

**EXPERIENCES OF MOTHERS CARING FOR CHILDREN WITH SCHIZOPHRENIA  
IN VHEMBE DISTRICT, SOUTH AFRICA**

**BY**

**AZWIHANGWISI JOSPHINAH NEGOTA**

**DISSERTATION**

**Submitted in fulfillment of the requirements for the degree of**

**MASTERS OF ARTS IN RESEARCH PSYCHOLOGY**

**In the**

**FACULTY OF HUMANITIES (SCHOOL OF SOCIAL SCIENCES)**

**DISCIPLINE OF PSYCHOLOGY**

**UNIVERSITY OF LIMPOPO (TURFLOOP CAMPUS)**

**SUPERVISOR**

**S MASHEGOANE**

**CO- SUPERVISOR**

**DR. S MORIPE**

**2013**

## **Declaration**

I, **NEGOTA AZWIHANGWISI JOSPHINAH**, declare that this dissertation hereby submitted to the University of Limpopo for the Master of Arts in Research Psychology contains my own original work, that I am the owner of the copyright and that I have not previously submitted it for obtaining any qualification. I also certify that all information sources and literature used are indicated in the dissertation.

---

**A. J. Negota**

---

**Date**

## Dedications

I dedicate this study to my brother **Tshifhiwa Samuel Negota** and my mother **Tshimangadzo Dorah Negota**.

## **Abstract**

Mothers who care for schizophrenic children go through various personal experiences and face enormous challenges. The aim of the study was to explore the experiences of mothers whose children were diagnosed with childhood schizophrenia. Participants consisted of eight mothers of children with schizophrenia from a rural village in the district of Vhembe, South Africa. They were interviewed at their homes, using in-depth, phenomenological interviews. Eight themes emerged from the participating mothers' articulations. They were identified as poverty and unemployment, emotional reactions of mothers, blaming witchcraft, dealing with the children's violence, aggression and destructiveness, financial and social support, effect of schizophrenia on the mother-child relationship, and the loss that mothers go through. The study reconfirmed that caring for individuals with schizophrenia is not an easy task for mothers. Recommendations were advanced on the basis of the findings.

Keywords: caregiving, children, expressed emotion, objective burden, parenting, phenomenology, schizophrenia, subjective burden

## Acknowledgments

I would like to express my sincere gratitude to the following:

- Almighty God, for giving me the opportunity to complete this study.
- S. Mashegoane, my supervisor, who tolerated my attempts to grasp concepts with good humour whilst always supportive and encouraging. He has been an extraordinary guide and motivating advisor down this very challenging path.
- Dr S. Moripe, my co-supervisor for his support and encouragement.
- The Limpopo Department of Health and the Vhembe District Primary Health Care Managers, for their permission to access study subjects in their health care system.
- Mothers of children with schizophrenia, for their participation and willingness to share their intimate experiences. Needless to say that this study would not have been possible without their participation.
- My mom Tshimangadzo Dorah Negota and my dad Bethuel Muvhulawa Negota, for their financial support, encouragement and outgoing patience.
- My siblings Tshifhiwa, Rabelani, Takalani, Thinandavha, Nndanduleni for being patient all these years.
- My sister Mrs Ndivhudzannyi Netshivhambe and her husband Musatondwa Netshivhambe, for their financial and spiritual support.
- My friend Lehlogonolo Makola, for helping, supporting and encouraging me throughout my study. I will forever remember her kindness.

- To Percy Taruvinga, Bongiwe Nematswerani, Happy Raligilia and Mabula Mashamba, thanks so much for your support.
- Lastly, I would like to thank all the people who made their positive contribution to this study, whose names do not appear on the list.

## TABLE OF CONTENTS

---

<b>CONTENTS</b>	<b>PAGES</b>
Declaration	ii
Dedications	iii
Abstract	iv
Acknowledgements	v
 <b>CHAPTER 1: INTRODUCTION</b>	
1.1 Introduction	1
1.2 Background to the study	2
1.3 Statement of the problem	3
1.4 Aim of the study	4
1.5 Research question	4
1.6 Scope of the study	5
1.7 Theoretical formulations	5
1.7.1 Operational definitions of terms	5
1.7.2 Theoretical framework	6
 <b>CHAPTER 2: LITERATURE REVIEW</b>	
2.1 Introduction	9
2.2 Family members' conceptions of causes of schizophrenia	10
2.3 Effects of schizophrenia on mothers	11

2.4	Mothers' reactions after their children are diagnosed with schizophrenia	14
2.5	Experiences of giving care to children with schizophrenia	14
2.5.1	Understanding the caregiving experience in the context of the family	14
2.5.2	Frustration experienced by the mothers who have children with schizophrenia	15
2.5.3	Mothers as caregivers of children with schizophrenia	16
2.5.4	Mothers' experiences of providing home care to their children	17
2.6	Caregiving burden	18
2.6.1	Burden on the caregivers of children with schizophrenia	18
2.6.2	Subjective and objective burden	19
2.6.3	The burden of caregiving among carers of psychiatric patients	21
2.6.4	Positive aspects of caregiving	22
2.6.5	Reason why do mothers take on the caregiving role	22
2.7	Social support to caregivers and children suffering from schizophrenia	24
2.7.1	Coping and social support in relation to mothers caring for a child with schizophrenia	24
2.8	Caregiving and expressed emotion (EE)	26
2.8.1	The genesis of the concept of EE	26
2.8.2	Cultural variability in familial EE	27
2.8.3	Summary	28

## **CHAPTER 3: RESEARCH METHODOLOGY**

3.1	The qualitative research approach used in the study	30
3.2	The phenomenological approach as a research strategy	30
3.3	Sampling	31
3.4	Procedure	32
3.4.1	Overview of a phenomenological data collection strategy	32
3.4.2	Data collection	33
3.4.3	Checking the validity of the data	34
3.5	Data analysis	35

## **CHAPTER 4: PRESENTATION OF FINDINGS**

4.1	Introduction	36
4.2	Description of participating mothers' demographic characteristics	36
4.3	Essential themes	38
4.3.1	Theme 1: Poverty and unemployment	38
4.3.2	Theme 2: Emotional reactions of mothers who have children with schizophrenia	39
4.3.3	Theme 3: Blaming witchcraft	40
4.3.4	Theme 4: Dealing with the children's violence, aggression and destructiveness	40
4.3.5	Theme 5: Financial support	42
4.3.6	Theme 6: Social support	42
4.3.7	Theme 7: The effects of schizophrenia on the mother-child relationship	43
4.3.8	Theme 8: The loss that the mothers go through	44

## CHAPTER 5: DISCUSSION

5.1	Introduction	45
5.2	Emotional response of mothers who have schizophrenic children	46
5.3	Attributing or blaming witchcraft on the illness of their children	47
5.4	Difficulty of dealing with violence and aggressive behaviour	48
5.5	Financial support	48
5.6	Social support	49
5.7	The effects of schizophrenia on the mother-child relationship	50
5.8	The loss that mothers go through	51
5.9	Conclusion and recommendations	52
5.10	Limitation of the study	53
5.11	Implications of the study	53
6.	<b>REFERENCES</b>	54
7.	<b>APPENDICES</b>	
	<u>Appendix A</u> : DSM-IV-TR diagnosis of schizophrenia	72
	<u>Appendix B</u> : Recruitment letter	75
	<u>Appendix C</u> : Informed consent letter	77
	<u>Appendix D</u> : General interview questions	79
8.	<b>TABLE</b>	
	<u>Table 1</u> : Demographic information	37

## CHAPTER 1

### 1.1 Introduction

Western studies published during the last three decades make it clear that parents living with schizophrenic children at home face complex problems (Kent & Wahass, 1997). The problems include, for example, lack of social support, financial problems as well as emotional difficulties. These studies showed that parents were affected by the illness in a variety of ways: a parent's life becomes disorganized, household routines are upset, and family members fear psychotic episodes (Landis, 1996). However, research examining the implications of home-based care for mothers is sparse, especially in the context of Limpopo. Therefore, this study examines the care of seriously ill, schizophrenic children in families, to understand how mothers experience the process (Kent & Wahass, 1997).

There are a few studies that have been conducted among South African parents who have mentally ill children. For example, Mphalane (2006) studied the role played by families of mentally ill relatives in a rural community in Limpopo, and found a number of positive aspects. For instance, parents treated their mentally ill children with compassion, and preferred taking care of them at home. Clearly, their views fly in the face of the "family burden" views of care (Biegel, Sales & Schulz, 1991). However, when it came to the causes of the illness, they departed from scientific notions. Nevertheless, they relied on contemporary mental illness treatment. Although most relatives knew the manifestations of psychotic symptoms, they did not know the aetiology and were worried about patients' symptoms (Ratanatikanon, Assanangkornchai, & Tanchaisawad, 1997). Chesla and Rungreangkulkij found that parents used three common ways of coping with stress, including: consulting family members to help solve problems, relying on religion, and talking with others about their problems (Chesla & Rungreangkulkij, 2001).

Though studies have been conducted in South Africa about schizophrenia, for example Wood (2010), none of them focussed exclusively on the experiences of mothers who have schizophrenic children in the Vhembe District located in Limpopo, South Africa. The phenomenological studies are not many, and the pioneering ones in this area need to be complemented. Further understanding of how mothers are involved in the caregiving process is needed. The present phenomenological study of mothers who have schizophrenic children was conducted to explore the general meaning or life experience of caring for a schizophrenic child.

## 1.2 **Background to the study**

Studies of mothers' experience with children who have schizophrenia go back several decades to the beginning of deinstitutionalization (Kreisman & Joy, 1974). Past research focused on what has come to be known as the "family burden" of caring for a schizophrenic patient, and has emphasized the negative aspects of caregiving (Biegel et al., 1991; Boyd & Maurin, 1990). Current research attempts to approach the issue with neutrality, and if and when necessary, look at more positive aspects of the mothers' experiences, such as the emotional and financial support they provide to a schizophrenic child (Bulger, Goldman & Wandersman, 1993). It is in that context that the present study is conducted. The researcher aims to approach the issue with neutrality and openness, and allow the information to emerge unhindered and uncensored. More research is needed, however, to understand the role of caregiving for schizophrenic patients. As already implied, the picture emerging from studies already conducted needs to be supplemented with more research, especially in Makhado, a local municipality falling within the district municipality of Vhembe in Limpopo, South Africa.

### 1.3 Statement of the problem

Having a child with a diagnosis of schizophrenia is stressful for families, and parents in particular (Saunders, 2003). Generally, the diagnosis of a major mental health problem in a child is a severe stressor in itself, eliciting negative responses such as fear, anxiety, anger, depression and guilt (Hornsby, 1994). Those who are close to the child experience considerable psychological stress just from knowing about the diagnosis. The stress of the family or parents is compounded in instances when mental health professionals are not helpful or do not provide adequate support to them in particular (Saunders, 2003). The stress is further complicated by the daily demands of the child's condition. Moreover, other areas of functioning, including the caregiver's quality of life, may subsequently be affected (Carlsson, Ivarsson & Sidenvall, 2004; Sales, 2003). For instance, as mothers respond to the increased demands of caring for a child with schizophrenia, time and attention given to adult or spousal relationships often decrease, resulting in marital conflict and strain (Petcharat & Tongurai, 1989).

Studies conducted in Western countries provide a somewhat concise picture regarding the care of psychiatrically ill children by their mothers. Certain areas of functioning are particularly affected. Mothers also experience financial stress as they strive to meet the needs of their sick child. Even when health-care expenses are covered by a third party, there are costs to the mothers when the child goes to the doctor or is hospitalized, including transportation and parking, meals away from home, special treats for the child, and child care for other children of the family (Mu, 2004). There are also personal costs, such as time away from work and abandonment of career aspirations or advancements. A mother may miss an opportunity to advance in her career or may choose not to return to school because of the increased demand of motherhood (Newacheck & Taylor, 1992). Some mothers who would otherwise work outside the home forgo employment to care for the child full time and to perform the many tasks involved in coordinating care. It is not unusual for one parent in a two parent household to take on additional

employment to meet the increased financial burden of the child's illness. The problems become even more complex for single parents (Mu, 1998).

Although many studies have been done to investigate burden, coping strategies and related concepts, few studies have holistically examined the mothers' experiences in the Vhembe District, Limpopo. Available studies which have been conducted in Limpopo seem to concur with Western observations regarding the issue of psychiatric caregiver burden (Manamela, 2001; Mphalane, 2006). However, they are too few to offer any conclusive statement on the issue. For instance, it is not clear if caregivers experience largely positive or negative outcomes from the experience. It is therefore important to investigate both positive and negative experiences of mothers who have schizophrenic children in the Vhembe District. Also, it is necessary to use a phenomenological method since the aim is to explore the mothers' experiences further, without restricting the study to pre-conceived concepts and notions. The assumption is that whatever comes out from this exercise, will confirm and complement whatever is already known.

#### **1.4 AIM OF THE STUDY**

The aim of this study was to explore the experiences encountered by mothers who care for children with schizophrenia in a rural South African context Limpopo (Vhembe district).

#### **1.5 Research question**

What are the lived experiences of a mother caring for a child with schizophrenia in a rural context?

## 1.6 **SCOPE OF THE STUDY**

An interested group of mothers who have schizophrenic children were involved. Only mothers of schizophrenic children in a rural village in Vhembe district, South Africa participated in this study.

## 1.7 **Theoretical formulations**

### 1.7.1 **Operational definitions of terms**

#### 1.7.1.1 **Experience**

Experience constitutes the process of meaning construction whereby people think about themselves and their position in relation to others, and the world around them.

