

**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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Dissertation submitted to
School of Nursing
Faculty of Health Sciences
College of Health Sciences
University of KwaZulu-Natal, Durban

in partial fulfilment of the requirements for the
Course Work Master's Degree in Nursing
(Mental Health Nursing)

Supervisor:
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November 2011

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 of 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.

Acknowledgements

I would like to acknowledge my sincere thanks and appreciation to the following persons and institutions for their support and guidance during the course of this work. This dissertation would not have been completed without such support and encouragement.

Dr Lyn Middleton, my research supervisor for constantly pointing me in the right direction and providing the constructive criticism during the work.

Mrs Joanne Naidoo and support staff of the School of Nursing, University of KwaZulu-Natal for their unfailing assistance and guidance.

The research student support group who provided the stimulus to move forward.

The KwaZulu-Natal Department of Health and the Northdale Psychiatric Community Services Clinic in Pietermaritzburg for permitting me to do the study.

The nursing staff of the clinic for allowing me access to the participants and supporting my study.

The participants who willingly allowed me access to their homes and experiences for the study.

To Alvin, Edwin and Vanessa, a special thank you for helping me with my zero computer skills and audio taping. Thank you for the encouragement.

To my dear friends, my appreciation for the well wishes and helping hands when I needed you most.

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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 MHCUs 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 MHCUs 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 MHCUs.

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: care giver; 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; Seloiwe, 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

carer's "Karma" (cycle of birth and rebirth). Religious practices, rituals, distractions, withdrawal, and tolerance were used, when necessary, to cope and adhere to caregiving practices (Manoleous, 1995; Sethabouppha & Kane, 2005).

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 care givers, 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 care givers 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

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

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 care givers. 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).

“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: lines 1695- 1705).

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).

“Do you feel sometimes it is just too much for you?” [R] “Never. No I cope, Sister.” (Transcript 2: lines. 579- 581).

“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 care givers 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 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

Statements	Location in transcripts
OK, I do cook for him I make sure that he eats healthy. I make tea for him and I. . .	Transcript 4: ll. 1078–1079
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.	Transcript 4: 1086–1087
We give him food, we wash clothes we see that he's neat.	Transcript 5: ll. 1325–1336
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
Do you feel like you are looking after another child? Yah! It feels like that at times.	Transcript 1: ll. 274–276
Well I fright to leave keys, She can open the door and go away night time and we'll be left.	Transcript 2: ll. 444–445
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
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
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.	Transcript 2: ll. 384–385 and 389–390
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
Not 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
But she don't do things for herself, Oh I feel sad. Doctor said we can't let go.	Transcript 2: ll. 498 and 503
No extra company, because he does not talk.	Transcript 3: l. 771
He got no time for me. (Caregiver had tears running down her face as she spoke).	Transcript 1: ll. 246–247
No, we manage somehow, my in-laws help also.	Transcript 1: ll. 195
Financially it is difficult but we are coping what else can we do?	Transcript 3: ll. 928–929

Statements	Location in transcripts
<p>I don't know later stage if I get sick or anything happen to me or whatever maybe in time.</p> <p>I will need someone who can take care of him like as a mother, how I do it.</p> <p>Worries me a lot, yes.</p>	Transcript 4: ll. 1136–1138, and l. 1142
<p>I find it very hard because we have to manage with everything.</p> <p>I mean we don't have anything. Best part is at least we have food on our table.</p>	Transcript 4: Line 1158 Lines 1188–1189
<p>No he don't have friends, I don't allow him to have any friends.</p>	Transcript 4: ll. 1248–1249
<p>Yah, when it is cold he puts the heater on, we sit and watch TV and now he stays at home in the holidays. . . . 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.</p>	Transcript 4: ll. 1235–1236; 1240–1241
<p>When he is well he can come and talk to you.</p> <p>And he find out what you need and what he can do to help me.</p>	Transcript 6: ll. 1795–1795
<p>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.</p>	Transcript 6: ll. 1831–1834
<p>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.</p>	Transcript 6: ll. 1806–1809
<p>So you've been looking after him, and financially how has that been for you?</p> <p>A little bit difficult.</p>	Transcript 6: ll. 1734–1737
<p>Financial problems.</p> <p>He was demanding his money from me and his father.</p>	Transcript 5: ll. 1386 and 1390
<p>I am quite comfortable taking care of him.</p>	Transcript 3: Line 846
<p>No but I said while we living we'll take care of her. When we can't manage then Sister Ann said we must come to her.</p>	Transcript 2: ll. 508–509
<p>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 . . .</p>	Transcript 4: ll. 1091–1092
<p>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.</p>	Transcript 6: ll. 1720–1723

Statements	Location in transcripts
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.	Transcript 6: ll. 1793–1794
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.	Transcript 2: ll. 402–404
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.	Transcript 2: ll. 616–617
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).	Transcript 1: ll. 69–71
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.	Transcript 1: ll. 157–160
Mm, have they given you enough information, 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. Yes they did tell me, that he has to take his medication every night.	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: ll. 1595–1596
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.	Transcript 6: ll. 1759–1761
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

Table 4.3 Themes / associated significant statements / location in the transcripts

Theme	Associated Significant Statements
Family as a support structure	<p>“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).</p> <p>“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).</p> <p>“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).</p> <p>“Do you feel like you are looking after another child “? (Transcript 1: ll. 274–276).</p>
Commitment to care	<p>“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)</p> <p>[Q]”Do you feel sometimes it is just too much for you” with response “Never. No I cope Sister” (Transcript 2: ll. 579–581).</p> <p>“we can’t let go” (Transcript 2: l. 504)</p> <p>“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).</p> <p>“I will need someone who can take care of him like as a mother, how I do it” (Transcript 4: line 1139.</p>
Disruption to family life	<p>She stay with her father. Yes and if he go anywhere I look after her” (Transcript 2: ll. 369 and 372).</p> <p>“ “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)</p> <p>“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).</p> <p>“I want him to be the way he was before . . . now he is like that, easy <i>to</i> take advantage of him “ (Transcript 1: ll. 256–257).</p> <p>“No extra company, because he does not talk ” (Transcript 3: l. 772)</p> <p>“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).</p>

