa ko nomorong ya 72856173 or email ya sefmoahi@yahoo.co.uk.

Nna ......................................................... / mothokomedi, ke itetla go tsaya karolo mo dipatlisisong.

Ke tlhaloganya gore ga ke patikege go tswelela le dipatlisiso fa ke se battle, e bile ke ka lesa go tsaya karolo nako nngwe le nngwe.

Ke tlhaloganya gore ga ke a tshepiswe tuelo epe.
Monwana wa motsaya karolo

Letsatsi

Monwana wa mmatlisisi

Letsatsi
ANNEXURE V: REQUEST FOR ASSISTANCE AS INDEPENDENT CODER
University of Johannesburg
School of Nursing
Department of Psychiatric Nursing
Auckland Park

Dear Mrs Temane

I am kindly requesting you to be an independent coder for the research entitled “Experiences of families living with a member suffering from chronic schizophrenia in Lobatse”.

Your acceptance will be highly be appreciated.

Yours faithfully,

Sefense Moahi
M. CUR Psychiatry Student
ANNEXURE VI: EXCERPTS FROM TRANSCRIPTS OF INTERVIEWS
Researcher: How is it for you to live with a family member who suffers from Chronic Mental Illness?

Participant: (Clears throat)

Mh - Mh My sister, I have had a very tough time! A very tough time even though I may look well. But I’ve had devastating life situations in my marriage, so much that whenever my wife and I had a conflict and consulted we were consulted with our in-laws to iron out our differences, traditionally, everybody would just marvel at the way my wife conducts herself.

Researcher: Mb - Mh - Mh, may I interrupt. Could you please elaborate exactly what you mean when you say you have had a tough time, and devastating life situations?

Participant: (Maintains eye contact)

I mean that I have had an experience of living with someone who was not mentally stable. Which I did not know about on entering the marriage contract although this was a blessing in disguise for me and for her.

Researcher: You have just mentioned that this was a blessing in disguise. Can you explain further exactly what you mean?

Participant: (Clears his throat again)

It was a blessing for me because, I got to know my wife better and we discovered that all along she was secretly getting help from the Mental Hospital. She had been seeing a psychiatrist for about two to three times, and it was a blessing for her because as the ailment progressed, it was quite
obvious that she would seek appropriate intervention in form of counseling. And I got to understand the nature of her ailments.

Researcher: Mh – Mh. I am interested in all that you are saying. Earlier on you mentioned that everybody in your family used to marvel at the way your wife conducted herself whenever you had conflicts. Could you please tell me what the conflicts were all about?

Participant: (Looks up) Mm.., I am a Christian, and so was my wife. From time to time, like morning and evenings I would listen to Gospel music. Each time I played this music my wife would become so angry that she would shake and become agitated. She would tell me that only rock music comforts her.

Researcher: Mh Mh – I am listening, just continue talking.

Participant: So my wife continued to get angry whenever I played gospel music until one day her sisters came visiting and was annoyed by her fit of anger. Her sister said to me, “Would never understand the reasoning that is influenced by schizophrenia”. This annoyed her even further.

Researcher: You keep talking about anger and annoyance, can you say more about this.

Participant: (Nods his head) My wife used to get very angry and annoyed when I went to church. Although we were members of the same church, she stopped going to church and one day as I was preparing to go to church, she made sure that she locked the burglar bar and left the other door unlocked so that I could not go out. I could
see her basking in the sun and giggling, cutting her finger nails as if nothing abnormal had happened!

Researcher: Ehee Rra. You have just told me about your wife’s behaviour. I am interested in knowing how you left when she locked you up.

Participant: (chuckles uneasily)

You know what; I was very angry and sweaty. What annoyed me was that she was giggling without any remorse for what she had done to me. I felt like beating her up but let’s thank the lord that for she sustained me and I did not act out what I felt. I had an emotional turmoil.

Researcher: Mh Mh. Is there any other experience that you would love to share with me?

Participant: Emma. There was this other time that I invited her friend to church, and that day she decided to come along, but she made sure that she dressed in a very unacceptable manner.

Researcher: Can I please interject, exactly what do you mean by unacceptable dressing.

Participant: (Claps and unclaps hands)

I mean she would dress in a manner that is out of keeping with our church doctrines like adoring self with jewellery, short skirts saying I want to revolutionalise the way you look at things.

Researcher: Whom is she referring to when she says “I want to revolutionalies the way you look at things”? 
Participant: (Nods his head)

She meant the church community. She knows all the Doctrines but in short, she later decided otherwise and I went with her friend who does not belong to church but had removed her jewellery. This annoyed her and she did not want to speak to me, later did not greet the visitor but kept passing by, so I said to her. Let me introduce you to this young man. In response she said to the visitor, “Are you married?” When the visitor said not yet, she removed her jacket to expose her pregnancy and said “When you marry, make sure you behave like a gentleman and outshine this thing”, meaning me. “He has impregnated me but is shy to be seen with me!!”

Researcher: Ehee, Ehee! Am interested in knowing your feelings with regard to the situation you have just described.

Participant: (With a voice charged with emotion)

I was very annoyed, my mouth went dry. I was sweating and shaking and we decided to stop studying the Bible. The friend left, and the thought of spending the night with her was detestable. I felt like beating her, but I didn’t because if I did, I might have gone to the prison. I took my clothes and spent the night elsewhere, called in our significant others because the matter was now out of hand.