#### 1.7.1.2 **Psychiatric illness**

The concept psychiatric illness covers problems that some people have in connection with what they think, feel and experience. It is also a broad generic label for a category of illnesses that may include affective or emotional instability, behavioural deregulation, or cognitive dysfunction or impairment. Specific ailments known as psychiatric illnesses include major depression, generalized anxiety disorder, schizophrenia, and attention deficit hyperactivity disorder, to name but a few. Psychiatric illness can be of biological (e.g., anatomical, chemical, or genetic) or psychological (e.g., trauma or conflict)

origin. The present study focuses on one category of psychiatric illness, namely schizophrenia.

### 1.7.1.3 **Childhood Onset Schizophrenia**

Schizophrenia is a psychiatric diagnosis that describes mental disorder characterized by abnormalities in the perception or expression of reality. Childhood or early-onset schizophrenia occurs before the age of 13 years. Warning signs for the disorder include disorganized behaviour, extreme fearfulness, and confused thinking. It most commonly manifests with any of the following symptoms: (a) auditory hallucination (b) paranoid or bizarre delusion, (c) disorganized speech, and (d) catatonic or grossly disorganised behaviour. A diagnosis of early-onset schizophrenia is usually made by a child and adolescent psychiatrist, using the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000). Also, the disturbance must affect important areas of functioning, such as schooling or interpersonal relationships. The child who is ill also shows the signs continuously for a period of not less than six months. Important to note is that symptoms of schizophrenia are similar to disorders such as schizoid and schizotypal personality disorders, and schizophreniform disorder. Schizophrenia is sometimes confused with disorders such as manic depression (bipolar disorder) or Asperger's syndrome (autism), because they share some symptoms. The DSM-IV-TR criteria for schizophrenia can be found in appendix A.

### 1.7.2 **Theoretical framework**

Phenomenology will be the guiding theoretical framework throughout this study. In a broad sense, the purpose of phenomenology is to describe particular phenomena, or the appearance of things, as lived experience (Carpenter & Speziale, 2007). Lived experiences involve the immediate

consciousness of life's events prior to reflection and without interpretation, and are influenced by those things that are internal or external to them. It is the lived experience that gives meaning to each individual's perception of a particular phenomenon and thus presents to the individual what is true or real in his or her life (Giorgi, 1997).

Phenomenology has its source in social philosophy and psychology. It arose in the late 19th century in response to positivism which, as a scientific approach, could not adequately address the problems being presented to the humanities (Adorno & Sadala, 2001). It was initially developed by, and is most often associated with, the philosopher Husserl (1931/1999). It was Husserl's belief that subjectivity underpins scientific understanding and the life-world of daily experience, seeing a phenomenon and the being that experiences that phenomenon as inextricably linked. Husserl (1931/1999) contended that phenomenology allows the researcher to revisit the world as it is lived and experienced, describing phenomena as they reveal themselves rather than explaining or reasoning their cause.

Underlying this approach is the notion that the fundamental nature of a phenomenon can be seen through the principle of intentionality: consciousness understood as consciousness of something (Adorno & Sadala, 2001). Interpretive phenomenology developed from the philosophy of Heidegger (1947/1993), a student of Husserl, who contended that it is neither possible nor necessary to attempt to separate one's experience from the phenomenon being observed and interpreted. Therefore, the aim of interpretive phenomenological research is to create a mutually meaningful account, from both the participants and the researcher, of the phenomenon under research. According to Heidegger (1947/1993), the purpose of descriptive phenomenological research is to create a structure of the phenomenon observed whilst interpretive phenomenology seeks to create an account, in text or story, that provides insights into the phenomenon observed.

Appreciating a Husserlian understanding that the essence of a phenomenon arises through the conscious awareness and intention toward it (Adorno & Sadala, 2001), this study nevertheless used a descriptive phenomenological approach in order to provide a structure for understanding the phenomena of experiences among mothers. Therefore, in this study, the researcher's aim was to get the experiences of mothers about their children who suffer from schizophrenia. Phenomenology is selected in order to understand how mothers live their experiences of caring for their sick children. Mothers in the Vhembe District, Limpopo are seen as unique, holistic beings with their own historical, socio-cultural backgrounds that direct the ways they interpret and understand the world. The researcher attempted to understand what mothers experience when raising their schizophrenic children. Phenomenology is therefore particularly suitable as a method of discovering how mothers perceive and understand the caring process (Adorno & Sadala, 2001).

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 Introduction

Schizophrenia is one of the most devastating of psychiatric disorders, leading to long-term and progressive disability in numerous areas of functioning (see appendix A for the diagnosis of schizophrenia). These disabilities are an onerous burden on both patients and their caregivers (Kung, 2003; Martyn, 1992). Caregiver burden in mental illness can either be objective or subjective. Objective burdens are defined as readily verifiable behavioural phenomena, for example, the disruption of the caregivers' lives in terms of domestic routine, social activities and leisure, social isolation and financial and employment difficulties (Brown, Greenberg, Greenly, & McKean, 1997; Kuipers, 1993). Subjective burdens comprise emotional strain on caregivers, for instance, fear, sadness, anger, guilt, loss, stigma and rejection. In all, the shift towards community care for patients with mental disease has resulted in transferring responsibility for day-to-day care of patients to their family members (Dolan, Eisle, Staples, Stern, & Szmukler, 1999), which has led to profound psychosocial, physical and financial burdens on family members, particularly those who are solely responsible for the patient.

This literature review focuses on issues specifically relevant to mothers' experiences with caring for mentally ill children, especially those diagnosed with schizophrenia. It reviews studies conducted on parents' reactions after their children are diagnosed with schizophrenia, explores the idea of burden on mothers who have schizophrenic children, and illuminates the role of the theory of expressed emotions (EE) among caregivers. Furthermore, the literature review highlights the role of social support provided by families and other significant support providers to mothers who care for schizophrenic children.

## 2.2 Family members' conceptions of causes of schizophrenia

Beggington and Kuiper (1987) have stated that people's views about causes of schizophrenia have changed because previously it was believed that schizophrenic persons were bewitched and consequently possessed with evil spirits. They were also labelled mad or insane, presumably because they were bad or have been cursed. Nowadays the majority of people understand that schizophrenia is not caused by witchcraft, although some still adhere to that erroneous belief (Beggington & Kuiper, 1987).

Beggington & Kuiper (1987) indicated that mental illness covers problems that some people have in connection with what they think, feel and experience. Martin (1983) stated that heredity, organic disease, biochemical disturbances and social and cultural pressures and disturbance in family relationships work together to produce psychiatric illness. On the other hand, organic disorders may be caused primarily by excessive intake of alcohol and drugs or head injury.

There is a school of thought which states that some people's schizophrenia is caused by distressing events in their lives which render them unable to cope (Worden, 1991). People who live in troubled communities, or who lose family members and friends close to them, may be victims of schizophrenia. This causes them to have strange thoughts or feelings and to behave in rather odd ways (Worden, 1991).

Other studies focus on what family members consider to be the causes of schizophrenia. Studies done with German, Italian, Indian, and Chinese family members have shown that many are likely to choose more than one particular cause of schizophrenia, including both psychosocial and biological explanations (Holzinger, Muller & Priebe, 2001). Because of limited research

in this area, especially in the United States and among African-Americans in particular, the descriptive study of Holzinger et al. (2001) investigated the causes of schizophrenia reported by family members of hospitalized African-Americans with schizophrenia. The study of Angermeyer, Klusmann and Walpuski also assessed the most commonly reported causes of schizophrenia according to family members. The authors' interest was based on beliefs about family-related causes specifically, as well as what Angermeyer, Klusmann and Walpuski (1998) have termed besoteric Q causes.

Some causes and/or factors related to schizophrenia are unveiled by research. Family-related causes of the disease that were assessed by Angermeyer, Klusmann and Walpuski (1998) included hostile or rejecting attitudes of parents, a broken home, lack of parents' love, too high expectations of parents, and an overprotective mother. However, some factors are related to lay beliefs. The term besoteric Q refers to types of beliefs that are not commonly accepted in psychiatry as causes of schizophrenia, such as magical or spiritual causes. The esoteric causes assessed by Angermeyer et al. (1998) included possession by evil spirits, environmental pollution, lack of vitamins, and punishment by God, radiation, and an unfavourable horoscope. The main aim of the study was to address differences in reported causes between family members of individuals with first-episode psychosis (referred to as the first-episode group Q) and family members of those with persistent schizophrenia hospitalized for an acute exacerbation (referred to as the persistent group Q) (Angermeyer et al., 1998).

### **2.3 Effects of schizophrenia on mothers**

Mothers of schizophrenic children are subjected to a number of demands. Any degree of psychiatric illness affects the entire life schedule of the mother as

well as the child. However, socio-economic status seems to ameliorate or mediate this association. The higher the family's educational level, social position and aspirations, the more they can cope with the child's demands. If the child is born defective, they mourn for the loss of the longed for healthy child. However, their reactions depend on the type of the defect, its severity, and their own past experience and personalities.

Mothers with a schizophrenic child eventually experience a sense of failure, disappointment and helplessness (Gubman & Tessler, 1987). These emotions may interfere with their ability to accept the child and meet its needs. In fact, all family members need time to accept and work through their disappointment, loss and guilt. The mother may react in any of the various ways, including devoting herself exclusively to the defective child, neglecting her child, or feeling defective or inadequate herself, and consequently withdrawing from the child. Some parents overprotect the schizophrenic child and displace their anger onto other children. When parents are first informed that their child has schizophrenia, a lifelong and life-wide process is set in motion (Gubman & Tessler, 1987).

A child's schizophrenia is usually heart breaking for both mothers and fathers. Often they feel guilty as if something they may have done has caused the problem (Dolan, Eisle, Staples, Stern & Szmukler, 1999). Worden (1991) indicated that some parents feel capable of coping with such problems; however raising a child with schizophrenia can seem overwhelming. Fathers and mothers also worry about who will take responsibility for their child when they can no longer care for him/her themselves. They gain helpful support from sharing with other parents. They learn new ways to deal with all their children from teachers (Worden, 1991).

## 2.4 Mothers' reactions after their children are diagnosed with schizophrenia

After being told the diagnosis (namely, early-onset schizophrenia), feelings and behaviours of mothers unfold like those in the bereavement process (Nemecek, 2004). However, the way in which parents are given the bad news has been found to have an impact which goes beyond immediate parental feelings. For most mothers, there is a period of shock, followed by sadness, and frequently anger, and sometimes denial (Nemecek, 2004). The need of the mother at this stage is to receive emotional support. The mother's reactions to having a child with schizophrenia, how these reactions were handled from the start, and what supportive services were available, are directly relevant. Other mothers even show their reaction by crying when they find out that their children are schizophrenic (Andrews & Boyle, 1999).

Mothers experience a wide range of emotions following the schizophrenic diagnosis of their child. Grief, symbolic loss, chronic sorrow, and empathetic pain are reactions mothers can experience in response to their schizophrenic children (Johnson & Marsh, 1997). Johnson and Marsh described how mothers can have a more specific reaction to the diagnosis: "When a child develops schizophrenia, his or her mother generally experiences a range of intense losses, both real and symbolic" (Johnson & Marsh, 1997, p. 229). Johnson and Marsh added that mothers are prone to feelings of guilt and responsibility and frequently become primary caregivers for a lifetime. Johnson and Marsh wrote, "They (mothers) seemed to be trying to find out the causes of it. It was just devastating" (Johnson & Marsh, 1997, p. 308). Johnson and Marsh's findings showed that mothers have a wide range of reactions to the diagnosis of a child. Given these findings, it can be safe to assume that family dynamics shift in response to that diagnosis. Although Marsh and Johnson left out the responses to psychiatric hospitalization, they clearly described the devastating effects of schizophrenia upon mothers (Johnson & Marsh, 1997).

Somewhat different to the findings of Johnson and Marsh's (1997) study, where the mother's reactions to the schizophrenic child were ones of concern and sadness, a separate study conducted by Buchanan and Flouri (2002) described parents whose reactions to their child's psychiatric diagnosis and hospitalization was distant and uninvolved. Nevertheless, it appears that a diagnosis such as schizophrenia has a major impact on the emotional state of the mothers.

## **2.5 Experiences of giving care to children with schizophrenia**

### **2.5.1 Understanding the caregiving experience in the context of the family**

The caring experience has many dimensions and poses demands which may last for years (Bernheim & Lehman, 1994). The failure of health professionals to understand the family caregiving experience and the reinforcement of societal expectations that all families will take on the caring role (Jeon & Madjar, 1998) may result in family members experiencing increased levels of burden. Many factors impact on the level of caregiving burden experience by families and these include the developmental stage of the family (Cohler, Cook, Lefley & Pickett, 1994; Rose, 1997), whether the ill member lives at home (Jones, 1996) and the socioeconomic status of the patient and the family concerned (Biegel et al., 1991). Although the caregiver burden may not be obvious to people outside the family, it impacts on the family's level of resilience and their continued commitment to care. Camann (1996) reported that families often provide care with limited support and resources from the health care system. They receive little information from health professionals and may not be included in the decision-making process. Families are left to construct their own meaning of the mental disorder, and ultimately understand its causes and consequences (Jeon & Madjar, 1998).

Family is also affected by the caregiving experience and, while community programmes focus on the wellbeing of the consumer, they do not generally support and meet the needs of the family. Caregivers must reconcile obligation and love for the family member with the emotions of fear, bewilderment, loneliness, exhaustion, depression, frustration, guilt, resentment, anger, and even hate (Chambers, 1998; Karp & Tanarugsachock, 2000). These emotions change regularly throughout the different phases of the caregiving process.

A significant problem appears to be the continual volume and volatility of emotions experienced by caregivers and ill family members. Caregivers reported that they were repeatedly trying to complete their obligations to the ill person while simultaneously managing an array of changing feelings and emotions (Karp & Tanarugsachock, 2000). It is argued that the current body of knowledge on family caregiving has constrained the ability to understand the depth of the experience (Kellett, 1996). Irrespective of our current level of understanding, family caregiving is increasingly a reality in an economic climate of reduced public spending on health and welfare services. According to Kellett (1996), family care has been disguised by the 'rhetoric of community care' and although some researchers have demonstrated that families obtain satisfaction and a sense of self-worth from caregiving, families continue to experience considerable burden (Cohen, 1994). In most cases, the family member who shoulders the burden of caring on behalf of the family is the mother.