Theme	Associated Significant Statements
Value in contributing to care	<p>“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).</p> <p>“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 <i>or helps me</i>” (Transcript 6: ll. 1945 and 1950).</p> <p>“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).</p> <p>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).</p> <p>“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).</p>
Maintaining hope	<p>“I am quite comfortable taking care of him” (Transcript 3: l. 847).</p> <p>“ but I was missing him a lot, but now I’m happy that he’s at home and when I come home I feel <i>very</i> happy” (Transcript 4: ll. 1136–1137).</p> <p>“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).</p> <p>“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).</p>
Support and guidance: ongoing assistance	<p>“Mm, have they given you enough information on treatment, diagnosis?” “Yes, after she was in Town Hill hospital” (transcript 2: ll. 645–650);</p> <p>“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);</p> <p>“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);</p> <p>“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).</p> <p>“he get very tired when he comes from there” (Transcript 3: l. 781);</p> <p>“I like someone to do a home visit cause he’s not supposed to go out of the house” (Transcript 5: ll. 1622–1623).</p>

Theme	Associated Significant Statements
Concern over continuity of care	<p>“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).</p> <p>“OK, so if anything happens to you so they will take responsibility for their brother. Yah” (Transcript 5: ll. 1658–1659)</p> <p>“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).</p> <p>“I will need someone who can take care of him like as a mother, how I do it” (Transcript 4: line 1139.</p>
Fears and difficulties experienced in caring	<p>“these things effect by making him sleepy from way back and then he is grumpy all the time” (Transcript 3: l. 818–819).</p> <p>“Not 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);</p> <p>“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)</p> <p>“She don’t go when she looks top” (Transcript 2: l. 398)</p> <p>“ No he don’t have friends, I don’t allow him to have any friends” (Transcript 4: ll. 1248–1249)</p> <p>Yah, she likes chips 2’o clock, 3’o clock morning. When she wake up I go see what she’s <i>doing</i> “(Transcript 2: ll. 389 -390)</p> <p>“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).</p> <p>“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).</p> <p>“He got no time for me” (Transcript 2: l. 246–247).</p> <p>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).</p>
Misuse of Social Grants	<p>“He was demanding his money from me and his father” (Transcript 5: l. 1391).</p> <p>[Q]”So you’ve been looking after him, and financially how has that been for you?”</p> <p>“A little bit difficult”. Transcript 6: ll.1734-1737).</p> <p>“Financially it is difficult but we are coping what else can we do?”(Transcript3: ll.928-929).</p> <p>“I find it very hard because we have to manage with everything.</p> <p>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).</p>

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 SMT*", 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.

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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):

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 (

5. Length of time MHC

6. Are you employed?

8. Which other family member/person living n the home helps you in caring for the elderly?

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

Interview Probes

(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. Nelyanee 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.

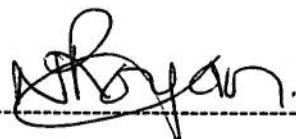
The records of this study will be kept confidential. In any sort of report we might publish, we will not include any information that will make it possible to identify a participant. Research records will be stored securely and only researchers will have access to the records. Results of this study may 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 (MHCUs) for Research Study by the Educator Miss Nelyanee Royan from Grey's Nursing Campus Pietermaritzburg in Masters Programme.

Dear Sister E. Rathanam

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)



DEPARTMENT OF HEALTH - KWAZULU-NATAL
GHANDI ROAD ASSESSMENT CENTRE

TEL NO: (033) 3970382

DATE: 09.02.2010

FAX NOS (033) 3970389

ENQUIRIES: Sr E. Rathanam

Greys Campus
P/Bag X9124
Pietermaritzburg
3200

Attention: Miss N. Royan

RE: Reply to your letter

Permission has been granted for you to access family of MHCU in waiting room.

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

Yours Sincerely
Sr E. Rathanam

*E. Rathanam
Clinical Nurse Specialist*

DEPARTMENT OF NATIONAL HEALTH
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Appendix E: Ethical clearance to conduct research study



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28 October 2009

Ms N Royan
5 Barbet Road
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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

A handwritten signature in black ink, appearing to read "Steve Collings".

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

line 3 **Interview No. 1**

line 4 Gender: female Age: 41

line 5

line 6 *Interviewer:* Alright we can begin now hey!

line 7

line 8 *Interviewer:* Alright, eh, tell me about how you care for your husband at

line 9 home?

line 10

line 11 *Participant:* I cook for him, wash his clothes, dish out his food, make his

line 12 breakfast, tie his lunch, all that I do in the week.

line 13

line 14 *Interviewer:* How many days does he work?

line 15

line 16 *Participant:* Maybe 3 or 4 days that he goes to work.

line 17

line 18 *Interviewer:* May I ask what he does there?

line 19

line 20 *Participant:* He's the supervisor there.

line 21

line 22 Interviewer: Where?

line 23

line 24 *Participant:* It's at Busby Oils. It's not a big factory, they only got about five

line 25 of them there.

line 26

line 27 Interviewer: I see.

line 28

line 29 *Participant:* They make eucalyptus oil over there. That is all.

line 30

line 31 *Interviewer:* Does he take medication during the day?

line 32

line 33 *Participant:* No, only in the night. He only takes that side-effects tablet

line 34

line 35 *Interviewer:* So there is no need for him to carry his tablets to work.

line 36

line 37 *Participant:* No.

line 38

line 39 *Interviewer:* Alright. He is okay presently, now.

line 40

line 41 *Participant:* Okay,

line 42

line 43 *Interviewer:* Have you had difficulties looking after him at any time?

line 44

line 45 *Participant:* You mean before or after taking treatment?

line 46
line 47 *Interviewer:* Before or after taking his treatment.
line 48 *Participant:* Yah! Since he is on treatment he is so much better, much
line 49 calmer.
line 50
line 51 You can at least talk to him only he does not communicate with us.
line 52
line 53 *Interviewer:* Who does he speak to more?
line 54
line 55 *Participant:* He speaks more to my daughter.
line 56
line 57 *Interviewer:* When he wants something does he communicate with you?
line 58
line 59 *Participant:* He talks sometimes. He is not totally quiet to himself no, no.
line 60 When he wants something he will call one of the children and ask them.
line 61 He just goes to work and comes back.
line 62
line 63 *Interviewer:* Does he drive to work?
line 64
line 65 *Participant:* Yes he drives to work and comes back.
line 66
line 67 *Interviewer:* You mentioned what you do for him, what he does in the
line 68 house. Is there anything he does to help you along?
line 69
line 70 *Participant:* He does not do much. I want him to...Before he used to do so
line 71 much, he used to make the burglar guards, he was a qualified fitter. All this
line 72 he put ... (points to windows).
line 73
line 74 *Interviewer:* Yes.
line 75
line 76 *Participant:* Now I told him to fit the burglar gate. He has all the equipment
line 77 for it in the house.
line 78
line 79 *Interviewer:* You are very proud of his work. This shows he is coping very
line 80 well.
line 81
line 82 *Interviewer:* Has he started already?
line 83
line 84 *Participant:* He wanted to start but he's waiting for the weekend when he
line 85 will have enough time.
line 86
line 87 *Interviewer:* He has about six days when he can do it.
line 88
line 89 *Participant:* He'll have enough time.
line 90
line 91 *Interviewer:* When he wants to do something, do you – does he have
line 92 motivation to do so? Do you have to remind him to do things?

