A Phenomenological Study of Caring Experiences of Caregivers Caring for Mentally Ill Individuals at Home in the Northdale Area of Pietermaritzburg

by

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Declaration

I, Nelyanee Royan, honestly declare that this dissertation entitled “A Phenomenological Study of Caring Experiences of Caregivers Caring for Mentally Ill Individuals at Home in the Northdale Area of Pietermaritzburg” is my original work. It has not been submitted for any other degree or academic qualification at this or any other University. I also declare that sources of information utilised in this work have been acknowledged in the reference list.

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Abstract

In the context of recent shifts in South African national health policies that integrate mental health care into primary health care, the family rather than the institution has become the primary site of ongoing care for psychiatric clients. The purpose of this qualitative phenomenological study was to describe how caring is rendered at home for the mentally ill person by family caregivers, living in Northdale, Pietermaritzburg.

Purposeful sampling was used to recruit six family caregiver participants from the psychiatric clinic waiting room. These were caregivers who had accompanied their family member with mental illness for treatment on that particular day. Data generated from in-depth interviews with these participants provided personal experiences of their caregiving practices, behaviours, and problems. Data analysis was based on descriptive phenomenology and Colaizzi’s method of data analysis and data representation.

Significant statements were extracted and grouped to form larger units or clusters. The clusters were then organised into nine themes, with associated significant statements made by the caregivers:

Theme 1: Family as support system. These aspects related to daily maintenance of nutrition, hygiene and grooming for the family member with mental illness. The participants indicated that the maintenance of these activities for daily living were very important in the care of the SMI individual at home.

Theme 2: Commitment to care. Evident throughout the interviews were issues of how caregivers perceived and sustained the ongoing responsibilities of home care for the mentally ill. There was a willingness and complete commitment to caring for the SMI family member with all its responsibilities.

Theme 3: Disruption to family life. Details emerged from the interviews about how families adjusted to the constant needs of care provision, supervision, and vigilance demanded by home care giving. The participants accepted that problem behaviours were part of caring.
Theme 4: Value in contributing to care. The interviews revealed various aspects of how caregivers drew reassurance and a sense of positive accomplishment from successes in teaching, supervising and managing a mentally ill relative at home. There were positive aspects to caring in that the SMI individuals could be of help to the caregivers. Simple tasks such as emptying of bins, shopping and dish washing were part of the daily routine which proved beneficial to the caregiver and the family member with mental illness.

Theme 5: Maintaining hope. Various implications emerged in the study such as being hopeful, and having a positive outlook as caregiver, despite the behaviour problems and chronic nature of the client’s mental illness. Participants indicated that despite the fact that they have a responsibility to care they are hopeful that one day the family member would be as normal as any other person.

Theme 6: Support and Guidance: Ongoing assistance. Several issues emerged in relation to the involvement of the community psychiatric clinic professional staff in giving support and guidance to the individual caregivers, such as provision of information about side effects of medication, especially drowsiness, impaired communication and inactivity, guidance on how to cope with taking of substances by the client, and assistance with preparing for lifelong care of the family member with mental illness.

Theme 7: Concern for Continuity of care. There was the need to look at what would be the outcome if the parents were not there to care for the SMI individual. Even though this is something to think about and had been broached at one time with the psychiatrist the family and care giver are hopeful that another family member will step into the caring role should they not be there.

Theme 8: Fears and difficulties experienced in caring. Problem behaviours and danger to self and others is always upper most in the minds of the care givers, this resulted in even limiting friends because the SMI individual could be influenced into taking drugs. Care giving involved taking steps to ensure the family member does not hurt himself or herself.
Theme 9: Misuse of Social Grant. Financial burdens were experienced by the family of the mentally ill individual. Social grants were being used to maintain the whole family for food, lights and rent. Sometimes the caregivers are forced to hand over the social grant to the MHCU just to ensure that there will be no problems at home if they were refused. Money is used to purchase cigarettes and drugs. Fear that the grant would be stopped results in the family not willing to report the abuse to the clinic staff.

Implications for psychiatric nursing practice that the study highlighted included need for intervention by the community psychiatric nurses in regard to side-effects of medication, management of problem behaviours, and education for caregivers concerning the illness and especially its progressive signs and symptoms.

Further research might explore current supportive programmes available in the community to keep pace with societal changes, with particular focus on whether caregivers are included in the visits to the clinic with the mentally ill family member and what attention is given to their needs and problems so that they feel appreciated and valued.

**Key words:** care giver; community mental health services; challenges in home care; caring experiences at home; lived experiences of care givers.
Dedication

This dissertation is dedicated to my supervisor Dr. Lyn Middleton who motivated and encouraged me to persevere and continue with the work. To my late father, who had encouraged me to study, daughter, Nicky, and family for the support and concern throughout, despite my failing physical health.
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# Table of Contents

Declaration .................................................................................................................................................................. ii  
Abstract ...................................................................................................................................................................... iii  
Dedication .................................................................................................................................................................... vi  
Acknowledgements ................................................................................................................................................... vii  
Table of Contents ....................................................................................................................................................... viii  
List of Tables ............................................................................................................................................................... x  

Chapter 1 Introduction to the study ................................................................................................................................. 1  
1.1 Background to the study .................................................................................................................................................. 1  
1.2 Problem statement ............................................................................................................................................................ 5  
1.3 Study purpose ................................................................................................................................................................. 7  
1.4 The Research objectives ................................................................................................................................................... 7  
1.4.1 The Research objectives ............................................................................................................................................. 7  
1.5 The significance of the study ............................................................................................................................................ 7  
1.6 Definitions: commonly used terms in mental health/psychiatry ...................................................................................... 8  
1.6.1 Caring .............................................................................................................................................................................. 8  
1.6.2 Serious mental illness .................................................................................................................................................... 8  
1.6.3 Caregiver ....................................................................................................................................................................... 8  
1.6.4 Mentally ill individual .................................................................................................................................................. 9  
1.6.5 Home ........................................................................................................................................................................... 9  
1.6.6 Experiences ................................................................................................................................................................. 9  
1.7 Summary .......................................................................................................................................................................... 9  
1.8 Conclusion .................................................................................................................................................................... 10  

Chapter 2 Literature review ................................................................................................................................................... 11  
2.1 Introduction .................................................................................................................................................................... 11  
2.2 Family caregiving in South Africa .................................................................................................................................. 11  
2.3 Psychiatric illnesses and the burden of care .................................................................................................................... 13  
2.3.1 Family burden .......................................................................................................................................................... 14  
2.3.2 Health care providers’ experiences of families providing home care ........................................................................... 16  
2.3.2.1 Processes of family caregiving ................................................................................................................................. 18  
2.3.2.2 What families want from health services ................................................................................................................ 20  
2.3.2.3 Issues in family-centred care ................................................................................................................................. 21  
2.3.2.4 Themes that emerged in studies by previous researchers .................................................................................... 22  
2.5 Summary ...................................................................................................................................................................... 24  
2.6 Conclusion .................................................................................................................................................................. 24  

Chapter 3 Phenomenology as theory and method .............................................................................................................. 26  
3.1 Introduction ................................................................................................................................................................. 26  
3.2 Philosophical assumptions of phenomenology .............................................................................................................. 27  
3.3 Steps in the descriptive phenomenological approach ................................................................................................ 27  

viii
# Table of Contents

3.3.1 Bracketing ................................................................. 28
3.3.2 Intuiting ................................................................. 29
3.3.3 Analysing and describing ........................................ 29
3.4 The study context ......................................................... 30
3.5 Selecting participants for the study .............................. 31
3.6 Participant inclusion and exclusion criteria .................... 31
3.7 Procedure for collecting and recording data .................. 32
3.8 Strategies to validate findings ...................................... 33
3.8.1 Rigour ................................................................. 33
3.8.2 Trustworthiness ....................................................... 34
3.8.4 Credibility ............................................................ 34
3.8.5 Conformability ....................................................... 35
3.8.6 Transferability ....................................................... 35
3.9 Ethical considerations .................................................. 35
3.10 Data management ....................................................... 36
3.11 Summary ............................................................... 36
3.12 Conclusion .............................................................. 37

Chapter 4 Data analysis ....................................................... 38
4.1 Introduction .............................................................. 38
4.1.1 Description of the participants in the study ............... 38
4.2 Colaizzi’s method of data analysis and data representation 39
4.2.1 Acquiring a sense of the transcripts ....................... 40
4.2.2 Extracting significant statements ......................... 40
4.2.3 Formulating meanings ........................................... 40
4.2.4 Organising the formulated meanings into clusters of themes 41
  Theme 1: Family as a support structure ................. 42
  Theme 2: Commitment to caring ........................... 43
  Theme 3: Disruption to family life ......................... 44
  Theme 4: Value in contribution to care ................ 45
  Theme 5: Maintaining hope .................................. 46
  Theme 6: Support and guidance: ongoing assistance ... 47
  Theme 7: Concern for continuity of care ................. 48
  Theme 8: Fears and difficulties experienced in Caring ... 49
  Theme 9: Misuse of social grant ................................ 50
4.3 Exhaustive description of the phenomenon ............. 51
4.4 Summary .............................................................. 52
4.5 Conclusion ............................................................ 53

Chapter 5 Discussion, recommendations and summary ........ 60
5.1 Introduction ............................................................ 60
5.2 Experiences of caregiving ....................................... 60
5.3 Researcher reflexivity and limitations ...................... 66
5.4 Recommendations .................................................. 69
List of Tables

Table 4-1 Demographics of caregivers and family member with mental illness 39
Table 4.2 Significant statements and their location in the transcripts 54
Table 4.3 Themes / associated significant statements / location in the transcripts 57
Chapter 1
Introduction to the study

This chapter presents the background, problem statement, purpose, and objectives of the thesis, including the significance of the study in community psychiatric nursing.

1.1 Background to the study

One of the most significant outcomes of the integration of mental health care into primary health care in South Africa is that the family, rather than the institution, is the primary site of ongoing care for psychiatric clients (Sokhela & Uys, 1998; Uys & Middleton, 2004). The South African Mental Health Care Act No. 17 of 2002 focuses on acute treatment and ongoing rehabilitation of people with psychiatric illnesses as a community-based primary health care function. This Act regards families as directly responsible for the client’s ongoing care in the community. This principle of ongoing community and family care is further supported in the Strategic and Implementation Plan for Delivery of Mental Health Services in KwaZulu-Natal (2003) and by the WHO (2001). This plan emphasises and provides for: psychiatric deinstitutionalization and community care rather than hospitalisation; families rather than professionals to assume full responsibility for caregiving at home; and availability of psychiatric treatment in all public health clinics and services rather than in separate psychiatric clinics. The recent integration of mental health care into primary health care has meant a shift in the site of ongoing care from the hospital to the community and in the roles and responsibilities of caregivers and professionals providing care to clients with psychiatric illnesses (Middleton & Uys, 2009).

Most serious psychiatric illnesses are chronic (to a greater or lesser extent) and therefore require long-term and lifelong management and care (Kelly, 2002). Mental health care users (MHCUs) with serious mental illnesses (SMIs), most notably schizophrenia and bipolar disorder, are being discharged from hospital, after
treatment, into the care of the family, with the expectation that the patient will be provided with the necessary care and support (Mbalo, 2000; Mphelane, 2006). Studies indicate that caring by caregivers can be provided by the members living with the mentally ill family member (Connell, 2003; Mays & Lund, 1999). Caregivers may include parents, siblings, spouses and grandparents and other relatives living with that particular family member. Care and support usually involves the following responsibilities for caregivers: assisting and encouraging the SMI patient to adhere to the treatment; assisting and supervising the basic daily activities of personal hygiene; maintaining fluid and food intake, undertaking safety observations and managing the side-effects of medication; supervising the care of environment; and taking decisions when helping in crises (Mphelane, 2006).

Caregivers frequently experience caring for their mentally ill member as a challenge to their physical, social, and psychological well-being. This kind of challenge has been described in the psychosocial nursing and rehabilitation literature as family burden (Doornbos, 1996; Mbalo, 2000; Rudnick, 2004). Family burden is conceptualised as having objective, subjective, and practical or managerial components. Objective burden is associated with the time and effort taken up in caregiving, financial disruptions, and disruption of the daily routine and social life, including ongoing attempts to cope with the person’s mental illness (Sales, 2003; Yip, 2005). Chang and Horrocks (2006) point, for example, to the time-consuming and demanding burden of helping a relative with SMI to bathe, dress and eat, and supervising their safety on a daily basis. Subjective burden is associated with the emotions the caregiver experiences during the process of caring. These are many, and include feelings of loss, shame, worry, anger, and hopelessness, with the situation and with the client (Mphelane, 2006; O’Brien, 1998). The practical burden or managerial component includes having to cope with assault, problem behaviours, mood swings, and negative symptoms. Connell (2003), Kohn-Wood and Wilson (2005), Sethabouppha and Kane (2005), and Yip (2005) have described similar objective, subjective and managerial burdens, such as having to come to terms with the illness, the chronic nature of the condition, lack of knowledge about mental illness, inadequate support from health care providers, disruption in social and family roles, and financial strain, as among the most significant challenges to family caring. Yen
and Wilbraham (2003) suggest that these challenges make it more difficult for families to adequately care for their ill family member at home.

A number of studies have shown that caregivers’ experiences of caring impact on both the caregivers’ health and the health of the mentally ill. Connell (2003), Kohn-Wood and Wilson (2005), Robinson et al. (2005), and Yen and Wilbraham (2003) have described a number of psychological issues experienced by caregivers. These were centred on their own happiness and satisfaction, on goal achievement for self and peace of mind, and included feeling guilty, blaming self, feeling burdened, and being unable to cope. Perceived social stigma of mental illness also impacts upon the family and the client. Families tend to avoid seeking help for problems, sharing information with relatives and friends, and discussing problems with health providers (Yen & Wilbraham, 2003).

On the other hand, a number of studies have identified positive factors of caring for the client at home. Kahn and Kelly (2001), Karp (2000), Mbalo (2000) and Yip (2005) refer to a number of positive aspects, such as the benefit of having the person at home rather than in an institution. Financial benefit of welfare or disability entitlement helps the caregivers. Many caregivers experienced caring as increased awareness of and sensitivity to their family member’s needs and illness pattern, increased feelings of compassion, and a greater sense of maturity. Caregivers learnt to be less judgmental and self-centred, and discovered previously unknown personal strengths such as joy in caring (Yip, 2005).

Mays and Lund (1999) explored the positive aspects of caring done by men for their spouses at home. Some men reported that being able to “give back” in caring to their spouses increased their personal sense of worth. Although caring was perceived as difficult, many expressed pride in their accomplishment of the caregiving role and in their sense of duty towards the family member. Zheng and Arthur (2006) explored perceptions of Chinese caregivers and found that families believed caring was expected of them both culturally and as part of the family’s role, despite the problems and issues experienced. Connell (2003) explored children’s perception of caring for their sick parent and found that while they saw caring as an obligation and a commitment to their mothers, they also experienced spiritual meaning and personal growth in providing loving care.
The process of family caring, along with experiential themes, has also been well described. Howard (1994) explored maternal caregiving and found that it involved broad overlapping themes of watching, working, and waiting. Embedded within each theme are a number of specific stages and experience descriptions. Watching involved the stages of perceiving a problem and searching for solutions. A number of related experiences were described within these two stages, including a sense of knowing something was wrong, realising there is a problem, shock as the acute psychiatric symptoms emerged, groping for information and assistance, grappling with the illness, and anguish and distress related to persistent problems. The theme of working was found to encompass the stage of enduring the situation and involved persisting with helping efforts, persisting with worry and caregiving, and acknowledging the nature of the illness. The theme of waiting related to the ongoing stage of surviving the experience and involved coming to terms with the situation, developing hope in the face of worry and anguish, and resolving to help the family member, self, and others (Uys & Middleton, 2004).

These themes, stages, and experiences are similar to those described by Wynaden (2007) in her grounded theory of family caring for a mentally ill person. This theory is further described in the literature review. In summary, this grounded theory describes how families constantly seek balance to overcome being consumed by the nature of the problem. There are explicit stages and tasks associated with being consumed and seeking balance. These stages and tasks involve recognising the problem, experiencing a disruption in lifestyle, and engaging in efforts to maintain equilibrium in the face of the crisis. Caring is influenced by certain conditions mainly centred on the amount and quality of support, knowledge and understanding and crisis management offered by the health care providers. In seeking balance with the experience of being overwhelmed, family members engage in tasks that include, trying to make sense of the illness, seeking knowledge, coping with the situation in a trial and error way, engaging in activities to restore self-identity, and reaching out to others to make a difference. Other conditions that influence attempts to seek balance include the participants’ level of social support and well-being, their knowledge of mental illness, and the availability of support from health care providers (Chang & Horrocks, 2006).
What do caregivers want from mental health service providers as they engage with the process of caring? The literature suggests that families caring for mentally ill members at home have very clear education and support needs. Education needs, identified by Drapalski et al. (2009), Mbalo (2000), and Mphelane (2006), include knowledge about the illness, skills to cope with disturbing behaviour, and knowledge of what to expect from the mentally ill family member when she or he is relapsing. Support needs, for the family and for the SMI patient, were identified as support from health care providers in the decisions they need to make with respect to the client; more regular communication with the health care providers and the health care providers to focus on the family and not just on the client in the routine provision of care (Asplund et al. 2005). Generally families feel that they are not recognised as important to the care of the mentally ill relative (Piercy, 2007; Asplund et al. 2005).

As carers, mental health care workers frequently lose sight of the needs of stigmatised groups such as people with serious mental illness, mental handicap, and their caregivers (Swartz, 2000). Mentally ill persons have indicated that caregiving is more meaningful if caring practices are culturally congruent, flexible, and growth-enhancing, and focus on supporting their potential and growth needs (Leininger in George, 1990). Many of the MHCUs reported that family caregiving was focused on their basic needs and their ongoing use of psychotropic medication. Although MHCUs value the support and the normalcy of family living, the culture of family caregiving is similar to that of being institutionalised and is often different from the cultural context of the family and client. Manoleous (1995) argues that the cultural background of the family guides and determines the pattern of behaviour between the caregivers and the MHCU.

1.2 Problem statement

This study is informed by the body of knowledge concerned with family caring and psychiatric nursing and by the researcher’s own experience with caregivers in community-based psychiatric services. The researcher is a mental health nurse educator and has been involved for many years in this capacity in the clinical supervision of diploma mental health nursing students at various local psychiatric
clinics. Over time, the researcher had noted that caregivers who accompany their mentally ill relative to the clinic have limited involvement in the monitoring and management process and little or no interaction with the community mental health staff. They are generally not asked about their well-being and only volunteer information about the MHCU if he/she is presenting a problem.

The psychiatric clinics provide long-term management and medication on a monthly basis for community-based MHCUs (Middleton & Uys, 2009). The primary focus of these clinics is on the psychiatric well-being of the ill person, rather than on the well-being of the person-in-family (Middleton & Uys, 2009). The family per se gets little or no attention in some cases. Although a great deal has been written about family caregiving over the years, most of this literature focuses on caregivers for mentally ill members in developed countries.

Studies in family caregiving are, however, beginning to emerge from the African context (e.g., from Nigeria, Uganda, Kenya and Botswana). These studies have indicated that there is a great need for understanding how caring for clients with mental illness is conceptualised by family members within the local context (Kelly, 2002; Kahn & Kelly, 2001; Swartz, 2000; Yen & Wilbraham, 2003).

Connell (2003) argues that nurses as caregivers need to understand the experiences of caring by the caregivers and the meaning attributed to that caring in order to be able to provide family-centred care that is tailored to their specific needs. This author suggests that family caregiving based on the lived experience of caregiving will assist in normalising the care of the mentally ill in the community. The idea of normalisation is particularly important for the South African context where MHCU care and treatment is an aspect of a national primary health care approach that regards the family and the community as the primary site of ongoing care (Haggerty et al., 2003; Ip & Mackenzie, 1998; Kipp et al, 2006).

This study is accordingly based on the assumption that if the lived experiences of family caregiving are understood, health care providers might be better placed to provide appropriate support and assistance to family members.
1.3 Study purpose

The purpose of this phenomenological study is to describe how caring for a mentally ill person at home is experienced by family members living in the Northdale area of Pietermaritzburg.

1.4 The Research objectives

The central question for the study is this: How is caring experienced by caregivers for a mentally ill family member in the home in the Northdale area?

1.4.1 The Research objectives

- To describe the meanings which family members caring at home for a relative with SMI ascribe to their experience.
- To describe the events, situations and contexts that have typically influenced these experiences of caring.

1.5 The significance of the study

The insights generated by this study will enable the health care providers to be more aware of, sensitive to, and proactive in dealing with caregivers’ experiences and needs. In this way, they will have a better understanding of the challenges faced by these caregivers and thus be in a better position to actively support them in the process of family-based caring. Insights from this study could assist in developing nursing interventions aimed at improving family caring in the community context. These insights could assist the community mental health nurse in developing caregiver support programmes that enhance the family’s ability to fulfil their function of caregiving and, in turn, improve the quality of life of the MHCU.

The findings would also be of help in developing in-service programmes for primary health care service professional nurses who see MHCUs on a monthly basis to better understand the caring role of the family. Recommendations from this study could lead
to further research similar to this study such as nurses’ perception of caring roles of the family. In the students’ clinical practice, during their training, case studies of the family role in caring would be of benefit in better understanding the role they have in supporting and helping to care for the MHCU at home. Since the shift towards deinstitutionalization according to the Mental Health Care Act No. 17 of 2002 the student nurses in clinical training could be involved in supervised home visits, which are seldom done now after the move to Primary Health Care services.

1.6 Definitions: commonly used terms in mental health/psychiatry

1.6.1 Caring

In this study, caring is the central phenomenon of interest. According to Leininger (1990), caring can be defined as human actions and processes which assist or support another individual or group, or which enable a person who has evident or anticipated needs, or which express interest or particular concern for that person. The caring actions may involve assessment or recognition of the patient as a person, and include emotions such as liking or affection, or certain duties. The duties will arise out of interest between two human components of the caring relationship: the caregiver and the one cared for.

1.6.2 Serious mental illness

SMIs are defined as diagnosable disorders, in persons 18 years and older, that are so enduring that they significantly and persistently interfere with the person’s ability to engage with major life activities (American Psychiatric Association, 1997).

1.6.3 Caregiver

A caregiver is defined as a member of the household where the client is living and who is involved in the care of the client at home. This could include an immediate family member, or a member of an extended family who is considered to be part of the immediate family and who lives together with the MHCU (Mays & Lund, 1999).
1.6.4 Mentally ill individual

A person who has been diagnosed and is suffering from a mental disorder because he/she is not in touch with reality and could be a danger to themselves or others. Their behavior is perceived as a biological, behavioural or psychological dysfunction needing constant care or supervision and support (DSM IV, 2002).