### **2.5.2 Frustration experienced by the mothers who have children with schizophrenia**

Rejection of the people who suffer from schizophrenia also affects their mothers, and leads to isolation and humiliation. These people are not rejected only by the community, but also by some of the health professionals because

of the stigma attached to schizophrenia. According to the World Health Organization (WHO), stigma is a “mark of shame, disgrace or disapproval which results in an individual being shunned or rejected by others” (World Health Organization, 2001, p. 1). The misconception that schizophrenia results from witchcraft also affects the family, so that when a child does not respond to medication, they become frustrated. The inactivity of a schizophrenic child also frustrates the mother, as the child tends to loiter around without being involved in household chores. Another factor that frustrates the mother in particular is that of lack of assistance and guidance from health professionals about the child’s illness.

### **2.5.3 Mothers as caregivers of children with schizophrenia**

The study conducted by Heffern (1993) in America estimated that one of four mothers have a child diagnosed with schizophrenia. These mothers play an increasingly important role in facilitating the provision of mental health services in the community (Boland & Sims, 1996). According to Skelton “the present policy of treating schizophrenic children in the community could not exist without carers who bear the main burden of care; carers are the glue that holds the system together” (1994, p. 99). Mothers were not always viewed as important, and during the last century health professionals rejected and blamed them for contributing to their children’s illness. This left many mothers with extreme feelings of guilt (Doornbos, 1996). Several types of mental disorders have now been re-conceptualized as neurophysiologic diseases with an associated chronic disability (DuMont, Evans, Shupe & Tuck, 1997). This has changed perceptions concerning mothers and the aetiology of psychiatric diseases.

The mothers’ caring role is now appreciated and has become the centre of focus in the illness process. Mothers are increasingly viewed as central to the rehabilitation and wellbeing of schizophrenic children. Moreover, community

mental health care has shifted many of the responsibilities for the management of the mother's health care needs and costs from the health care system to "the home care system" (Smitka, 1998). The "home care system" has made mothers responsible for the physical, emotional, financial and social tasks associated with caring for schizophrenic children at home (Gubman, Minsky, Horwitz & Reinhard, 1994). Camann is of the view that "community care became by default family care with little understanding of the implications for families" (Camann 1996, 481). This is a contradiction, in that society has redefined its role concerning schizophrenic children. It has shifted the responsibility of care to the patient's significant others. However, those significant others are sometimes unprepared for their assigned role and its novel tasks.

While caring for a schizophrenic child in the home environment sets the stage for purposeful and meaningful involvement in life (Fitzgerald & Roberts, 1991), the mother is also confronted with managing behaviours that are rarely encountered by most mothers (Reinhard, 1994). When thrust into the caregiving role, many mothers display a range of responses and emotions such as fear, anger, self-blame, or guilt (Hartley & Peternelj-Taylor, 1993). In 1963, Grad and Sainsbury first described the strain on families posed by the caregiving role (Saunders, 1997). It is widely acknowledged that schizophrenia creates a burden for caregivers (Rose, 1997). The caregiving burden affects and alters (sometimes permanently) family functioning, relationships and roles, financial security and stability, level of mental health, coping, and adjustment (Bernheim & Lehman, 1985; Marsh, 1992; Jeon & Madjar, 1998). In 1966, Hoenig and Hamilton described the objective and subjective components of the burden experienced by caregivers. Despite decades of research, this burden is not well understood and remains a problem for families (Boyd & Maurin, 1990; Rose, 1997).

#### **2.5.4 Mothers' experiences of providing home care to their children**

Mothers with a schizophrenic child at home report satisfaction in relation to witnessing the emotional and social growth of their child. Enabling children to participate in education is reported as a vital agenda of parents. Although mothers struggle with education systems about provision of suitable resources and care, they develop knowledge and persistence in finding ways to meet the needs of their sick child (Noyes, 1999).

Schizophrenic children living at home bring challenges to their families, and even to their mothers. Caring for a child who needs life-saving support at home can result in adverse health impacts on the primary caregiver. Social support is the most significant factor in determining the employment status of carers. Unemployed mothers who are from single parent families, or have no social support, are reported to have poorer mental health status and, as a result, are more likely to compromise the quality of care of their sick children and families (Kuhlthau, Thyen & Perrin, 1999).

### **2.6 Caregiving burden**

#### **2.6.1 Burden on the caregivers of children with schizophrenia**

Mothers of children with schizophrenia have been the subject of caregiver research interest for several decades. Early theorists highlighted pathological patterns of interaction and communication in these mothers, considering them (the patterns) as an etiological factor in the illness (Bateson, Haley, Jackson & Weakland, 1956). Later, researchers began to examine the impact of the illness and its consequences for the mothers, rather than the child-mother dynamics per se. This line of research was given further impetus by the

growth of the deinstitutionalization movement, characterized by a shift from hospital-based care to home care for children with schizophrenia. Deinstitutionalization in respect of mentally ill children led to mothers having to assume a major portion of caregiving responsibilities. Thus, the concept of “burden of care” came into being.

The World Health Organisation’s definition of caregiver burden states that it emanates from emotional, physical and financial demands and responsibilities of an individual’s illness that are placed on the mothers, friends or other individuals involved with the individual outside the health care system (WHO, 2004). The term was first used by Treudley, to describe the consequences for those in contact with severely psychiatric patients (Treudley, 1946). In 1966, Hamilton and Hoenig (1966) differentiated between two domains of burden, which are “subjective” and “objective”. These will be explained immediately hereafter.

### **2.6.2 Subjective and objective burden**

The burden experienced by caregivers can be classified as either objective or subjective. Objective burden refers to the caregiving tasks that are the direct consequences of the patient’s symptoms, such as effects on the caregivers own health, social and occupational functioning and leisure time (Hamilton & Hoenig, 1966). It refers to those activities that a caregiver has to do, or is prevented from doing as a result of the caregiving role. While objective burden is predominantly related to close contact between schizophrenics and their caregivers, subjective burden is determined by many factors, including resilience, different coping mechanisms used by the carers, the strength of relationships prior to the most recent onset of illness, level of support from social networks and availability of and access to formal services (Mangliano & McDavid, 2004).

Subjective burden refers to the caregiver's short term and long term reaction to the patient's symptoms and behaviours, and the caregiving task resulting from it. Perceived distress and interpersonal strain are examples. It refers to the extent to which the caregiver feels he or she is burdened. The short term reaction can lead to more enduring consequences in terms of impact on overall well-being, satisfaction with life, physical and mental health and social activities of caregivers (Koeter & Van Wijngaarden, 2002; Kuiper, 1993; Platt, 1985) in a comprehensive definition of burden, described it as "the presence of problems, difficulties or adverse events, which affect the lives of schizophrenic children significant others, i.e., members of the household family" (Platt, 1985, p. 383).

Hamilton and Hoeing (1966) examined objective and subjective burden in their study of 66 families of patients with schizophrenia over a 4 year period. Seventy-six percent of the caregivers reported that the patients had some kind of adverse effects on the household (Hamilton & Hoeing, 1966). Families, in which the patients had been initially employed, experienced greater burden (Stevens, 1972). This suggests that carers' perception of the patient as a burden was an important factor in contributing to distress. The unpredictable nature of the illness, extensive needs of the mentally ill person and inadequate mental health care infrastructure (lack of information, lack of continuity of care and inadequate resources) were cited as factors contributing to burden in a study by France (Conn, Francell & Gray, 1988).

The level of distress and burden in 25 primary caregivers of patient with schizophrenia was assessed by Hughes and Oldridge (1992). Greater distress was associated with negative symptoms in patients. Objectives burden was significantly corrected with the anxiety and insomnia. Jones, Roth and Jones (1995) interviewed 189 caregivers-client dyads to assess the client's need for help and potentially troublesome client behaviours. Caregivers reported greater objective than subjective burden (Jones, Jones & Roth, 1995). The predictors of burden in 25 patient-caregiver dyads were

examined by Fuji, Hasui, Miyata, Kitamura, Koshiishi, Sakomoto and Sunguira (2002). Caregivers were assessed on subjective and objective burden. Subjective burden was negatively correlated with the age of the patient, while objective burden was positively correlated with the duration of illness. The patient's level of functioning was the only significant predictor of both objective as well as subjective burden (Fuji et al., 2002).

### **2.6.3 The burden of caregiving among carers of psychiatric patients**

The proportion of children with schizophrenia living with their relatives ranged between 40% in the West, to more than 90% in the East. Family and individual distress is not necessarily lower when the sufferer lives far away from home. Factors likely to influence caregiver burden are numerous. These could be patients' and caregivers' characteristics, family type and size, economic and educational status, role expectation and illness related beliefs. There are however, cross cultural differences (Doku, Fannon, O'Ceallaigh, Soni & Tennakoon, 2000).

The prevalence of physical abuse and burden experienced by 101 relatives of persons with a psychiatric disorder admitted to an in-patient facility was assessed in one study. Burden was positively correlated with abuse, and 79% of caregivers scored above the cut off on the GHQ. Verbal abuse, threats, and temper outbursts were reported by half the sample and 32% reported being physically abused on more than one occasion. Abuse was associated with younger age of the patient, drug misuse and poor premorbid relationship between the caregiver and patient (Aldard, Gilleard & Vaddadi, 1997).

In the study, the dimensions of caregiving and their relationship to distress were found. It was found that patient symptomatology, caregiver's ability to cope with patient symptoms and more contacts with mental health

professionals were related to the caregiving domains and the overall caregiving score. Patient's symptoms and increased hours of contact with the patient were depressed.

#### **2.6.4 Positive aspects of caregiving**

While the term carer's burden is usually perceived in unduly negative terms, it is of crucial importance to recognize that there are both rewards and difficulties associated with the caregiving experience. A sense of satisfaction may be derived by the carers, or caregivers, from knowing that they are able to help and improve the quality of life, love and pride (Cameron, Stewart & Veltman, 2000). Studies on burden in caregivers have been carried out since the 1950s. Numerous studies have explored the existence of burden among caregivers and family members of patients with schizophrenia (Kumar & Mohanty, 2007).

#### **2.6.5 Reasons mothers take on the caregiving role**

When assessing the level of burden a mother experiences, it is of crucial importance to identify the reasons why they make the commitment to care. A study by Herrmen, Jablensky, McGrath, et al. (1999) found that 42% of caregivers of people with mental disorders (particularly schizophrenia) were women and were often the ill person's mother. Historically, there has been a gender and ideologically-based assumption that it is natural for women to want to care (Lee, 2001). As yet, there is no full appreciation and understanding of the impact of societal expectation that women will care for a sick person. While it is acknowledged that it is middle aged women who are most likely to provide care (Orbell, 1996), these women are themselves an extremely vulnerable group and often have reduced social and economic power.

However, Orbell (1996) concluded that not all mothers were willing to take on the caregiving role, and that in reality the family does not operate to the kind of fixed rules that caring is “naturally” a part of the family relationship. A Caregiving impact on all areas of family life reflects through each family member’s behaviours, feelings, and emotions (Kellett & Mannion, 1999). Kellett and Mannion also provided further insight into the reasons why families make the commitment to care. Their research specifies that families commit to the caring because they: 1) feel obligated; 2) are owners of their own difficulties; 3) believe that a family should protect vulnerable members; and 4) feel that families are self-reliant units. Kellett and Mannion (1999) also identified themes which were based on the concepts of reciprocity in the relationship: families are obligated to care; home care is the best care for the affected family member, and the positive outcomes of providing care within the family.

Brown and Stetz (1999) also reported that a family’s willingness to care was based on the sense of obligation and the relationship with the person who is mentally ill. One or more of these themes may determine a family’s on-going commitment to caregiving even when the personal cost to family life is considerable. Researcher like Kavanagh (1995) has suggested that, while experiencing considerable burden, families commit to care because they receive positive outcomes from the experience (Kavanagh, 1995).

For some theorists, mothering remains a critical factor in the child’s development. John Bowlby and psychoanalysts in general believed that infants needed the mother for the purpose of meeting basic psychological and physiological needs. Bowlby deemphasized the physiological in favour of the psychological aspects of mothering though (Bowlby, 1980). Bowlby, a major contributor to the field of attachment, postulated that infants need the bond with their mothers for development (Bowlby, 1958). The mother is an infant’s primary attachment figure, through whom the child learns how the world in

general and relationships in particular function. The first primary relationship with a mother figure influences the way in which an individual develops subsequent attachments with others. In other words, the first and primary relationship is deterministic, and serves as a prototypical schema of future relations. That is why, for instance, early loss of an attachment figure can be devastating (Ainsworth, 1989; Berzoff, Flanagan & Hertz, 2002). The mother's role after the infancy stage is unquestionable. Thus, if a child is diagnosed with schizophrenia, the mother is likely to be the one who will take on the role of caregiver.

## **2.7 Social support to caregivers and children suffering from schizophrenia**

### **2.7.1 Coping and social support in relation to mothers caring for a child with schizophrenia**

Relatively little research has been conducted on the use of coping mechanisms, including social support, by mothers caring for a child with a disability of any nature (Eiser, 1990). Eiser examined the mediating influence of social support on the stress and strain of mothers of children with mental retardation, physical disabilities, and developmental risks (Eiser, 1990). Parental satisfaction with support was the only variable significantly impacting parental well-being. Findings also indicated that a supportive network mediates the degree of parents' protectiveness of their children, as well as their perception of the difficulty of their child's behaviour. In mothers with children with developmental disabilities, studies suggested that the degree of support available from one's spouse and friends is significantly associated with the level of satisfaction with family functioning (Cameron, Dunham & Snowden, 1994).