- line 93 He waits for you to tell him?
- line 94
- line 95 *Participant:* No, you have to tell him to do it. When he needs a bath,
- line 96 you got to take out clean clothes for him to change. He won't take out clean
- line 97 clothes I have to do it.
- line 98
- line 99 *Interviewer:* Do you think that sometimes this is a problem for you?
- line 100
- line 101 *Participant:* Yah! You got to remind him to do things. Especially when I
- line 102 have to remind him to shave. You have to tell him what to do.
- line 103
- line 104 *Interviewer:* Alright, do you have any angry feelings about this ... what are
- line 105 your feelings about this?
- line 106
- line 107 *Participant:* Sometimes I get angry because the children will trouble you
- line 108 and he does not help, it's a bit difficult for me to see to him and the children.
- line 109
- line 110 *Interviewer:* How many children do you have?
- line 111
- line 112 *Participant:* I have three children, 2 boys and a girl.
- line 113
- line 114 *Interviewer:* How old .., what is the age of the children?
- line 115
- line 116 *Participant:* The big one is 17 and the girl is 15, my little one is 9.
- line 117 (points to child in room and asks him to go).
- line 118
- line 119 *Interviewer:* Are there other difficulties you had like eh, like eh, if you
- line 120 have to go out?
- line 121
- line 122 *Participant:* He's fine by himself. Say if I go to my mom's house he won't
- line 123 come. He likes to be alone like that, by himself.
- line 124
- line 125 *Interviewer:* Is that the reason that he is not socialising with people?
- line 126
- line 127 *Participant:* He does not talk to anyone.
- line 128
- line 129 *Interviewer:* What is nice about having him at home, when he comes
- line 130 from work. When you need help does he help you?
- line 131
- line 132 *Participant:* It's a bit difficult when you need help with the children when
- line 133 they are at each other's throats ,especially when this child
- line 134 (indicating to child in room) is here.
- line 135
- line 136 *Interviewer:* Fortunately he is not here all the time.
- line 137
- line 138 *Participant:* Yah, fortunately he is not here all the time. Especially my big
- line 139 one gets irritated with him when he worries them. He is not here when you

line 140 need help. My daughter gets upset with him.
line 141
line 142 *Interviewer*: Who talks to her, does he take the initiative?
line 143
line 144 *Participant*: Father talks to her more than he talks to me. Indicating to child
line 145 (Aroo I'm going to tell Mummy about you, today. You better go from here).
line 146
line 147 *Interviewer*: You talked to him about this.
line 148
line 149 *Participant*: He has no time for me.
line 150
line 151 *Interviewer*: When was your husband admitted to hospital?
line 152
line 153 *Participant*: End of April last year.
line 154
line 155 *Interviewer*: Did you ever have the need to be included in his treatment?
line 156 What would you say, have they kept you involved in his care?
line 157
line 158 *Participant*: Yah! When he was hospitalized Dr. Asmal, he asked for me
line 159 to be there. When ever they changed his treatment he asked me to come in
line 160 and he discussed it with both of us. Also he had an intern Dr. Vather who
line 161 also included me when he saw my husband.
line 162
line 163 *Interviewer*: Do you think you need more information to get to manage him
line 164 at home?
line 165
line 166 *Participant*: Not to manage him. The thing is that he sleeps too much.
line 167
line 168 *Interviewer*: What would you like us to help you with?
line 169
line 170 *Participant*: Not to sleep all the time during the day. 10 minutes after he had
line 171 his breakfast he goes to sleep again.
line 172
line 173 *Interviewer*: Have you ever discussed that with the sister?
line 174
line 175 *Participant*: No.
line 176
line 177 *Interviewer*: Have there been any other problems?
line 178
line 179 *Participant*: Yah! At work he was also sleeping in the car in the hot sun.
line 180
line 181 *Participant*: So now that man phoned saying that he used to even have his
line 182 tea in the car in the boiling hot sun. (child screaming in room).
line 183 I told them at the clinic and they spoke to him, the doctor said he is lucky
line 184 to get this job (child making noise in room).
line 185
line 186 *Interviewer*: So you are having some satisfaction with that problem?

line 187
line 188 *Participant: Yah!*
line 189
line 190 *Interviewer: How are you coping financially?*
line 191
line 192 *Participant: It is okay*
line 193
line 194 *Interviewer: He does not get a grant?*
line 195
line 196 *Participant: No, we manage somehow, my in-laws help also.*
line 197
line 198 *Interviewer: How does he manage when you are not here?*
line 199
line 200 *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.*
line 202
line 203 *Interviewer: So that is one thing that you would like to see change?*
line 204
line 205 *Participant: Yah! He needs to come in and help me. He won't tell them a word.*
line 207
line 208 *Interviewer: So he makes it your responsibility to talk to the children?*
line 209
line 210 *Participant: He is very quiet. Even if he is watching TV. (children making noise in background).*
line 212
line 213 *Interviewer: He does not comment on anything in terms of other activities?*
line 214
line 215 *Participant: If he wants something then he will ask the children not me.*
line 216
line 217 *Interviewer: Does he involve himself in any of the other activities like prayers?*
line 219
line 220 *Participant: Like our prayers he knows he does everything I don't have to call him, he knows what to do.*
line 222
line 223 *Interviewer: The children, when they want something do they go to him or do they come to you?*
line 225
line 226 *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.*
line 228
line 229 *Interviewer: What does he do when he is off from work say over the weekend?*
line 231
line 232 *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*
line 233