1.6.5 Home

In this study “Home” is considered to be the abode where the MHCU is living with his/her family. It is at the home that the MHCU is in constant contact with the care giver who has the responsibility to care for him or her (Mays & Lund, 1999).

1.6.6 Experiences

Experiences as reflected in this study is based on the definition from the Oxford dictionary and the study by McCann et al, (2011) which is “knowledge” acquired from contact; evidence; practice; struggle; understanding and wisdom. It is an action word which implies “doing”. An affective component maybe expressed with the experiences.

1.7 Summary

This chapter provided an introduction to the study, indicating the background and purpose of the study. It stated the research objectives and the significance of the study for psychiatric nursing in family caring of the mentally ill at home within the community of Northdale, Pietermaritzburg. Caregiving is considered an important aspect of family care to enhance the family’s ability to maintain the SMI patient at home. The caregiver’s experiences, situations, events and activities impact on their caregiving to the family member. Describing the experiences and the meaning of the experiences for the caregiver would improve the quality of caring by the family and the MHCU, which could also have significance for nursing interventions by the community health nurse.
1.8 Conclusion

The chapter has provided the way forward with regards to the study to be undertaken by the researcher. Clearly indicated research objectives including the purpose will enable the researcher to draw on information from previous studies needed in the next chapter of the literature review.
Chapter 2
Literature review

2.1 Introduction

This chapter reviews some of the relevant studies of caring experiences of caregivers for mentally ill individuals at home. Aspects of concern that emerge in the literature are: family caregiving in the South African context, psychiatric illnesses and the burden of care, studies in family burden, what families do when caring, health care provider’s experiences of providing family care, issues in family-centred nursing, and processes of family caregiving.

Specific concepts that were researched were: the role of the family, professional interventions to support family caregivers, experiences of caregivers and problems experienced in caring, need for information on mental health and its impact on family life, and the family’s expectations of the health care worker. Keywords looked at were: mental illness, psychiatric or mental health care, community mental health, and the family’s role in caregiving. Internet resources that provided information were PUBMED, HEALTH SCIENCES, and MEDSCAPE, together with specific journals available through these resource centres.

Key words: caregiver; community mental health services; challenges in home care; caring experiences at home; lived experiences of care givers.

2.2 Family caregiving in South Africa

Family caregiving has been significantly influenced by the integration of mental health care into primary health care. In South Africa, as in other African countries, mental health care has moved away from institutional custodial care based on the medical model towards a more behavioural model, and in the changes that have taken
place in health services since the end of apartheid the emphasis is on deinstitutionalization and psychosocial rehabilitation. A related factor has been inequalities in psychiatric services between urban and rural areas.

Recent developments promote a primary health care approach which would enable clients and families to access professional services on a daily basis, and in support of this approach the Mental Health Care Act No. 17 of 2002 makes provision for the MHCU to become a contributing member of the community following discharge from hospitals (Pillay & Harvey, 2006). The family has accordingly become the primary site of ongoing care for psychiatric clients in South Africa, with the Act regarding families as directly responsible for the client’s ongoing care in the community (Uys & Middleton, 2004).

This principle of ongoing community and family care is given further endorsement in the Strategic and Implementation Plan for Delivery of Mental Health Services in KwaZulu-Natal (2003). There is thus an overall shift from hospital to the community, with roles and responsibilities being assigned to caregivers and professionals providing care within the community. In South Africa institutional care had previously been the practice, whereby mentally ill individuals remained in hospital for long periods of time. The Mental Health Care Act No. 17 of 2002 and the above-mentioned guidelines for implementation of health services make several references to having the client in the community within the family. A family member is thus required to take responsibility for the care of the mentally ill family member. The family member who has access to the social welfare grant of the SMI individual is expected to use the monies to care for the relative, but caregivers often indicated that this was not sufficient to meet all their needs. This shift from institutional care to community-based care is not without its problems. Many mentally ill individuals are unable to cope with independent living in the community because they are unable to manage money, maintain safe surroundings, and shop for themselves, with the result that families are obligated to take over these functions for them. In a study by Mphelane (2006), who cites WHO (2001/2008), persons with mental problems were found to be more vulnerable than others in their social dealings and at risk of having their human rights and freedom violated, especially by family taking over their social welfare grants.
Furthermore, stigma associated with mental illness impacted on whether or not a family would agree to keep the patient at home (Sethabouppha & Kane, 2005). Socially and emotionally the affected family felt isolated and ostracised. Caregivers worried about their situation and felt helpless to control it, but acceptance of their situation was a necessity if the client was to be maintained at home. Reducing the stigma of mental illness is one of the goals of the new Mental Health Care Act (Act N0.17 of 2002). New pathways for admission with a 72 hour assessment period and inclusion of mental illnesses in mainstream health care would gradually help to reduce stigma.

2.3 Psychiatric illnesses and the burden of care

Most serious psychiatric illnesses are chronic and therefore require long-term and lifelong management and care (Kelly, 2002). The usual pattern is that mental healthcare users with SMI, most notably schizophrenia and bipolar disorder, are discharged from hospital after treatment into the care of family, with the expectation that the ill person will be provided with the necessary care and support (Mbalo, 2000; Mphelane, 2006).

Section 34 of the Mental Health Care Act No. 17 of 2002, which allows for the admission and treatment of the MHCU at any district hospital or facility for a period of 72 hours, now means that, for the first time, MHCUs can access care, treatment, and management as part of a comprehensive approach. The new Act brings delivery of mental health treatment into the mainstream of health care provision by incorporating it into community-based care or primary health care. (Uys & Middleton, 2004). In moving towards provision of mental health care in the community, one positive dimension of such deinstitutionalization is that it acknowledges the responsibility of care for the mentally ill to be exercised by family and relatives. Once the MHCU is discharged he/she returns to the community (to the family) irrespective of the type of illness or its seriousness or the condition of the ill person; ongoing care of the patient is located within the community, with the family as primary caregivers.

The kind of care and support usually involved in family caregiving relates to basic physical needs of the patient and ongoing use of psychotropic medication. The chief
responsibilities of the caregivers are: assisting and encouraging the SMI individual to adhere to the treatment, including monthly visits to the psychiatric clinic and follow-up, assisting and supervising the basic daily activities of personal hygiene, maintaining fluid and food intake, safety observations and managing the side-effects of medication, supervising care of the environment, and taking decisions when helping in crises (Mphelane, 2006). Inadequate understanding by the family of mental illness and insufficient information about the condition of the patient on discharge are likely to undermine the family’s ability to manage the care of the individual at home, and chronic conditions make it more stressful to provide care to the SMI patient (Mphelane, 2006).

2.3.1 Family burden

Caregivers frequently experience caring for the mentally ill family member as a challenge to their physical, social, and psychological well-being. These effects are described in studies by Doornbos (1996), Mbalo (2000) and Rudnick (2004) that considered how family burden is experienced by caregivers. Chang and Horrocks (2006) identified the time-consuming and demanding burden of helping a relative with SMI to bathe, dress, and eat, and supervising their safety on a daily basis. Burden was experienced as objective or subjective, and practical or managerial. Objective burden was associated with the time and effort taken up in caregiving, financial problems, and disruptions of the daily routine and social life, including ongoing attempts to cope with the person’s mental illness. Subjective burden was associated with emotions that the caregiver experienced, such as feelings of loss, shame, worry, anger, and hopelessness with the situation and with the family member (Mphelane, 2006; O’Brien, 1998). Practical burden was associated with having to cope with assault, problem behaviour, mood swings and negative symptoms. Connell (2003), Kohn-Wood and Wilson (2005), Sethabouppha and Kane (2005), and Yip (2005) describe similar burdens, such as having to come to terms with the illness, the chronic nature of the condition, lack of knowledge, and financial strain, as among the most significant challenges to family caring. Learning to accept the role in caring meant having to tolerate some degree of deviant behaviour, and setting a routine would be expected of the family. Families see their role as vague, without a set of guidelines or rules to follow. There is no manual to refer to in caring.
Ostman (2004) and Yen and Wilbraham (2003) indicate that families experience numerous challenges in caring for a mentally ill family member at home. The caregiver’s reaction to caring would often be one of harbouring resentment towards the responsibility associated with daily care of the individual, and while the physical and emotional aspects of providing care are closely linked, caregivers would rather focus on the physical health aspects rather than the emotional aspects. Several studies have shown that caregivers also experience some impact on their own health. Connell (2003), Kohn-Wood and Wilson (2005), Robinson et al. (2005), and Yen and Wilbraham (2003) have described a number of psychological aspects experienced by caregivers, centred on their own happiness, satisfaction and goal achievement for self, and peace of mind, including feeling guilty, blaming self, and feeling burdened and unable to cope.

Perceived social stigma of mental illness impacts on both the family and the client. According to the study by Uys and Middleton (2004) lack of knowledge and education about mental illness on the part of the community resulted in a climate of unacceptance by society. Society believes that all mentally ill persons are violent and dangerous, irrespective of their diagnosis.

Families tended to avoid seeking help from relatives. Caregivers were reluctant to discuss issues of information with relatives and friends, and avoided discussing problems with health care providers. In the study by Rose et al. (2006), disruptive behaviour and restricted time for own activities by the caregivers resulted in anxiety and depression. The study identified negative effects that developed in caring for the SMI individual such as fatigue, loss and grieving, and feeling trapped by the caregiving role and responsibility. Family burden was measured by using a “burden assessment scale” developed for the caregivers. The results indicated the need to encourage the family to promote independence of the client and to positively reinforce the family to maintain the client at home. Coping strategies of avoidance and confrontation were indicators of increased anxiety. Coping styles were thus associated with the levels of frustration or helplessness or the caregiver’s overwhelming feelings. Some caregivers report becoming angry but feel ashamed to divulge such feelings (Rose et al., 2006; Seloilwe, 2006).
Caregiving impacts on the whole family. Endrawes et al. (2007) indicated in their study how caring at home influences the whole family’s way of coping and adaptation to the situation. Desire to have a normal family life was always uppermost in the caregivers’ minds but emotional demands and self-imposed isolation affected all members of the family. Because having to answer questions about their ill family member was burdensome, they considered that it was best to avoid or reduce social contact with people who failed to understand the situation. Reference was also made in the same study the tendency to lay blame: blaming in relation to how the condition came to be (i.e., factors of heredity), blaming parents, or whoever, with consequences for marriage of other family members and future prospects.

2.3.2 Health care providers’ experiences of families providing home care

Sethabouppha and Kane (2005) indicate that health care providers need to be more sensitive to the consequences of managing the client at home. Their study found that there was need for physical and social support, including financial assistance, and for caregivers to have an understanding of behaviours and problems associated with mental illness. Families lacked necessary knowledge about mental illness and recurring symptoms of relapse, about causes of mental illness, and about unpredictable symptoms that could occur.

A publication by the International Council of Nurses (2002), entitled “Nurses always there for you: Caring for families”, focused on the larger social system with the family as a subsystem, indicated that family structures and functions of the family are constantly changing and adapting to the external environment. Within the community, nurses were identified as the main care providers to the family and those of its members who have illnesses, including mental illness. Nurses should use this opportunity to broaden the family’s understanding of the causes of mental illness and the impact on their lives. The method of care would then be case studies which would provide a wider range of management including both family and the mentally ill member.

A lot is expected from the caregivers. The demands can be overwhelming yet it is taken for granted that the caregiver will be there all the time, doing whatever is necessary for the SMI relative at home. Caregivers who failed to do this feel “bad and
guilty” when they cannot cope. A study by Ostman (2004), in which 162 relatives of patients were interviewed after first admission and then subsequent re-admissions, indicated a need for boundaries in caring to protect caregivers from exhaustion and burnout. Home caregiving basically goes on 24 hours a day, leaving little or no time out.

The same study found that there was relatively little difference between management of patients by caregivers and by those within the hospital. The study showed that family and patients used psychiatric services less than expected, with stigma and dissatisfaction with services cited as reasons for this. Because the families regarded their problems as mostly being related to psychological issues with the ill member, such as being burdened, they did not feel it necessary to seek out psychiatric services. The findings of this study suggest that it is important for psychiatric services to maintain hope of recovery for family and relatives of all patients. The focus would be to improve psycho-education, reduce the more practical burdens for the relatives, and see that services are used despite concerns such as stigma.

Family members can and do play a very positive role in the treatment process, through the protection and support they provide in relation to their relative’s environment and biological vulnerability (Intagliata, Willer & Egri, 1986). When family caring occurs, rates of relapse can be reduced with use of programmes developed by the clinicians. Families were identified as a crucial resource in the treatment and management processes for the SMI client and they assist the professional health services to reduce re-admissions to institutions through sustained treatment regimes and symptom reduction (Uys & Middleton, 2004).

Caregiving by an elderly person poses particular challenges for the caregiver. When the caregiving is long-term, and the caregiver is unable to meet the needs of the SMI relative, there may be denial of the condition or illness. Acceptance and hope is often difficult for an elderly caregiver, especially if she is the mother of the mentally ill person. Sales (2003) found that caregivers used emotion-focused coping strategies such as mental and behavioural disengagement and denial. In some cases the caregiver’s response is hope of a miracle to change the situation with God’s blessing; prayer is perceived as an answer and this is what some caregivers turn to as a form of escape (Ensink & Robertson, 1999; Finlay, 1998).
2.3.2.1 Processes of family caregiving

Family caregiving for a SMI relative is time-consuming and demanding, and caregivers have identified various ways that they manage the process. One approach, mentioned by Lefley (1997), Mays and Lund (1999) and Mbalo (2000), has been through sheltered workshops which help to give the caregiver a deeper understanding of the condition and of therapy, and a positive goal in management. Further enhancement was provided in the form of advice from the health professional, medication supervision, and timely intervention so that the caregiver could cope with the illness. They valued whatever assistance they got from the health services.

Being on medication reduced the symptoms of the ailment and subsequently the behaviour problems associated with the illness (Uys & Middleton, 2004). Caregivers treated the SMI relative with compassion, love, and support, with the health services providing help financially, physically and emotionally. In the studies by Sethabouppha and Kane (2005), other members in the immediate and extended family assisted with the caring role as and when they were available.

Families who have to cope with mental illness see the role of health professionals from a particular perspective. The training manual for health professionals by Shankar and Menon (1991) makes the following points in this regard: Families come from different backgrounds culturally, socially, and environments; families differ from professional health teams in their needs and expectations; families interact with professionals at different levels and in different settings; family caring and interventions will accordingly involve various aspects including a partnership to promote the best possible recovery in the person disabled by mental illness. In the South African context, culture and language play a significant role in care for the SMI client and health professionals need to be culturally sensitive. African culture influences the accessibility of professional health services but the numbers are gradually increasing of those persons who may at some time in their lives seek help from the professionals for mental health issues (Pillay & Harvey, 2006).

Traditional, religious, and spiritual aspects play a significant part in the way that families cope with the stress and burden of caring for the SMI relative. Studies of caregivers in Buddhist families disclosed the belief that it was a person’s destiny to suffer and that the burden of caring for a relative with mental illness will enlighten the
Help-seeking behaviour by caregivers was also noted. Assistance from other family members and friends was used to escape from the stressful situation. The study by Doornbos (1996) found that families caring for an SMI relative which had sought education or support (or a combination of both) regarding symptoms, treatment and specific resources reported significant reduction in anxiety, personal distress and better coping behaviours such as life and social skills; feelings of resentment and helplessness, a sense of entrapment, and restriction in leisure activities came to be seen as normal reactions rather than as family pathology. Because having a mentally ill relative at home gave rise to embarrassment, shame and emotional distress for the caregivers, families often isolated themselves from others, which unduly heightened their suffering.

Receiving a social service grant made the tasks of caregiving acceptable to the caregiver, and the money was used both for the SMI relative and for other expenses, since the fact that caregivers often had to stay at home to look after the ill family member reduced the family income, ultimately leading to further social problems and isolation (Mkhize & Kometsi, undated).

The unanticipated task of caring for the mentally ill person often totally disrupts and dominates the lives of parents and siblings (Howard, 1994; Uys & Middleton, 2004). The family resorts to admission of the mentally ill family member to a health care facility with anticipation of long-term management, and the period when the individual is in hospital is seen by the caregivers as a reprieve from caring.

Coping strategies used by families in times of stress also included efforts to master, tolerate or minimise the stressful events. If the caregiving was long-term, coping eventually became dysfunctional as negative emotions and feelings increased, resulting in mental or behavioural disengagement. These strategies also influenced the outcomes in caring behaviours by the family or primary caregiver (Mbalo, 2000; Minaar, 2001).
Providing the family member with nutritious food, ensuring adequate sleep, and trying to keep the atmosphere peaceful and pleasant with minimal levels of disruptions and disturbance, especially when the SMI relative is restless, resulted in increased co-operation and management in the caregiving processes. This relationship, in which caring was health related, assisted in building a trusting and acceptable bond between the caregiver and SMI client.

2.3.2.2 What families want from health services

Some studies indicated that families feel that they are not recognised as important to the care of the mentally ill relative, especially in the daily routine provision of care. Health professionals need to take into account the support needs of the family and the SMI client. The health providers should communicate more regularly with caregivers, and focus on the family as a family, rather than just on the client (Asplund et al., 2005). The literature suggests that families caring for mentally ill members at home have very clear education and support needs. Drapalski et al. (2009), Mbalo (2000), and Mphelane (2006) described family educational needs as wanting knowledge about the illness, skills to cope with disturbing behaviour, and knowledge of what to expect from the family member when he or she is relapsing.

In a study by Knudson and Coyle (2002), support from mental health services was generally perceived to be lacking, although informational and emotional support was available from self-help and support groups for carers or families. Belonging to a support group has helped meet needs of the caregivers which were frequently not met elsewhere. Basic information of the course or nature of the illness has been rated as one of the most important needs of relatives. This is because when family caregivers take on the task of caring for the MHCU, they do not comprehend the enormous responsibility it will be for them (Nolan et al, 1995). Caregivers felt excluded from the caring treatment process with the health professional because there was also a lack of information from them about the behavioural management of the individual, especially in the early stages. Families wanted more co-operation with the mental health services and criticised strict interpretations of confidentiality that they felt were sometimes inappropriate. Many of them also felt that they could have benefited from psychological help and support from the professionals. Knudson and Coyle (2002)
emphasise that professionals need to recognise the differences experienced by families, and should adopt a needs approach which would suit the individual families.

Families want to be fully involved in the care of their ill member. They want to be considered as part of a dual role in that they are involved with the health team and at the same time recipients of care and support. One complaint from caregivers has been, “no-one asks how I am, what about me”. The client is the centre of attention in the clinics, at the community services, and in the hospitals, and often caregivers feel that their personal needs are not acknowledged by the health services (Evavold, 2003).

Doornbos (1996) indicated that the professional nurse should be involved for specific interventions in programmes that were suggested by study participants, such as assisting in bonding, conflict management, and informative teaching regarding mental illness. Similar needs were identified by Chang and Horrocks (2006), O’Brien (2001), Mays and Lund (1999; 2002) and Spaniol, Zipple, and Lockwood (1992). Nurses are the main care providers to the family. They have the opportunity at the community clinics to broaden knowledge and understanding of the causes and management of mental illness. This knowledge would ultimately have a positive impact on caregivers’ personal lives, providing confidence and reducing self-blame and anger.

2.3.2.3 Issues in family-centred care

Mental illness is still stigmatised in the community despite attempts to rationalise and provide mainstream treatment for MHCUs. Kokanovic et al. (2001) note that it is especially difficult for caregivers to seek the assistance and support they require because of the social isolation that accompanies the illness, and they highlight the way that caregiving becomes a constant and exhausting duty once the mentally ill individual is settled in at home and the caring became exclusively the family’s responsibility. Financial burdens, disruptions to daily life and periods of verbal violence with threats or physical violence with the SMI individual is often distressing and frustrating, and places considerable pressure on the caregiver (Kokanovic et al., 2001).

Another problem for caregivers is access to supportive health services. Caregivers felt that they were not referred to other health services for assistance because there was an assumption that caring was the family’s responsibility, but they also lacked
knowledge of services that did exist in the community because they failed to indicate their needs to the health care providers. A possible reason for this was shortness of consultation time with the client and family, and communication difficulties made it difficult for caregivers to have their concerns heard. Caregivers also lacked help-seeking behaviours, because the stigma attached to “mental illness” led them to cope in isolation (Chang & Horrocks, 2006).

Family care remains a burden to the family. Lefley (1996) and Chang and Horrocks (2006) indicated that the client is an endless burden to family caregivers. Although families have experiential knowledge of their relative’s disorder, professionals often provide inadequate and vague factual information about the disorder, its course, and the day-by-day effects of the illness on the family. As outlined in Chapter 1, the burden is objective (time involved in caring), subjective (impact on the caregiver) and managerial (finances, etc.).

Some caregivers who are unable to cope because of the economic burden come to rely on the disability grant of the ill family member as their source of household income. Because there would be no money coming in if the MHCU is admitted to hospital, the family will try to avoid seeking medical help should the ill person’s condition worsen, requesting assistance only when the situation is out of hand (Mphelane, 2006).

Although women are by far the principal caregivers, there are widely differing family and personal circumstances within which this may occur. Some do it because they receive external financial assistance while others do it because they find it fulfilling, as emerged in the study by Mays and Lund (1999). Females provided the mothering aspect of caring and nurturing. Because men generally work, they are less likely to become burdened in this way. Females focused on grooming, hygiene, cooking, and emotional support to the SMI relative at home. Because of these differences in the way the caregiving role is perceived, Rudnick (2004) in his when study caring for his wife, concluded that females were significantly more burdened than males. This is manifested in burnout and reduced caregiver well-being.

2.3.2.4 Themes that emerged in studies by previous researchers

In data analysis, a range of relevant themes emerge in the meaning structures of statements given by participants in a study. In the study by Chang and Horrocks
(2006), meaning structures that became apparent in the lived experiences of participants in the Chinese community were: managing; enduring; surviving the daily experiences. The impact of stigma in mental illness on the caregiver and the family was all pervading and very strong. Coping behaviours were identified as avoiding discussions of the illness and adopting positive behaviour and attitudes to prevent losing face in the community. Other issues that emerged in this study related to the activities of daily living that seemed to cause much distress to caregivers each day, such as having to remind or persuade their SMI relative to bathe, eat, and not mess up the house; it was particularly stressful when a mentally ill family member carried on doing what they usually did in the home without any thought to the consequences.

Five themes emerged in the study by Endrawes et al. (2007) of caregiving by Egyptian families: Why did it happen? (blaming oneself or God); How do I care for my loved one? (coping strategies); What has it done for me? (personal burden); What has it done for us? the family as a whole; How do I survive? (living in hope). These themes focused on the hopelessness of the situation and its obligatory nature. What made the situation bearable were religious and cultural factors.