Similar findings regarding a positive relationship between social support in times of crisis, and current satisfaction with life, were reported in a study of families with a child who has a severe physical disability (Sloper & Turner, 1993). An early ethnographic study of mothers who have a child with a progressive neuromuscular disorder identified a range of coping strategies

used by the mothers such as the development and cultivation of coping resources, including social support, and coping strategies that were specifically directed at “resource maintenance” (Bregman, 1980). A matched comparison study found that mothers of a child with spina bifida had smaller social networks (i.e., fewer friends) and greater boundary density (proportion of network connections between the two parents’ social networks) than mothers of a child without a disability (Kazak & Wilcox, 1984).

The impact of acute versus chronic parenting stress was specifically evaluated in a study of parents caring for a child who is hearing impaired (Glueckauf, Jackson & Quittner, 1990). A buffer effect was not indicated but evidence was found for a mediating effect of social support on maternal stress through the paths of perception of competence and role restriction. Explanations for the lack of a buffering effect under chronic stress are found in studies using the conservation of resources theory which assumes that individuals attempt to conserve the quality and quantity of their resources, and the cost of coping hypothesis, which states that stressors and social support are not always independent factors, especially under chronic stress situations (Lepore, 1997). In summary, chronic stress may affect and limit both help-seeking behaviour and support provision (Gottlieb, 1992).

Caregiver stress and coping resources are variables examined in one of the few research studies on stress and coping in families who have a child with an emotional disability (Early, Gregoire, McDonald & Poertner, 1997). Findings in Early et al. (1997) indicated that increases in the perception of the child made a positive contribution to the family, as well as informal supports from family, friends, and community, mediate the impact on caregiver stress by enhancing the caregiver’s coping resources.

Social support can also be considered as a factor contributing to perceptions of isolation and loneliness. Parents of disabled children consider themselves to be isolated and lonely (Feinstein, Melnyk, Moldenhouer & Small, 2001). Social isolation is often one of the most taxing facets of caring for a disabled

child (Pahl & Quine, 1985). These parents may be afraid to leave their child. Exhaustion may be a complicating factor in parental social isolation, causing the parent to lack the time or energy resources necessary to pursue friendships. Moreover, family members and friends may not be sure of how they can help. At the same time, the affected parent may be in need of help. It must be understood that practical support from the extended family, especially in the form of caring for the children, is important (Brown & Hepple, 1989).

Social support is a key to the mother's coping. Since many schizophrenic children live with their parents, and the mother is usually the primary caregiver, social support towards her needs should be a major and fundamental component of community and family support programmes. Other family members will also need to be supported, so that they can be of help to the mother. Family circumstances of a schizophrenic child improve when family members have more mental elbowroom while being supporters. The mother and the child are the chief beneficiaries when that happens.

## **2.8 Caregiving and expressed emotion (EE)**

### **2.8.1 The genesis of the concept of EE**

George Brown developed the construct of expressed emotion in the 1960s (Lefley, 1998). During that time, Brown and his colleagues observed that patients with schizophrenia who were discharged from the hospital and went on to live with their siblings or in lodges, as opposed to living with their families of origin, did better (Hooley, 2007). Therefore, Brown and his colleagues made a link between the mother and relapse of patients with schizophrenia (Hooley, 2007). Hooley states that Brown, together with Michael Rutter, began working on the problems of how to measure the range of feelings and emotions in the families of people with schizophrenia. The end result of such work was the development of the construct of EE (Lefley, 1998). Although EE as a construct was first developed to explain communication in families of people with schizophrenia, it has been applied in a plethora of

psychiatric disorders (Leff, 1998). Since the current study is based on schizophrenia, only the literature on EE and schizophrenia will be reviewed.

### 2.8.2 Cultural variability in familial EE

Studies in various cultures have now confirmed that schizophrenic patients in families that manifest high EE tend to relapse relatively quicker and more frequently than their counterparts who are from low EE families. Schizophrenic patients who are from families whose members' remarks about the patient express hostile criticism or emotional over-involvement; have significantly higher relapse rates than patients in low EE families that express little or none of these attitudes (Kavanagh, 1992). Low EE families have been described by EE researchers Leff and Vaughn (1985) as empathic, calm, tolerant, and respectful, although their relatives presumably are as disturbed as those in the high EE families. The major component of high EE appears to be hostile criticism (Leff & Vaughn, 1985). Importantly, this seems to be significantly more common in Western urban settings than in traditional cultures.

Despite an emphasis on high EE among some clinicians, it is noteworthy that international research found that the majority of families of persons with schizophrenia manifest low EE, independent of their relatives' level of psychopathology. This pattern, reported by Leff and Vaughn (1985), continues in subsequent research (Lefley, 1992). Low EE seems to be normative in traditional cultures, including traditional ethnic groups in England and the United States. High EE seems to be much more prevalent among Anglo-European families in the United States, the United Kingdom, and Australia (Jenkins & Karno, 1992; Lefley, 1992; Weisman, 1997).

Lefley (1998) has suggested that different family structure may be the critical mediating variable in the interrelated findings of lower EE and better prognosis in the developing world. In traditional cultures, the extended family offers an emotional and economic buffering mechanism and provides family supports, in the form of many individuals who can interact with and support the patient. This is in contrast to the emotionally charged, overburdened nuclear family of modern Western societies. In nuclear families there are at most two, and frequently only one major caregiver to provide support, to negotiate the mental health, medical welfare, and sometimes the criminal justice systems, and to balance the patient's needs against those of other family members.

The stresses of caregiving have been well documented in the research on family burden (Koeter & Van Wijngaarden, 1998; Lefley, 1998; Marsh, 1998). Hostile criticism towards a patient, refusing to take medications, or emotional over-involvement with a depressed and defeated person may indeed be more likely under these circumstances. Another cultural factor involves perceptions of accountability. Hooley (1987) noted that high EE appears to be related to familial attributions in which the person with mental illness is perceived as being in control of and accountable for symptomatic behaviours. Some subsequent studies offered further evidence that attributions of control differentiate low EE and high EE relatives (Weisman, 1993). Various authors found that low EE relatives made fewer personal references and attributions of accountability than did high EE relatives (Lefley, 1998; Marsh, 1998; Koeter, & van Wijngaarden, 1998). The latter were highly critical and implied that the mentally ill person was wilfully symptomatic.

### 2.8.3 Summary

Burden on mothers of children with schizophrenia can bring the risk of mental ill-health to them in the form of emotional stress, depressive symptoms, or

clinical depression. Most schizophrenic children live in their homes and are cared for by their mothers. The caring process can be quite taxing and exhausting, and in the long-run, becomes a source of considerable stress to the mother, who is the primary caregiver. Behavioural problems associated with schizophrenia further increase the stress level of the mother and therefore impact significantly on her mental health and quality of life in general. The quality of care provided to the sick child can be expected to decline if the mother herself is under stress.

The literature review reveals that schizophrenic children are more likely to have a subsequent relapse of symptoms if the child is living with her mother as caregiver, caregivers of schizophrenic children are assessed to be high in expressed emotion. EE is now a well-validated predictor of poor clinical outcome for schizophrenia as well as for other psychiatric conditions. However, expressed emotion is accepted as a culturally concept and there are few relevant research studies relevant to schizophrenia in Vhembe District. A greater understanding of EE will also help health care teams and mothers of schizophrenic children to understand why problematic interpersonal environments are associated with more unfavourable course of schizophrenia and other psychiatric illnesses. Therefore, good psychometric properties of the EE measures are needed to enhance the effectiveness of clinical interventions by nurses and the professional health care team.

## CHAPTER 3

### RESEARCH METHODOLOGY

#### 3.1 **The qualitative research approach used in the study**

The purpose of this study was to explore the experiences of everyday life and challenges faced by a mother when her child suffers from schizophrenia. Phenomenology, one type of qualitative research methods, was used in this study in an effort to better understand the realities that a family experiences when confronted with such a stressful and life-altering event. Through the use of interviews, the researcher gathered data and discovered emergent themes throughout the duration of the study.

This study employed a phenomenological approach (Groenewald, 2004). The method focused on understanding the phenomenon or experience of mothers of schizophrenic children. Cohen (1994) describes phenomenological research as the study of the meaning of experience. The following sections will attempt to elucidate phenomenology as a research concept and strategy, and in the process illuminate the design of the study. In other words, conceptual analysis will automatically clarify issues of design.

#### 3.2 **The phenomenological approach as a research strategy**

The design for this study was based on the qualitative method of phenomenology. Phenomenology is an appropriate and useful method for examining the experiences of mothers who have schizophrenic children. By using a phenomenological qualitative research approach, the experiences of mothers caring for their schizophrenic children were discovered and

understood. Phenomenological research describes real, direct experiences that happen daily, and can interpret experiences of participants in order to understand their essence as perceived by them (Cubbin, 1987).

The chief objective of phenomenology is to describe the full structure of what an experience means to those who live it. According to Marton (1988) the aim of phenomenology is to discover the structural framework within which various categories of understanding exist. Such structures (a complex of categories of description) should prove useful in comprehending other people's understanding.

According to David and Sutton (2004), a phenomenological position sees an individual and his or her world as co-instituted. This means that the person is viewed as having no existence apart from the world, and as having no existence apart from others in his or her environment. As a result, a qualitative method of data collection was used in this study. It was directed at obtaining insight about the behaviour, perspectives and experiences of the mothers being studied.

### **3.3 Sampling**

In this study the researcher used non-probability sampling. Under non-probability sampling, purposive sampling was used as the specific sampling technique to select participants. The advantage of purposive sampling was that it was compatible with a phenomenological method, since it allowed the researcher to hand-pick units of the sample based on the phenomenon under study. Only those individuals who fitted the criteria of the study were recruited. Mothers with children who suffered from schizophrenia, and lived with them in their homes, were recruited.

A hospital situated in a rural village in Vhembe district, South Africa was used as a starting point of recruitment. Mothers of children who received a formal diagnosis of schizophrenia from the hospital were considered for inclusion in the sample. Prospective candidates were identified through hospital records. This was done with the permission of the hospital CEO, and the help and co-operation of the nursing staff. From the available population, ten mothers were randomly selected for inclusion in the study. All of them met the criteria for inclusion in the study. For instance, they cared for their children in their homes, have done so for a while since the child was diagnosed with the disease, and resided in the rural village chosen for the study. However, two of the ten potential participants were not at home during data collection. Eventually, they were left out, since data saturation occurred by the sixth interview, and eventually data collection was terminated with the eighth participant.

### **3.4 Procedure**

#### **3.4.1 Overview of the phenomenological data collection strategy used**

Phenomenology was used to guide the study (Carpenter & Streubert, 1999). Unstructured, in-depth or phenomenological interviews were used to collect data about the mother's life experiences of supporting and caring for her sick child. The interview used can be equated with what has been referred to as "a conversation with a purpose" (Marshall & Rossman, 1995, p. 80). In order to acquire more information, probing questions were used to encourage further exploration of the subject at hand. Regarding the language of the interviews, Xitsonga and Tshivenda were used, depending on what language each mother understood well or preferred.

### 3.4.2 Data collection

The participants were informed about the aim and procedures of the study, and the possible risks involved in the research. All aspects regarding informed consent were observed. The participants were made aware that they were not forced to participate and that they were also free to withdraw at any time if they ever felt uncomfortable with the process. The participating mothers were also assured that information shared during the interview would remain confidential and used only for the purpose of the study, unless they gave consent to do otherwise (American Psychological Association, 2003).

The researcher used a tape-recorder to gather information from the participating mothers. The recordings were done with the permission of the interviewees. The participants were made aware that it was necessary to record their utterances verbatim for accurate analysis and interpretation. As a precautionary measure, extra batteries for the recorder and the microphone were always at hand. Also, the interviewer tested the equipment before the actual interview took place to ensure that was in order and functional.

The actual interview involved asking each of the participating mothers to explain what their experiences of caring for their sick child were. The interviewer listened carefully and recorded the utterances electronically. Moreover, the interviewer also took hand notes of key points. Probing and follow-up questions were also used to clarify issues and to acquire more information from the participants. Probing was also used to encourage the participants to talk more about their caregiving experiences.

Participating mothers were allowed to present their point of view without their thoughts being interrupted or interfered with. However, probing was used to increase the researcher's understanding of what each participating mother

was saying. The probing included inquiries about known caregiver issues, if the participant had not said them. A sample of primary questions used during the main interviews is included as Appendix D.

The size of the sample made identification easier. However, precautions were still taken to ensure accuracy. Where more than one interview took place on a specific date, the different interviews were identified by a numerical character, for example (participant #1, participant #2). The researcher recorded each interview on a separate cassette. Each cassette was labelled with the assigned interview code. Immediately after each interview, the researcher listened to the tape-recorder and made notes. The researcher also transcribed key words, phrases and statements in order to allow the voices of the research participants to speak.

Field notes were also taken during each and every interview as emphasized by Lofland and Lofland (1999). Field notes include the following: observational notes, methodological notes, theoretical notes, and analytical memos. The researcher took field notes so that she would not forget some of the information from the respondents, since the human mind tends to forget quickly. The researcher was disciplined to record observations, subsequent to each interview, as comprehensively as possible, but without judgmental evaluation (Bailey, 1996).

### **3.4.3 Checking the validity of the data**

For validity checking the researcher conducted a 'validity check' by returning to the participants to determine if the essence of the interview has been correctly captured before the data was analysed.

### 3.5 Data analysis

The researcher listened repeatedly to the audio recordings of each interview to familiarize herself with the words of the participating mothers. This was done as a first step, so as to develop a holistic sense, the gestalt. After that, the researcher made a substantial amount of judgement calls, while consciously bracketing her own presuppositions in order to avoid inappropriate subjective judgements. The list of units of relevant meaning extracted from each interview was carefully scrutinized and the clearly redundant units eliminated. And then clusters of themes were typically formed by grouping units of meaning together and the researcher identified significant topics, also called units of significance. The researcher reviewed both the recorded interview and the list of non-redundant units of meaning to derive clusters of appropriate meaning. Often there was an overlap in the clusters, which was expected, considering the nature of human phenomena. By interrogating the meaning of the various clusters, central themes were determined, which expressed the essence of these clusters. After that the researcher did validity checking by returning to the informant to determine if the essence of the interview was correctly captured.