- line 234 tells me he can't do it but I know he can.
line 235
line 236 *Interviewer*: When you get angry, when the children are worrying you,
line 237 what do you do?
line 238
line 239 *Participant*: I leave them with their father but it does not bother him. When
line 240 I get angry it does not affect him. I scold the children and him and after that
line 241 feel bad.
line 242
line 243 *Participant*: Once when we went out to a funeral we left him at home and
line 244 we came back very late. He was lying down and after a while he got up and
line 245 came to the kitchen. I told him "only now you bother to ask me
line 246 all this time you never ask". I asked him why he was only coming now
line 247 to check why we came so late. He got no time for me. (Care giver had tears
line 248 running down her face as she spoke).
line 249
line 250 *Interviewer*: Here, I have some tissues. Must I carry on, will you be okay?
line 251
line 252 *Participant*: Yes I'm okay.
line 253
line 254 *Interviewer*: What would you like to change if you had the chance to change
line 255 anything?
line 256
line 257 *Participant*: There is a lot. I want him to be the way he was beforenow
line 258 he is like that, easy to take advantage of him.
line 259
line 260 *Interviewer*: What would you say ... (children making noise) is the problem?
line 261
line 262 *Participant*: Eh....he has no say in the house.
line 263
line 264 *Interviewer*: Yes.... Who has the say in the house?
line 265
line 266 *Participant*: His brother has the say, they also live here and he is
line 267 younger than him.
line 268
line 269 *Interviewer*: So in fact your husband has to listen to him?
line 270
line 271 *Participant*: Yah!
line 272
line 273 *Interviewer*: Do you think that he is a burden? You stood by him all the time.
line 274
line 275 *Interviewer*: Do you feel like you are looking after another child ?
line 276
line 277 *Participant* : Yah! It feels like that at times.
line 278
line 279 *Interviewer*: Do you have problems with him to take his tablets?
line 280 How many times did you go the clinic with him?

line 281

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

line 284

Interviewer: He is very committed to his treatment hey!

line 286

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.

line 290

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

line 293

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

line 296

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

line 300

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?

line 304

Participant: No.

line 306

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

line 308

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

line 311

Interviewer: With you?

line 313

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

line 315

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

line 317

Participant: Yah! She was upset and it worried her.
(child making noise in room).

line 320

Interviewer: How is she coping now?

line 322

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

line 324

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

line 326

Participant: But they are bright children and are doing well. They want to

- line 328 study further. That costs a lot of money.
- line 329
- line 330 *Interviewer:* Just out of curiosity does your husband drink or smoke?
- line 331
- line 332 *Participant:* He don't drink, he used to smoke. When we got married he was
- line 333 smoking I did not know only later I found out. He don't smoke now.
- line 334 (child crying making a lot of noise)
- line 335
- line 336 *Interviewer:* I will stop now, if I need more I will come back, okay.
- line 337 (child crying in room).
- line 338
- line 343 **Interview No. 2**
- line 344 Gender: Female Age: 61
- line 345
- line 346 *Interviewer:* Aunty Kay
- line 347
- line 348 *Participant:* Yes
- line 349
- line 350 *Interviewer:* Aunty Kay you say you are at home, looking after
- line 351 your daughter, what do you do?
- line 352
- line 353 *Participant:* You see in the morning when I wake up, I have to give
- line 354 clothes to bath. She won't take her own clothes from the drawer.
- line 355
- line 356 *Interviewer:* Yes.
- line 357
- line 358 *Participant:* I have to give her dress, half slip, underwear, and towel.
- line 359 She go and bath and she come out I give her medication and give her
- line 360 something to drink. She has porridge. Then I'll comb her hair, give
- line 361 her lotion everything and she is sorted out for the day.
- line 362
- line 363 *Interviewer:* And what about her meals? Do you cook for her?
- line 364
- line 365 *Participant:* Yes
- line 366
- line 367 *Interviewer:* Alright, and if you had to go anywhere? Would you leave
- line 368 her at home?
- line 369
- line 370 *Participant:* She stay with her father .
- line 371
- line 372 *Interviewer:* Her father takes care of her?
- line 373
- line 374 *Participant:* Yes. And if he go anywhere I look after her.
- line 375
- line 376 *Interviewer:* Mm And what, what things that she does at home, that

- line 377 helps you?
- line 378
- line 379 *Participant:* She mostly only set the dishes and she can help me when I
- line 380 fold the clothes, she put the clothes in the draw, like clean the vegetables
- line 381 that's all.
- line 382
- line 383 *Interviewer:* That's the
- line 384
- line 385 *Participant:* But she likes chips in the night. Sometimes I'm fast asleep.
- line 386 She's in the kitchen, she making chips.
- line 387
- line 388 *Interviewer:* She does her own cooking at that time?
- line 389
- line 390 *Participant:* Yah, she likes chips 2'o clock, 3'o clock morning.
- line 391 when she wake up and go see what she's doing.
- line 392
- line 393 *Interviewer:* Do you have any fear that she may hurt herself or....?
- line 394
- line 395 *Participant:* Yah, with the stove.
- line 396
- line 397 *Interviewer:* Do you not think may be that uh...
- line 398
- line 399 *Participant:* She don't go when she looks top, she's clever.
- line 400
- line 401 *Interviewer:* I see, I see. Side-effects, alright.
- line 402
- line 403 *Participant:* only when It's hot, she look top every week, even last night.
- line 404 She don't eat when she look top. She'll walk up and down, up
- line 405 and down. Then I give her something to drink, when I go to bed then
- line 406 she goes to bed.
- line 407
- line 408 *Interviewer:* This is difficult for you at times, at any time?
- line 409
- line 410 *Participant:* Yes and then when she gets her "suzy". She don't do
- line 411 anything for herself.
- line 412
- line 413 *Interviewer:* Mm.
- line 414
- line 415 *Participant:* I have to wash her clothes.
- line 416
- line 417 *Interviewer:* And do you remind her to go to the bathroom or anything
- line 418 like that?
- line 419
- line 420 *Participant:* Yes she goes, she goes and bath.
- line 421
- line 422 *Interviewer:* On her own?
- line 423

- line 424 *Participant:* When she don't look top but when she look top, she don't I
line 425 have to wait for her, come down, then I go give her a bath.
line 426
line 427 *Interviewer:* Have you ever mentioned that she looks up like that to the
line 428 sisters in the clinic?
line 429
line 430 *Participant:* Yah, Sister Ann knows it. Ask my husband what they
line 431 said. Balraj (calls husband into room)
line 432
line 433 *Interviewer:* Wait I'm recording there. OK, alright so what would you say?
line 434
line 435 *Participant:* The Doctor said to me, Dr Padaychee told me she had a eye
line 436 op. long time. Dr ... did the eye op and she was using glasses you see, I must
line 437 get the glasses for her and I see after that what happens to her.
line 438
line 439 *Interviewer:* What are some of the negative things that you experience
line 440 when you care for her? I know you said one of those is danger at night . You
line 441 not sure what would happen when she's at the stove and frying those
line 442 chips for herself, 2' o clock in the morning. The other one is about her
line 443 personal hygiene, when she's having her menstruation. Any other
line 444 things that you can?
line 445
line 446 *Participant:* Well I fright to leave keys, She can open the door and go way
line 447 night time and we'll be left.
line 448
line 449 *Interviewer:* Has she ever wandered away like that, and where was she?
line 450
line 451 *Participant:* Yes, she did sister. She goes away and we get worried
line 452 about her.
line 453
line 454 *Participant* Yes she's sitting in the hospital, and police Station.
line 455
line 456 *Interviewer* She gets to those places?
line 457
line 458 *Participant:* But not now Darling (referring to the researcher as darling)
line 459 it's about now 14 years. I was spending lot of money for Vimla. Then
line 460 somebody referred me to Gandhi Road.
line 461
line 462 *Interviewer :* So that was her behaviour before she went on treatment but
line 463 since then
line 464
line 465 *Participant:* She was a really fit girl. She should do everything.
line 466
line 467 *Interviewer :* How are you coping with your health, when the asthmatic
line 468 attack comes , What do you do?
line 469
line 470 *Participant:* I've got that eh... spray.