The study by Mays and Lund (1999) identified three principal themes: expressions of burden; duration and depth of commitment; role affirmation. This was a study with male caregivers, but the issues that they faced were similar to those faced by any caregiver, and arose from the psychosocial, physical and financial impacts that the family or caregiver experienced.

Similar issues emerged in a study by O’Brien (1998), which noted how factors such as learning to live with the mentally ill person, having to make a conscious effort to accept that he/she is mentally ill, and having to remember this each time things changed or got worse, all profoundly affected family life. One conclusion of the O’Brien study was that nurses should proactively meet the needs of family and caregivers, rather than just dropping in to find out if they are doing “okay”. Another was the need to heed what the caregiver has to say as often they are the most reliable source of information about the family member’s behaviour and caring requirements (O’Doherty & Doherty, 2008).
Spaniol, Zipple, and Lockwood (1992) identified themes that focused on the behaviour of the SMI relative and concluded that additional coping strategies were required for bizarre and abnormal behaviour such as antisocial and aggressive behaviour, social isolation and withdrawal, hygiene and appearance problems, and sometimes suicidal threats. Fear, guilt, and social perception influenced how the caregiver responded and how care was provided by caregivers.

In the study by Knudson and Coyle (2002), the common theme in family interviews was that family members with schizophrenia tended to isolate themselves and withdraw from activities and exhibited a lack of motivation. This was difficult and trying aspect for the family to deal with. Eventually caregivers gave up the struggle and disappointedly accepted the situation of caring for what it was. Social isolation and withdrawal slowly became acceptable as the coping strategy, with the SMI client eventually having minimal interaction with family members and community activities.

2.5 Summary

These studies suggest that managing the mentally ill relative at home is a burdensome process, coupled with a health system that is at times unresponsive to the caregivers or families’ needs. It seems that there is difficulty in managing the balance between caring for their own care and well-being and caring for the mentally ill family member. Furthermore, not all families have the knowledge, skills, and support to cope with certain behaviours of the SMI relative. Caregivers want ongoing assistance of health professional and services with care of their family member, not just when he/she presents problems or fails to attend the clinic. The caregivers own well-being and health should also be of concern to the nurses and doctors and other health professionals.

2.6 Conclusion

A number of studies were undertaken regarding the phenomena of caring and the lived experiences of caregivers for their mentally ill relative at home. Some of the
studies have highlighted aspects pertaining to the caring as burdensome while others have acknowledged the challenges and hopes for future associated in caring despite the degree of mental illness in the individual. The effects on the individual as a caregiver were also evident such as guilt, blaming self and fear for the future should they not be around to provide care. The next chapter will provide the phenomenological framework and Colaizzi’s method for descriptive phenomenology.
Chapter 3
Phenomenology as theory and method

3.1 Introduction

The study was guided by the descriptive phenomenological framework and Colaizzi’s method for descriptive phenomenology (Creswell, 2007; Polit & Beck, 2008). Phenomenology is founded on the premise that human experience is the basis for building knowledge about different social realities (Creswell, 2007). Phenomena are defined as appearances or immediate objects of awareness in experiences which may be objective (external to the person’s awareness of it) or subjective (for example, a thought or a feeling) (Creswell, 2007). Consciousness is always directed towards an object, and what can be known about the object is intertwined with the person’s consciousness of it. The reality of the phenomenon is appreciated as both object and subject as it appears in consciousness within the meanings attributed to it by the experiencing individual (Creswell, 2007; Polit & Beck, 2008). Phenomenology is therefore concerned with understanding the lived experience of individuals and, to this extent, is a useful methodological framework for psychiatric nursing since it shares the same goal (O’Brien, 2001).

Phenomenology involves the study of the nature and meaning of phenomena (Creswell, 2007). There are basically two types of phenomenology commonly used in health care research (Creswell, 2007). The first is hermeneutical phenomenology and the second is transcendental or psychological phenomenology. Both types focus on developing descriptions of the understanding of phenomena. The former approach focuses on the researcher’s interpretations of the different meanings of expressed understandings, while the latter is concerned with building clear descriptions of the phenomenon while bracketing out as far as possible the interpretations (meanings) of the researcher (Creswell, 2007; Polit & Beck, 2008). Phenomenological study is therefore a useful methodological framework for understanding the experiences of
nurses and patients and building knowledge of different aspects of psychiatric nursing practice (O’Brien, 2001).

3.2 Philosophical assumptions of phenomenology

The descriptive approach focuses mainly on distilling and describing essences of experiences, while the interpretive approach both describes and interprets the meaning of the essence for the participants (Polit & Beck, 2008). Both approaches share common assumptions, which include study of the lived experiences of persons, the view that these experiences are conscious ones, and the development of descriptions of the essences of the experiences, without explanation or analysis of the experiences.

The assumptions lead to true knowledge of an experience, coming from living in the world where meaning emerges and insight is revealed. There are common elements in the different phenomenological approaches. Polit and Beck (2008) describe the processes of intuiting, bracketing, analysing, and describing as common threads underlying phenomenology as a study of lived experiences. Bracketing involves the researcher suspending his/her personal opinions and judgements as he/she enters and separates from the lived experience being described (Creswell, 2007). Analysing and describing involves reducing the data through uncovering common themes, significant statements, and narratives to illustrate the themes and statements. Finally, the experience described in its essences is, in this case, the experience of the family members caring for the mentally ill relative at home (Polit & Beck, 2008).

3.3 Steps in the descriptive phenomenological approach

The study was based on the principles of descriptive phenomenology. Polit and Beck (2008) identify four steps in the descriptive phenomenological process: bracketing, intuiting, analysing, and describing.
3.3.1 Bracketing

The first step is bracketing. According to Burns and Grove (2008) qualitative research is a systematic, subjective means used to describe life experiences and give them meaning. It is thus a means to explore the depth, richness, and complexity of phenomena and their usefulness in human experience. The researcher needs to bracket out, set aside, his/her beliefs, thoughts, and assumptions so as to discover insights, meanings, and understanding of the phenomena under study. In the present study the researcher operationalised this step by setting aside her usual and natural assumptions about the phenomena, suspending her beliefs in the existence or nonexistence of the phenomena (Finlay, 2005; Polit & Beck, 2008). Following Terre Blanche, Durrheim and Painter (2006), the researcher clearly stated her personal interest in the topic and position with respect to the phenomenon. In the research report the researcher makes reference to the bracketing of her own beliefs with regard to the phenomena. Bracketing (also known as “epoché”) was continued throughout the research process.

In reflexivity, the researcher describes the problems experienced in applying the phenomenological method in the interview process. While engaging with the clients in the interview process, the researcher’s own points of view, her personal experiences, values and beliefs, were set aside so that these would not interfere with the data collection and questioning of the participants. The researcher often had to repeat questions or rephrase them so as to simplify them for the participants to answer. This led to many closed-ended questions and lengthened the interview. The participants initially viewed the researcher with suspicion and reservation, until she explained that the interview had no bearing on receipt of the social welfare grant. Gradually the participants opened up, appreciating the conversation, and sharing personal information. See also section 3.8.1 for the comments regarding researcher’s preconceived assumptions and opinions which were bracketed out. With respect to understanding and knowledge for the researcher of caregiving experiences, the bracketing process enabled her to continue with the data collection and subsequent analysis by focusing on the outcome (i.e., by describing the phenomena as seen and experienced by the caregivers). The subjective interpretations of the researcher were thus bracketed out as far as possible. The researcher found it difficult to stop herself from giving assistance, help, and support to the caregiver while she was recording the
interview. Often she had to check herself and focus on the task at hand to avoid contamination of the data.

### 3.3.2 Intuiting

This step involves immersing oneself in the data and being attuned to the meanings given to the phenomena by those who have experienced it (Polit & Beck, 2008). Intuiting is considered to be an aspect of bracketing. Intuiting is a form of openness, of being open to the diverse potential of meanings and being willing to listen, see, and understand with sensitivity, respect and humility for the experiences of others (Finlay, 2005 and Sanders, 2003). During the initial interviews the researcher began to identify the phenomena in the study as described by the participants. With this uppermost in mind the researcher avoids all opinions, criticism, and evaluation by paying particular attention solely to the phenomenon under study. Although at times the researcher found it extremely difficult to remain objective during the interview, she needed to focus on being an instrument of the research process by continuing the interview and collecting the data. The information from the interviews, taped on audiocassettes, was then transcribed and repeatedly reviewed to determine the phenomena and later extract these in the data analysis.

### 3.3.3 Analysing and describing

The final two steps are analysing and describing, drawing on the procedures outlined in Colaizzi’s method for representing and analysing data (Creswell, 2007; Polit & Beck, 2008).

In the analytical process, the researcher identified the essence of the phenomenon under study, based on all the data obtained during the interviews. Initially the researcher looked through the transcribed information for categories and subcategories that described the phenomenon. Such statements provided a description of how the families saw their role in caring for the mentally ill family member at home. The essence identified from these statements was “how the caregiver sees or describes his/her role”. The process continued as further themes were formulated from the categories. Each theme was linked to statements from individual participants that describe a phenomenon. These statements were then collated to bring out the essence
of their meanings, and common threads in the statements assisted the researcher to
group them into categories and subcategories.

In the descriptive process, the researcher recorded the information that was present in
verbal or non-verbal depictions of critical elements of the phenomenon in the
participants’ statements, based on the grouping of the phenomena. The researcher
classified statements that were common to each participant’s description of the caring
experiences. All four steps were undertaken simultaneously and the findings were
understood within the context of the collective groupings.

3.4 The study context

The setting for the study was the psychiatric clinic in the Northdale suburb of
Pietermaritzburg. Northdale is historically and currently home to a prominently Asian,
English-speaking population, classified as middle- to lower-income (Pietermaritzburg
Municipal Offices). A number of informal settlements have been established in the
area over the past ten years, many of the occupants being Zulu-speaking.

The community psychiatric clinic in this suburb provides services to between 990 and
1065 MHCU per month (Conversation with clinic sister and administrative assistant,
dated 30.04.09). This number has recently increased owing to the closure of the clinic
in the city centre. English-speaking clients constitute 96.5% of the clinic population
and 3.5% are Zulu-speaking (telephone conversation with the clinic sister, Sr.
Rathnam). The clinic offers an English-based psychiatric service with the services of
a psychiatrist, social worker, and psychologist once a week and a part-time medical
practitioner every day for approximately two hours. There are four registered
psychiatric nurses, of whom only one speaks Zulu. They coordinate the services;
provide rehabilitation and service needs to Northdale and Sobantu, to a school for the
mentally challenged, and to hostels in the area. Home visits and a depression group
are also conducted once a week from the clinic.

Communication was generally in English, and the same format was used in all
interviews. Caregivers frequently accompany their MHCU to the clinic and the clinic
sister reports that on any one day at least six caregivers (usually family members) are
seated in the waiting room while their relative (MHCU) is interviewed by the nurse, psychologist or doctor.

3.5 Selecting participants for the study

Purposive convenience sampling was used to select the participants for this study (Creswell, 2007), based on knowledge of the phenomena under study and likelihood that they would provide rich experience from years of caring for the family member with mental illness at home.

The researcher approached caregivers who were in the waiting room of the clinic while the family member was with the doctor or with the sister in the pharmacy.

Terre Blanche, Durrheim, and Painter (2006) suggest that as a rule of thumb, six to ten interviews are sufficient for an in-depth qualitative analysis but that this figure is determined by the point at which information reaches saturation and no new data emerges. A total of seven caregivers were approached to be interviewed and all seven met the criteria for the study. All seven participants were interviewed and audiotaped, but an equipment failure meant that only six interviews were transcribed. The researcher found, however, that six was adequate as there was saturation of information and no new data emerged after the second, third, and fourth interviews.

3.6 Participant inclusion and exclusion criteria

Adult caregivers (over the age of 18) who had accompanied the client to the psychiatric clinic and who live with the client at home were included. Caregivers who did not live with the client were not included and neighbours and friends were also excluded. The study purpose was explained to the caregivers and the consent form was signed by them. Participants selected were those who directly cared for the mentally ill family member. All were English-speaking caregivers who willingly volunteered their time to be involved in the study. Ability to speak English was taken into account but not regarded as an exclusion criterion.
As there was inadequate privacy in the waiting room the caregivers opted to have the interview at their homes. To this end telephone numbers and addresses were recorded so that a visit could be scheduled according to the convenience of the caregiver, but no names were linked to information in the data collection, and privacy and confidentiality of data was maintained throughout the process. A tape recorder was used for data collection and again for verification of findings.

Telephonic appointments were made and a time at their convenience was arranged to meet the participants at their homes. Most of the interviews were during the afternoons as it gave the caregivers time to complete tasks at home. Interviews were conducted in the dining room (x4), lounge (x2), Kitchen (x1). At one home one child presented some disturbance until his grandmother assisted in sending him out of the dining room. I later was informed that he i.e. the child was diagnosed with Attention Deficit Disorder hence his behavior. Another participant kept calling her husband into the room to clarify information such as time intervals or dates and names.

Meeting the participants at their homes gave the researcher added opportunity to observe and gauge each participant’s level of understanding of the questions and focus on the interview.

### 3.7 Procedure for collecting and recording data

Data was collected through in-depth interviews lasting from 45 minutes to one hour, following approvals received from the head offices at Kwa Zulu-Natal Department of Health, the psychiatric clinic, and the Ethics Committee at the University of KwaZulu-Natal. Interviews were audiotaped and later transcribed and typed to facilitate analysis. A list of open-ended questions based on each research objective was used as probes in the interviews. To describe characteristics of the sample a form was used to collect biographical data such as the age, gender, relationship to the MHCU, and state of health of the caregiver.

The final stage of the data collection/analysis process involved returning to the participants (called member checking) to hear their opinion of the extent to which the phenomenological analysis corresponded with their experiences of caregiving. For
this data validation task the researcher returned to five of the participants, and their verification of the findings was audiotaped separately and placed by the researcher in safekeeping with the first recording in a locked cupboard. The researcher was unable to return to the sixth participant as the caregiver was away on holiday.

### 3.8 Strategies to validate findings

In validating the study several verification strategies were applied during the research process. These included rigour, trustworthiness and dependability, credibility and conformability, and transferability.

#### 3.8.1 Rigour

In maintaining rigour or trustworthiness, explicitly conceptualised and generalised types of specific questions were pursued with the participants. This was done by maintaining a critical and reflexive lookout for the study context, keeping the audiotapes and transcripts documented, and collectively examining the study data throughout. To ensure that the researcher validated the accuracy of the transcribed account, constructive member checking was done by returning to five of the participants to verify the conclusions reached by the researcher following the initial analysis (Lincoln & Guba, 1985).

By taking cognizance of reflective thoughts identified by the researcher, dependability of the data collection was maintained, including interpretation of the data and analysis (Terre Blanche, Durrheim, & Painter, 2006). Being involved in the clinical field with student nurses in psychiatric nursing, the researcher had been of the opinion that family caregivers were often marginalised in relation to information about the MHCU’s illness, treatment, and management at home. Caregivers’ dependence on the social grant had been seen by the researcher as a catalyst for seeking treatment at the clinic. In her opinion, families feared that should they not seek treatment their social welfare grant would be cut off. The researcher had felt that far too little time was spent in verbal interaction with caregivers when they brought their family member for treatment and review. Stability of all information was maintained throughout the process by bracketing out these assumptions, opinions, thoughts, and feelings.
As a means of validation the researcher was able to ask the participant to comment on the researcher’s understanding of the meanings that she formulated during the subsequent interviews. Throughout the process, there was consultation involving the researcher in discussion with her supervisor to address investigator adequacy, and later reflexivity. Data collection processes and probe questions, including the transcribed interviews, were initially checked and rechecked with the supervisor for comment and corrections so as to maintain objectivity and conformation of the data.

### 3.8.2 Trustworthiness

Trustworthiness indicates that the findings of the study are a reflection of lived experiences and personal expressions of the phenomenon under investigation. In qualitative studies it is necessary to ensure that the findings are authentic, transferable and dependable (Creswell, 2007; Polit & Beck, 2008).

### 3.8.3 Dependability

Dependability must provide the readers with evidence that if such a study was repeated with the same or similar participants in the same context the findings would be similar (Polit & Beck, 2008).

The researcher ensured dependability of the entire process of data collection, analysis, and interpretation of the data in the study by ensuring that the research was closely monitored and constantly evaluated by the research supervisor, who provided expertise in scrutinising and giving feedback to the researcher. Dependability was also ensured through maintaining consistency in the interview process, using only one interviewer, and checking the required areas of interest in the content of the transcriptions.

### 3.8.4 Credibility

Credibility hinges on how interpretations are formulated from the data. The researcher listened to the interviews then compared them to the verbatim transcripts that she had completed at the end of each interview. The researcher ensured that these were consistent and that both were saying and meaning the same thing (Creswell, 2007).
3.8.5 Conformability

By returning to the participants to verify the conclusions drawn by the researcher, both conformability and objectivity was maintained. This ensures that the researcher focuses on the inquiry and not on the biases of her own (Lincoln & Guba, 1985). Should the conclusions, interpretations and recommendations need to be traced to their sources they would be supported by the study. This can be ensured by use of the field notes and tape recorded information of the raw data available.

3.8.6 Transferability

Transferability refers to the extent to which the findings of the study could be generalized to similar studies in the same or similar context. This could be determined by those who consider the findings to be of relevance and useful in their studies (Lincoln & Guba, 1985).

A small sample size was used in this qualitative study. It provides a base of information for a particular area or region which could be of interest to other similar regions in the provision of caregiving of a mentally ill relative in the community by a family member. All observations and content of data were clearly recorded as they occurred. These findings could be transferable to similar studies in nursing practice.

3.9 Ethical considerations

Ethical approval was obtained from the Ethics Committee at the University of KwaZulu-Natal. Thereafter written approval was obtained from the Department of Health at Natalia, Research section and from the community psychiatric clinic in Northdale, i.e. The Ghandi Road Assessment Centre.

In this research, confidentiality and privacy was maintained by the researcher with each contact and interview with the participant. Initially the participants received the letter informing them of the study by the researcher and thereafter they completed a consent form. They were given a full explanation of the study, its purpose, their freedom to withdraw from the study, and their freedom to request to have any data
they provided to be removed from the study. They were also informed that there were no payments for participating in the study.

Once the interviews were completed, all transcripts were stored with the audio disc in a locked cupboard in the researcher’s place of residence. They would be held for a period of 5 years. Names and addresses were not included on the disc or in the transcripts.

3.10 Data management

The researcher transcribed the interviews on her computer at home. Only the researcher had access to this computer, using a secret access code. The transcribed transcripts had no identification of the participants as names and addresses were not included. Following examination of the thesis the corrected report will be bound and submitted to the library at the University of KwaZulu-Natal. A further copy will be sent to the Department of Health at its head office, Natalia, as requested on the approval for the study.

3.11 Summary

The chapter described the methodology of the study undertaken by the researcher. The study described how the caregivers experienced caregiving to their family member with mental illness. The essence of their caregiving and themes were formulated from their experiences. When no new categories or themes were found, member checking to validate the findings with their experiences was done. When participants had confirmed the concluding themes, credibility was achieved. The participants were willing to share these experiences and offered further assistance should the need arise. Formal ethical approval and administrative clearance was obtained for the study. Participants consented to the study after being fully informed about the purpose of the study, that no benefits were attached to participation, and that their anonymity and confidentiality of self and data would be maintained.
3.12 Conclusion

The chapter included the research design and the methodology used in the study together with measures to maintain rigour or trustworthiness. Chapter 4 will provide the research data and the specific themes that emerged.
Chapter 4
Data analysis

4.1 Introduction

This chapter presents the qualitative data on how family caregivers in Northdale, Pietermaritzburg experience and provide care to their family member with mental illness at home.

4.1.1 Description of the participants in the study

A total of six family caregivers, all of whom were females, (five being the mothers and one being the wife) were interviewed in this study. Each participating caregiver lived with a family member who was receiving treatment for schizophrenia from the Northdale psychiatric clinic. The caregivers often accompanied their family members to the clinic to obtain treatment or for review with the doctor. At times registered nurses in the clinic would consult participants about the MHCU’s behaviour at home and participants would inform the nurses of problems their family member might have had. Visits to the clinic were monthly or two-weekly, depending on the treatment the MHCU was receiving. All participants selected for the study were females, being either the mother or, in one case, the wife of the MHCU. The participants who were mothers(5) had been caring for their family member from the very first time that the MHCU was diagnosed with mental illness and had lived with them since birth. From the interviews it would seem that the parent is ultimately responsible for the care of the MHCU. This is also described in the studies by Lefley (1996) and Spaniol et al. (1992). In the literature, page 22 the researcher had indicated that females were primary care givers due to cultural and traditional nurturing practices hence the participants in this study happened to be females.

Communication was not an issue as the participants spoke English, but at times there was need to repeat or rephrase questions so that they could understand what was being
asked. They understood the questions and shared information as accurately as possible. Each interview lasted approximately an hour to an hour and a half. Often open-ended questions were posed but followed with some closed-ended questions and remaining unstructured and interactive. There was a need for clarification at times and the researcher had to prompt the caregiver in some instances. The taped audio sessions were terminated once there were no more new themes that could be identified. Thereafter the audiotaped sessions were transcribed, making note of any particular information that needed clarification during the verification process.

The demographic details of the participants are set out in Table 4.1 indicating participants’ age, gender and physical health and whether their family member was in receipt of a social welfare grant.

Table 4-1 Demographics of caregivers and family member with mental illness

<table>
<thead>
<tr>
<th>Caregiver</th>
<th>Age</th>
<th>Relationship to MCHU</th>
<th>MCHU</th>
<th>Age of MCHU</th>
<th>Caregiver’s health</th>
<th>MCHU receiving social grant?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>41</td>
<td>wife</td>
<td>husband</td>
<td>45</td>
<td>Well</td>
<td>yes</td>
</tr>
<tr>
<td>2</td>
<td>61</td>
<td>mother</td>
<td>daughter</td>
<td>34</td>
<td>asthmatic</td>
<td>yes</td>
</tr>
<tr>
<td>3</td>
<td>71</td>
<td>mother</td>
<td>son</td>
<td>37</td>
<td>hypertensive</td>
<td>yes</td>
</tr>
<tr>
<td>4</td>
<td>57</td>
<td>mother</td>
<td>son</td>
<td>27</td>
<td>Thyroid problems, high Cholesterol, diabetes and hypertension</td>
<td>yes</td>
</tr>
<tr>
<td>5</td>
<td>54</td>
<td>mother</td>
<td>son</td>
<td>23</td>
<td>Arthritis, hypertension</td>
<td>yes</td>
</tr>
<tr>
<td>6</td>
<td>56</td>
<td>mother</td>
<td>son</td>
<td>25</td>
<td>Surgery for colitis, now well</td>
<td>no</td>
</tr>
</tbody>
</table>

4.2 Colaizzi’s method of data analysis and data representation

The data obtained in this study was analysed using Colaizzi’s (1978) method. Creswell (2007) and Polit and Beck (2008) both indicate six stages in the analysis process: acquiring a sense of the transcripts; extracting significant statements; formulating meanings from the identified statements; organising clusters of themes from the formulated meanings; exhaustively describing the investigated phenomena; returning to the participants to validate the exhaustive descriptions with them.
4.2.1 Acquiring a sense of the transcripts

The researcher began by reading and re-reading each transcript to identify statements and phrases that described the caregiver’s experiences of caregiving. The researcher looked critically at the six transcriptions, paying particular attention to statements to acquire an essence of what the participant was saying, meaning and conveying to the listener. Repeated readings of the transcripts to examine the interactions with the collected data provided a sense of what could be extracted and concluded from the transcripts. The understandings acquired from the transcripts were then used to describe the participant’s lived experiences of caring for her relative with mental illness.