Once the process outlined was done for all the interviews, the researcher looked for the themes common to most, or all of the interviews, as well as individual variations. The unique or minority voices were important counterpoints to bring out regarding the phenomenon researched. The researcher concluded by writing a composite summary, which reflected the context or “horizon” from which the themes emerged.

## CHAPTER 4

### PRESENTATION OF FINDINGS

#### 4.1 Introduction

This study aimed to explore the experience encountered by mothers who have a child diagnosed with schizophrenia. This chapter will present the data collected from interviews with eight mothers of the children. Demographic details of the sample will be presented first, followed by the major themes that emerged from their articulations.

#### 4.2 Description of participating mothers' demographic characteristics

The sample for this study consisted of eight mothers who had schizophrenic children. All eight participating mothers lived in the same rural village, in the district of Vhembe, South Africa. All the eight participants were biological parents of the schizophrenic children. The ages of participating mothers at the time of the interviews ranged from 40 years to 66 years. Of the eight participating mothers five were married. Only one was employed full-time as a professional nurse at the time of the interview.

The ages of the children of the participants ranged from 6 years to 22 years. They were all diagnosed with schizophrenia when they were between 6 years and 10 years of age. Seven of the schizophrenic children were males. All the children lived at home with the participating mother. Four participants were Xitsonga speaking mothers and four were Tshivenda speaking mothers. Details of the sample's demographics are presented in table 1 below.

**Table 1:** Demographic information of participants

<i>Participant</i>	<i>Mother's age</i>	<i>Marital status</i>	<i>Child's age</i>	<i>Child's gender</i>	<i>Age diagnosed</i>	<i>Home language</i>	<i>Employment status</i>
#1	46 yrs.	Widowed	22 yrs.	Male	9 yrs.	Tshivenda	Unemployed
#2	52 yrs.	Divorcee	17 yrs.	Male	8 yrs.	Xitsonga	Hawker
#3	44 yrs.	Married	22 yrs.	Male	9 yrs.	Tshivenda	Professional nurse
#4	42 yrs.	Married	20 yrs.	Female	10 yrs.	Xitsonga	Unemployed
#5	49 yrs.	Married	12 yrs.	Male	6 yrs.	Xitsonga	Unemployed
#6	66 yrs.	Married	20 yrs.	Male	9 yrs.	Tshivenda	Pensioner
#7	58 yrs.	Widow	20 yrs.	Male	10 yrs.	Tshivenda	Pensioner (disability grant)
#8	50 yrs.	Married	23 yrs.	Male	8 yrs.	Xitsonga	Unemployed

**Note:** All participants were Black Africans and all the mothers were biological parents of the children.

### 4.3 Essential themes

Briefly, eight major themes emerged after transcribing and coding the interviews. Some themes emerged directly from the interview questions while others emerged spontaneously. The first major theme that appeared was poverty and unemployment. The second theme was emotional responses from mothers who have schizophrenic children. The third was that participating mothers were blaming witchcraft for the illness of their children. The fourth theme was dealing with the violence and aggression of the children. The fifth theme that appeared was concerned with financial support and the sixth theme was social support. The seventh theme was based on the effects of schizophrenia on the mother-to-child relationship, and the last theme was the loss that mothers went through.

#### 4.3.1 Theme 1: Poverty and unemployment

The study revealed how poverty and unemployment compounded the burdens of mothers of children with schizophrenia. Most mothers raised their concerns about being unemployed and therefore experiencing financial difficulties. Some of them had to make ends meet from the monthly social grants they were receiving from the government. For instance, from the same social grant, they had to save some money for transport in case there was a need to transport the children to hospitals which in most cases, were far. In addition, they also had to repair their own properties and those of their neighbours, vandalized by their schizophrenic children. Regarding damages to property, participant #1 expressed her anguish with the following words:

*“I am losing a lot of money because he is vandalizing properties of community members ... and I am always paying for the damage.”*

In this study some mothers indicated that since they were experiencing serious financial difficulties, they were using the small grant money paid to their children to cover all expenses they were incurring.

#### **4.3.2 Theme 2: Emotional reactions of mothers who have children with schizophrenia**

Most of the participating mothers became emotionally affected when they found out that their children were schizophrenic. The common emotional responses were fright, anger and frustration. What made the situation difficult for them was that they lacked knowledge of how to manage the condition and control the situation. For instance, they did not know what should be done when their schizophrenic children exhibited symptoms of the disorder. For that matter, it was striking that all the participating mothers did not know how to absorb the revelation and protect themselves when such moment come.

To most of the participating mothers, the instance of hospitalization of their schizophrenic children brought about relief from stress and anxiety. Soon as the children showed symptoms of psychiatric illness, they were sent to hospital. At that time, each of the participating mothers said they were highly stressed, and their lives were preoccupied with the illness of their children. Hospitalization brought about a feeling of relaxation and comfort. Importantly, it also brought respite and relief since for a while; they could concentrate on other day-to-day matters without worrying about the illness of their schizophrenic children. However, when the children were released into their care, the cycle of burden started all over again.

Caring for their sick children was usually accompanied by negative emotions or affect. Participating mothers said that their emotional state was usually characterized by fear, sadness and unhappiness. Compared with the first time, participating mothers' negative emotion towards their schizophrenic children for the second time at home was minimized.

Apart from negative effects, it was common for the participating mothers to feel disappointed. Most of them had high hopes and expectations towards their children. The diagnosis of schizophrenia came as a let-down. Schooling was the single area they hoped their children would do well in. They expected their children to go far with it. Some participants expressed anger and frustration right from the moment they heard that their children were diagnosed with schizophrenia.

#### 4.3.3 **Theme 3: Blaming witchcraft**

Most participants in this study blamed the illness on the friends of their children, relatives of patients and jealous neighbours. Participating mother # 6 said:

*“I think this was because of the hatred from people outside the family, like neighbours, I think he was bewitched”.*

It was also common that mothers described sleeplessness and restlessness as primary symptoms of the illness. This may be because the rest of the symptoms were less obvious to lay persons, and required clinical knowledge which caregivers did not have. Participating mother #2 indicated that her child could not sleep at night and that he would also be restless. Because she lacked knowledge of schizophrenia symptoms she believed that her child was bewitched. Participating mother #2 was also convinced by the behaviour of the child.

#### 4.3.4 **Theme 4: Dealing with the children’s violence, aggression and destructiveness**

Some participating mothers explained violence and aggression as the worst aspects of caring for children with schizophrenia. They reported that they are living with worries that their children might cause trouble to other family members and people in general. The participating mothers described the first

violent outburst as an extremely troubling experience. In the words of participating mother #3:

*“The difficult part that I am having with my child is that when the house is locked she tries by all means to open it. She will be using objects to force entry so that she can get what she wants in the house. After gaining entry into the house she just destroys the property in there, which is not good at all.”*

Verbal and behavioural aggressions were the most common symptoms that mothers noted and felt annoyed by. In the interviews, the mothers mentioned different violent incidents that happened during the onset of the illness of the children. Participant #1 alleged that his son knocked down his neighbour’s wooden front door at the onset of his illness. The family had to face many complaints from their neighbours. He once burned the furniture in his own bedroom. The police came and escorted him to hospital. This is what participant #1 said about her child:

*“He even burned all the blankets in the house. Even his uncle’s bed and mine were burnt by him. To tell you the truth he...he...he even broke the windows of his uncle’s house”.*

*Participant #6 was also complaining about the aggressiveness of her child. This is what she said:*

*“Hey.....this child is so aggressive and I do not know how to deal with this child. Even his siblings they donot want to be next to him because of his aggressiveness.”*

#### 4.3.5 Theme 5: Financial support

The financial support that participating mothers provided to their children in this study included giving them money for transport to the hospital to collect medication, buying food and clothes. Of all the eight participating mothers interviewed, only 50% had access to the grant of their children and were able to utilize it effectively. Some of them indicated that they were having financial difficulties when it came to supporting or taking care of their schizophrenic children. Others said their children were not eligible for a disability grant, thus worsening their financial situation. This is what participating mothers #5 said:

*“There’s no one in the family who’s supporting me financially in the sickness of my son; I’m just alone in this situation. It’s me and my children.”*

Apparently, some mothers were on their own and did not receive any material support from significant others such as family and spouse. Lack of financial support is only one aspect of social support amongst many that the participating mothers have to face. The next topic will highlight the issue of social support in general.

#### 4.3.6 Theme 6: Social support

Most participating mothers referred to the perceived stigma of schizophrenia. It appeared that this was a key factor underlying the social isolation experienced by some mothers. Some felt well supported by their social network. However, others did not feel that social support was forthcoming. They indicated that they did not receive emotional and financial support from significant others such spouses, family members, close relatives and intimate friends. Even distant relatives and the community were not helpful in respect

of support. Only two participants out of eight indicated that they got support from their relatives, fellow Christians, friends and neighbours. In general, the social supports to mothers of schizophrenic children were limited, especially support from family members. Participating mother #5 said:

*“There are no relatives to support us. They don’t even want to see us next to them at all, but they’re there. The relationship was not like this before I gave birth to this child. The relationship was good. After I had this child, they stopped visiting. Even our neighbours, we used to communicate and relate well, but now there are no cordial relations between us. They’re always gossiping about my child and go about as if I am the cause of his illness.”*

Marital status appears to be a mediating factor among the participating mothers. The four out of five who are married said they were satisfied with the support provided by their partners. One married mother said she did not receive support from her spouse. Yet it turned out that the spouse was also mentally ill.

#### **4.3.7 Theme 7: Effects of schizophrenia on the mother-to-child relationship**

It came as a surprise in this study that most participating mothers thought that schizophrenia improved their relationship with their children. Most of them spoke about how positive their sick children were. Slightly more than half of the participating mothers in this study reported that their sick children were loving and affectionate towards them. This is what participating mother #3 said:

*“She always loves me, not because I did something good to her, but she becomes happier when I’m around or when I’m next to her. There’s a strong*

*bond between me and her. She always listens to me when I speak to her and I also listen to her when she speaks.”*

The illness seemed to increase the closeness between the mothers and their children.

#### 4.3.8 **Theme 8: The loss that the mothers go through**

Participating mothers in this study indicated that they experienced a kind of symbolic loss because of their children's illness. They experienced loss in a number of areas, including the loss of an idealized child, family, employment and friendships. One of the participating mothers (participating mother # 5) put it as follows:

*“There’s no more good relationship between us and our relatives. They don’t even want to see us next to them at all, but they’re there. The relationship wasn’t like this before my child was diagnosed with schizophrenia. Once the child was diagnosed with schizophrenia, they stopped visiting us. Even our neighbours ... we used to talk to each other, but now there’s no good relationship between us at all.”*

Participating mother #1 also indicated that she used to work before but she had to give up her job because of her child's illness. There was no one to take care of him at home. A loss expressed by participating mother #6 is the loss of what her child once was, and the loss of her child's potential to be a productive contributor to society; that is, the loss of their dreams for his future.

## **CHAPTER 5**

### **DISCUSSION**

#### **5.1 Introduction**

The current study used the phenomenological approach to explore the lived experience of mothers who care for their schizophrenic children. There are some researchers who used qualitative approaches in an attempt to gain an understanding of the experience of parenting a child with schizophrenia (Glendy & Mackenzie, 1998). This study adds to that pool of knowledge by exploring dominant experiences of mothers who care for schizophrenic children. The current chapter will evaluate the findings in terms of the theoretical framework discussed earlier. Some of the findings are consistent with trends observed in the literature, while others are not. The various themes that emerged are further discussed.

#### **5.2 Emotional responses of mothers who have schizophrenic children**

Most participating mothers in this study have been caring for their schizophrenic children for periods ranging between 6 years to 13 years. However, the findings in this study suggest that some of them still have fresh emotions and are facing adjustment difficulties despite years of caring. This is what Gubman and Tessler (1987) considered a life-long struggle. Problems are attributed to compounding stressful situations and the concomitant lack of emotional and instrumental (particularly financial) support from significant others and relatives.

The findings of this study revealed that participating mothers went through various changes of feelings and emotions during their years of caring. At the beginning of their caring, that is, the early phase of the illness, most mothers in one way or another experienced negative emotions, which included anger and frustration. These were caused and precipitated by factors such as lack of

knowledge of schizophrenia in terms of process, symptoms, and treatment. Parents lacked experience in managing the distressing symptoms and behaviour, feared being harmed by their schizophrenic children during the acute, aggressiveness phase of the illness, and was also unable to cope with the stresses related to their new caregiving role. The experiences are consistent with studies done on caregivers' experiences and burden (Boyd & Maurin, 1990; Harvey & Winfred, 1994; Jones, 1996).

Over the years of caring, the mothers have learned ways to cope, and to accept the illness of their children in one-way or another. The acceptance of the child was partly a belief that all was fate and was test of patience from God. As Al-Ghazzali (1968) stated, "illness is one of the forms of experiences by which humans arrive at the knowledge of Allah" (cited in Rossool, 2000, p.1479). The illness of the child was cared for just like any normal children in the family and caring became like a routine in Malaysia. They reflected positive feelings and affect such as feeling more relaxed, happier, not crying anymore, lacking in sadness worry, less stressed, and more proud and satisfied with the caring. They gained confidence in their caring and were able to overcome their difficulties. However, they still have to endure and cope with various prolonged problems of the mental illness.