line 471
line 472 *Interviewer* : You take the pump?
line 473
line 474 *Participant*: Yes I keep the spray in the morning and in the night and I
line 475 take my tablets.
line 476
line 477 *Interviewer*: So you still can cope?
line 478
line 479 *Participant* : I can still cope . Only one time I didn't breathe because my
line 480 lungs didn't have no air , my daughter in law rushed me the hospital but
line 481 now I'm alright .
line 482
line 483 Interviewer: OK.
line 484
line 485 *Participant* : See every month they treat me in the hospital, check me.
line 486
line 487 *Interviewer* : How do you feel about having to look after her for so many
line 488 years of your life and its still not going to end, its going to carry on?
line 489
line 490 *Participant* : It's going to carry on but I said, Sister Ann said, we must
line 491 make up our mind up to leave her there in the hostel but now it felt so heart
line 492 sore .
line 493
line 494 *Interviewer* : Which hostel? Pathmavathi Pillay homes?
line 495
line 496 *Participant*: Yes
line 497
line 498 *Interviewer* : I see. What did you decide?
line 499
line 500 *Participant*; But she don't do things for herself, how she's manage
line 501 you tell me?
line 502
line 503 *Interviewer* : How does it make you feel?
line 504
line 505 *Participant*: Oh I feel sad. Doctor said we can't let go. He saying
line 506 that's our problem, Dr Padayachee.
line 507
line 508 *Interviewer*: Mm.... difficult.
line 509
line 510 *Participant* : No but I said while we living we'll take care of her..
line 511 When we can't manage then Sister Ann said must come to her.
line 512
line 513 *Interviewer*: So it's the decision you've made?
line 514
line 515 *Participant*: Yes.
line 516
line 517 *Interviewer* : Mm ...when you're sometimes upset about all these things,

line 518 about having to worry about her , look after her. How do you cope? What
line 519 do you do to relieve yourself of all that stress. Do you pray? Do you
line 520 read?
line 521
line 522 *Participant* : I pray, but I smoke Sister. Since Vimla got sick so it's 34
line 523 years that I smoke.
line 524
line 525 *Interviewer*: So that relieves.....
line 526
line 527 *Participant*: That relieves me, yes, calms me down.
line 528
line 529 *Interviewer*: Calms you down.
line 530
line 531 *Participant* : Yes otherwise I can get very sick.
line 532
line 533 *Interviewer*: How many do you smoke?
line 534
line 535 *Participant* : Not lot, say about 5.
line 536
line 537 *Interviewer*: It's not a routine thing with you or it's everyday
line 538
line 539 *Participant*: Every day.
line 540
line 541 *Interviewer*: Every day, alright, Mmm, that works for you?
line 542
line 543 *Participant*: That works for me.
line 544
line 545 *Interviewer*: You said thathave you ever been admitted?
line 546
line 547 *Participant* : In hospital?
line 548
line 549 *Interviewer*: Yes.
line 550
line 551 *Participant* : I was admitted for brain operation. It's a very long op; the
line 552 children wasn't married and I had a break in my wrist. I went for the op and
line 553 my teeth too Dr Rathi operated all because I couldn't take out one
line 554 tooth I used to faint.
line 555
line 556 *Interviewer* : So at that time they helped you?
line 557
line 558 *Participant*: No my in-laws was with me that time and my mother.
line 559 But now when we do work we share the work my daughter- in – law, I
line 560 and the maid.
line 561
line 562 *Interviewer*: Are there any times when you (screaming in the back
line 563 ground). (Words drowned out due to noise.....) do you take her ?
line 564

line 565 *Participant:* Her father take her.
line 566
line 567 *Interviewer:* Her Dad?
line 568
line 569 *Participant:* Yes.
line 570
line 571 *Interviewer:* Oh.
line 572
line 573 *Participant:* Father take her and bring her
line 574
line 575 *Interviewer:* Have you ever got the Sisters to sit down and explain anything
line 576 to him? When he goes there what happens?
line 577
line 578 *Participant:* Yes Sister Ann, she explained . Sister Ann. Yes.
line 579
line 580 *Interviewer:* Do you feel sometimes it is just too much for you?
line 581
line 582 *Participant:* Never. No I cope up Sister.
line 583
line 584 *Interviewer :* You cope, and previously there's I think, there's lot of
line 585 people that they look after sick people, they've been applying for the
line 586 money, state gives them R200.00.
line 587
line 588 *Interviewer:* Yes, yes.
line 589
line 590 *Participant:* When we went and they didn't give us they said she's not.
line 591 sick. You Know. Sister Ann even wrote a letter.
line 592
line 593 *Interviewer* When did you last speak to Sister Ann ?
line 594
line 595 *Participant:* About the money, to look after her?
line 596
line 597 *Interviewer:* Yes.
line 598
line 599 *Participant:* It's, eh, It' s oh I'd say it's about 5 - 6 months, 5 - 6 months.
line 600
line 601 *Interviewer:* Would you like to try that again?
line 602
line 603 *Participant:* Yes I want to try again.
line 604
line 605 *Interviewer:* Keep trying you never know you might be lucky.
line 606
line 607 *Participant:* OK.
line 608
line 609 *Interviewer* What was the worst thing you have experienced having to
line 610 look after her, the worst thing?
line 611

line 612 *Participant:* Mm, what I must tell you , you see when I usually wash all
line 613 her clothes .
line 614
line 615 *Interviewer:* I know you mentioned