4.2.2 Extracting significant statements

During this process the researcher made notes of which statements were linked together and also what meanings were implied in these statements. Notes were kept because the researcher had to go back several times to check if the statements had implied such meanings. Approximately 40 statements and phrases were extracted from the transcripts which related to the phenomena in the study. Following Creswell (2007), a list of the non-repetitive statements was used in the formulation of meanings. Then similar statements were combined that had meanings that related to a specific meaning. Manual extraction was done for the data analysis of the specific lines with similar meanings. Table 4.4 indicates the significant statements.

4.2.3 Formulating meanings

The researcher then grouped the statements into larger units or themes that would enable analysis through examination of the linkages between statements and themes. As outlined by Creswell (2007), the larger groups were then organised into clusters of themes. The themes emerging from the significant statements reflected what it means to the caregiver or relative with SMI when caring takes place. This was later verified when the researcher returned to the participants to confirm the descriptions. The term “themes” and “meaning units” are used interchangeably in Creswell (2007) and Terre Blanche, Durrheim, and Painter (2006). Table 4.2 and 4.3 provides for the statements and the emerging themes.
4.2.4 Organising the formulated meanings into clusters of themes

Having read and reread the sentences and phrases, the researcher began to systematically group the formulated meanings into clusters of themes. Each theme reflected a particular aspect of meaning according to the participant’s description of caring for the MHCU. Creswell (2007) notes that part of the phenomenological analysis is the “what and how” of the specific experiences that have occurred in caregiving, or the context and situation in which caregiving took place.

Nine themes were identified with associated significant meanings which indicated feelings, thoughts, and behaviours from the formulated meanings:

- Theme 1: Family as a support structure
- Theme 2: Commitment to care
- Theme 3: Disruption to family life
- Theme 4: Value in contributing to care
- Theme 5: Maintaining hope
- Theme 6: Support and Guidance: ongoing assistance
- Theme 7: Concern for continuity of care
- Theme 8: Fears experienced in caring
- Theme 9: Misuse of social grants

Each theme had between five and ten significant statements associated with it. Table 4.2 shows the associations of theme and meanings, and their location in the transcription, for the themes.
**Theme 1: Family as a support structure**

All the participants in this study indicated that they needed to provide structure in the SMI relative’s daily activities. They were responsible for providing food and shelter in addition to supervision of the relative’s personal hygiene and medication usage. Chang and Horrocks (2006) classify these tasks as “managing the day-to-day care”. Other researchers such as Mbalo (2000) and Mphelane (2006) use the term *family burden* as a theme that was common to their studies.

Statements that conveyed this theme are listed in the fourth column of Table 4.2, where I have also listed further instances in the transcripts that mention how family care and supervision was experienced by the participants. Significant statements were variously grouped as conveying this theme. All six participants indicated directly their experiences of family support as an important element of patient care at home. Of particular interest was that some SMI individuals could do things for themselves and function fairly independently, yet they were cared for in the way one looks after a child.

Caregiver statements conveyed how the caregivers were involved in maintenance of daily living for the SMI relative. Challenging tasks of personal hygiene made the mother of one SMI individual very sad that she had to do the washing of her underwear. Supervision of personal hygiene directly indicates tasks carried out by the caregiver.

The time spent in laying out the clothes of the MHCU or time spent in preparation of their meals was a daily routine to the caregivers. It also meant that once this aspect of the daily care was done then the caregiver could focus on other aspects. Maintaining personal hygiene, hydration and nutrition seemed to be important to the participants as each of them made reference to this aspect. Statements such as the following indicated how the family was perceived as a support structure:

“No, you have to tell him to do it. When he needs a bath, you got to take out clean clothes for him to change. He won’t take out clean clothes I have to do it”

(Transcript 1: lines 94–96).

“I cook for him, wash his clothes, dish out his food, make his breakfast, tie his lunch, all that I do in the week”

(Transcript 1: lines 10-11).
Tables 4.2 and 4.3 show more of the significant statements with associated meanings and the formulated meaning clusters for all nine themes.

**Theme 2: Commitment to caring**

The theme of commitment to caring is noted throughout the interviews. Keeping the family together as a whole, and protecting and keeping safe the ill family member is important to caregivers. Other family members, such as siblings or the father, are also included in assisting with caregiving when the primary caregiver is not available. Chang and Horrocks (2006) describe this as enduring the caregiving process, with an associated meaning of burden to caregivers and the family as a whole. Theme 1 in this study is closely linked to Theme 2 in the caregiver’s statements. There is a desire or willingness to take care and maintain responsibility despite the impact of burden. Caregiving was sometimes shared by other family members when the need arose. This shows the dedication and commitment that was maintained in caring. Similarly two participants did not communicate with the caregivers as a son or husband would do to the mother and wife. This emotional detachment which actually was part of the disease process made the caregivers sad and unhappy but despite this situation caring was maintained without reserve to their own physical health or age. Statements that indicated commitment to care such as:

“Do you feel like you are looking after another child?” [Response] “Yah! It feels like that at times” (Transcript 1: line 274–276).

“No, but I said while we living we’ll take care of her. When we can’t manage then Sister Ann said must come to her.” (Transcript 2: lines 509–510).


“I love my son and I like making and doing things for him and I always ask him if anything wrong, you know what I mean . . .” (Transcript 4: lines 1091–1092).

Maintaining care and doing so willingly, linked with the meaning commitment to care as parents would for a child at home. Also linked with this meaning cluster was when a caregiver who was told in the clinic to consider institutional placement for the MCHU
expressed sadness and a strong sense of commitment to care. A corresponding comment by the doctor that “we can’t let go”, acknowledged the strength of commitment by this particular caregiver to accepting the responsibility to carry on providing care (Transcript 2: lines 371–373). The formulated meaning of all these statements is acknowledgement that caring is part and parcel of parenting whatever the age of the member with mental illness.

A further associated meaning linked to Theme 2, is that a duty to care arises either from bonds of relationship or from cultural and social expectations of appropriate family responsibility. This set of associated meanings seem to relate to caregivers’ behavioural and cognitive strategies for preserving routines that help them tend to the needs of the mentally ill family member. The caregivers were able to endure the situation, despite its problems, because they could otherwise be regarded as failing in their commitment or duty to care.

**Theme 3: Disruption to family life**

At least nine participant statements indicated disruption to family life because of the need for constant vigilance against mishap for the SMI relative where other family members would also be involved should the primary caregiver not be available. Some other family member needed to be at home all the time to care for the SMI relative, Even if the care did not translate to doing anything for the SMI relative, just making sure nothing happened to them constituted a disturbance to the life of the family. The participants had to either take special care or do tasks in advance should they need to leave the individual alone at home.

Participants indicated that often they had to check if the MHCU had completed or remembered what was requested of them. This meant time was wasted in ensuring that he/she has complied with tasks at home. The parental role required of the SMI individual was almost non-existent as the care giver had to take over this task at home. The (2) participants expressed their disappointment that the relative with SMI failed to bring in an income and relied on the parents (caregivers) to provide them with money when needed. Particular note was made of the side effects of medication that caused the SMI to sleep most of the day. This was not understood by the wife who felt that her husband was lazy and shirked his responsibilities. Statements that indicated disruption to the family were:

“I mean I will ask him what he needs for the day because I must do this before I go anywhere, like if he need something you know and yah it just carry on like that” (Transcript 4:lines 1094–1096).
“She stay with her father, yes, and if he go anywhere I look after her”.
(Transcript 2: lines 369 and 372).

“I leave them with their father but it does not bother him. When I get angry it
does not affect him. I scold the children and him and after that feel bad”
(Transcript 2: lines 238–240).

“He’ll be sitting here and I’ll be talking to him but not always listening. . . . No,
like talk to him, takes so many times for him to respond” (Transcript 5: lines
1477 and 1481).

“Not to sleep all the time during the day. Ten minutes after he had his breakfast
he goes to sleep again” (Transcript 1: lines 167- 169)

**Theme 4: Value in contribution to care**

The caregivers felt a sense of worth in caring for the SMI relative at home. Just being able to
do chores that maintain personal hygiene and provide meals implied some worthiness, despite
other factors. The mother of the female SMI relative indicated how she taught her daughter to
do various tasks at home to assist the caregiver. These tasks, though supervised, make them
believe that they could accomplish something despite their illness. Caregivers continued to
maintain a sense of hope that with treatment the mentally ill person would be able to return to
as normal a life as possible. Participants felt proud of some responsibility that was taken over
at home with respect to tasks that they did before. Such activities as doing the shopping with
a list and also providing assistance in the kitchen or making a cup of tea has helped in
providing time for the caregiver.

This kind of reciprocal relationship gave the participants a sense of accomplishment in their
caring experiences, and strong supportive relationships also had the added advantage of
providing the participants with some help in their caring when needed. Two SMI individuals
had been going to the occupational workshop on 2 days a week only in the mornings. They
could do this entirely on their own and the caregivers maintained this as part of normalcy.
However the attendance was closely linked to fear of losing their social grants. In another
situation the caregiver provides money even though she is receiving a pension and her son is
not on a social grant. These statements in which participants expressed value in contributing
to care of the SMI relative are:
“Yah, I’m very happy with his progress, what I’ve seen of him, what he is like now you know, he has progressed very well... like, he can be independent you know, I can leave him because he is responsible, he shows me he’s responsible and he keeps motivated, wanting to do things or helps me” (Transcript 6: lines 1945 and 1950);

“She mostly only set the dishes and she can help me when I fold the clothes, she put the clothes in the draw, like clean the vegetables” (Transcript 2: lines 378–379); He dusts the furniture for me. Sometimes I tell him to sweep, vacuum the floor, he does it for me” (Transcript 3: lines 759 and 763–764).

“He’s so stable at the moment where if I can give him a shopping list and he can go and do the shopping” (Transcript 6: lines 1809–11810).

**Theme 5: Maintaining hope**

Caregivers were positive in their outlook and hopeful that they coped with assistance from the clinic staff. The challenging situations had not deterred them from caring for their loved one at home. Even though the mother had to cope with side-effects of medication and wash her adult daughter’s clothes, placement in a hostel was out of the question. The caregivers were caring and patient with the mentally ill family member with mental illness despite financial or other problems. One care giver alluded to problems with the SMI relative taking drugs but the response indicated that she would still willingly care for her relative. When the participants had established a routine at home it became easier to manage the SMI individuals. The care giving tasks were less disturbing if that routine was maintained. Four of the participants spoke of having to accomplish the morning activities of daily living for the SMI individuals thus implying that their tasks were done for the day. They continued with this practice on a daily basis with hope that their family member with mental illness was just like any other person at home. Going to the workshop, shopping, cleaning the house and helping in the kitchen during meal times were normal behaviours to be proud of. The caregivers positive attitude and support fostered hope for the future. In another interview the caregiver maintained hope by contributing to her son being positive about finding employment despite his illness.

The following statements indicated that participants maintained hope:

“I can still cope” (Transcript 2: line 478).
“I told him to continue applying, looking at the papers. I give him money to buy papers so that he get to look at the vacancies there so he can apply for the jobs like he want which is suitable for him” (Transcript 6: lines 1917–1919).

“I want him to be the way he was before . . . now he is like that, easy to take advantage of him” (Transcript 1: lines 256–257).

“Sister he is a qualified fitter, he was going to complete his course, you know N1 but he just snapped. But he can do, he is just lazy, he tells me he can’t do it but I know he can” (Transcript1: lines 232-234).

**Theme 6: Support and guidance: ongoing assistance**

The participants indicated that they had support and assistance from the community psychiatric services. Several of them confirmed that they could both personally and telephonically reach out for help from the staff at the clinic, who were in turn willing to provide clinical assistance. Mental health education and medical services had given the participants knowledge and information about the effects and side-effects of medication, as was indicated in their responses. Some participants indicated that they would require further assistance in the future from the community psychiatric clinic. This would be more for the possible placement of the SMI relative or to send the SMI relative to a rehabilitation facility. There were also responses referring to management of side-effects which caregivers could discuss with the clinic staff: The following statements indicated support and guidance to the family:

[Q] “Mm, have they given you enough information, have they given you enough information on treatment, diagnosis?” [R] “Yes, after she was in Town Hill hospital” (Transcript 2: lines 645–650);

“Yah the sisters are nice over there, they talk to me and explain to me. I don’t have problem with the sisters but not the doctor. I don’t know him” (Transcript 4: ll. 1207–1208: lines 1224–1225);

“But if there is a problem before 6 months then they let him talk to the doctor, they let us even talk to the doctor” (Transcript 5: lines 1595-1596);
“Then sometimes I contact the clinic sisters that I know, and sometimes phone the doctor who treats him and just to ask her what can I do” (Transcript 6: lines 1824–1825).

On a different note, one caregiver remarked that she preferred the clinic staff to carry out home visits so that her son would be forced to stay at home and not join his friends whom they disapproved of. This comment was linked to the fact that the SMI relative still used substances which the family hoped that the clinic personnel could stop by visiting the home.

“I like someone to do a home visit ’cause he’s not supposed to go out of the house” (Transcript 5: lines 1622–1623).

**Theme 7: Concern over continuity of care**

Participants made reference to lifelong obligations that will have to be carried out for as long as the caregiver is there and is able to maintain them. Questions centered round what would happen if the care giver (participant) was not there to care for the relative. One participant had spoken to the sister in the clinic about this and she was told that she should prepare to have her daughter placed in an institution but they, the parents did not want to do so just yet. The caregivers were in the older adult age group and they felt that the family member with SMI would not be given the same type of care that they provided if they were not around anymore. In one case the mother insisted that other family members would go on to carry out the caring role but this was not spoken of at home with them as yet. There was a time when the clinic staff tried to discuss this situation with the participant but she reassured them that as long as she was able to she would continue to carry out the caring tasks. Many of the participants had physical illnesses that were chronic and their quality of life had slowed down. The researcher found that some participants had not really involved other family members into a discussion of who should take responsibility if they i.e. if the primary caregiver was not there. The following statements show cause to this:

“No, but I said while we living we’ll take care of her. When we can’t manage then Sister Ann said must come to her” (Transcript 2: lines 509–511);

“When I come home I feel very happy, but I’m getting old, I don’t know later stage if I get sick or anything happen to me or whatever, maybe in time I will need someone who can take care of him like, as a mother, how I do it” (Transcript 4: lines 1137–1139).
“Worries me a lot, yes” (Transcript 4: lines. 1136–1138 and line 1142).

“I will need someone who can take care of him like as a mother, how I do it” (Transcript 4: line 1139).

**Theme 8: Fears and difficulties experienced in Caring**

Participants had fears of danger for their loved ones and also that they could be involved in dangerous activities such as use of drugs and alcohol. The statements indicated that they preferred the SMI individuals to remain at home rather than them going out. The participants also tried to restrict them from joining friends or going out with friends. Two SMI individuals were already abusing substances and this was of concern to the parents. Fears of MHCU wandering away from home were very difficult to deal with making the need to keep keys away from her. Fear of burning self, linked to cooking in the middle of the night (making chips) was expressed by one of the caregivers’. Even though this was just one MHCU it was frightful for the family. Having to cope with side effects of medication also is difficult to manage by the family.

Difficulty with some behaviours was mentioned by two participants. The first was linked to anger and destructive behavior and the other was based on needing money to buy drugs. Difficulty with communication was also experienced by the caregivers. This was apparent when the caregivers stated that they did not talk to the family especially the wife, children and the mother. The caregiver had the perception that the husband would assist at home with supervision of the children and possibly help her in their homework. Statements that illustrate these are:

“**He got no time for me**” (Caregiver had tears running down her face as she spoke) (Transcript 2: lines 246–247).

“**Sometimes I get angry because the children will trouble you and he does not help and it’s a bit difficult for me to see to him and the children**” (Transcript 1: lines 106- 107).

“**Yah, she likes chips two o'clock, three o'clock morning. When she wakes up I go see what she’s doing**” (Transcript 2: lines 389–390).

“**Well I fright to leave keys, she can open the door and go away night time and we’ll be left**” (Transcript 2: lines. 445–446).
“Does it worry you about his safety and what could happen to him? [R] “I worry but what can I do, he does not listen to us” (Transcript 5: lines 1452–1455).

“She don’t go when she looks top” (Transcript 2: line 398).

“When he leaves home I get very worried and I’m getting old, I don’t know what’s happening to him, you know, if he goes anywhere” (Transcript 4: lines 1243–1244).

“He get very tired when he comes from there” (Transcript 3: line 781).

“These things affect by making him sleepy from way back and then he is grumpy all the time” (Transcript 3: lines 818–819).

“No he don’t have friends, I don’t allow him to have any friends” (Transcript 4: lines 1248–1249).

**Theme 9: Misuse of social grant**

Financial difficulties arose with caring for the SMI relative at home. The participants indicated that they relied on the social grant for the family as well as the SMI individual. Those who did not have the grant relied on their parents or others at home for money. The money was used for cigarettes, petrol for their cars and also in two cases substance abuse. The older caregivers used their own social grants to assist their SMI relative. This disrupted the family as it put pressure on the caregiver to also cope with the social grant from the SMI relative. The family member with mental illness often took away his money and this added to their problems. If money was not given to the relative with mental illness then disruptive behaviours were bound to occur such as messing up the kitchen, eating all the food and not leaving any for others and shouting at other family members. When limits were placed on such behavior the MHCU would destroy items at home. This behavior resulted only when money i.e. the social grant was not given when demanded. This theme was evident in statements such as:

“He was demanding his money from me and his father” (Transcript 5: line 1391).

“The most difficult thing is when sometimes he used to get like a bit, when he’s not like sometimes he used to have these terrible moods, really like he can become very much like violent not as much but damaging like, you know he will
destroy something he had. His brother gave him a cell phone he destroyed that phone and he became aggressive in the sense of violence, not hitting anybody never, but damaging things only” (Transcript 6: lines.1833-1839).

“So financially it is a problem for you to refuse him money?” [R] “Yes” (Transcript 5: lines 1410-1412).

The themes with the significant statements are shown in Tables 4.3.

4.3 Exhaustive description of the phenomenon

In this stage of the data analysis, following Creswell (2007), the researcher collated and linked the issues that emerged from the data collection to compile an exhaustive description of phenomena relating to psychiatric nursing practice in Northdale. Many of the participants, who are from a lower income group, revealed their sincerity in genuinely caring for the person with mental illness through caring behaviours such as ensuring personal hygiene and nutrition. Their pride in the caregiving can be seen as an important part of their values and beliefs. This is a reflection of the mental state examination for any patient who could be visited at home at any given time.

Several caregiver responses indicated that they felt a need for more input from the clinical psychiatric staff on the side-effects of medication, in particular acute dystonic reactions: [Q] “Do you think you need more information to get to manage him at home?” [R] “Not to manage him. The thing is that he sleeps too much” (Transcript 1: ll. 162–165); “I want him to take Bioplus. Isn’t it is good for him he won’t sleep so much, or are there any other vitamins that we can him” (Transcript 2:96–298); “She don’t go when she looks top, she look top every week, even last night she don’t eat when she look top” (Transcript 2: ll. 402–403). Another participant had this to say about tiredness and weakness experienced by the SMI relative: “and I got something for energy and strength for him to drink” (Transcript 3: l. 884). When the researcher queried the need for the health drink – [Q] “Why is he experiencing low energy, was he feeling weak and stiff previously?” – the response was, [R] “Yes, he said he feels weak” (Transcript 3: ll. 898,901). Participants would therefore benefit from more information on the possible side-effects of medication.
Caregiver statements also mentioned a need for more intervention with possible psychosocial rehabilitation and job coaching: [Q] “Just to go back to my question with you, can you remember, is there anything else you would like the clinic to help you with your son in the future?” [R] “When it comes to the future I need to, you know, what I . . . maybe something to learn, a skill maybe?” (Transcript 3: ll. 1031 -1033). Another participant said, “I like someone to do a home visit ’cause he’s not supposed to go out of the house” (Transcript 5: ll. 1622–1623). “Well at the moment now you, I don’t know for him to get a job because at the moment you see he’s been applying for jobs, now he is not getting any replies like any respond from them”(Transcript 6: ll. 105–1007)

There were some benefits alluded to in caring for the mentally ill family member. This was because there was continuity of care within the family, and family members appreciated their relative being at home in other ways. “Father talks to her more than he talks to me” (Transcript 1: line143); “Sometimes I tell him to sweep, vacuum the floor, he does it for me” and when this was checked out by the researcher, [Q] “So he is not upset that he has to do this every day?” the reply was [R] “No not upsetting” (Transcript 3: ll. 763–768). Another participant explained that her son spends time with her and assists her by driving her to do her shopping, and it seemed to give great pleasure that he had progressed to this level: “Yah, I’m very happy with his progress, what I’ve seen of him, what he is like now, you know, he has progressed very well. I mean he took something like six months like, you know, to reach this point now where he is, like, he can be independent you know. I can leave him because he is responsible, he shows me he’s responsible and he keeps motivated, wanting to do things or helps me” (Transcript 6: ll. 1945–1951).

4.4 Summary

Following Creswell (2007), Colaizzi’s six-stage method of data analysis and interpretation was used in this analysis of the researcher’s data. The understanding of the care provided by the caregivers to their family member with mental illness was interpreted from their experiences and behaviours. They understood care as providing basic supervision, support, and guidance with personal hygiene and nutrition. They indicated further how they had been able to include the SMI relative in the daily schedule of their lives with simple tasks and activities. In so doing, they seemed to meet the needs of the individual and their own caring
responsibilities. They indicated some need for intervention from the community psychiatric nurses and at the same time expressed their gratitude for the assistance, support, and willingness to help on the part of the staff.