The findings also indicated that feelings of participating mothers, as caregivers, were not stagnant, but changed and fluctuated according to the severity of the illness process of the children, the availability of support from fellow Christians during those critical times and their coping styles. When children were not exhibiting those distressing, disruptive behaviours and were easy to manage, participants felt more relaxed, less stressful and happier. On the other hand, when the children refused to take medication, exhibited distressing symptoms and behaviours, and family members showed lack of emotional support, caregivers felt very stressed, tensed and sad. They were also fearful of their children when they became too aggressive to be handled and seemed prone to cause harm to them.

The findings in this study also showed that being a mother to a child with schizophrenia can be stressful and demanding. Halterman and Montes (2007) found that mothers of children with schizophrenia displayed higher levels of stress than mothers of children without the diagnosis, but also found that they were able to cope as well as the mothers of children without schizophrenia. Although this study did not utilize quantitative measures for stress, all participating mothers reported having a schizophrenic child as a difficult situation to handle. However, the participating mothers seemed to have ways of coping with the situation. They all reported functioning at extremely high levels with regards to all the obstacles they were facing on a daily basis.

### **5.3 Attributing or blaming witchcraft on the illness of their children**

Adebimpe investigated the relationship between witchcraft beliefs and schizophrenia, and asserted that the belief that witchcraft causes illness is very common everywhere in black societies, especially in the case of schizophrenia (Adebimpe, 1997). These findings are also reflected in this study, as some of the participants attributed the illness of their children to witchcraft. As alluded to earlier, belief in witchcraft could be seen against the backdrop of the participants' cultural background. Some of the participants attributed the illness of their children to spirit possession.

Witchcraft and schizophrenia have been documented in case studies of the middle ages (Erinosho, 1977). Schizophrenia has often been diagnosed as witchcraft. Erinosho (1977) investigated the belief system and the concept of mental illness among Nigerian medical students. He found that although the students had been sufficiently exposed to various specialities in the field of medicine, including psychiatry, many believed that schizophrenia can be influenced by witchcraft. This was also to the case with some of the participants in this study; they had a strong belief that the illness of their children was caused by witchcraft. Koen, Mbanga, Niehaus and Stein (2005) documented a case study of "ifufunyane", a Xhosa culture-bound syndrome similar to schizophrenia. They found that the Xhosa people felt strongly that

traditional medicine is the only means to cure “ifufunyane”, which in their view was the same as schizophrenia.

#### **5.4 Difficulty of dealing with destructiveness, violence and aggressive behaviour**

The findings in this study demonstrated how difficult it was for participants to deal with schizophrenia, even when they knew that this was the probable diagnosis for their children. The greatest burden was the expense incurred when the affected family member became aggressive and damaged people’s property.

Threats and overt expressions of aggression and violence of children with schizophrenia towards their family members and other community members were also reported. This issue of violence by schizophrenic children made the participating mothers to fear for their own lives. This subsequently had a negative effect on the role of mothers as caregivers. The issue of looking after a child with schizophrenia is a difficult challenge on its own, much less having to deal with violence that seems to be a prominent feature in the lives of some mothers. Dahlgren, Kullgren and Nordstrom (2006) stated that violent conduct of persons with schizophrenia in combination with a mental disorder complicates the parent-child relationship. There are many possible causes for aggression by people with mental illness towards their family members, all of which may apply to the relatives of participants in this study. For instance, not taking medication regularly was one of the possible causes.

#### **5.5 Financial support**

Financial support was commonly mentioned as the biggest challenge experienced by most mothers. Financial support in this study was caused by the poverty and unemployment of mothers. Mothers of schizophrenic children in this study indicated they did not have adequate finances to cover the expenses related to the illness of their children. They also had inadequate financial support from their relatives and the government. This finding is similar

to that of Johnson and Lefley (1990) who also indicated that financial hardship faced by mothers led to financial stress. In a nutshell, financial support is important to caregivers of schizophrenic children. The caregiving mothers were sometimes forced to quit their employment because they wanted to take care of their sick children full time. Beebe (2002) observed that in some cases. Mothers of psychiatrically disordered children lose their jobs because of their caregiving responsibilities.

Ntswane and Van Rhyn (2007) are of the opinion that poverty is responsible for feelings of despair and isolation in mothers who cared for their mentally ill children at home. The poverty of the carers seems to also contribute to the illness process. In the study by Harvey and Winfred (1994), low quality of life and negative affectivity in individuals with schizophrenia, evidenced by depression, psychotic symptoms and alcohol abuse had been attributed to poverty and unemployment.

## 5.6 **Social support**

Dimensions of social support, as well as its sources, vary. Social support can be provided both informally, by family, friends, neighbours, social groups and so on, and formally, by professionals and agencies (Deal, Dunst & Trivette 1988). Some evidence in the literature exists that the amount and quality of social support available to caregivers is an important factor in moderating the impact of caregiving (Feinstein et al., 2001). Data from the Victorian Carers Programme research indicates that caregivers who reported having larger informal support networks reported greater life satisfaction, greater perceived support from family and friends, and less resentment and anger than did caregivers reporting smaller informal support networks (Schofield, 1998). In a study by Dunst, Trivette and Cross (1986), satisfaction with sources of social support, both formal and informal, was significantly related to emotional wellbeing in parents of children with disabilities.

Although some participants indicated that they were receiving social support from their spouses, especially those who were married, four mothers who

were not married reported that they were not receiving any social support from their relatives. Yet they considered social support from relatives as important. Participating mother #1 indicated that she was getting social support from fellow Christians, and in her view, it was not enough. Participating mother #7 was staying with her schizophrenic child. She too is mentally ill, so she reported that she was not getting any social support from relatives and friends and that she needed to be assisted.

The findings of this study are consistent with those of Dunst et al. (1986), who found that satisfaction with sources of social support, both formal and informal, was significantly related to emotional wellbeing in parents of children with disabilities (also, Kirkham, Schilling & Schinke, 1985). However, these previous studies only focused on particular support types for example, family support or professional support and so this ignores the complex relationships and interactions among many sources of support which makes it hard to manage. This study also revealed that support from friends provided emotional strength, and religious connections encouraged hope and positive attitudes amongst some mothers who espoused a faith.

## **5.7 The effects of schizophrenia on the mother-child relationship**

The findings of this study suggest that participants felt that their children were generally affectionate and loving towards them. This seems to suggest that they are securely attached to their mothers. In contrast, Rutgers (2004) found that children with schizophrenia were less securely attached than those without the disorder. Harris and Hoppes (1990) also reported this, stating that children with schizophrenia displayed fewer attachment behaviours, and mothers felt a lower sense of gratification with regards to attachment than in children without schizophrenia and their mothers. Apparently, the results from the particular rural village in Vhembe district, South Africa suggest that the issue of the mother-child relationship plays out differently in different contexts and samples.

## 5.8 The loss that mothers go through

To some degree, the findings in this study suggest that participants went through different stages of mourning in relation to parenting a child with schizophrenia. Bowlby (1980) described stages of loss and mourning that a mother may go through in response to the discovery that their child is schizophrenic. The first was detachment from the emotions. Although the participants did not talk about being detached, when speaking about the process of acquiring the initial diagnosis, all participants spoke about anger. Bowlby's (1980) second stage was that of anger generally directed at the medical profession. This was seen with the majority of the participants in this study, who spoke of anger and frustration due to the diagnosis of schizophrenia.

The next stage Bowlby (1980) described was that of intense caring, where parents ignore everything in their lives apart from the child. This can be seen with the participants in this study, who have had to submerge themselves in the lives of their sick children. The majority of the participants were not employed because they wanted to accommodate the needs of their schizophrenic children. Unlike mothers of children who do not have schizophrenia, the mothers of children diagnosed with schizophrenia in this study saw this as a stage that did not have a definite ending. During the last stage, Bowlby (1980) stated that parents often blamed themselves for their children's illnesses. However, the self-blame aspect was not observed in this study. This tallies with the fact that in this sample, parents and their children were attached, ruling out the possibility of self-blame.

Dolev, Koren-Karie, Oppenheim, Sher-Censor, Yirmiya and Salomon (2007) described the difficulties that parents went through before accepting that their children were diagnosed with schizophrenia. This supports the findings in this study as all the participants explained the process that they had gone through. It appears that the participants were constantly moving back and forth between stages described by Bowlby (1980), experiencing multiple stages at any given time.

## 5.9 Conclusion and recommendations

The findings of the study indicate that caring for individuals with schizophrenia was not always a pleasant or easy task. Various emotions, including anger and frustration, seemed to occupy the everyday lives of the mothers. The emotional burden was compounded by physical expressions and behaviours such as outbursts of violence and destructiveness, and changes in the child's personality. The mother, who is the primary caregiver, takes a toll in the process. She is emotionally affected. Inadequate support and rejection by other family members and the community made caring a difficult task.

It may be useful to do a further study investigating professional support and assistance given to the mothers. It could be that professionals limit their role to the medical care of the patients, and spend less time focussing on the welfare of the carers. The success of home-care depends on the self-sufficiency of the home environment. Mothers themselves can be asked to explore what they feel needs to change with regards to the systems dealing with theirs and their children's needs. Such an understanding would be useful for families of children with schizophrenia, as well as the professionals working with them.

It may turn out cheaper to care for schizophrenic children at home. Yet, problems related to home care should be appreciated by powers that be. Besides material support, professionals need to provide support by way of educating mothers and other significant others about the nature of schizophrenia. For instance, they have to be educated about its manifestations, the clinical picture, and how to manage problematic symptoms. In that way schizophrenia will become less of a puzzle and will be managed with confidence at home.

## 5.10 Limitations of the study

This study is limited by the small sample size utilized. By its nature, qualitative research compels the researcher to use a smaller sample. There is no point in continuing to collect data if additional participants do not add any new

knowledge to the research. However, the results are risky to generate in that it is not clear how far generalization can be made. This limitation is not exclusive to qualitative research, however, it is more pronounced in this format of research.

### **5.11 Implications of the study**

This study provides insights into the lives and needs of caregiving mothers who are constantly rewarded and challenged by the unique needs of their schizophrenic children. This study shows that mothers with a sick child need more support in a number of different areas. With schizophrenia generally diagnosed more often, professionals such as psychiatric social workers, nurses and psychologists may need to come up with programmes to support mothers caring for schizophrenic children at home. The psychosocial aspects of the illness must be taken into account. Schizophrenia has implications in the lives of those who are close to the patient, and the community at large. Managing the illness must go beyond medical treatment and incorporate relational and social implications. For instance, once a child is identified and diagnosed as schizophrenic, it should not be difficult for the mother to arrange for a grant for the child.

## 6. REFERENCES

- Adebimpe, V. R. (1997). Mental illness among African Americans. In I. Al-Issa & M. Tousignant (Eds.), *Ethnicity, immigration, and psychopathology* (pp. 95-106). New York: Premium.
- Adorno, R., & Sadala, M. L. A. (2001). Phenomenology as a method to investigate the experiences lived: A perspective from Husserl and Merleau-Ponty's thought. *Journal of Advanced Nursing*, **37**, 282-293.
- Ainsworth, M. D. S. (1989). Attachments beyond infancy. *American Psychologist*, **44**, 709-716.
- Aldard, S., Gilleard, C. J., & Vaddadi, K. S. (1997). Mental illness, physical abuse and burden of care on relatives. A study of acute psychiatric admission patient. *Psychiatric Journal*, **93**, 313-317.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders (4<sup>th</sup> ed.)*, Text Revised. Washington, D.C.: Author.
- American Psychological Association. (2003). *Ethical principles of psychologists and code of conduct*. Washington, D.C.: Author. Retrieved on 16 January, 2009 from <http://www.apa.org/ethics>.
- Anderson, C., Bayer, T., Hogarty, G., & Needleman, R. A. (1984). Expressed emotion and social networks of parents of schizophrenic patients'. *British Journal of Psychiatry*, **144**, 247-55.

- Andrews, M. M., & Boyle, J. S. (1999). *Transcultural concepts in nursing care* (3<sup>rd</sup> ed.). Philadelphia: Lippincot Williams.
- Angermeyer, M. Klusmann, D., & Walpuski, O. (1998). The causes of functional psychoses as seen by patients and their relatives: II. The relatives' point of view. *European Archives of Psychiatry & Neurology Science*, **238**, 55–61.
- Bailey, C. A. (1996). *A guide to field research*. Thousand Oaks, CA: Pine Forge.
- Bateson, G., Haley, J., & Jackson, D. D., & Weakland, J. (1956). Towards a theory of schizophrenia. *Behavioural Science*, **1**, 251-264.
- Begginton, P., & Kuipers, L. (1987). Relatives as a resource in the management of functional illness. *British Journal of Psychiatry*, **147**, 465-470.
- Beebe, L. H. (2002). Problems in community living identified by people with schizophrenia. *Journal of Psychosocial Nursing and Mental Health Services*, **40**, 38-45.
- Bernheim, K. Lehmann, A. F. (1994). *Working with families of mentally ill*. New York: W. W. Norton.
- Berzoff, J., Flanagan, L. M., & Hertz, P. (2002). *Inside out and outside in: Psychodynamic clinical theory and practice in contemporary multicultural contexts*. Oxford: Jason Aronson.

- Biegel, D. E., Sales, E., & Schultz, R. (1991). *Family caregiving in chronic illness: Alzheimer's disease, cancer, heart disease, mental illness and stroke*. Newbury Park, CA: Sage.
- Boland, D. L., & Sims, S. L. (1996). Family care giving at home as a solitary journey. *Image: Journal of Nursing Scholarship*, **28**, 55-58.
- Bowlby, J. (1958). The nature of the child's tie to his mother. *International Journal of Psycho-Analysis*, **40**, 1-23.
- Bowlby, J. (1975). *Attachment and loss, 2. Separation: Anxiety and anger*. Harmondsworth: Penguin.
- Bowlby, J. (1980). *Loss, sadness and depression*. New York: Basic Books.
- Boyd, C. B., & Maurin, J. T. (1990). Burden of mental illness on the family: A critical review. *Archives of Psychiatric Nursing*, **4**, 99-107.
- Bregman A. M. (1980). Living with progressive childhood illness: Parental management of neuromuscular disease. *Social Work in Health Care*, **5**, 387-408.
- Brown R., Greenberg, J. S., Greenly J. R., Griffin-Francell., C. & McKean, D., (1993). Mothers caring for an adult child with schizophrenia: The effect of burden on maternal health. *Family Relations*, **42**, 205-211.
- Brown, A., & Hepple, S. (1989). *How parents cope*. Hertford, England: Barnardo's Research & Development.
- Buchanan A., & Flouri, E. (2002). The protective role of parental involvement in adolescent suicide. *Crisis*, **23**, 17-22.