line 616
line 617 *Participant:* Yah, that because maids don't do that I . I have to rinse it,
line 618 put surf, soap and wash her clothes. It's every month.
line 619
line 620 *Interviewer:* Once a month during that period of time?
line 621
line 622 *Participant:* Yes, yes.
line 623
line 624 *Interviewer:* Was she ever admitted to hospital?
line 625
line 626 *Participant:* There was one, admitted in Durban Hospital when she
line 627 had her wisdom teeth in which hospital? In Durban? (asking relative to
line 628 assist in her response)
line 629
line 630 *Interviewer:* But not a psychiatric hospital?
line 631
line 632 *Participant:* No, it was in town hospital.
line 633
line 634 *Interviewer:* When was that? How long ago?
line 635
line 636 *Participant:* Town hospital, she was bad that time. Long time, sister
line 637 when we put her in town hospital she used to scream. She should bang her
line 638 head on the wall. She was very sick I can tell you.
line 639
line 640 *Interviewer:* So the medication has helped her?
line 641
line 642 *Participant:* The medication helped . They even did a brain scan on
line 643 her. The brain scan shows nothing wrong. Dr Padaychee is treating her now
line 644 for the schizophrenia and depression.
line 645
line 646 *Interviewer:* Mm have they given you enough information have they
line 647 given you enough information on treatment, diagnosis?
line 648
line 649 *Participant:* Yes, after she was in Town Hill hospital. She was very fine
line 650 when we brought her at home. Ask my daughter in law. She relapsed again.
line 651 Isn't?
line 652 *Interviewer:* What did you say she relapsed because
line 653
line 654 *Participant:* She was doing very well.
line 655
line 656 *Interviewer:* And after that how long that she got sick again?
line 657
line 658 *Interviewer:* (daughter in law) The medication..., wasn't giving her

line 659 properly.
line 660 That's why she got sick.
line 661
line 662 *Interviewer*: Oh I see. Alright.
line 663
line 664 *Participant*: But the tablets is helping her , I won't talk lies she is
line 665 better than what she was.
line 666
line 667 *Interviewer*: Alright, think I got most of the information I need.
line 668 I'm going to stop there. If I need more I will contact you...
line 669
line 670 *Participant*: Yes.
line 671

line 679 **Interview No. 3**

line 680 Gender: Female Age: 71
line 681 *Interviewer*: Mom can we start?
line 682
line 683 *Participant*: Yes.
line 684
line 685 *Interviewer*: Mom there's questions here, in front of you look in
line 686 front, so you can read it. OK – tell me what sort
line 687 of things you do when you care for your son?
line 688
line 689 *Participant*: It is a long story.
line 690
line 691 *Interviewer*: Mm.
line 692
line 693 *Participant*: I do his washing.
line 694
line 695 *Interviewer*: Mm, do you also have to dish his food for him?
line 696
line 697 *Participant*: Yes I dish food for him.
line 698
line 699 *Interviewer*: Do you have to remind him to do anything?
line 700
line 701 *Participant*: He's very forgetful sometimes.
line 702
line 703 *Interviewer*: What does he forget?
line 704
line 705 *Participant*: Because
line 706
line 707 *Interviewer*: What does he forget?
line 708
line 709 *Participant*: He forget, like the soap he leave in the bath water
line 710

line 711 Interviewer: Mm.
line 712
line 713 *Participant:* What else, sometimes I switch off the geyser and sometimes
line 714 he forgot to put it on.
line 715
line 716 *Interviewer:* When you say you cook for him and wash his cloths for
line 717 him, do you not have any assistance like somebody at home to work?
line 718
line 719 *Participant:* No, I do it myself.
line 720
line 721 *Interviewer:* You do everything yourself?
line 722
line 723 *Participant:* Yah
line 724
line 725 *Interviewer:* Alright, but if you were sick and somebody needed to
line 726 care for him because you wouldn't be able to wash and cook?
line 727
line 728 *Participant:* I haven't been through that situation.
line 729
line 730 *Interviewer:* I remember when I came in you mentioned that you had high
line 731 blood pressure?
line 732
line 733 *Participant:* Yes.
line 734
line 735 *Interviewer:* How long have you had high blood pressure?
line 736
line 737 *Participant:* Um, just some time, this year now.
line 738
line 739 *Interviewer:* This past year, alright.
line 740
line 741 *Interviewer:* And do you go to clinic and collect some tablets for that
line 742
line 743 *Participant:* Yes – had gone to the doctor first.
line 744
line 745 *Interviewer:* You haven't had any other problems?
line 746
line 747 *Participant:* No.
line 748
line 749 *Interviewer:* OK – so far what is the most difficult for you to do when it
line 750 comes to caring for your son?
line 751
line 752 *Participant:* He co-operates with me very well.
line 753
line 754 *Interviewer:* So you don't have any difficult situations with him?
line 755
line 756 *Participant:* Yes.
line 757

- line 758 *Interviewer:* So what is he involved in at home, what does he do for you?
- line 759
- line 760 *Participant:* He dust the furniture for me.
- line 761
- line 762 Interviewer: Mm.
- line 763
- line 764 *Participant:* Sometimes I tell him to sweep, vacuum the floor, he does it for me.
- line 765
- line 766
- line 767 *Interviewer:* So he is not upset that he has to do this every day?
- line 768
- line 769 *Participant:* No not upsetting.
- line 770
- line 771 *Interviewer:* Oh, every evening you have extra company?
- line 772
- line 773 *Participant:* No extra company, because he does not talk.
- line 774
- line 775 *Interviewer:* OK, has there been any difficulty that he has experienced that had impacted / influenced you?
- line 776
- line 777
- line 778 *Participant:* No really – walking down there going to the clinic
- line 779
- line 780 *Interviewer:* Has that been a problem?
- line 781
- line 782 *Participant:* Yes – he get very tired when he comes from there.
- line 783
- line 784 *Interviewer:* How many days is that?
- line 785
- line 786 *Participant:* Just twice a week.
- line 787
- line 788 *Interviewer:* Just twice?
- line 789
- line 790 *Participant:* Yah
- line 791
- line 792 *Interviewer:* Which days?
- line 793
- line 794 *Participant:* Mondays and Wednesdays.
- line 795
- line 796 *Interviewer:* Mm – and that been very helpful for him?
- line 797
- line 798 *Participant:* Because he does something.
- line 799
- line 800 *Interviewer:* Has that been helpful for him?
- line 801
- line 802 *Participant:* For him, yes he takes some work and he take some tablets.
- line 803
- line 804 *Interviewer:* Taking about tablets – do you know what is wrong with him?