### 4.5 Conclusion

In this chapter the researcher concluded the data analysis and presented the themes that emerged from the data. The next chapter will present the discussion of the themes, reflexivity and the recommendations.
Table 4.2 Significant statements and their location in the transcripts

<table>
<thead>
<tr>
<th>Statements</th>
<th>Location in transcripts</th>
</tr>
</thead>
<tbody>
<tr>
<td>OK, I do cook for him I make sure that he eats healthy. I make tea for him and I . . .</td>
<td>Transcrip 4: ll. 1078–1079</td>
</tr>
<tr>
<td>I also take care in other ways that he must have a bath, he must shave, he must have a haircut, and he must be neat and tidy.</td>
<td>Transcript 4: 1086–1087</td>
</tr>
<tr>
<td>We give him food, we wash clothes we see that he’s neat.</td>
<td>Transcript 5: ll. 1325–1336</td>
</tr>
<tr>
<td>I do quite a few things for him because he lives with me. I like to make sure that I cook his meals and he has proper meals.</td>
<td>Transcript 6: ll. 1695–1705</td>
</tr>
<tr>
<td>Do you feel like you are looking after another child? Yah! It feels like that at times.</td>
<td>Transcript 1: ll. 274–276</td>
</tr>
<tr>
<td>Well I fright to leave keys, She can open the door and go away night time and we ‘ll be left.</td>
<td>Transcript 2: ll. 444–445</td>
</tr>
<tr>
<td>When he leaves home I get very worried and I ‘m getting old, I don’t know what’s happening to him, you know, if he goes anywhere.</td>
<td>Transcript 4: ll. 1243–1244</td>
</tr>
<tr>
<td>Does it worry you about his safety and what could happen to him? I worry but what can I do he does not listen to us.</td>
<td>Transcript 5: ll. 1452–1455</td>
</tr>
<tr>
<td>But she likes chips in the night. Sometimes I’m fast asleep. She’s in the kitchen, she making chips. Yah, she likes chips two o’clock, Three o’clock morning. When she wake up and I go see what she’s doing.</td>
<td>Transcript 2: ll. 384–385 and 389–390</td>
</tr>
<tr>
<td>Sometimes I get angry because the children will trouble you and he does not help and it’s a bit difficult for me to see to him and the children.</td>
<td>Transcript 1: ll. 106–107</td>
</tr>
<tr>
<td>Not to sleep all the time during the day. Ten minutes after he had his breakfast he goes to sleep again.</td>
<td>Transcript 1: ll. 167–169</td>
</tr>
<tr>
<td>But she don’t do things for herself, Oh I feel sad. Doctor said we can’t let go.</td>
<td>Transcript 2: ll. 498 and 503</td>
</tr>
<tr>
<td>No extra company, because he does not talk.</td>
<td>Transcript 3: l. 771</td>
</tr>
<tr>
<td>He got no time for me. (Caregiver had tears running down her face as she spoke).</td>
<td>Transcript 1: ll. 246–247</td>
</tr>
<tr>
<td>No, we manage somehow, my in-laws help also.</td>
<td>Transcript1: ll. 195</td>
</tr>
<tr>
<td>Financially it is difficult but we are coping what else can we do?</td>
<td>Transcript 3: ll. 928–929</td>
</tr>
<tr>
<td>Statements</td>
<td>Location in transcripts</td>
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<tr>
<td>---------------------------------------------------------------------------</td>
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<tr>
<td>I don’t know later stage if I get sick or anything happen to me or</td>
<td>Transcript 4: ll. 1136–1138, and</td>
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<tr>
<td>whatever maybe in time.</td>
<td>l. 1142</td>
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<tr>
<td>I will need someone who can take care of him like as a mother, how</td>
<td></td>
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<tr>
<td>I do it.</td>
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<td>Worries me a lot, yes.</td>
<td></td>
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<tr>
<td>I find it very hard because we have to manage with everything.</td>
<td>Transcript 4: Line 1158</td>
</tr>
<tr>
<td>I mean we don’t have anything. Best part is at least we have food on</td>
<td>Lines1188–1189</td>
</tr>
<tr>
<td>our table.</td>
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<tr>
<td>No he don’t have friends, I don’t allow him to have any friends.</td>
<td>Transcript 4: ll. 1248–1249</td>
</tr>
<tr>
<td>Yah, when it is cold he puts the heater on, we sit and watch TV and</td>
<td>Transcript 4: ll. 1235–1236; 1240–</td>
</tr>
<tr>
<td>now he stays at home in the holidays. . . . if I just tell him like</td>
<td>1241</td>
</tr>
<tr>
<td>certain things to be done or the dirt bin has to be taken out on the</td>
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<tr>
<td>road he does all.</td>
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<tr>
<td>When he is well he can come and talk to you.</td>
<td>Transcript 6: ll. 1795–1795</td>
</tr>
<tr>
<td>And he find out what you need and what he can do to help me.</td>
<td></td>
</tr>
<tr>
<td>The most difficult thing is when sometimes he used to get like a bit,</td>
<td>Transcript 6: ll. 1831–1834</td>
</tr>
<tr>
<td>when he’s not like sometimes he used to have these terrible moods,</td>
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<tr>
<td>really like he can become very much like violent, not as much but</td>
<td></td>
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<tr>
<td>damaging like, you know he will destroy something he had.</td>
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</tr>
<tr>
<td>He goes and does shopping for her, she tells him what he must buy</td>
<td>Transcript 6: ll. 1806–1809</td>
</tr>
<tr>
<td>you know, all that and he goes and get it for her and um he’s so</td>
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<tr>
<td>stable at the moment where if I can give him a shopping list and he</td>
<td></td>
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<tr>
<td>can go and do the shopping.</td>
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<tr>
<td>So you’ve been looking after him, and financially how has that been</td>
<td>Transcript 6: ll. 1734–1737</td>
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<tr>
<td>for you?</td>
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<tr>
<td>A little bit difficult.</td>
<td></td>
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<tr>
<td>Financial problems.</td>
<td>Transcript 5: ll. 1386 and1390</td>
</tr>
<tr>
<td>He was demanding his money from me and his father.</td>
<td></td>
</tr>
<tr>
<td>I am quite comfortable taking care of him.</td>
<td>Transcript 3: Line 846</td>
</tr>
<tr>
<td>No but I said while we living we’ll take care of her. When we can’t</td>
<td>Transcript 2: ll. 508–509</td>
</tr>
<tr>
<td>manage then Sister Ann said we must come to her.</td>
<td></td>
</tr>
<tr>
<td>I love my son and I like making and doing things for him and I</td>
<td>Transcript 4: ll. 1091–1092</td>
</tr>
<tr>
<td>always ask him if anything wrong you know what I mean . . .</td>
<td></td>
</tr>
<tr>
<td>He helps me, with sometimes washing of the dishes you know, helps</td>
<td>Transcript 6: ll. 1720–1723</td>
</tr>
<tr>
<td>me with packing the dishes away and also when he’s well, he also</td>
<td></td>
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<tr>
<td>vacuums the house.</td>
<td></td>
</tr>
<tr>
<td>Statements</td>
<td>Location in transcripts</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------</td>
</tr>
<tr>
<td>Like at least you know that during the day or the evening always there is somebody at home with him you know, and I always like that, you know.</td>
<td>Transcript 6: ll. 1793–1794</td>
</tr>
<tr>
<td>She’ll walk up and down, up and down. Then I give her something to drink, when I go to bed then she goes to bed.</td>
<td>Transcript 2: ll. 402–404</td>
</tr>
<tr>
<td>Yah, that because maids don’t do that I. I have to rinse it, put surf, soap and wash her clothes. It’s every month.</td>
<td>Transcript 2: ll. 616–617</td>
</tr>
<tr>
<td>He does not do much. I want him to . . . Before he used to do so much, he used to make the burglar guards, he was a qualified fitter. All this he put . . . (points to windows).</td>
<td>Transcript 1: ll. 69–71</td>
</tr>
<tr>
<td>Yah! When he was hospitalised, Dr. Asmal, he asked for me to be there. Whenever they changed his treatment he asked me to come in and he discussed it with both of us. Also he had an intern Dr. Vather who also included me when he saw my husband.</td>
<td>Transcript 1: ll. 157–160</td>
</tr>
<tr>
<td>Mm, have they given you enough information, have they given you enough information on treatment, diagnosis? - Yes, after she was in Town Hill hospital.</td>
<td>Transcript 2: ll. 645 -650</td>
</tr>
<tr>
<td>Yah, the sisters are nice over there, they talk to me and explain to me. I don’t have problem with the sisters but not the doctor. I don’t know him.</td>
<td>Transcript 4: ll. 1207–1208</td>
</tr>
<tr>
<td>Yes they did tell me, that he has to take his medication every night.</td>
<td>Lines 1224–1225</td>
</tr>
<tr>
<td>But if there is a problem before 6 months then they let him talk to the doctor, they let us even talk to the doctor.</td>
<td>Transcript 5: ll. 1595–1596</td>
</tr>
<tr>
<td>He sees the Sister there, the sisters are very good there, He goes and get his card out he sees one of the sisters there, Sister Anne and Sister Vani, one of them is always there.</td>
<td>Transcript 6: ll. 1759–1761</td>
</tr>
<tr>
<td>Then sometimes I contact the clinic sisters that I know, and sometimes phone the doctor who treats him and just to ask her what I can do,</td>
<td>Transcript 6: ll. 1824–1825</td>
</tr>
<tr>
<td>Theme</td>
<td>Associated Significant Statements</td>
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</tbody>
</table>
| **Family as a support structure** | “I do quite a few things for him because he lives with me. I like to make sure that I cook his meals and he has proper meals (Transcript 6: ll. 1695–1705).”  
“Yah, that because maids don’t do that. I have to rinse it, put surf, soap and wash her clothes. It’s every month” (Transcript 2: ll. 616–617).  
“No, you have to tell him to do it. When he needs a bath, you got to take out clean clothes for him to change. He won’t take out clean clothes I have to do it.” (Transcript 1: ll. 94–96).  
“Do you feel like you are looking after another child” “? (Transcript 1: ll. 274–276). |
| **Commitment to care**         | “No but I said while we living we’ll take care of her. When we can’t manage then Sister Ann said must come to her “ (Transcript 2: ll. 509–510)  
[Q]”Do you feel sometimes it is just too much for you” with response “Never. No I cope Sister” (Transcript 2: ll. 579–581).  
“We can’t let go” (Transcript 2: l. 504)  
“and when I come home I feel very happy but I’m getting old, I don’t know later stage if I get sick or anything happen to me or whatever maybe in time I will need someone who can take care of him like as a mother, how I do it”(Transcript 4: ll. 1137–1139).  
“I will need someone who can take care of him like as a mother, how I do it” (Transcript 4: line 1139. |
| **Disruption to family life**  | She stay with her father. Yes and if he go anywhere I look after her” (Transcript 2: ll. 369 and 372).  
“ ‘I mean I will ask him what he needs for the day because I must do this before I go anywhere, like if he need something you know and yah it just carry on like that “.  
(Transcript 4: ll. 1094–1096)  
“I leave them with their father but it does not bother him. When I get angry it does not affect him. I scold the children and him and after that I feel bad” (Transcript 2: ll. 238–240).  
“I want him to be the way he was before . . . now he is like that, easy to take advantage of him “ (Transcript 1: ll. 256–257).  
“No extra company, because he does not talk” (Transcript 3: l. 772)  
“He’ll be sitting here and he’ll be talking to you but not always listening. No, like talk to him, takes so many times for him to respond” (Transcript 5: ll. 1477 and 1481). |
<table>
<thead>
<tr>
<th>Theme</th>
<th>Associated Significant Statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Value in contributing to care</td>
<td>“I told him to continue applying, looking at the papers. I give him money to buy papers so that he get to look at the vacancies there so he can apply for the jobs like he want which is suitable for him” (Transcript 6: ll. 1917–1919). “Yah, I’m very happy with his progress, what I’ve seen of him what he is like now you know, he has progressed very well”, like, he can be independent you know, I can leave him because he is responsible he shows me he’s responsible and the he keeps motivated, wanting to do things or helps me” (Transcript 6: ll. 1945 and 1950). “She mostly only set the dishes and she can help me when I fold the clothes, she put the clothes in the draw, like clean the vegetables” (Transcript 2: ll. 378–379). He dusts the furniture for me, Sometimes I tell him to sweep, vacuum the floor, he does it for me” (Transcript 3: ll. 759 and 763–764). “he’s so stable at the moment where if I can give him a shopping list and he can go and do the shopping” (Transcript 6: ll. 1809 –11810).</td>
</tr>
<tr>
<td>Maintaining hope</td>
<td>“I am quite comfortable taking care of him” (Transcript 3: l. 847). “but I was missing him a lot, but now I’m happy that he’s at home and when I come home I feel very happy” (Transcript 4: ll. 1136–1137). “But he can do, he is just lazy, he tells me he can’t do it but I know he can” (Transcript 2: ll. 232–233). “I can still cope” (Transcript 2: l. 478); “I love my son and I like making and doing things for him” (Transcript 4: ll. 1092–1093).</td>
</tr>
<tr>
<td>Support and guidance: ongoing assistance</td>
<td>“Mm, have they given you enough information on treatment, diagnosis?” “Yes, after she was in Town Hill hospital” (transcript 2: ll. 645–650); “Yah the sisters are nice over there they talk to me and explain to me. I don’t have problem with the sisters but not the doctor. I don’t know him” (Transcript 4: ll. 1207–1208); “But if there is a problem before 6 months then they let him talk to the doctor, they let us even talk to the doctor” (Transcript 5: ll. 1595- 1596); “Then sometimes I contact the clinic sisters that I know, and sometimes phone the doctor who treats him and just to ask her what can I do” (Transcript 6: ll. 1824- 1825). “he get very tired when he comes from there” (Transcript 3: l. 781); “I like someone to do a home visit cause he’s not supposed to go out of the house” (Transcript 5: ll. 1622–1623).</td>
</tr>
<tr>
<td>Theme</td>
<td>Associated Significant Statements</td>
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</tbody>
</table>
| Concern over continuity of care                 | “I don’t know later stage if I get sick or anything happen to me or whatever maybe in time I will need someone who can take care of him like as a mother, how I do it. Worries me a lot, yes” (Transcript 4: ll. 1136–1138).  
“OK, so if anything happens to you so they will take responsibility for their brother. Yah” (Transcript 5: ll. 1658–1659)  
“No but I said while we living we’ll take care of her. When we can’t manage then Sister Ann said must come to her” (Transcript 2: ll. 509–511).  
“I will need someone who can take care of him like as a mother, how I do it” (Transcript 4: line 1139).                                                                 |
| Fears and difficulties experienced in caring    | “these things effect by making him sleepy from way back and then he is grumpy all the time” (Transcript 3: l. 818–819).  
“One to sleep all the time during the day. Ten minutes after he had his breakfast he goes to sleep again” (Transcript 1: ll. 167- 169);  
“When he leaves home I get very worried and I ‘m getting old, I don’t know what’s happening to him, you know, if he goes anywhere” (Transcript 4: ll. 1243–1244)  
“She don’t go when she looks top” (Transcript 2: l. 398)  
“No he don’t have friends, I don’t allow him to have any friends” (Transcript 4: ll. 1248–1249)  
Yah, she likes chips 2’o clock, 3’o clock morning. When she wake up I go see what she’s doing’ (Transcript 2: ll. 389 -390)  
“Does it worry you about his safety and what could happen to him? I worry but what can I do he does not listen to us” (Transcript 5: ll. 1452- 1455).  
“Sometimes I get angry because the children will trouble you and he does not help and it’s a bit difficult for me to see to him and the children (Transcript 1: ll. 106–107).  
“He got no time for me” (Transcript 2: l. 246–247).  
Well I fright to leave keys, she can open the door and go away night time and we’ll be left” (Transcript 2: ll. 445–446). |
| Misuse of Social Grants                         | “He was demanding his money from me and his father” (Transcript 5: l. 1391).  
[Q]”So you’ve been looking after him, and financially how has that been for you?”  
“Financially it is difficult but we are coping what else can we do?”(Transcript3: ll.928-929).  
“I find it very hard because we have to manage with everything. I mean we don’t have anything. Best part is at least we have food on our table”.(Transcript 4: ll. 1158 and 1188-1189). |
Chapter 5
Discussion, recommendations and summary

5.1 Introduction

In this chapter the researcher summarises the essential experiences of caregiving by the family from the analysis data and then discusses the caregivers’ experiences in relation to the study. During the bracketing process the researcher encountered some issues which are included under “reflexivity”. Limitations in the study are included, and recommendations for psychiatric nursing practice and education, followed by summary and conclusion.

5.2 Experiences of caregiving

The central question for this study is “How is caring experienced by caregivers for a mentally ill family member in the home in the Northdale suburb of Pietermaritzburg?” The participants regarded caregiving as being able to manage and maintain the mentally ill family member within the family, focusing on provision of nurturing, nourishment, personal hygiene, and safety and security. These are closely linked to providing support and supervision of medication use, and scheduled visits to the community clinics to manage the condition. They described caregiving as physically “doing things/tasks” for the MHCU, such as preparing their meals and seeing to their personal hygiene. The aspect of “doing”, though physical in nature, seems to provide a great deal of satisfaction and pleasure in accomplishment for the caregiver. According to Uys and Middleton (2004), the family was identified as the primary site of ongoing care in the community. The Mental Health Care Act No. 17 of 2002 has supported this view, which seems to be implemented successfully by the mental health services.
Consideration of the themes in this study has provided the researcher with the opportunity to determine the impact of caregiving for the caregiver, the MHCU, and the community psychiatric services professional team. Caring appeared to be a daily part of the caregiver’s life, taking responsibility to oversee the different activities of daily living. The study highlights the stabilising influence of the services of nursing staff from the clinics. The studies by Sethabouppha and Kane (2005) indicated a need for health providers to be more sensitive to the consequences in managing the clients at home, including more provision of knowledge on problem behaviours and relapse symptoms. In the study by Intagliata, Willer, and Egri (1986) the findings indicated that families played a positive role in the treatment process. Protection and support for biological and environmental vulnerability was and the study results also indicated reduction in readmission rates. Caregivers treated the MHCU with compassion, love, and support.

Experiences of maintaining the responsibility of caring had a personal bearing on caregivers’ abilities to successfully “look after the SMI”, and their accomplishments in shouldering the burden of care increased their sense of self and worth, in that they would not “lose face” with the other family members, community and the mental health team. Chang and Horrocks (2006) indicate that this ensured that they managed to endure and successfully survive the day-to-day experiences of caregiving. As long as the family member looked well-groomed and behaved himself/herself in the acceptable manner in social settings then all was well for the family as a whole, with little attention to any dysfunction.

The caregivers indicate that, in their caring, responsibility for the family member is ultimately theirs and that the caring has to be done no matter how long the caregiving continues. Sethabouppha and Kane (2005) refer to acceptance of the situation by the caregivers which made it easier for them to continue with the day-to-day tasks. This could emanate from cultural values and probably religious background where caring is expected from the family caregiver, and in particular the mother or mother figure. Acceptance of responsibility resulted in positive attitudes that reflect contentment, satisfaction, and genuine comfort in knowing that their family member with mental illness is okay for each day. This seemed to provide a deep connexion between caregiver and the family member, irrespective of problems experienced in caring (Murray-Swank, 2007).
The participants spoke of their caring as though MHCUs were children who needed to have tasks completed for them (Milliken, 2003). A physical and emotional dependency developed between the caregiver and the ill family member, with a strong need for sustainability and commitment. Families did not have a particular or defined role to play in supporting the caregiver when it meant direct supervision (Endrawes et al., 2007). Having to accept their role in caring meant some tolerance of deviant behaviour was acceptable, just as with children. On the other hand, it could be part of the practical burden which gave the caregiver the opportunity to access the social grant of the MHCU for use at home. This would justify the caring for the MHCU as a child at home. The caring given by the caregiver and the nature of such caring created apprehension for the future should they not be around anymore. Caregiving was provided despite the caregiver’s age and physical health. The older the caregiver, the greater were their fears for the future about who would continue such caring. Chronic conditions with substance abuse in the case of two of the mentally ill family members made it more stressful to provide care for them (Nemecek, in Mphelane, 2006).

Caregiving tasks such as helping the MHCU to bath and shave were seen by caregivers as an important aspect of their daily routine. The aspect of caring that emerged from their responses as an important element in their relationship with the family member. Humility, responsibility, and calm, logical thinking proved that they could provide for and care for the mentally ill at home. This was seen with five of the six participants, with one exception where the participant did indicate that the SMI relative was a burden to her and to her family and did not want him at home. In a follow-up visit to the same participant there seemed, however, to be mixed messages, indicating a problem with not being able to get the South African Police Service to intervene to take him for admission to the district hospital despite having a court order restraining him from intimidating or threatening the family at home. The caregiver was told that her intervention approach should be “tough love”, but she could not follow through. She felt that if the clinic staff and doctor could talk to her son he would listen and comply with good behaviour at home. But this would not happen, because he refused to meet with them, and would run away from home if and when the staff of the clinic ever visited. The caregiver indicated a subjective burden of great anxiety, hoping that the professional team could help her but being told that the solution lay in her own hands. She experienced feelings of hopelessness, loss, worry and shame with the family member.
(Mphelane, 2006; O’Brien, 2001). It was evident that the caregiver did not want to break the relationship with her son or be seen as a bad parent who does not care. She was angry with her situation and the position she found herself in but felt ashamed to divulge such feelings as a parent (Rose et al. 2006).

The participants relied predominantly on support and guidance from the clinic professional mental health team. Problem solving, especially with behaviour problems, was referred to the clinic staff so that decisions could be implemented by the caregiver with the support of the mental health team. Non-compliance by the client was then dealt with by the health team rather than by the caregiver who did not want to break the caring relationship with the MHCU. In this way harmonious relationships and peace within the home were ensured. What participants needed from the clinic, according to what they indicated, was help with management of perceived crisis situations, like getting the ill relative involved in tasks at home, excessive daytime sleeping, getting the MHCU to communicate with the rest of the family and express his/her emotions and needs, or putting a stop to substance abuse and the associated disturbing behaviours. The participants felt they were not able cope with these behaviours and that clinic staff should provide home visits more often so that the MCHU would fear them or view them as persons of authority to whom he or she was answerable.

Caregiver statements also revealed a degree of stress experienced by the caregivers despite coping strategies they have developed over the years. Stressful aspects include safety and security, influences of bad company, and financial burdens. In the study by Chang and Horrocks (2006) caregivers expressed their thoughts about what would happen should they no longer be there to care for the family member. Provision for future care was seen as a subjective burden by the caregiver but this was not discussed with other family members so that a way forward could be mapped. The researcher got the impression that by voicing these concerns one or other close family member would step up and indicate their intention to continue. Financial burdens were shared with those who had some income within the home, and for short intervals the MHCU worked in part-time jobs. Social grants were also shared for food, clothes, toiletries, and payment of lights and rent. Ostman (2004), too, refers to demands on the caregiver’s time (practical burden), which occurred, he suggests, because there was no boundary to caring. In the present study it was also evident that the caregivers
ensure the safety and security of the MCHU, which would also lessen the exhaustion and burnout they experience.