Researcher: The matter was now out of hand. What exactly do you mean by this?

Participant: (Narrows his eyes)

The situation was out of control because I realised that I was very angry and I did not want to fight so I protected myself from fighting against her by
moving away from home for a week and it was only after traditional counseling that we managed to stay together again because this time around she was remorseful for her actions.

Researcher: Okay, can I take you back to the statement you uttered on starting the interview? You mentioned that initially you were not told on your wife’s mental illness and you would like to expose the feelings surrounding that.

Participant: (He has pressure of speech)
Well, I was not told but I could see that not all was well and I was in denial because of love. In any case let me rush to tell you some other things and I will come back to that. My wife continued to hate church and one day when I had gone to church she went to see a certain officer in connection with official duties who later slept with her. Later on she turned around to say, this man had slept with her because he could see that she went about unprotected, alone, yet she consented to go to the man’s bedroom!

Researcher: I realise that you are talking in a loud voice and would like to probe further your feelings regarding this accusation.

Participant: (Licks his lips)
You know I did not trust my wife and believe did believe she did this to spite me. Nevertheless she killed all the love I had for her. I went to God and pleaded my case, for I realised that Christianity is no child’s play. I felt I had an emotional turmoil.

Researcher: Ehee, Ehee! You had an emotional turmoil. Exactly what did that entail?
Researcher: Mh! Mh! Go on Sir...

Participant: For some time I was in denial about my wife's illness but she continued to behave abnormally such that, she would throw parties out of the blue without telling me. She demanded expensive things that we could not afford using derogatory statements and even taught my stepdaughter (her child) to disrespect me. She would continually take transfer from one school to another for the child until the child stayed away from school for weeks. This situation got out of hand such that I was convinced my wife sick and her family of origin knew what to do and called for urgency order for her to the Mental Hospital.

Researcher: Mh - Mh - Mh.

Participant: Following the ordeal of mental relapse, she decided to divorce me. She is processing the divorce and I am happy for I have been emotionally abused and I see this divorce as a way out, the lord is freeing me.

Researcher: You say you have been emotionally abused. Can you say more about this abuse?

Participant: (Clears throat)

I was just there in the relationship passively there was nothing I could do. I no longer had love that gave me hope and strength to carry on with the relationship. I just did not care whether they take her to mental hospital or not. I had suffered enough by staying with her, so to me divorce was just a blessed escape that God had prepared for me. Prior to this divorce I had fasted and
prayed in the wilderness alone and with other brethren and so I was convinced that indeed it was God's intervention that she should leave me.

Researcher: Is there any other experience you will like to share with me?

Participant: (Smiling) No mam...

Researcher: (thank you for your time and agreeing to participate in the study).
ANNEXURE VII: NAÏVE SKETCH FROM A FAMILY MEMBER LIVING WITH A MEMBER SUFFERING FROM CHRONIC SCHIZOPHRENIA
Dear/Madam

Botlhelo iswa molweni wa
Mmelelo ya reke le molweni Molwapan
Bilcalo tsa fekhele tsego

O o leka mmena ka go tsemaya, ditha,
a tsewa molwapano ka (o) wa jehoela,
a tsha lela bo le sited ope le ka a tsa
a bo go naa botlhela, ditha, mo go rong.
a tsa go o litlwe le bafhe le ka fe,
a samotse o bane o rufelo fe tsa ena
 ga le ka le ka (3) ema sehlohego sebo 10 monato a ka bali go chencha elispapelo lele
 a bo a tsemaya e siphiskwa go fe,
a go molwapano me monaketseng en bono,
a bo a ena a bo a ena a sa kop,

a bo a simphelo go tsa ogolwapo,
a baukho ati wa baukho, e kop a deko,
a baukho be bo baukho, e kop a deko

a rohale a ka bane go bo go ao ang

a bo a ka tswa a a rene under a rohale

a bo go tsha la Molwapano ka Sepatele ka

o o leka tsewa molwapano genti ka dilo se le rere

o o leka tsewa Molwapano ka se ka Molwapano a gan gane.
& naalee e ngwe wene lea uulu.

Methnoko thal a tsaya mabele ee qadik a bo a aja a sabutuka a bo a fillheq ledik e e lama a bo a lisho mo mana. a bo e tsaya lee le renace e le gaalik a lej e le sabutsuka kedu ke rapel e lee be lee mimita wene e koqen go reece, go le bosigo e. He fettie, gape jene bosigo joo gene go le kemo go leposa le maktegaqo ca bo a tsaya ledik e gaqwe e toma a bo e rapar a tsewele undwene fel a bo a lemaaya a tro bosigo go aqee. Kilewe leene le ka khebqo go. Buse leene le bowe bosigo ke mokhaha leen lea nang. Fadikhe lea lela ke to lea rapela. Mene lea kifin e tu melhate e mathe e gaqwe o lemaaya kene lea bosigo le mokhheqo go qenwe e kele e la lemaaya a saqala sepe fe efe e go wale gape o thomay bele e tughe ree. Modimo e e saqalola boko go lemaaya ma ca wabo e la iro go. Modimo fe lulela go qe gana eliwi gi felhe gatlhe ebe rebika koloi ya sekele ebe e la ebo a gana go. Peni go ba mokhheqo e gana kalok go السن e que gaqwe e le go lemaaya fe.
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