line 805
line 806 Participant: Yes.
line 807
line 808 *Interviewer:* And do you know what tablets he takes?
line 809
line 810 Participant: Yes.
line 811
line 812 *Interviewer:* And do you know what time he take those tablets?
line 813
line 814 Participant: Yes – he takes 1 a day.
line 815
line 816 *Interviewer:* OK, has he had any like side-effects from those tablets that you
line 817 had to report to sister?
line 818
line 819 Participant: Mm, these things effect by making him sleepy from way back
line 820 then and he is grumpy all the time.
line 821
line 822 Interviewer: Yeah.
line 823
line 824 Participant: Then when I went down to the clinic I told doctor to change
line 825 the tablets
line 826
line 827 *Interviewer:* So you do go down with him?
line 828
line 829 Participant: Yah not always.
line 830
line 831 *Interviewer:* How often?
line 832
line 833 Participant: Not always because it distance to walk for me.
line 834
line 835 *Interviewer:* Mm, if you had to go down with him, do you go down the days
line 836 when he has to speak to doctor or any time?
line 837
line 838 Participant: I went couple of times with him when he saw doctor.
line 839
line 840 *Interviewer:* Alright, because he sees doctor every six
line 841 months.
line 842
line 843 Participant: Yeah.
line 844
line 845 *Interviewer:* Is there anything that the clinic can do for you to help
line 846 look after him better than what you are doing now?
line 847
line 848 Participant: I am quite comfortable taking care of him.
line 849
line 850 *Interviewer:* Mm, and is there anything more they can explain about
line 851 his illness?

line 852
line 853 *Participant:* Yes they did explain in the beginning.
line 854
line 855 *Interviewer:* Mm, do you need any more information about his illness or
line 856 and how to cope?
line 857
line 858 *Participant:* At the clinic .
line 859
line 860 *Interviewer:* Mm from the sisters or doctor?
line 861
line 862 *Participant:* Yah in the beginning but now he's stable.
line 863
line 864 *Interviewer:* He's stable, so you are coping very well?
line 865
line 866 *Participant:* Yah.
line 867
line 868 *Interviewer:* You said to me earlier on that sometimes he's forgetful, what
line 869 have you done to deal with the situation? What have you done to help him
line 870 remember things, because you said that he leaves the soap in the bath.
line 871 He's forgetful in this way?
line 872
line 873 *Participant:* Yeah.
line 874
line 875 *Interviewer:* Have you tried reminding him when he...
line 876
line 877 *Participant:* I remind him.
line 878
line 879 *Interviewer:* Yes.
line 880
line 881 *Participant:* But still he forget.
line 882
line 883 *Interviewer:* OK.
line 884
line 885 *Participant:* And I got something for energy and strength. for him to drink.
line 886
line 887 *Interviewer:* Yes...
line 888
line 889 *Participant:* I've got a health syrup and he's taking that.
line 890
line 891 *Interviewer:* Yes, has it helped him in anyway?
line 892
line 893 *Participant:* He just been drinking that, I started giving him that recently.
line 894
line 895 *Interviewer:* So you can see a difference?
line 896
line 897 *Participant:* Yeah I can see a difference.
line 898

- line 899 *Interviewer*: Why is he experiencing low energy, was he feeling weak and
line 900 stiff previously ?
line 901
line 902 *Participant*: Yes, he said he feels weak.
line 903
line 904 *Interviewer*: Yes from when?
line 905
line 906 *Participant*: Yeah a while now.
line 907
line 908 *Interviewer*: Have you brought this to the doctor's attention or told sister in
line 909 the clinic
line 910
line 911 *Participant*: Yes.
line 912
line 913 *Interviewer*: What did they say about it?
line 914
line 915 *Participant*: They did the same check-up.
line 916
line 917 *Interviewer*: Can you remember what they said?
line 918
line 919 *Participant*: Yes.
line 920
line 921 *Interviewer*; OK, when you go back again would you remember to remind
line 922 them that he has low energy and that is the reason why sometimes he doesn't
line 923 do things at home correctly?
line 924
line 925 *Participant*: Yes.
line 926
line 927 *Interviewer*: OK, I want to come back, has been difficult for you
line 928 to cope looking after him financially?
line 929
line 930 *Participant*: Financially it is difficult but we are coping what else can we
line 931 do?
line 932
line 933 *Interviewer*: Mm.
line 934
line 935 *Participant*: Yah it is difficult.
line 936
line 937 *Interviewer*: I noticed there's only two of you, so you've lost your
line 938 husband?
line 939
line 940 *Participant*: Yeah, seventeen years.
line 941
line 942 *Interviewer*: Seventeen years and any brothers / sisters that he has?
line 943
line 944 *Participant*: He got a sister in Jo'burg.
line 945

- line 946 *Interviewer:* Oh, so how he doesn't see her very often.
- line 947
- line 948 Participant: Yah
- line 949
- line 950 *Interviewer:* OK, does he go up to Johannesburg to visit her?
- line 951
- line 952 Participant: He went twice.
- line 953
- line 954 Interviewer: Yes.
- line 955
- line 956 Participant: He won't now, he goes to the clinic and therapy, can't see him
- line 957 go to Jo'burg now.
- line 958
- line 959 *Interviewer:* Is it the medication that you are worried about?
- line 960
- line 961 Participant: Medication can get here. He have to go to the OT and he'll
- line 962 miss all that.
- line 963
- line 964 Interviewer: Mm.
- line 965
- line 966 Participant: Yeah, if it a holiday then only.
- line 967
- line 968 *Interviewer:* Like in December?
- line 969
- line 970 Participant: Yah
- line 971
- line 972 *Interviewer:* Or maybe she comes down and give you a break?
- line 973
- line 974 Participant: She comes, not often.
- line 975
- line 976 *Interviewer:* Not often, is she married and settled there?
- line 977
- line 978 Participant: She's married
- line 979
- line 980 *Interviewer:* OK, do have any break from looking after him at home, do
- line 981 you have a break?
- line 982
- line 983 Participant: I don't really, um
- line 984
- line 985 *Interviewer:* Can I assume that you...?
- line 986
- line 987 Participant: Like one of my nephew is here.
- line 988
- line 989 Interviewer: Yes ...
- line 990
- line 991 Participant: So he takes care of him like while I'm not here.
- line 992

line 993 Interviewer: Mm.
line 994
line 995 *Participant:* Yah, it is easier for him.
line 996
line 997 *Interviewer:* OK, I see you as quite involved making beads and key
holders.
line 999
line 1000 *Participant:* Yes.
line 1001
line 1002 *Interviewer:* Does that give you some way of also coping with your stress?
line 1003
line 1004 *Participant:* Yes.
line 1005
line 1006 Interviewer: Mm.
line 1007
line 1008 *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.
line 1010
line 1011 Interviewer: Yes.
line 1012
line 1013 *Participant:* They're making this nearly about 40,000.
line 1014
line 1015 Interviewer: So lots of people are doing it?
line 1016
line 1017 *Participant:* Yah lots of people are doing it, so I'm giving this time to do it.
line 1018
line 1019 Interviewer: but does it gives you a feeling of great peace and?
line 1020
line 1021 *Participant:* Yes that feeling yes, Yah I got something to do you know.
line 1022
line 1023 Interviewer: Yes, alright now one last question. Is there any way that you
think that you would want help in the future for anything?
line 1024
line 1025
line 1026 *Participant:* Like what (phone ring, answers phone).
line 1027
line 1028 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?
line 1029
line 1030
line 1031
line 1032 *Participant:* When it comes to the future I need to, you know, what I
line 1033
line 1034 Interviewer: What would you like him to know, maybe something to
learn, a skill maybe?
line 1035
line 1036
line 1037 *Participant:* He must say "I want to do something".
line 1038
line 1039 Interviewer: Mm.