Participants expressed approval of interventions by the registered nurses from the mental health clinic and confidence in the advice and assistance they provided. Evavold (2003) refers to a mutual trust and unwritten partnership between caregiver families and health care team members which encourages families to accept the MHCU into the home by provided the carers with the necessary information and a course of action that will meet their needs and allow them to make informed decisions. The staff of the Northdale clinic achieve this with the family caregivers, giving them the requisite information and advice they for managing daily needs, medication compliance and follow-up treatments at the clinic. The group that was interviewed by the researcher were in a lower income category and their simplicity, acceptance and humility was evident throughout because they neither demanded for, nor expected anything more from the mental health team. This could also be linked to the cultural behaviour associated with how the family views the doctor, whose words are final, unchallenged, and based on only what you need to know.

In this study there could have been more focus on psycho-education and aspects of general care including psycho-pharmacology. What was of note, however, were statements by caregivers that the MCHU seldom or never had spontaneous conversation or verbally communication with other in the family. Three participants indicated that the MCHU did not talk to them, and over the years seemed to get quieter. This was a symptom of progression in the illness which they had evidently not been told about; hence their mention of it to the researcher. One participant who was most distressed by this was the wife who felt unloved and under-appreciated by her husband. The family was not aware this was a symptom of the illness and felt isolated and under-appreciated by the SMI relative. The SMI relative failed to show any expression or feelings to their caregivers with the result that they used mental and behavioural disengagement and denial (Howard, 1994). Such aspects could be better managed and understood if explained to the caregivers by the professional staff.

The study also showed a need for caregivers to be given a better understanding of the possible effects of medication, such as excessive drowsiness which could disrupt a client’s daily activities and capacity for interaction with the family. Another issue was how to
manage the needs of the MCHU with regard to menstruation and personal care, which the caregiver communicated to the researcher without any embarrassment. Studies by Burns (2004) and Yen and Wilbraham (2003) indicate that these are issues that can present difficulties in caregiving. The caregiver may resent the responsibility associated with caregiving. Emotional and physical care seems so closely linked, but the researcher formed the impression that the caregivers preferred to focus on the physical aspects of their caregiving rather than the emotional aspects.

Commitment to caring by the caregivers was illustrated in daily activities of supervising hygiene, nutrition, and medication, along with cooking for the relative and getting him or her to stop any bad behaviour. Often they had to contend with an MCHU either not wanting to eat or eating too much (when under influence of substances such as dagga), or with embarrassing manipulative behaviour or refusal to communicate. Feelings of frustration arose but seldom provoked anger because over time the caregivers had found a way to cope with the situation (either smoking or detachment and ignoring the situation). Studies by Chang and Horrocks (2006) and Mphelane (2006) emphasise the frustration family caregivers expressed with a client’s inactivity, sleeping during the day, and inability to perform household. Karp (2000) refers to emotional coping strategies used by the caregivers. In this study the researcher found the participants used smoking or detachment and ignoring of the situation as a means to cope with the situation.

The findings from literature and those expressed in this study coincide as to be both negative and positive impacts of caregiving on the carer and on the MHCU. It is evident that management of care at home by the primary caregiver is fundamental to maintaining psychosocial rehabilitation and reducing relapse. In relation to personal supervision of nutrition and day-to-day management of the MHCU, the findings indicated a partnership that strongly influenced the process of care. The common thread seemed to be the dependence of the MHCU on the family, including the use of the social grant for the home. Allowing the MHCU to be independent and take responsibility for own care was expressed on a minimum level. Empowering the MHCU to take on specific tasks and duties for himself or herself would have meant less subjective, objective, and practical burden on the caregiver (Mays & Lund, 1999). Only two of the six participants indicated that the MHCU attended occupational therapy for approximately five hours a day, excluding weekends.
Some limiting factors centred on lack of knowledge about symptoms of the illness and the effects of the medication by the caregivers. The participants could have benefited from better information that would give them a more realistic understanding of caregiving, rather than having expectations that could not be met. Martins and Addington (2001) and Ostman (2004) indicated that increased insight into the condition would mean reduced personal anxiety and distress with better coping resources in caregiving activities. Participants fears of what would become of the family member when they were no longer available to provide care was viewed as a limiting factor. The researcher gave particular attention to this point, because it is a very real problem for many caregivers that could deter families from taking on the responsibility for the SMI relative.

The caregivers faced some challenges which they were dealing with as best as they could. These were the challenge of continuity of care and fears and difficulties faced in caring. They did not approach the clinic staff with some of these problems such as fears experienced and misuse of social grants as it may have resulted in the social grant being stopped by the doctor in the future. The need for concern over continuity of care was always at the back of their minds but no plans were made for this. During the subsequent visit the researcher had made some recommendations (see 5.4) that the caregiver should approach the sister at the clinic for support and assistance with their problems.

5.3 Researcher reflexivity and limitations

Reflexivity in qualitative studies refers to critical self-reflection about the researcher’s own biases, preferences and preconceptions (Polit & Beck, 2008). On a personal level, the researcher immersed herself in the study, and her own opinions and thoughts often emerged in wanting to help the participants, with the result that on occasions she had to stop herself from intervening in problem situations or in instances when her feelings started to overshadow her interview. This aspect was difficult for the researcher – having to remain detached from emotional involvement with the participants.

Reflections on observations in the interviews enabled the researcher to attach meaning to the expressions, behaviour, and emotions of the participants. Having to make sense of deep
feelings of isolation, loss, and duty to care expressed by the participants, sometimes with tears streaming down their face, made me aware of what it truly meant to care for someone with SMI at home. The tones of feeling expressed when stating certain points, such as not wanting the MHCU in the home ever again, indicated desperation and anguish because of substance abuse by the client. The financial burdens often overshadowed the experiences of caregiving. On a personal level, emotional involvement became evident in the way three participants expressed their desperation at having no food and no money for rent, school fees and transport. Discovering this made it opportune, after consultation with the research supervisor, to get their permission to refer them to NGOs which could assist them.

Reflexivity provided insight on the methodological aspects of the study. The researcher found that audiotaped interviews were the best method of obtaining the data, but for subsequent studies the researcher should specify that other people should not be in the same room when the recorder is switched on. On a few occasions there was noise, interruption from other family members, or invitation to another family member to validate what the participant had just said. In follow-up meetings with participants to confirm concluding themes (establishing credibility for the study), they were more open about their experiences than initially. The researcher initially perceived them as guarded in their approach in case they were being checked on and could lose the social grant. The change in subsequent meetings made the researcher realise that a positive relationship had developed and trust had been established. The recorded dialogue between the researcher and the participant should have made more use of open-ended questions. Probing questions helped to keep the interview focused and elicit more significant data. Two participants exhibited a degree of suspicion about being interviewed when they wanted to see the probe questions before we started the audiotaping. Participants were fairly honest in their responses to questions asked by the researcher. The interaction with the researcher seemed to give them an opportunity to share their experiences, thoughts and feelings openly with some very personal data.

Difficulties that were experienced such as problem behaviours could be reduced by team approach from the clinic professional team. Constant monitoring and evaluation of the situation may decrease the behaviours that had put pressure on the care givers and their caring roles.
Support for the families could be provided by active involvement in support groups (Uys & Middleton, 2004). Families can share information, support each other, promote a sense of belonging, listen to experiences and also foster and develop coping strategies. The caregivers would then not feel that they are alone with the problems but have the knowledge others face similar situations especially for participant in interview no six.

Prior to the research I had believed that families needed to be more interactive in the recovery process and psychosocial rehabilitation of the MHCU at home. After the data collection I realised why this would be difficult for caregivers, since the emphasis in the community clinics has more to do with the day-to-day activities of the MHCU, nutrition and hydration, and shelter and safety. Ultimately, the best intervention is just having the SMI relative at home rather than prolonged institutionalisation. Families should be acknowledged for the ceaseless task of caring, especially the primary caregiver who often experiences physical illnesses as well. I think that nursing sisters can do more to support the caregiver by spending a few minutes talking to them when they accompany their family member to the clinic. Unfortunately Pietermaritzburg does not have a support group for schizophrenic patients and has not been successful in hosting local PHRENAID groups which could have been of tremendous support to the family. Hence the coping impacted on the psychological well-being of the caregiver, resulting in some negative defence mechanisms.

The purposive sample, though appropriate for the study did not provide the researcher opportunity to obtain data from a different group, such as male caregivers, or caregivers from a different socioeconomic category. My initial perception was that, being in the community, the MHCU is able to do most things for himself or herself, but analysis of the results showed that these female caregivers mothered the MHCU, keeping them in the role of sick patient, and this pattern included the one participant who was the wife of the MHCU. In the study by Mays and Lund (1999), the participants were the husbands of the SMI person, and reference is made to the caregiving role as largely a parental or female nurturing endeavour. With men there was minimal emotional pain, as seen by the researcher in her study.

The process of transcription of the audiotapes was time-consuming and difficult. It was therefore typed twice manually by me and provided opportunity to get to understand the data better second time around.
The researcher found that saturation was reached very early in the data collection. This could have been because the researcher asked leading questions that invited the responses given by the participants. Often the style of questioning where the researcher had to either repeat or rephrase the question in a simpler way (e.g., “did you cook for him; wash his clothes . . .?”) may have been responsible for saturation being reached following just four interviews. This may have limited the data.

### 5.4 Recommendations

In this study the research findings from the phenomenological experiences of caregiving by caregivers at home is consistent with other research conducted in this mental health setting (Chang & Horrocks, 2006; Mays & Lund, 1999; Mphelane, 2006; Sethabouppha & Kane, 2005). The study provides a base of information which those interested in community psychiatric nursing can draw on, and which could be extended by further research into caregivers’ experience of psychosocial, physical, emotional, and financial management concerns for ongoing empowerment of caregiving in the family home.

Future research might explore the current supportive programmes available in the community for the families and caregivers of mentally ill family members. Society is changing in that roles in caring are broader than just parents and mothers. A new paradigm in keeping with societal change and its impact would provide a framework to caregivers emphasising the psychosocial rehabilitation of the SMI individual.

The shift in the integration of mental health nursing into primary health care and the implementation of the 72-hour assessment period (Mental Health Care Act, 2002) will strengthen the need for care at home of SMI clients. Clinical nursing practice therefore needs to focus on expanding care to include the client and the caregiver. Case-based community nursing management (Uys & Middleton, 2010) would be the current practice that could include the caregiver and the whole family should the need arise. The community psychiatric nurse can play a vital role in augmenting management strategies in the home with more understanding of the problems and situations experienced on a day-to-day basis.
Workshops and in-service training should be implemented and scheduled by the mental health services so that knowledge and skills on case-based management is disseminated and utilised to keep abreast of societal changes. Since there is a need for adequate knowledge by caregivers on side-effects of medication and also progressive signs and symptoms of the illness, education and clinical assessment of the family’s understanding of illness and medication use should be reinforced either on home visits or during follow-up at the clinic.

More supportive programmes are needed for families caring for SMI clients in the community. It is imperative that the MHCU and family be linked to all mental health and social services so that they maximise use of these facilities, instead of being left desperate from lack of basic needs. Future studies could focus on service links on health outcomes of psychiatric patients in home settings.

### 5.5 Summary

This chapter considered discussion of the results, researcher reflexivity, limitations of the study, and recommendations. The caregiving experiences of the participants has indicated and highlighted issues in family-centred care; impact on the caregivers, family, and the SMI client; responsibility to care; needs of the family from the health professionals; and families’ concerns for the future should they not be available to provide the care.

Limitations that were identified included lack of knowledge on the part of the family and the primary caregivers of the side-effects of medication, and of signs and symptoms of the chronic nature of the illness. The data collected in the study dispelled preconceived notions of the caregiving experience that were held by the researcher and led her to realise how difficult it actually is for the family to provide care. Need was identified for future studies to determine the impact of burden and financial aspects on the caregiver.
5.6 Conclusion

The study focussed on the experiences of caregivers in caring for a mentally ill relative at home. The family takes on a central role in provision of care whatever their physical well-being or age. They experience problems but accept their responsibility to care as part of nurturing, even though adequate resources for family caregiving have not been provided. Finally, shifting responsibility for care from the institution to the family has highlighted the burdens experienced by those who provide care at home. Recommendations should be further explored and supported by continuous research, establishing projects for nursing education, utilising the suggestions for community mental health and also providing much-needed support to the caregivers.
Reference list


Mkhize, N., & Kometsi, M. (undated). Community access to mental health services: Lessons and recommendations. School of Psychology, University of KwaZulu-Natal.


Appendix A: Caregiver demographic data
Care Giver Demographic Data

Date of interview: ____________________________ Place of interview: ____________________________

1. Initials or first name, for the purposes of contacting for a follow-up confirmation interview):

2. Gender: ____________________________ 3. Age: ____________________________

4.1 Gender and age of relative with mental illness: Gender: ____________________________ Age: ____________________________

4.2 Diagnosis (if known, or type of illness) of relative: ____________________________

4.3 Relationship to Mental Health Care User (MHCU): ____________________________

5. Length of time MHCU has lived with you: ____________________________

6. Are you employed? ____________________________

7. Are you or anyone in the family receiving a social grant? ____________________________

8. Which other family member/person living in the home helps you in caring for the MHCU: ____________________________

9. Do you have any physical condition(s) or disability? ____________________________

10. Contact telephone number for follow-up interviews: ____________________________

Cell: ____________________________ Phone number with code: ____________________________

Best time of day to call: ____________________________

Field Notes
Appendix B: Interview probes

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<th>Interview Probes</th>
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(Probes with respect to who, what, when, where will be asked if necessary)

1. What sorts of things do you do in taking care of your family member with a mental illness?

2. So far, what has been the most difficult for you to do?

3. So far, what have been the positive experiences of caring for the person?

4. How have you dealt with this experience or situation?
Appendix C: Research study Information sheet

Research Study Information Sheet

Ethical Approval Number: HHS/0766/2009

Title: A Phenomenological study of Caring Experiences of Care Givers Caring for Mentally Ill Individuals at Home in the Northdale Area of Pietermaritzburg.

Student Investigator: Miss. Nelyane Royan
Contact number/s: 033 3876888/ 0338973517 (w)
Student No: 204520127
Position: Post-graduate nursing student studying mental health/psychiatric nursing in the School of Nursing,
University of KwaZulu-Natal.

Research Supervisor: Dr. Lyn Middleton
Contact number/s: +27 31 2601655
Institution: School of Nursing, Desmond Clarence Building, Faculty of Health Sciences, University of KwaZulu-Natal, Durban, South Africa.

I am a student at the School of Nursing, University of KwaZulu-Natal, pursuing a Masters Degree in Mental Health Nursing programme. I am conducting this research study in partial fulfilment of this programme.

The purpose of this study is to better understand how the care givers at home provide care to their mentally ill family member.

You are invited to participate in this research. 6 – 10 caregivers will be asked to volunteer to be interviewed and to share their experiences with us. Your opinions as a person living with and caring for a mentally ill person in the home are therefore very important.

Your participation in this study is voluntary and your participation does not involve any physical risk or emotional risk to you. There are also no benefits for you in participating in this study.

If you agree to participate in the study you will be interviewed on an individual basis in a private at the clinic. Interviews will take about 45-60 minutes of your time. I will first ask for
general information about yourself and then ask questions that are focused on your understanding of the lived experiences in caring for the person with mental illness at home.

There are no penalties for declining to participate and should you decide to volunteer, you are free at any point during the study to withdraw from the study and to ask for your data to be removed from the study. Your request will be respected without question.

The records of this study will be kept confidential. In any sort of report we might publish, we will not include any information that will make it possible to identify a participant. Research records will be stored securely and only researchers will have access to the records. Results of this study may be used for publications in scientific journals and presentations at scientific meetings.

If you have any questions about this study, or would like additional information to assist you in reaching a decision about participation, please feel free to contact either me or my supervisor on the telephone numbers given above.

This study has been reviewed and received ethics clearance through the University of KwaZulu-Natal.

If after reading this information sheet you are willing to share your experiences of this topic, please complete the consent statement. By participating in this study you will help us gain an insight into care giving experiences.

I thank you for your time.

Ms N. Royan
Appendix D: Letters of Consent

5 Barbet Road
Northdale
Pietermaritzburg
3201
09/02/2010

The Person In charge
Psychiatric Community Clinic
Ghandi Road Assessment Centre
Northdale
3201

Re - Use of Psychiatric Clinic for the acquisition of Families of Mental Health Care Users (MHCU) for Research Study by the Educator Miss Nelyanee Royan from Grey's Nursing Campus Pietermaritzburg in Masters Programme.

Dear Sister E. Rathnam

During the last year I had indicated my intention of using the clinic to access the families of the MHCUs to include in my research study. I have the approval from the Ethics Committee from the University of KZN, Health Sciences Dept.

The Research Committee from Natalia Request a letter from you indicating that you; Give permission for me to access families of the MHCU in the clinic waiting room and that you support the study undertaken by myself.

Please assist me with a letter outlining the above to submit with my proposal to the Research Committee at Natalia.

You can email it to me or I could call in and collect it.

P.S. I have informed Mrs. May Zuma Makanza at District office per phone today. Awaiting your reply urgently.

Yours truly,
N Royan
033 3876888
083 331 8682
Fax: 0338973500 (w)
0338973517 (w)
Dear Mr. Davis

The Grand Psychiatric Community Nurses support the study undertaken by you.

Yours sincerely,

[Signature]

Reference: [Redacted]
Appendix E: Ethical clearance to conduct research study

28 October 2009

Ms N Royan
5 Barbet Road
Northdale
PIETERMARITZBURG
3201

Dear Ms Royan

PROTOCOL: A Phenomenological Study of Caring Experiences of Care givers Caring for Mentally Ill Individuals at Home in the Northdale Area of Pietermaritzburg
ETHICAL APPROVAL NUMBER: HSS/0766/2009: Faculty of Health Sciences

In response to your application dated 02 October 2009, Student Number: 204520127 the Humanities & Social Sciences Ethics Committee has considered the abovementioned application and the protocol has been given FULL APPROVAL.

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

Professor Steve Collings (Chair)
HUMANITIES & SOCIAL SCIENCES ETHICS COMMITTEE

SC/sn

cc: Dr L Middleton
cc: Mr S Reddy
Appendix F: Transcripts of interviews with study participants

Interview No. 1

Gender: female  Age: 41

Interviewer: Alright we can begin now hey!

Interviewer: Alright, eh, tell me about how you care for your husband at home?

Participant: I cook for him, wash his clothes, dish out his food, make his breakfast, tie his lunch, all that I do in the week.

Interviewer: How many days does he work?

Participant: Maybe 3 or 4 days that he goes to work.

Interviewer: May I ask what he does there?

Participant: He’s the supervisor there.

Interviewer: Where?

Participant: It’s at Busby Oils. It’s not a big factory, they only got about five of them there.

Interviewer: I see.

Participant: They make eucalyptus oil over there. That is all.

Interviewer: Does he take medication during the day?

Participant: No, only in the night. He only takes that side-effects tablet

Interviewer: So there is no need for him to carry his tablets to work.

Participant: No.

Interviewer: Alright. He is okay presently, now.

Participant: Okay,

Interviewer: Have you had difficulties looking after him at any time?

Participant: You mean before or after taking treatment?
Interviewer: Before or after taking his treatment.

Participant: Yah! Since he is on treatment he is so much better, much calmer.

You can at least talk to him only he does not communicate with us.

Interviewer: Who does he speak to more?

Participant: He speaks more to my daughter.

Interviewer: When he wants something does he communicate with you?

Participant: He talks sometimes. He is not totally quiet to himself no, no. When he wants something he will call one of the children and ask them. He just goes to work and comes back.

Interviewer: Does he drive to work?

Participant: Yes he drives to work and comes back.

Interviewer: You mentioned what you do for him, what he does in the house. Is there anything he does to help you along?

Participant: He does not do much. I want him to…Before he used to do so much, he used to make the burglar guards, he was a qualified fitter. All this he put … (points to windows).

Interviewer: Yes.

Participant: Now I told him to fit the burglar gate. He has all the equipment for it in the house.

Interviewer: You are very proud of his work. This shows he is coping very well.

Interviewer: Has he started already?

Participant: He wanted to start but he’s waiting for the weekend when he will have enough time.

Interviewer: He has about six days when he can do it.

Participant: He’ll have enough time.

Interviewer: When he wants to do something, do you – does he have motivation to do so? Do you have to remind him to do things?
He waits for you to tell him?

Participant: No, you have to tell him to do it. When he needs a bath, you got to take out clean clothes for him to change. He won’t take out clean clothes I have to do it.

Interviewer: Do you think that sometimes this is a problem for you?

Participant: Yah! You got to remind him to do things. Especially when I have to remind him to shave. You have to tell him what to do.

Interviewer: Alright, do you have any angry feelings about this … what are your feelings about this?

Participant: Sometimes I get angry because the children will trouble you and he does not help, it’s a bit difficult for me to see to him and the children.

Interviewer: How many children do you have?

Participant: I have three children, 2 boys and a girl.

Interviewer: How old ... , what is the age of the children?

Participant: The big one is 17 and the girl is 15, my little one is 9.

Interviewer: Alright, do you have any angry feelings about this … what are your feelings about this?

Participant: Sometimes I get angry because the children will trouble you and he does not help, it’s a bit difficult for me to see to him and the children.

Interviewer: How many children do you have?

Participant: I have three children, 2 boys and a girl.

Interviewer: How old ... , what is the age of the children?

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Interviewer: Alright, do you have any angry feelings about this … what are your feelings about this?

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Interviewer: How many children do you have?

Participant: I have three children, 2 boys and a girl.

Interviewer: How old ... , what is the age of the children?

Participant: The big one is 17 and the girl is 15, my little one is 9.

Interviewer: Alright, do you have any angry feelings about this … what are your feelings about this?

Participant: Sometimes I get angry because the children will trouble you and he does not help, it’s a bit difficult for me to see to him and the children.

Interviewer: How many children do you have?

Participant: I have three children, 2 boys and a girl.

Interviewer: How old ... , what is the age of the children?

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Participant: The big one is 17 and the girl is 15, my little one is 9.

Interviewer: Alright, do you have any angry feelings about this … what are your feelings about this?

Participant: Sometimes I get angry because the children will trouble you and he does not help, it’s a bit difficult for me to see to him and the children.

Interviewer: How many children do you have?
need help. My daughter gets upset with him.

Interviewer: Who talks to her, does he take the initiative?

Participant: Father talks to her more than he talks to me. Indicating to child (Aroo I’m going to tell Mummy about you, today. You better go from here).