- Bulger, M. W., Goldman, C. R., & Wandersman, A., (1993). Burdens and gratifications of caregiving: Appraisal of parental care of adults with schizophrenia. *American Journal of Orthopsychiatry*, **63**, 255-265.
- Butler, A., & Pritchard, C. (1983). *Social work and mental illness*. London: Macmillan.
- Camann, M. (1996). Family-focused mental health care policy. *Issues in Mental Health Nursing*, **17**, 479-486.
- Cameron, J., Stewart, D. E. & Veltman, A., (2002). The experience of providing care to relatives with chronic mental illness. *Journal of Nervous Mental Disorder*, **190**, 108-11.
- Carlsson, M., Ivarsson, A. B., & Idenvall, B. (2004). The factor structure of the burden assessment scale and the perceived burden of caregivers for individuals with severe mental disorders. *Scandinavian Journal of Caring Science*, **18**, 396-401.
- Carpenter, D. R., & Speziale, H. J. S. (2007). *Qualitative research in nursing: Advancing the humanistic imperative* (4<sup>th</sup> ed.). Philadelphia: Lippincott Williams & Wilkins.
- Carpenter, D. R., & Streubert, H. G. (1999). *Qualitative research in nursing*. Philadelphia: Lippincott.
- Castle D., Gureje O., Herrmen H., Horten A. Jablensky, A., McGrath J., & Morgan V, (1999). *People living with psychotic illness: An Australian*

study. Retrieved 1 March 2009 from <http://www.health.gov.au/hsdd/mentalhe.htm>.

Chambers, M., (1998). Interpersonal mental health nursing: research issues and challenges. *Journal of Psychiatric & Mental Health Nursing*, **5**, 203-211.

Chesla, C., & Rungreangkulkij, S. (2001). Smooth a heart with water: Mothers care for a child with schizophrenia. *Archives of Psychiatric Nursing*, **15**, 120–127.

Cohen, M. Z. (1994). Schools of phenomenology: implication for research. In J. M. Morse, (2<sup>nd</sup>ed.), *Critical issues in qualitative research methods* (pp. 136-156). Thousand Oaks, CA: Sage.

Conn, V. S., Francell, C. G., & Gray, D. P. (1988). Family perception of burden of care for the chronic mental ill relatives. *Psychiatry Service*, **39**, 1296-1300.

Cohler, B. J., Cook, J. A., Lefley, H. P., & Pickett, S. A., (1994). Age and family burden among parents of offspring with severe mental illness. *American Journal of Orthopsychiatry*, **64**, 435–447.

Cross, A. H., Dunst, C. J., & Trivette, C. M. (1986). Mediating influences of social support: Personal, family and child outcomes. *American Journal of Mental Deficiency*, **4**, 403-17.

Dahlgren, L., Kullgren, G., & Nordstrom, A. (2006). Schizophrenia and violent crime: The experience of parents. *International Journal of Law and Psychiatry*, **29**, 57-67.

- David, M., & Sutton, C. R. (2004). *Social research: The basics*. London: Sage.
- Deal, A. G., Dunst, C. J., & Trivette, C. M. (1988). *Enabling and empowering families. Principles and guidelines for practice*. Cambridge, MA: Brookline Books.
- Doku, V., Fannon, D., O'Ceallaigh, S., Soni, W. & Tennakoon, L., (2000). Experience of caregiving: Relatives of people experiencing a first episode of psychosis. *The British Journal of Psychiatry*, **177**, 529-533.
- Dolan, M., Eisler, I., Staples E., Stern, S., & Szmukler, G. L. (1999). Disruptive and Reconstructive: Narrative insight into the experience of family member caring for a relative with diagnosis of serious mental illness. *Family Process*, **38**, 353-369.
- Dolev, S., Koren-Karie, N., Oppenheim, D., Salomon, S., Sher-Censor., & Yirmiya, N. (2007). *Parental resolution of the child's diagnosis and the parent-child relationship*. In D. Oppenheim & D. Goldsmith (Eds.), *Attachment theory in clinical work with children* (pp. 109-135). New York.
- Doornbos, M. M. (1996). The strengths of families coping with serious mental illness. *Archives of Psychiatric Nursing*, **10**, 214-220.
- DuMont, P., Evans, G., Tuck, I., & Shupe, J. (1997). The experience of caring for an adult child with schizophrenia. *Archives of Psychiatric Nursing* **11**, 118-125.
- Early, T. J., Gregoire, T. K., McDonald, T. P., & Poertner, J. (1997). Building a model of family caregiving for children with emotional disorders. *Journal of Emotional & Behavioural Disorders*, **5**, 138-148.

- Eiser, C. (1990). *Chronic childhood disease: An introduction to psychological theory and research*. Cambridge, MA: Cambridge University.
- Erinosho, O. A. (1977). Belief-system and the concept of mental illness among medical students in a developing country: a Nigerian example. *Journal of Anthropological Research*, **33**,158-166.
- Feinstein, N. F., Melnyk, B. M., Moldenhouer, Z., & Small, L. (2001). Coping in parents of children who are chronically ill: Strategies for assessment and intervention. *Pediatric Nursing*, **27**, 547-557.
- Fitzgerald, L. & Roberts, K., (1991). Serenity: Caring with perspective. *Scholarly Inquiry for Nursing Practice*, **5**, 127-146.
- Fuji, Y., Hasui, C., Miyata, R., Kitamura, T., Koshiishi, F., Sakomoto, S., & Sanguira, T. (2002). Burden on the family members of the mentally ill: A naturalistic study in Japan. *Comprehensive Psychiatry*, **43**, 219-222.
- Fromm-Reichmann, F., (1948). Notes on the development of treatment of schizophrenics by psychoanalytic therapy. (pp. 263-274). <http://www.ispsch.org/fr/archives/archives%20historiques/Fromm-Reichmann-Psychiatry1948.pdf>
- Giorgi, A. (1997). Sketch of a psychological phenomenological method. In Giorgi, A. (Ed.), *Phenomenology and psychological research*, (p. 263-274). Pittsburgh, PA: Duquesne University Press.
- Glendy, S. H., & Mackenzie, A. E. (1998). Caring for relative with serious mental illness at home: the experience of family cares in Hong Kong. *Archives of Psychiatric Nursing*, **5**, 288-294.

- Glidden, L., Haworth, A., & Hill, A. (1996). Measuring religiousness of parents of children with developmental disabilities. *Mental Retardation*, **34**, 271–279.
- Glueckauf, R. L., Jackson, D. N., & Quittner, A. L. (1990). Chronic parenting stress: Moderating versus mediating effects of social support. *Journal of Personality & Social Psychology*, **59**, 1266–1278.
- Gottlieb, B. H. (1992). Quandaries in translating support concepts to intervention. In U. Baumann (Ed.), *The meaning and measurement of social support* (pp. 293–309). New York: Hemisphere.
- Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods*, **3**(1). Article 4. Retrieved on 23 April, 2010 from [http://www.ualberta.ca/~iiqm/backissues/3\\_1/pdf/groenewald.pdf](http://www.ualberta.ca/~iiqm/backissues/3_1/pdf/groenewald.pdf)
- Gubman, G. D., Horwitz, A. V., Minsky, S., & Reinhard, S. C. (1994). Burden Assessment Scale for families of the seriously mentally ill. *Evaluation & Program Planning*, **17**, 261–269.
- Gubman, G., & Tessler, R. (1987). The impact of mental illness on families. *Journal of Family Issues*, **8**, 226-245.
- Halterman, J. S., & Montes, G. (2007). Psychological functioning and coping among mothers of children with schizophrenia: A population based study. *Journal of the American Academy of Pediatrics*, **119**, 1040-1046.
- Hamilton, M. W., & Hoenig, J. (1966). The schizophrenic patient in the community and his effect on the household. *International Journal of Social Psychiatry*, **12**, 165-176.

- Harris, S. L., & Hoppes, K. (1990). Perceptions of child attachment and maternal gratification in mothers of children with autism and Down syndrome. *Journal of Clinical Child Psychiatry*, **19**, 365- 370.
- Hartley, V., & Peternelj-Taylor, C. (1993). Living with mental illness: Professional / family collaboration. *Journal of Psychosocial Nursing* **31**, 23-28.
- Harvey, E. J & Winfred, H. R., &. (1994). Needs of family caregivers in chronic schizophrenia. *Schizophrenia Bulletin*, **20**, 557-566.
- Harvey, E. J. & Winfred, H. R. (1993). Determinants of psychological distress in relatives of people with chronic schizophrenia. *Schizophrenia Bulletin*, **19**, 619-625.
- Heffern, R. (1993). Our society is still giving mental illness a bum rap. *National Catholic Reporter*, **29**, 18-20.
- Heidegger, M. (1947/1993). Letter on humanism. In D. F. Krell (Ed.), *Basic writings* (pp.302-307). New York: Harper & Collins.
- Holzinger, A., Muller, P., & Priebe, S. (2001) Causes of schizophrenia - Beliefs of patients' relatives. *Psychiatric Praxis*, **28**, 139-143.
- Hooley, J. M. (1987). *The nature and origins of expressed emotion*. In K. Hahlweg & M. Goldstein (Eds.), *Understanding major mental disorder: The contribution of family interaction research* (pp. 176–194). New York: Family Process.

- Hornsby, G. (1994). *Counseling in child disability*. London: Chapman & Mall.
- Hughes, I. C. T., & Oldridge, M. L. (1992). Psychological well-being in families with a member suffering from schizophrenia. An investigating into long standing problems. *British Journal of Psychiatry*, **161**, 249-251.
- Husserl, E. (1931/1999). The Essential Husserl: Basic writings in transcendental phenomenology. *Qualitative Health Research*, **8**, 694-706.
- Jenkins, J., & Karno, M. (1992). The meaning of expressed emotion: Theoretical issues raised by cross-cultural research. *American Journal of Psychiatry*, **149**, 9-21.
- Jeon, Y. H., & Madjar, I. (1998). Caring for a family member with chronic mental illness. *Qualitative Health Research*, **8**, 694-706.
- Johnson, D. L., & Lefley, H. P. (1990). *Families as Allies in Treatment of the Mentally Ill: New Directions for Mental Health Professionals*. Washington, DC: American Psychiatric press.
- Johnson, D., & Marsh, D., (1997). The family experience of mental illness: Implications for intervention. *Professional Psychology: Research & Practice*, **28**, 229-237.
- Jones, S. (1996). The association between objective and subjective caregiver burden. *Archives of Psychiatric Nursing*, **10**, 77-84.
- Jones, S. L., Jones P. K. & Roth, D. (1995). Effect of demographic and behavioural variables on burden of caregivers of chronic mentally ill person. *Psychiatric Service*, **46**, 141-145.

- Kane, D. J., & Snowdon, A. W. (1995). Parental needs following the discharge of a hospitalized child. *Journal of Pediatric Nursing*, **21**, 425-428.
- Karp, D. A., & Tanarugsachock, V. (2000). Mental illness, caregiving and emotion management. *Qualitative Health Research*, **10**, 6-25.
- Kavanagh, D. J. (1992). Recent developments in expressed emotion in schizophrenia. *British Journal of Psychiatry*, **160**, 601–620.
- Kazak, A. E., & Wilcox, B. L. (1984). The structure and function of social support networks in families with handicapped children. *American Journal of Community Psychology*, **12**, 77-80.
- Kellett, U. (1996). Caring in nursing homes: The family perspective. *Geriatrics*, **14**, 18-23.
- Kellett, U. M., & Mannion J. (1999). Meaning in caring: reconceptualising the nurse – family carer relationship in community practice. *Journal of Advanced Nursing*, **29**, 697–703.
- Kent, G., & Wahass, S. (1997). Coping with auditory hallucinations: A cross-cultural comparison between Western (British) and non-Western (Saudi Arabian) patients. *Journal of Nervous & Mental Diseases*, **185**, 664–668.
- Kirkham, M. A., Schilling, R. F., & Schinke, S. P. (1985). Coping with a handicapped child: Differences between mothers and fathers. *Social Science & Medicine*. **21**, 857-863.

- Koen, L., Mbanga, N., Niehaus, D., & Stein, D. J. (2005). A Case of "Ifufunyane": A Xhosa culture bound syndrome. *Journal of Psychiatric Practice*, **11**, 411-413.
- Koeter, M. W. J., & Van Wijngaarden, B. A. H. (1998). Caregiving consequences in the Netherlands and other European countries: The development and use of the involvement questionnaire. In Lefley H. P. & Johnson D. L. (1<sup>st</sup> Ed.), *Family interventions in mental illness: International perspectives*. Connecticut: Praeger.
- Kreisman, D. E., & Joy, V. D. (1974). Family response to the mental illness of a relative: A review of the literature. *Schizophrenia Bulletin*, **10**, 34-57.
- Kritzinger, A., & Magaqa, V. (2000). De-institutionalizing the mentally ill in rural-areas: A case study of the official caregiver. *Social Work*, **36**, 296-309.
- Kuhlthau, K., Perrin, J. M. & Thyen, U. (1999). Employment, child care, and mental health of mothers caring for children assisted by technology. *Pediatrics*, **103**, 1235-1242.
- Kuiper, L. (1993). Family burden in schizophrenia: implication for services. *Social Psychiatry & Psychiatric Epidemiology*, **28**, 207-210.
- Kumar, S., & Mohanty, S. (2007). Spousal burden of care in schizophrenia: *Journal of the Indian Academy of Applied Psychology*, **2**, 189-194.