Interviewer: You talked to him about this.

Participant: He has no time for me.

Interviewer: When was your husband admitted to hospital?

Participant: End of April last year.

Interviewer: Did you ever have the need to be included in his treatment? What would you say, have they kept you involved in his care?

Participant: Yah! When he was hospitalized Dr. Asmal, he asked for me to be there. When ever they changed his treatment he asked me to come in and he discussed it with both of us. Also he had an intern Dr. Vather who also included me when he saw my husband.

Interviewer: Do you think you need more information to get to manage him at home?

Participant: Not to manage him. The thing is that he sleeps too much.

Interviewer: What would you like us to help you with?

Participant: Not to sleep all the time during the day. 10 minutes after he had his breakfast he goes to sleep again.

Interviewer: Have you ever discussed that with the sister?

Participant: No.

Interviewer: Have there been any other problems?

Participant: Yah! At work he was also sleeping in the car in the hot sun.

Interviewer: So now that man phoned saying that he used to even have his tea in the car in the boiling hot sun. (child screaming in room).

Participant: I told them at the clinic and they spoke to him, the doctor said he is lucky to get this job (child making noise in room).
Participant: Yah!

Interviewer: How are you coping financially?

Participant: It is okay

Interviewer: He does not get a grant?

Participant: No, we manage somehow, my in-laws help also.

Interviewer: How does he manage when you are not here?

Participant: He can manage on his own, pour his own tea, not all the time. I say to myself he’s big enough he can do things when he needs.

Interviewer: So that is one thing that you would like to see change?

Participant: Yah! He needs to come in and help me. He won’t tell them a word.

Interviewer: So he makes it your responsibility to talk to the children?

Participant: He is very quiet. Even if he is watching TV. (children making noise in background ).

Interviewer: He does not comment on anything in terms of other activities?

Participant: If he wants something then he will ask the children not me.

Interviewer: The children, when they want something do they go to him or do they come to you?

Participant: Like our prayers he knows he does everything I don’t have to call him, he knows what to do.

Interviewer: The children, when they want something do they go to him or do they come to you?

Participant: They come to me if it something I must do but they go to him if they want something, like take them to the shop.

Interviewer: What does he do when he is off from work say over the weekend?

Participant: Sister he is a qualified fitter, he was going to complete his course, you know N1 but he just snapped. But he can do, he is just lazy, he
tells me he can’t do it but I know he can.

Interviewer: When you get angry, when the children are worrying you, what do you do?

Participant: I leave them with their father but it does not bother him. When I get angry it does not affect him. I scold the children and him and after that feel bad.

Participant: Once when we went out to a funeral we left him at home and we came back very late. He was lying down and after a while he got up and came to the kitchen. I told him “only now you bother to ask me all this time you never ask”. I asked him why he was only coming now to check why we came so late. He got no time for me. (Care giver had tears running down her face as she spoke).

Interviewer: Here, I have some tissues. Must I carry on, will you be okay?

Participant: Yes I’m okay.

Interviewer: What would you like to change if you had the chance to change anything?

Participant: There is a lot. I want him to be the way he was before ….now he is like that, easy to take advantage of him.

Interviewer: What would you say …(children making noise ) is the problem?

Participant: Eh….he has no say in the house.

Interviewer: Yes…. Who has the say in the house?

Participant: His brother has the say, they also live here and he is younger than him.

Interviewer: So in fact your husband has to listen to him?

Participant: Yah!

Interviewer: Do you think that he is a burden? You stood by him all the time.

Interviewer: Do you feel like you are looking after another child?

Participant: Yah! It feels like that at times.

Interviewer: Do you have problems with him to take his tablets?

How many times did you go the clinic with him?
92

Participant: No sister, we both go all the time even if he is working he will take me and then go to work.

Interviewer: He is very committed to his treatment hey!

Participant: Mmm… sister I think he needs something to keep him awake, he sleeps too much. Dr Asmal said that this was the best treatment for him.

Interviewer: Did you not see the difference with him with this treatment with the time before he was sick?

Participant: When last did you speak to the sister in the clinic about any problems.

Interviewer: About 3 months ago. I want him to take Bioplus. Isn’t it is good for him he won’t sleep so much, or are there any other vitamins that we can give.

Interviewer: Don’t give him Bioplus. Only with Doctor’s permission. I think that’s about it. Is there any question that you want to ask me about all the things I asked you?

Participant: No.

Interviewer: I forgot about the kids, how do they relate to their father?

Participant: They like their father especially my daughter when he was in hospital she used to go every day.

Interviewer: With you?

Participant: She didn’t come with me she would rather go with her aunty.

Interviewer: Did she ever talk about her father in hospital?

Participant: Yah! She was upset and it worried her.

Interviewer: How is she coping now?

Participant: I don’t know, she does not talk about it. She’s okay now.

Interviewer: This is a difficult age where they need both parents not one.

Participant: But they are bright children and are doing well. They want to
study further. That costs a lot of money.

Interviewer: Just out of curiosity does your husband drink or smoke?

Participant: He don’t drink, he used to smoke. When we got married he was smoking I did not know only later I found out. He don’t smoke now.

(child crying making a lot of noise)

Interviewer: I will stop now, if I need more I will come back, okay.

(child crying in room).

Interview No. 2

Gender: Female  Age: 61

Interviewer: Aunty Kay

Participant: Yes

Interviewer: Aunty Kay you say you are at home, looking after your daughter, what do you do?

Participant: You see in the morning when I wake up, I have to give clothes to bath. She won’t take her own clothes from the drawer.

Interviewer: Yes.

Participant: I have to give her dress, half slip, underwear, and towel. She go and bath and she come out I give her medication and give her something to drink. She has porridge. Then I’ll comb her hair, give her lotion everything and she is sorted out for the day.

Interviewer: And what about her meals? Do you cook for her?

Participant: Yes

Interviewer: Alright, and if you had to go anywhere? Would you leave her at home?

Participant: She stay with her father.

Interviewer: Her father takes care of her?

Participant: Yes. And if he go anywhere I look after her.

Interviewer: Mm And what, what things that she does at home, that
Participant: She mostly only set the dishes and she can help me when I fold the clothes, she put the clothes in the draw, like clean the vegetables that’s all.

Interviewer: That’s the ….

Participant: But she likes chips in the night. Sometimes I’m fast asleep. She’s in the kitchen, she making chips.

Interviewer: She does her own cooking at that time?

Participant: Yah, she likes chips 2’o clock, 3’o clock morning, when she wake up and go see what she’s doing.

Interviewer: Do you have any fear that she may hurt herself or…? 

Participant: Yah, with the stove.

Interviewer: Do you not think may be that uh…

Participant: She don’t go when she looks top, she’s clever.

Interviewer: I see, I see. Side-effects, alright.

Participant: only when It’s hot, she look top every week, even last night. She don’t eat when she look top. She’ll walk up and down, up and down. Then I give her something to drink, when I go to bed then she goes to bed.

Interviewer: This is difficult for you at times, at any time?

Participant: Yes and then when she gets her “suzy”. She don’t do anything for herself.

Interviewer: Mm.

Participant: I have to wash her clothes.

Interviewer: And do you remind her to go to the bathroom or anything like that?

Participant: Yes she goes, she goes and bath.

Interviewer: On her own?
Participant: When she don’t look top but when she look top, she don’t I have to wait for her, come down, then I go give her a bath.

Interviewer: Have you ever mentioned that she looks up like that to the sisters in the clinic?

Participant: Yah, Sister Ann knows it. Ask my husband what they said. Balraj (calls husband into room)

Interviewer: Wait I’m recording there. OK, alright so what would you say?

Participant: The Doctor said to me, Dr Padaychee told me she had a eye op. long time. Dr … did the eye op and she was using glasses you see, I must get the glasses for her and I see after that what happens to her.

Interviewer: What are some of the negative things that you experience when you care for her? I know you said one of those is danger at night. You not sure what would happen when she’s at the stove and frying those chips for herself, 2’o clock in the morning. The other one is about her personal hygiene, when she’s having her menstruation. Any other things that you can ….?

Participant: Well I fright to leave keys, She can open the door and go way night time and we’ll be left.

Interviewer: Has she ever wandered away like that, and where was she?

Participant: Yes, she did sister. She goes away and we get worried about her.

Participant: Yes she’s sitting in the hospital, and police Station.

Interviewer: She gets to those places?

Participant: But not now Darling (referring to the researcher as darling) it’s about now 14 years. I was spending lot of money for Vimla. Then somebody referred me to Gandhi Road.

Interviewer: So that was her behaviour before she went on treatment but since then …..

Participant: She was a really fit girl. She should do everything.

Interviewer: How are you coping with your health, when the asthmatic attack comes, What do you do?

Participant: I’ve got that eh… spray.
Interviewer: You take the pump?

Participant: Yes I keep the spray in the morning and in the night and I take my tablets.

Interviewer: So you still can cope?

Participant: I can still cope. Only one time I didn’t breathe because my lungs didn’t have no air, my daughter in law rushed me the hospital but now I’m alright.

Interviewer: OK.

Participant: See every month they treat me in the hospital, check me.

Interviewer: How do you feel about having to look after her for so many years of your life and its still not going to end, its going to carry on?

Participant: It’s going to carry on but I said, Sister Ann said, we must make up our mind up to leave her there in the hostel but now it felt so heart sore.

Interviewer: Which hostel? Pathmavathi Pillay homes?

Participant: Yes

Interviewer: I see. What did you decide?

Participant: But she don’t do things for herself, how she’s manage you tell me?

Interviewer: How does it make you feel?

Participant: Oh I feel sad. Doctor said we can’t let go. He saying that’s our problem, Dr Padayachee.

Interviewer: Mm…. difficult.

Participant: No but I said while we living we’ll take care of her. When we can’t manage then Sister Ann said must come to her.

Interviewer: So it’s the decision you’ve made?

Participant: Yes.

Interviewer: Mm …when you’re sometimes upset about all these things,
about having to worry about her, look after her. How do you cope? What do you do to relieve yourself of all that stress. Do you pray? Do you read?

Participant: I pray, but I smoke Sister. Since Vimla got sick so it’s 34 years that I smoke.

Interviewer: So that relieves……

Participant: That relieves me, yes, calms me down.

Interviewer: Calms you down.

Participant: Yes otherwise I can get very sick.

Interviewer: How many do you smoke?

Participant: Not lot, say about 5.

Interviewer: It’s not a routine thing with you or it’s everyday

Participant: Every day.

Interviewer: Every day, alright, Mmm, that works for you?

Participant: That works for me.

Interviewer: You said that ……have you ever been admitted?

Participant: In hospital?

Interviewer: Yes.

Participant: I was admitted for brain operation. It’s a very long op; the children wasn’t married and I had a break in my wrist. I went for the op and my teeth too Dr Rathi operated all because I couldn’t take out one tooth I used to faint.

Interviewer: So at that time they helped you?

Participant: No my in-laws was with me that time and my mother. But now when we do work we share the work my daughter-in-law, I and the maid.

Interviewer: Are there any times when you …… (screaming in the background). (Words drowned out due to noise…..) do you take her?
Participant: Her father take her.

Interviewer: Her Dad?

Participant: Yes.

Interviewer: Oh.

Participant: Father take her and bring her ....

Interviewer: Have you ever got the Sisters to sit down and explain anything to him? When he goes there what happens?


Interviewer: Do you feel sometimes it is just too much for you?

Participant: Never. No I cope up Sister.

Interviewer: You cope, and previously there’s I think, there’s lot of people that they look after sick people, they’ve been applying for the money, state gives them R200.00.

Participant: When we went and they didn’t give us they said she’s not sick. You Know. Sister Ann even wrote a letter.

Interviewer When did you last speak to Sister Ann ?

Participant: About the money, to look after her?

Interviewer: Yes.

Participant: It’s, eh, It’s oh I’d say it’s about 5 - 6 months, 5 - 6 months.

Interviewer: Would you like to try that again?

Participant: Yes I want to try again.

Interviewer: Keep trying you never know you might be lucky.

Participant: OK.

Interviewer What was the worst thing you have experienced having to look after her, the worst thing?
Participant: Mm, what I must tell you, you see when I usually wash all her clothes.

Interviewer: I know you mentioned ….

Participant: Yah, that because maids don’t do that I. I have to rinse it, put surf, soap and wash her clothes. It’s every month.

Interviewer: Once a month during that period of time?

Participant: Yes, yes.

Interviewer: Was she ever admitted to hospital?

Participant: There was one, admitted in Durban Hospital when she had her wisdom teeth in which hospital? In Durban? (asking relative to assist in her response)

Interviewer: But not a psychiatric hospital?

Participant: No, it was in town hospital.

Interviewer: When was that? How long ago?

Participant: Town hospital, she was bad that time. Long time, sister when we put her in town hospital she used to scream. She should bang her head on the wall. She was very sick I can tell you.

Interviewer: So the medication has helped her?

Participant: The medication helped. They even did a brain scan on her. The brain scan shows nothing wrong. Dr Padaychee is treating her now for the schizophrenia and depression.

Interviewer: Mm have they given you enough information have they given you enough information on treatment, diagnosis?

Participant: Yes, after she was in Town Hill hospital. She was very fine when we brought her at home. Ask my daughter in law. She relapsed again. Isn’t?

Interviewer: What did you say she relapsed because ….

Participant: She was doing very well.

Interviewer: And after that how long that she got sick again?

Interviewer: (daughter in law) The medication…., wasn’t giving her
properly.
That’s why she got sick.

*Interviewer*: Oh I see. Alright.

*Participant*: But the tablets is helping her, I won’t talk lies she is better than what she was.

*Interviewer*: Alright, think I got most of the information I need. I’m going to stop there. If I need more I will contact you…

*Participant*: Yes.

**Interview No. 3**

*Interviewer*: Mom can we start?

*Participant*: Yes.

*Interviewer*: Mom there’s questions here, in front of you look in front, so you can read it. OK – tell me what sort of things you do when you care for your son?

*Participant*: It is a long story.

*Interviewer*: Mm.

*Participant*: I do his washing.

*Interviewer*: Mm, do you also have to dish his food for him?

*Participant*: Yes I dish food for him.

*Interviewer*: Do you have to remind him to do anything?

*Participant*: He’s very forgetful sometimes.

*Interviewer*: What does he forget?

*Participant*: Because ….

*Interviewer*: What does he forget?

*Participant*: He forget, like the soap he leave in the bath water
101

Interviewer: Mm.

Participant: What else, sometimes I switch off the geyser and sometimes he forget to put it on.

Interviewer: When you say you cook for him and wash his cloths for him, do you not have any assistance like somebody at home to work?

Participant: No, I do it myself.

Interviewer: You do everything yourself?

Participant: Yah

Interviewer: Alright, but if you were sick and somebody needed to care for him because you wouldn’t be able to wash and cook?

Participant: I haven’t been through that situation.

Interviewer: I remember when I came in you mentioned that you had high blood pressure?

Participant: Yes.

Interviewer: How long have you had high blood pressure?

Participant: Um, just some time, this year now.

Interviewer: This past year, alright.

Interviewer: And do you go to clinic and collect some tablets for that

Participant: Yes – had gone to the doctor first.

Interviewer: You haven’t had any other problems?

Participant: No.

Interviewer: OK – so far what is the most difficult for you to do when it comes to caring for your son?

Participant: He co-operates with me very well.

Interviewer: So you don’t have any difficult situations with him?

Participant: Yes.
Interviewer: So what is he involved in at home, what does he do for you?

Participant: He dust the furniture for me.

Interviewer: Mm.

Participant: Sometimes I tell him to sweep, vacuum the floor, he does it for me.

Interviewer: So he is not upset that he has to do this every day?

Participant: No not upsetting.

Interviewer: Oh, every evening you have extra company?

Participant: No extra company, because he does not talk.

Interviewer: OK, has there been any difficulty that he has experienced that had impacted / influenced you?

Participant: No really – walking down there going to the clinic

Interviewer: Has that been a problem?

Participant: Yes – he get very tired when he comes from there.

Interviewer: How many days is that?

Participant: Just twice a week.

Interviewer: Just twice?

Participant: Yah

Interviewer: Which days?

Participant: Mondays and Wednesdays.

Interviewer: Mm – and that been very helpful for him?

Participant: Because he does something.

Interviewer: Has that been helpful for him?

Participant: For him, yes he takes some work and he take some tablets.

Interviewer: Taking about tablets – do you know what is wrong with him?
Participant: Yes.

Interviewer: And do you know what tablets he takes?

Participant: Yes.

Interviewer: And do you know what time he take those tablets?

Participant: Yes – he takes 1 a day.

Interviewer: OK, has he had any like side-effects from those tablets that you had to report to sister?

Participant: Mm, these things effect by making him sleepy from way back then and he is grumpy all the time.

Interviewer: Yeah.

Participant: Then when I went down to the clinic I told doctor to change the tablets

Interviewer: So you do go down with him?

Participant: Yah not always.

Interviewer: How often?

Participant: Not always because it distance to walk for me.

Interviewer: Mm, if you had to go down with him, do you go down the days when he has to speak to doctor or any time?

Participant: I went couple of times with him when he saw doctor.

Interviewer: Alright, because he sees doctor every six months.

Participant: Yeah.

Interviewer: Is there anything that the clinic can do for you to help look after him better than what you are doing now?

Participant: I am quite comfortable taking care of him.

Interviewer: Mm, and is there anything more they can explain about his illness?
Participant: Yes they did explain in the beginning.

Interviewer: Mm, do you need any more information about his illness or and how to cope?

Participant: At the clinic.

Interviewer: Mm from the sisters or doctor?

Participant: Yah in the beginning but now he’s stable.

Interviewer: He’s stable, so you are coping very well?

Participant: Yah.

Interviewer: You said to me earlier on that sometimes he’s forgetful, what have you done to deal with the situation? What have you done to help him remember things, because you said that he leaves the soap in the bath.

Interviewer: He’s forgetful in this way?

Participant: Yeah.

Interviewer: Have you tried reminding him when he…

Participant: I remind him.

Interviewer: Yes.

Participant: But still he forget.

Interviewer: OK.

Participant: And I got something for energy and strength for him to drink.

Interviewer: Yes…

Participant: I’ve got a health syrup and he’s taking that.

Interviewer: Yes, has it helped him in anyway?

Participant: He just been drinking that, I started giving him that recently.

Interviewer: So you can see a difference?

Participant: Yeah I can see a difference.
Interviewer: Why is he experiencing low energy, was he feeling weak and stiff previously?

Participant: Yes, he said he feels weak.

Interviewer: Yes from when?

Participant: Yeah a while now.

Interviewer: Have you brought this to the doctor’s attention or told sister in the clinic

Participant: Yes.

Interviewer: What did they say about it?

Participant: They did the same check-up.

Interviewer: Can you remember what they said?

Participant: Yes.

Interviewer: OK, when you go back again would you remember to remind them that he has low energy and that is the reason why sometimes he doesn’t do things at home correctly?

Participant: Yes.

Interviewer: OK, I want to come back, has been difficult for you to cope looking after him financially?

Participant: Financially it is difficult but we are coping what else can we do?

Interviewer: Mm.

Participant: Yah it is difficult.

Interviewer: I noticed there’s only two of you, so you’ve lost you husband?

Participant: Yeah, seventeen years.

Interviewer: Seventeen years and any brothers / sisters that he has?

Participant: He got a sister in Jo’burg.
Interviewer: Oh, so how he doesn’t see her very often.
Participant: Yah

Interviewer: OK, does he go up to Johannesburg to visit her?

Participant: He went twice.

Interviewer: Yes.
Participant: He won’t now, he goes to the clinic and therapy, can’t see him go to Jo’burg now.

Interviewer: Is it the medication that you are worried about?
Participant: Medication can get here. He have to go to the OT and he'll miss all that.

Interviewer: Mm.
Participant: Yeah, if it a holiday then only.

Interviewer: Like in December?
Participant: Yah

Interviewer: Or maybe she comes down and give you a break?
Participant: She comes, not often.

Interviewer: Not often, is she married and settled there?

Participant: She’s married

Interviewer: OK, do have any break from looking after him at home, do you have a break?

Participant: I don’t really, um

Interviewer: Can I assume that you…?

Participant: Like one of my nephew is here.

Interviewer: Yes …

Participant: So he takes care of him like while I’m not here.
Interviewer: Mm.

Participant: Yah, it is easier for him.

Interviewer: OK, I see you as quite involved making beads and key holders.

Participant: Yes.

Interviewer: Does that give you some way of also coping with your stress?

Participant: Yes.

Interviewer: Mm.

Participant: Yah but the bead work I’m not doing it for selling this is a token, I’m taking it to “Baba’s” ashram.

Interviewer: Yes.

Participant: They’re making this nearly about 40,000.

Interviewer: So lots of people are doing it?

Participant: Yah lots of people are doing it, so I’m giving this time to do it.

Interviewer: but does it gives you a feeling of great peace and ……?

Participant: Yes that feeling yes, Yah I got something to do you know.

Interviewer: Yes, alright now one last question. Is there any way that you think that you would want help in the future for anything?

Participant: Like what (phone ring, answers phone).

Interviewer: Just to go back to my question with you, can you remember, is there anything else you would like the clinic to help you with your son in the future?

Participant: When it comes to the future I need to, you know, what I ….

Interviewer: What would you like him to know, maybe something to learn, a skill maybe?

Participant: He must say “I want to do something”.

Interviewer: Mm.
Participant: And he must go for it.

Interviewer: OK, what is he presently interested in at the moment?

Participant: He just plays with the computer that’s all.

Interviewer: And are there any other jobs that he can do? Any jobs?

Participant: No.

Interviewer: Nothing.

Participant: No.

Interviewer: Has he learned anything from OT?

Participant: OT’s work he does there, but he makes things. He makes cards.

Interviewer: He must think about that by using the computer. Thank you, for spending time sharing information with me. I want to say that if I have a problem and or if I need to come back and clarify what you are asking me or telling me in my interview I’ll come back, thank you very much.

Participant: Thank you, sister.

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Interview No 4

Gender: Female Age: 57

Interviewer: OK, let’s begin, alright, I just want you to tell me, what you do when you care for your son? What sort of things do you do?

Participant: OK, I do cook for him I make sure that he eats healthy. I... make tea for him and I....

Interviewer: What else do you do?

Participant: And I also take care in other ways, that he must have a bath, he must shave, he must have a haircut and he must be neat and tidy.

Interviewer: OK carry on?

Participant: And, I love my son and I like making and doing things for him and I always ask him if anything wrong you know what I mean.
I mean I will ask him what he needs for the day because I must do this before I go anywhere, like if he need something you know and yah it just carry on like that.

Interviewer: Do you have to remind him to do certain things or he does it on his own?

Participant: No I have to remind him at times, there is time that he remembers certain things to be done on his own, there are times when I tell him because he forgot. I told him certain things to do during the day, it’s not done and he never do it because he does forget.

Interviewer: Alright, so the cooking and seeing to his hygiene first is done. What else do you do in caring for him? Who sees to his washing and clothes. Do you take care of this. Does he only stay at home or does he go out?

Participant: I do the washing and clothes and…

Participant: No he doesn’t, he stays at home unless I want him to go out. He just go to the shop and just buy bread and milk.

Interviewer: Does he attend any workshop or meeting like that?

Participant: He goes to Ghandi Road assessment centre or the clinic only.

Interviewer: Is that where he works making certain things?

Participant: Yes, he goes on his own.

Interviewer: How many days in the week?

Participant: Two days in a week.

Interviewer: Which days are those?

Participant: Now it changes, it’s Monday and Wednesday.

Interviewer: OK. What are the nice things you experienced of having him at home for you. What does he do that you can rely on him or are you finding it a nice experience having him at home with you?

Participant: OK, there was the case that he should just go away to his father but I was missing him a lot, but now I’m happy that he’s at home. And when I come home I feel very happy but I’m getting old, I don’t know later stage if I get sick or anything happen to me or whatever maybe in time I will need someone who can take care of him like as a mother, how I do it.
Interviewer: This concerns or worries you?

Participant: Worries me a lot, yes.

Interviewer: You said that sometimes he’s at home, this reassures you.
He gives you lot of company, provide you with company during the day?

Participant: Yes he does.

Interviewer: He could talk to you about anything?

Participant: There is times that I could talk to him certain things but not
everything because he’s not, like I mean perfect person like me to
know things like you know a lot of things.

Interviewer: What are difficult things that you coping with?

Participant: Well he’s the only child like, you know, the other is okay.
I find it very hard because we have to manage with everything.

Interviewer: I remember that you mentioned that he attends the workshop,
how does he get there?

Participant: Oh he takes a walk.

Interviewer: It’s quite a long distance?

Participant: Yes.

Interviewer: Are you not concerned about this?

Participant: Yes I do get worried and sometimes when the weather is too
hot you know, when I tell him not to go, and when he should go to therapy.

Interviewer: OK, what about shopping?

Participant: He goes when I need something like if I give him a list.

Interviewer: Alright, if you feel there is a difficult situation how do you
deal with it? Let’s say you mentioned one of your difficulties was that you
found it financially difficult, how would you deal with this? Do you budget?

Participant: Yes I do budget myself. We make it through with what we got
you know, we just carry on to where we are now, at the moment because
things are quite hard for us.

Interviewer: Yes….
Participant: I mean we don’t have anything. Best part is at least we have food on our table.

Interviewer: When last did you go to the clinic with him for his tablets or to see doctor?

Participant: Um well I’m a sick person as well in times I cannot make it and I send a note that I cannot make it and the sister down there she understand my situation and she helps me for him to see the doctor.

Interviewer: Has he spent time with you to explain what is wrong with him and how to help him, has he given information to you at any time?

Participant: No, not the doctor.

Interviewer: And the nursing sister …..?

Participant: Yah the sisters are nice over there they talk to me and explain to me. I don’t have problem with the sisters but not the doctor. I don’t know him, he just checks and says must take the medication, that’s all.

Interviewer: Mm, in the future what would you like them to help you with, if they had an opportunity to sit down and talk to you, maybe sister, what would you like them to help you with?

Participant: That depends on what they want to talk to me about and maybe they ask me certain questions that you know like what this is. We need to ask them or they can ask me what can we help you with in this way or that way, because I don’t know what they can do for me. I go to work I can’t take time from work.

Interviewer: Did they ever explain to you how he takes his medication and that you must help him take his medication?

Participant: Yes they did tell me, that he has to take his medication every night

Interviewer: Yeah.

Participant: Yah, morning and in the night, before in the morning same for morning and night but now he gives him strong medication for night so just only takes it and I make sure that when he takes his medication that he don’t mix it together.
Participant: Yah when it is cold he puts the heater on we sit and watch TV and now he stays at home in the holidays.

Interviewer: What does he do in the day?

Participant: Nothing he ask me what to do, if I just tell him like certain things to be done or the dirt bin has to be taken out on the road he does all that for me and whatever and he sits at home. I’m still happy his being at home. When he leave home I get very worried and I ‘m getting old I don’t know what’s happening to him, you know, if he goes anywhere.

Interviewer: Has he got friends and do they come home to visit him?

Participant: No he don’t have friends, I don’t allow him to have any friends.

Interviewer: There’s anybody else that helps you say you are sick and you can’t get out of bed to do anything for him, does anyone else help you with him?

Participant: No nobody helps me I tell him to go himself to the kitchen and if you want tea make your tea or this food you wanna eat not that doesn’t eat nothing in the day.

Interviewer: So he does dish his own food, make tea and little bit more for himself.

Participant: He does when I tell him to go to do it, he does it for himself I don’t always allow him to go do things but when I’m around him I make it or he do it in front like you know some things that he can do. But you know anything can just happen or whatever. I must be clear, no problems.

Interviewer: And do whatever?

Participant: Yah I’m very concerned about all that.

Interviewer: Alright, um you said that you are sick you mentioned to me that you got asthma and you experience high cholesterol and diabetes and you walk to hospital often to collect medication.

Participant: Yes I take treatment from the hospital.

Interviewer: How often do you go to hospital?

Participant: I go every six months to see the doctor. I go to the clinic for 5 months medication and every 6 months I see a doctor.
Interviewer: Are these only from the clinic?
Participant: Yes. Five months I only collect my medication.
Interviewer: From clinic, alright, ok, has that been stable for you so far?
Participant: Yes it’s quite long now that I’ve had an attack.
Interviewer: So you have been fairly well?
Participant: Yah.
Interviewer: Alright, is there any question that you want to ask me while we are talking now, any question you want to ask me?
Participant: You know that I am willing to answer your questions and you can phone me if you need any more information. Maybe you can give me advice you know, what to do whenever I need your help in the future when I have problems.
Interviewer: You’re welcome.
Participant: Yah that’s all.
I’ll stop there.

Interview No 5

Gender: Female    Age: 54

Interviewer: Alright, can we start now?
Participant: OK.

Interviewer: Alright, when you say you care for your son, what do you do when you care for your son?
Participant: We give him food, we wash clothes, we see that he’s neat.

Interviewer: Yes, When you say we who else helps you?
Participant: My daughter helps me when I go anywhere.

Interviewer: Yes, you mention here that you give him his food, who is the one that actually prepares his food?
Participant: I prepare it.

Interviewer: Everyday that’s your responsibility?

Participant: Yes.

Interviewer: Alright, and about his clothes you mention that you see that he dressed properly?

Participant: Yah I wash every day.

Interviewer: Mm.

Participant: Sometimes the girls hardly wash.

Interviewer: Mm

Participant: When it happen I have to go to somewhere.

Interviewer: When you say the girls you mean your daughters?

Participant: Yes.

Interviewer: So they do care for him also?

Participant: Yes they care for him.

Interviewer: Alright what are things do you do for him besides the cooking and seeing to his clothes, his meals, do you watch over his safety and check where he goes, what he does? Do you go with him to the clinic?

Participant: Yes, I go with him.

Interviewer: Mm.

Participant: And he’s home early, he don’t go anywhere.

Interviewer: Yes, so you keep a check, he doesn’t go out of the house in the night?

Participant: Yes.

Interviewer: Are there any time that things became difficult for you?

Participant: Yes it was.
Interviewer: Did it involve your son and caring for him?

Participant: Yes it was.

Interviewer: What would you say those difficult times were?

Participant: Financial problems

Interviewer: Mm

Participant: He was demanding his money from me and his father.

Interviewer: How do you really manage when this happens?

Participant: We collect grant for my son and also collect every time for us.

Interviewer: You are collecting just for physical illnesses how did …..

Participant: Every month I go there to check my blood pressure.

Interviewer: The grant helps you with the financial problems.

Participant: We give it to him to go out, calm himself, come back,

Interviewer: Mm, when you have this difficult moment, how do you actually deal with it? Do you leave him, ignore him, what do you do?
Participant: We can’t ignore him because you know he just want it.

Interviewer: So he put a demand on you for his money?

Participant: Yes.

Interviewer: Alright, and so you just have to listen and be obliging?

Participant: Yes we have to do that.

Interviewer: Alright then what is a nice thing about having him at home, let me give you an example, sweep the floor or iron his clothes?

Participant: No he doesn’t do all that.

Interviewer: Nothing at all?

Participant: Yes.

Interviewer: So you think there is really no benefit of having him at home?

Participant: No.

Interviewer: Does it worry you about his safety and what could happen to him?

Participant: I worry but what can I do he does not listen to us.

Interviewer: Okay, can I say that it has been really difficult looking after him.

Participant: What has made it easier to look after him, having company or the others helping you?

Participant: Others help. Like if he can, at least look after himself.

Interviewer: Yes.

Participant: Yah.

Interviewer: Yes.

Participant: You know all that stuff he’s taking is not good…..!

Interviewer: So he’s able to do things for himself, you are not looking after him 100%?
Participant: No he can like bath himself. He wears clothes, on his own.
He’ll be sitting here and he’ll be talking to you but not always listening.

Interviewer: Mm so he does not really pay attention?

Participant: No, like talk to him, like so many times for him to respond.

Interviewer: Mm. Who does he communicate with, you or his father, or his sisters?

Participant: All of us.

Interviewer: But is there any favourite one that he listens to?

Participant: He listens to all of us.

Interviewer: Has he any fear for his father?

Participant: Yah, sometimes.

Interviewer: But does he listen to him when he tells him something?

Participant: Yah he listen to him.

Interviewer: Okay, you mentioned that he leaves home when he wants money, he goes out, where does he go?

Participant: He goes to his friends.

Interviewer: Mm when he comes back what happens?

Participant: He is quiet but always hungry and he messes the kitchen.

Interviewer: And these friends do you know them?

Participant: Some of them we know.

Interviewer: Are they the ones who take the stuff you mentioned?

Participant: We don’t like him to be with you know those friends.

Interviewer: Mm, have you spoken to him about it?

Participant: Every day we talk to him.

Interviewer: About what!
Participant: To keep away from them because now with his condition he has to be at home.

Interviewer: Is he taking any medication?

Participant: He used to take one tablet in the evening.

Interviewer: How is he with that?

Participant: One is not helping so they give him the injection.

Interviewer: Has he stopped taking it or has he continued?

Participant: Yah every month he goes for the injection.

Interviewer: Taking one injection only per month now, and one tablet?

Participant: Yah.

Interviewer: Have you ever been to the clinic with him?

Participant: Yah when he goes I go with him

Interviewer: Have you told them about his behaviour?

Participant: Yes.

Interviewer: Did doctor explain to you what was wrong with him?

Participant: Yah it was the drugs.

Interviewer: Mm and did he tell you what treatment he is on and what could happen if he doesn’t take his tablets, have they given you information?

Participant: Yes they told us…..

Interviewer: Has he been to Town Hill and then discharged the clinic?

Participant: Yes, Ghandi Road.

Interviewer: Is there anything more the clinic staff can help you with, anything that you need to know or to find out from them, is there anything that you would want to tell you about your son?

Participant: No nothing.
Interviewer: Have you discussed anything that you are concerned about with the sisters?

Participant: Yes every month they talk to us and him.

Interviewer: When you go there do they include you in the interview also?

Participant: If there is any problems they ask me you know, and go to talk to him also.

Interviewer: Mm, has the doctor been able to talk to you at any time?

Participant: Yes he talk to us.

Interviewer: How often is that?

Participant: Every six months

Interviewer: Yes, so on the monthly visit the sisters speaks to you and then once in six months doctor speaks to you.

Participant: Yah.

Interviewer: Alright.

Participant: But if there is a problem before 6 months then they let him talk to the doctor, they let us even talk to the doctor.

Interviewer: Alright, has it ever happened that you needed to talk to the doctor before six months?

Participant: Yah it happened I think once.

Interviewer: What happened then, what was the situation?

Participant: He wasn’t taking his tablet, he wanted to stop it.

Interviewer: OK.

Participant: He spoke to the doctor and he said no, he must carry on.

Interviewer: Alright, mum is there any question you want to ask me, anything you want to ask me?

Participant: If I think of anything I can call you
Interviewer: You can tell your daughter to phone me and…

Participant: I'll phone you.

Interviewer: Alright.

Participant: I like someone to do a home visit cause he’s not supposed to go out of the house.

Interviewer: Has the sister ever suggest that he go to AA or SANCA?

Participant: SANCA he refused. I did try before he went to Town Hill and he was not willing…

Interviewer: There’s also a drug facility where they can go, ever thought of sending him there, the rehab centre?

Participant: They have, he doesn’t want to go there. Because when he was in Town Hill they wanted him to go and he refused. They said we can’t force him….

Interviewer: You look very tired, are you tired?

Participant: I am doing this room you know we had put in a new lino mat.

Interviewer: You must be tired, you and the girls did this?

Participant: Yah we did that.

Interviewer: They are very good, they help you a lot.

Participant: They are very helpful, Yah.

Interviewer: How do they help their brother do they talk to him?

Participant: They talk to him when he want anything, he want shoes, anything they can buy for him, when he want money too they give him

Interviewer: Are they both working?

Participant: Both working.

Interviewer: OK, so if anything happens to you so they will take responsibility for their brother

Participant: Yah?
Interviewer: And your husband, what are his thoughts? Is he supportive in looking after him?

Participant: Yah he looking after him at home.

Interviewer: So both of you are caring for him?

Participant: Yah because he’s old he’s 68.

Interviewer: 68 and well?

Participant: Yes.

Interviewer: So you got no questions to ask me, I can switch off the Recorder?

Participant: No questions.

Interview No 6

Gender: Female Age: 56

Interviewer: Can we start?

Participant: Yes.

Interviewer: Alright, Mum you are living alone with your son and he goes to Ghandi Road clinic for treatment. Can you tell me what you do for your son at home?

Participant: I do quite a few things for him because he lives with me. I like to make sure that I cook his meals and he has proper meals. I make sure his cloths are always washed and they are clean. all the time and I like um to make sure that if he is not feeling so well I can take him to the doctor so that he’s attending, in case he get the flu or anything and make sure that he get his treatment for that and also for treatment from the clinic. I make sure he is collecting his medication and goes on time for his injection, because the clinic sisters give the date you must come, so I take him on time for that and also his appointment at SANCA. He goes to SANCA for his appointment to the doctors appointments there. There the doctor makes appointment which he keeps.

Interviewer: So there’s quite a lot that you are doing for him?

Participant: Yes.
Interviewer: You say that you cook for him and you see to his clothes, also supervise at home, you see to it that he has a good meal during the day and that he takes his tablets.

Participant: Mm.

Interviewer: Does he do any cooking or helping at home?

Participant: He, yah, he comes to the kitchen while I’m in the kitchen. He helps me, with sometimes washing of the dishes you know, helps me with packing the dishes away and also when he’s well, he also vacuums the house and mm, when he’s well he does quite a bit of things because he can do the washing of the car so he doesn’t have, we don’t have to pay for this, also when he is well he can drive us to where ever I need to go.

Interviewer: Does he have his licence to drive?

Participant: Yah.

Interviewer: Is he not working?

Participant: Yah.

Interviewer: Alright so you’ve been looking after him and financially how has that been for you?

Participant: A little bit difficult.

Interviewer: Mm … How do you manage?

Participant: Yah, a little bit difficult because he’s like you know – everything is costly now because I’m supporting him with I’m getting a pension now, so supporting him and myself is financially a little bit difficult but –

Interviewer: Is he looking for a job?

Participant: Yah, at the moment yah, he’s looking for a job and he’s applying. He did his C.V. He did all his paper work.

Interviewer: He’s taking his medication and is quite stable now?

Participant: He’s yah, at the moment he’s very stable.

Interviewer: Mm.

Participant: Yah, because he’s now actually at this moment he’s very
stable and well, he goes to the clinic himself, he sees the sister there, the.

sisters are very good there, He goes and get his card out he sees one of the.
sisters there, Sister Anne and Sister Vani, one of them is always there.

Interviewer: So he’s quite capable to go on his own now?

Participant: Yah, and he… goes and takes his injection and they make sure
that he get his return date to go back for his next injection.

Interviewer: You said that sometimes you take him to the doctor
does he often get sick?

Participant: Not very often.

Interviewer: Yah.

Participant: You know this change of weather sometimes he get the flu so I
take him for his you know, to make sure that he’s on medication.

Interviewer: At the moment is he well?

Participant: Yah he’s well.

Interviewer: And you have generally been well also?

Participant: Yah I’m well.

Interviewer: What are the nice things about having him at home, as you
also full time at home?

Participant: Yes.

Interviewer: What does, what is a nice things or experience you
had you know with him being at home?

Participant: Like at least you know that during the day or the evening
always there is somebody at home with you and I always like you know,
he’s very caring and loving you know, when he is well he can come and talk
to you and he find out what you need and what he can do to help me.

Interviewer: Mm.

Participant: And you know like if I want to watch anything you know, like
TV or anything he can put a DVD on for us to watch, together spend time
together and mm….

Interviewer: And anybody else that he cares about?

123
Participant: Yah he cares very, very much for his granny, he goes and does shopping for her, she tells him what he must buy you know, all that and he goes and get it for her and um he’s so stable at the moment where if I can give him a shopping list and he can go and do the shopping.

Interviewer: How often does he get sick then?

Participant: Um only when the time when he get sick is when he takes too much of this drugs.

Interviewer: Mm.

Participant: That’s when you find that he’s unstable.

Interviewer: Then how do you cope?

Participant: Then sometimes I contact the clinic sisters that I know, and sometimes phone the doctor who treats him and just to ask her what can I do, what must I do. You know, how do you handle that situation, yah, that I get help from them and then also sometimes that the family is supportive, you know and also friends and family.

Interviewer: What has been the most difficult thing for you so far? The most difficult thing to cope with?

Participant: The most difficult thing is when sometimes he used to get like a bit, when he’s not like sometimes he used to have these terrible moods, really like he can become very much like violent not as much but damaging like, you know he will destroy something he had. His brother gave him a cell phone he destroyed that phone and he became aggressive in the sense of violence, not hitting anybody never, but damaging things only.

Interviewer: Does he demand any attention that way?

Participant: Yah like he want me to notice something yah.

Interviewer: OK.

Participant: Yah, yah, but not aggressive as such you know like violence to anybody but I haven’t seen that kind of thing.

Interviewer: How did you deal with that situation where he was breaking things?

Participant: I like just spoke to him, try to speak about his behaviour.
Interviewer: Do you just ignore him?

Participant: No I don’t ignore him I ask him you know why, you know why you’ve done those things, sometimes he stays quite, sometimes he tells you he was cross about something, something made him cross and made him do that.

Interviewer: I understand your relationship with your husband is strained.

Participant: Yah.

Interviewer: He’s quite comfortable being at home with you?

Participant: He’s very comfortable being at home.

Interviewer: Is there anything you would like the clinic sisters to have told or explained to you about him?

Participant: They did explain to me about his condition that what, what is wrong with him when I started taking him to the clinic and they explained to me in the first interview even when he went for his injections they explain you know, they want us to notify them if I want to know anything.

Interviewer: Mm.

Participant: They even speak to him, they ask him, does he want to know anything about his medication and the side effect they explain to him and both of us what will be the side-effects even the doctor will tell us of the effects of the medication, what we must look out for and how to manage.

Interviewer: Mm so you said the clinic have been very supportive.

Participant: Been very supportive.

Interviewer: And helpful.

Participant: And you can even phone them, we can phone them and ask them, if we need to know anything we phone and ask the sisters there.

Interviewer: Very approachable.

Participant: Yah very approachable.

Interviewer: Are you happy with this treatment that he is getting?
Participant: Yah, very, at the moment.

Interviewer: Is there anything that worries you that you want to ask me about his treatment or anything about his management?

Participant: Well at the moment now you, I don’t know for him to get a job because at the moment you see he’s been applying for jobs, now he is not getting any replies like any respond from them, at this moment I can see he’s getting a little bit quiet and then he’s looking like you know what, “will I ever get a job” you know like with his condition.

Interviewer: What are you doing about that? Are you giving him hope?

Participant: Yah.

Interviewer: You are encouraging him to carry on?

Participant: I told him to continue applying, looking at the papers. I give him money to buy papers so that he get to look at the vacancies there so he can apply for the jobs like he want which is suitable for him.

Interviewer: This is worrying to you and him very much?

Participant: Yah, that he must get into a job so that he can keep himself occupied.

Interviewer: Especially that now he’s functioning well.

Participant: Yah that he can cope you can see that he can cope you know with a job.

Interviewer: So far there’s no problem with his treatment or side-effects?

Participant: No, he’s doing very well with the treatment she put him on.

Interviewer: No side-effects or anything with the drugs he was taking?

Participant: No.

Interviewer: So he’s doing quite well on the injection and tablets?

Participant: Yah he’s doing very well.

Interviewer: And are you happy with his progress?.

Participant: Yah, I’m very happy with his progress, what I’ve seen of him what he is like now you know, he has progressed very well, I mean he took
time for him he look the way he is now. Something like six months like you
know, to reach this point now where he is, like, he can be independent
you know, I can leave him because he is responsible he shows me he’s
responsible and the he keeps motivated, wanting to do things or helps me,
Yah.

*Interviewer:* What, what did he do to keep him occupied at home?

*Participant:* At home apart from the chores that he does, he does the dishes,
reading and he does music on the computer, and he looks for
something that he can you know like apply for jobs on the computer I think,
e-mails all that he sends he can apply through that and he read a lot—oh! he
loves books. Just the other day when he, yesterday I think, he bought a book.

*Interviewer:* Mm.

*Participant:* There’s a nice book shop here that he went and bought a book.
He loves reading.

*Interviewer:* You mentioned that, in our conversation just now that he
has a brother? Does he, is he supportive of him?

*Participant:* Yah very supportive of him you know.

*Interviewer:* Yeah, and also helps him…..

*Participant:* Also helps him very much, he’s helping to find a job.

*Interviewer:* If you need to go somewhere who do you leave him with, do
leave him with anybody?

*Participant:* Oh at the moment no. I don’t have to leave him with somebody
if I have like go anywhere only when he worries me.

*Interviewer:* So he stays on his own.

*Participant:* Yeah, then with his father and brother. Not now.
He cares about the brother.

*Interviewer:* And then what about friends, does he have friends?

*Participant:* Yah he’s got friends he’s got a few friends that he visits.

*Interviewer:* And they’ve been supportive?

*Participant:* They’ve been very supportive of him, yah.
Interviewer: Excellent.

Participant: Yah.

Interviewer: Thank you so much for that, if there’s any other question I can call you, because now our interview is over.

Participant: Yes, you can call me, yah you can call me.

Interviewer: Thank you very, very much.