- Kung, W. (2003). The illness, stigma, culture or immigration? Burden on Chinese-American caregivers of patients with schizophrenia. *Family & Society*, **84**, 547-557.
- Landis, B. J. (1996). Uncertainty, spiritual well-being, and psychosocial adjustment to chronic illness. *Issues in Mental Health Nursing*, **17**, 217– 231.
- Lee, C. (2001). Experience of family caregiving among older Australian women. *Journal of Health Psychology*, **6**, 393-404.
- Leff, J., & Vaughn, C. (1985) *Expressed emotion in families: Its significance for mental illness*, New York: Guilford.
- Leff, L. (1998). Needs of the families of people with schizophrenia. *Advances in Psychiatric Treatment*, **4**, 277-284.
- Lefley, H. P. (1992). Culture and chronic mental illness. *Hospital & Community Psychiatry*, **41**, 277–286.
- Lefley, H. P. (1998). The family experience in cultural context: Implications for further research and practice. In H. P. Lefley (Ed.), *Families coping with mental illness: The cultural context* (pp. 97–106). San Francisco: Jossey-Bass.
- Lepore, S. J. (1997). Social-environmental influences on the chronic stress process. In B. H. Gottlieb (Ed.), *Coping with chronic stress* (pp. 133–156). New York: University Press.

- Lofland, J., & Lofland, L. H. (1999). Data logging in observation: Field notes. *Qualitative research*, **3**, 90-101.
- Manamela, K. E. (2001). A needs assessment of persons suffering from schizophrenia in the Mogoto Village, Zebediela district (Unpublished Masters Dissertation). Pretoria, South Africa: University of South Africa.
- Mangliano, L., & McDavid, D. (2004). Careers and families of people with mental health problems. *Mental Health Policy & Practice*, **105**, 374-396.
- Marsh, D. T. (1998). *Serious mental illness and the family: The practitioner's guide*. New York: John Wiley & Sons, Inc.
- Marshall, C., & Rossman, G. B. (1995). *Designing qualitative research* (2<sup>nd</sup> Ed). Beverly Hills, CA: Sage.
- Martin, P. (1983). *Care for the mentally ill*. London: Macmillan.
- Middleton, L., & Uys, L. (1999). *The mental health nursing* (3<sup>rd</sup> Ed.) Kenwyn: Juta.
- Mphalane, M. L. (2006). The role played by families in support of their mentally ill relatives in a rural community in Limpopo province (Unpublished masters dissertation). Pretoria, South Africa: University of South Africa.
- Mu, P. (1998). Parental coping in pediatric health crisis. *General Hospital Nursing*, **15**, 115–124.

- Mu, P. (2004). Maternal role transition experiences of hospitalized women with mental illness: A phenomenological study. *International Journal of Nursing Studies*, **41**, 825–832.
- Nemecek, M. D. (2004). Caring for the caregiver. *Health Care News*, **2**, 149-150.
- Newacheck, P. W. J., Taylor, W. R. (1992). Childhood chronic illness: Prevalence, severity, and impact. *American Journal of Public Health*, **82**, 364.
- Noyes, J. (1999). The impact of knowing your child is critically ill: A qualitative study of mother's experiences. *Issues and Innovations in Nursing Practice*, **29**, 427-435.
- Ntswane, M. A., & Van Rhyn, L. (2007). The life-world of mothers who care for mentally retarded children: The Katutura township experience. *Curationis*, **30**, 85-96.
- Orbell, S. (1996). Informal care in social context: a social psychological analysis of participation, impact and intervention in care of the elderly. *Psychology and Health*, **30**, 330-338.
- Pahl, J., & Quine, L. (1985). *Families with mentally handicapped children: A study of stress and service response*. University of Kent at Canterbury, England: Health Services Research Unit.

- Petcharat, B., & Tongurai, P. (1989). *Anxiety of psychiatric patients' relatives*. New York: State University of New York Press.
- Platt, S. (1985). Measuring the burden of psychiatric illness on the family: an evaluation of some rating scale. *Psychological Medicine*, **15**, 383-394.
- Rassool, G. H. (2000). The crescent and Islam: Healing, nursing and the spiritual dimension. Some considerations towards an understanding of the Islamic perspectives on caring. *Journal of Advance Nursing*, **32**, 1476-1484.
- Ratanatikanon, C., Assanangkornchai, S., & Tanchaisawad, W. (1997). Pattern of help seeking by relatives of psychiatric patients. *Journal of the Psychiatric Association of Thailand*, **42**, 226–233.
- Reinhard, S. C. (1994). Perspectives on the family experience in mental illness. *Image: Journal of Nursing Scholarship*, **26**, 70–74.
- Rose, L. E. (1997). Caring for caregivers: Perceptions of social support. *Journal of Psychosocial Nursing & Mental Health Services*, **35**, 2, 17-24.
- Rutgers, A. H. (2004). Schizophrenia and attachment: A meta-analytic view. *Journal of Child Psychology and Psychiatry*, **45**, 1123- 1134.
- Saunders, J. C. (2003). Family living with severe mental illness: a literature review. *Issues in Mental Health Nursing*. **24**, 175-198.

Schofield, H. (1998). *Family caregivers. Disability, illness and ageing*, Allen & Unwin, St Leonards, NSW.

Skelton, J. (1994). *ARAFMI Newsletter: Association of Relatives and Friends of the Mentally Ill*, NSW.

Sloper, P., & Turner, S. (1993). Risk and resistance factors in the adaptation of parents of children with severe physical disability. *Journal of Child Psychology & Psychiatry*, **34**, 167–188.

Stevens, B. (1972) Dependence of schizophrenic patients on the elderly relatives. *Psychological Medicine*, **2**, 17-32.

Treudley, M. B. (1946). Mental illness and family routines. *Mental Hygiene*, **15**, 407-418.

Weisman, A. G. (1997). Expressed emotion, attributions, and schizophrenia symptom dimensions. *Journal of Abnormal Psychology*, **107**, 355–359.

Wood, B. B. (2010). A study on a critical review of phenomenological literature on self-experience in schizophrenia (Unpublished masters dissertation). Pretoria, South Africa: University of Pretoria.

Worden, J. W. (1991). *Grief counselling and grief therapy* (2<sup>nd</sup> Ed.). New York: Springer.

World Health Organisation. (2001). *Mental health problems: The undefined and hidden burden*. Geneva: Author.

World Health Organisation. (2004). A glossary of terms for community health care and services: *World Health Organisation centre for the health development*, **5**, 109.115.

World Health Organisation. (1993). *The ICD-10 classification of mental and behavioural disorders*. Geneva: Author.

Wynaden, D. (2003). *The primary carer's experience of caring for a person with a mental disorder in the Western Australian community: A grounded theory study* (Unpublished doctoral dissertation). Curtin University of Technology, Perth, Western Australia.

## **APPENDIX A: DSM-IV-TR Diagnosis of schizophrenia.**

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, 2000) defines schizophrenia as “a mixture of characteristic signs and symptoms (both positive and negative) that have been present for a significant portion of time during a 1-month period (or for a shorter time if successfully treated), with some signs of the disorder persisting for at least 6 months” (p. 298). Positive symptoms include the presence of delusions, hallucinations, disorganized speech, and grossly disorganized or catatonic behaviour. Negative symptoms are recognized by a lack or paucity of emotions (affective flattening), of speech (alogia), or of goal-directed behaviour (avolition) (DSM-IV-TR, 2000, p. 299).

Schizophrenia and other psychiatric disorders are marked by certain similar symptoms. The following criteria are utilized in the diagnosis of schizophrenia (DSM-IV-TR, 2000): Characteristic symptoms, social/occupational dysfunction, duration, schizoaffective and mood exclusion, substance/general medical condition exclusion, relationship to a pervasive developmental disorder.

The DSM-IV diagnostic criteria for schizophrenia require the presence of symptoms from at least two of the groups listed above. Symptoms from only one group are required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person’s behaviour or thoughts, or two or more voices conversing with each other. Each of the symptoms must be present for a significant portion of time during a one-month period (or less if successfully treated).

According to DSM-IV, schizophrenia is accompanied by marked social or occupational dysfunction for a significant portion of the time since the onset of the disturbance. The dysfunction must be present in at least one major area such as work, interpersonal relations or self-care. DSM-IV requires that

continuous signs of the disturbance persist for at least 6 months. This 6-month period may include periods when only negative or less severe symptoms are present. Such periods are referred to as prodromal or residual, depending on whether they precede or follow the one-month period of characteristic symptoms described above.

Classification of course can be applied only after at least one year has elapsed since the initial onset of active-phase symptoms. According to DSM-IV, the course of schizophrenia is variable. The manual lists the following course specifics: episodic with inter-episode residual symptoms; episodic with no inter-episode residual symptoms; continuous; single episode in partial remission; single episode in full remission; other or unspecified pattern.

Concerning differential diagnosis, DSM-IV emphasizes the distinction between schizophrenia and mood disorders. If psychotic symptoms occur exclusively during periods of mood disturbance, the diagnosis is mood disorder with psychotic features. If mood episodes have occurred during active-phase symptoms, and if their total duration has been brief relative to the duration of active and residual periods, the diagnosis is schizophrenia. If a mood episode is concurrent with the active-phase symptoms of schizophrenia, and if mood symptoms have been present for a substantial portion of the total duration of the disturbance, and if delusions or hallucinations have been present for at least 2 weeks in the absence of prominent mood symptoms, the diagnosis is schizoaffective disorder.

The differentiation between schizophrenia, brief psychotic disorder and schizophreniform disorder rests upon a criterion of duration: less than one month for brief psychotic disorder; more than one month but less than 6 months for schizophreniform disorder; at least 6 months for schizophrenia. The differential diagnosis between schizophrenia and delusional disorder rests on the nature of the delusions (in delusional disorder they are non-bizarre) and the absence of other characteristic symptoms of schizophrenia such as hallucinations, disorganized speech and behaviour, or prominent negative symptoms.

Schizophrenia and pervasive developmental disorder are distinguished by a number of criteria, including in particular the presence of prominent delusions and hallucinations in the former but not in the latter. Finally, the diagnosis is not made if the disturbance is due to the direct physiological effects of a substance or a general medical condition.

## APPENDIX B: RECRUITMENT LETTER

Dear \_\_\_\_\_,

I have received your contact information from \_\_\_\_\_, who thought that you might be interested in participating in a study exploring how mothers experience their relationships with their children who have been diagnosed with schizophrenia.

I am currently a graduate student at the University of Limpopo (Turfloop Campus). I am registered for a Masters degree in psychology. The research I am conducting forms part of my studies for the degree.

In my study I will be interviewing mothers who have children who received a formal diagnosis of schizophrenia before they turned five. For the purpose of this study, the child must currently be under the age of 22. If you and your child meet these criteria, I would appreciate your consideration to participate in this study.

If you agree to participate, you will be interviewed at a time and place that is convenient for you. The interview will last between 60 and 90 minutes. The interview will be tape-recorded. Any information that would identify you to others will be kept confidential. I believe that by participating in this study, you will:

- 1) Have the opportunity to share your experiences of being a mother of a child diagnosed with schizophrenia
- 2) Help other mothers who are looking for information and validation of their own experiences
- 3) Create awareness among mental health professionals as well as the community.

Please contact me if you would like to participate and we can set up a time, date and place for the interview. If you require further information, feel free to call me.

Yours sincerely

**NEGOTA A.J.**

## **APPENDIX C: INFORMED CONSENT LETTER**

### **Dear Potential Research Participant**

My name is AZWIHANGWISI NEGOTA, a Masters student at the University of Limpopo (Turfloop Campus), an institution of higher learning in Polokwane. I am conducting a study on “Experiences of mothers who have schizophrenic children”. The information to be obtained from this study will be included in my Masters dissertation. However, I think it will also be of help to people like you, who care for a child who is ill.

Your participation is requested because you are a mother of a child diagnosed with schizophrenia. All the persons I want to talk to should have a child of their own, who was diagnosed with schizophrenia before the age of 13 and is presently under the age of 24. If you choose to participate, I will ask you a number of questions regarding your experience as a parent of a child with schizophrenia. In addition, I will ask you to provide information about yourself including age, ethnicity, and marital status. The discussion between me and you will be tape-recorded. I expect that it will last approximately 60 to 90 minutes.

Your name and other identifying information will remain confidential. No identifying information will be used when quoting you in the thesis. Audiotapes will be labelled with a code number, rather than your real name, for identification purposes. These will be kept in a safe place throughout the compilation of the thesis. After such time, I will either maintain the material in a secure location or destroy it. Personal information will not appear with corresponding participants’ interview responses, but will be used in a comparison with other participants to establish the overall common characteristics of the group. Your participation will be highly appreciated.

**Thank you.**

**If you do not wish to participate in the study, please state so without fear. If you agree to participate, please sign below:**

Do you agree to participate in the study described above?

NO

YES

**Signature: Participant:** \_\_\_\_\_

**Researcher:** \_\_\_\_\_

**Witness:** \_\_\_\_\_

## **APPENDIX D: GENERAL INTERVIEW QUESTIONS**

- 1) What are the experiences you encounter as a mother who has a child with schizophrenia?
- 2) What encourages you to take care of your schizophrenic child?
- 3) What are the support systems available for you as a mother of a child with schizophrenia?
- 4) What is it like having a child diagnosed with schizophrenia?
- 5) How would you describe your relationship with your child?
- 6) When do you feel loved by your child?
- 7) What is the most difficult part about your relationship with your child?
- 8) What is the most rewarding aspect of your relationship with your child?
- 9) If you had to describe your child using three words, what would they be?
- 10) Is there anything else you would like to tell me about or you think would be important for me to know?