line 1040
line 1041 *Participant:* And he must go for it.
line 1042
line 1043 *Interviewer:* OK, what is he presently interested in at the moment?
line 1044
line 1045 *Participant:* He just plays with the computer that's all.
line 1046
line 1047 *Interviewer:* And are there any other jobs that he can do? Any jobs?
line 1048
line 1049 *Participant:* No.
line 1050
line 1051 *Interviewer:* Nothing.
line 1052
line 1053 *Participant:* No.
line 1054
line 1055 *Interviewer:* Has he learned anything from OT?
line 1056
line 1057 *Participant:* OT's work he does there, but he makes things. He makes cards.
line 1058
line 1059 *Interviewer:* He must think about that by using the computer. Thank you,
line 1060 for spending time sharing information with me. I want to say that if I
line 1061 have a problem and or if I need to come back and clarify what you are
line 1062 asking me or telling me in my interview I'll come back, thank you very
line 1063 much.
line 1064
line 1065 *Participant:* Thank you, sister.
line 1066

line 1077 **Interview No 4**

line 1078 Gender: Female Age: 57
line 1079
line 1080 *Interviewer:* OK, let's begin, alright, I just want you to tell me, what you do
line 1081 when you care for your son? What sort of things do you do?
line 1082
line 1083 *Participant:* OK, I do cook for him I make sure that he eats healthy. I
line 1084 make tea for him and I....
line 1085
line 1086 *Interviewer:* What else do you do?
line 1087
line 1088 *Participant:* And I also take care in other ways, that he must have a bath,
line 1089 he must shave, he must have a haircut and he must be neat and tidy.
line 1090
line 1091 *Interviewer:* OK carry on?
line 1092
line 1093 *Participant:* And, I love my son and I like making and doing things
line 1094 for him and I always ask him if anything wrong you know what I mean.

line 1095 I mean I will ask him what he needs for the day because I must do this
line 1096 before I go anywhere, like if he need something you know and yah it
line 1097 just carry on like that.
line 1098

line 1099 *Interviewer:* Do you have to remind him to do certain things or he
line 1100 does it on his own?
line 1101

line 1102 *Participant:* No I have to remind him at times, there is time that he
line 1103 remembers certain things to be done on his own, there are times when I tell
line 1104 him because he forgot. I told him certain things to do during the day, it's not
line 1105 done and he never do it because he does forget.
line 1106

line 1107 *Interviewer:* Alright, so the cooking and seeing to his hygiene first is done.
line 1108 What else do you do in caring for him? Who sees to his washing and clothes.
line 1109 Do you take care of this. Does he only stay at home or does he go out?
line 1110

line 1111 *Participant:* I do the washing and clothes and...
line 1112

line 1113 *Participant:* No he doesn't, he stays at home unless I want him to go out.
line 1114 He just go to the shop and just buy bread and milk.
line 1115

line 1116 *Interviewer:* Does he attend any workshop or meeting like that?
line 1117

line 1118 *Participant:* He goes to Ghandi Road assessment centre or the clinic only.
line 1119

line 1120 *Interviewer:* Is that where he works making certain things?
line 1121

line 1122 *Participant:* Yes, he goes on his own.
line 1123

line 1124 *Interviewer:* How many days in the week?
line 1125

line 1126 *Participant:* Two days in a week.
line 1127

line 1128 *Interviewer:* Which days are those?
line 1129

line 1130 *Participant:* Now it changes, it's Monday and Wednesday.
line 1131

line 1132 *Interviewer:* OK. What are the nice things you experienced of having
line 1133 him at home for you. What does he do that you can rely on him or are
line 1134 you finding it a nice experience having him at home with you?
line 1135

line 1136 *Participant:* OK, there was the case that he should just go away to
line 1137 his father but I was missing him a lot, but now I'm happy that he's at home.
line 1138 And when I come home I feel very happy but I'm getting old, I don't know
line 1139 later stage if I get sick or anything happen to me or whatever maybe in time
line 1140 I will need someone who can take care of him like as a mother, how I do it.
line 1141

- line 1142 *Interviewer:* This concerns or worries you?
- line 1143
- line 1144 *Participant:* Worries me a lot, yes.
- line 1145
- line 1146 *Interviewer:* You said that sometimes he's at home, this reassures you.
- line 1147 He gives you lot of company, provide you with company during the day?
- line 1148
- line 1149 *Participant:* Yes he does.
- line 1150
- line 1151 *Interviewer:* He could talk to you about anything?
- line 1152
- line 1153 *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.
- line 1154
- line 1155
- line 1156 *Interviewer:* What are difficult things that you coping with?
- line 1157
- line 1158
- line 1159 *Participant:* Well he's the only child like, you know, the other is okay.
- line 1160 I find it very hard because we have to manage with everything.
- line 1161
- line 1162 *Interviewer:* I remember that you mentioned that he attends the workshop,
- line 1163 how does he get there?
- line 1164
- line 1165 *Participant:* Oh he takes a walk.
- line 1166
- line 1167 *Interviewer:* It's quite a long distance?
- line 1168
- line 1169 *Participant:* Yes.
- line 1170
- line 1171 *Interviewer:* Are you not concerned about this?
- line 1172
- line 1173 *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.
- line 1174
- line 1175
- line 1176 *Interviewer:* OK, what about shopping?
- line 1177
- line 1178 *Participant:* He goes when I need something like if I give him a list.
- line 1179
- line 1180 *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?
- line 1181
- line 1182
- line 1183
- line 1184 *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.
- line 1185
- line 1186
- line 1187
- line 1188 *Interviewer:* Yes....

line 1189

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line 1194

line 1195

line 1196

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line 1198

line 1199

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line 1203

line 1204

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.

Interviewer: Yeah.

line 1236

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line 1280

line 1281

line 1282

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.

line 1283
line 1284 *Interviewer:* Are these only from the clinic?
line 1285
line 1286 *Participant:* Yes. Five months I only collect my medication.
line 1287
line 1288 *Interviewer:* From clinic, alright, ok, has that been stable for you so far?
line 1289
line 1290 *Participant:* Yes it's quite long now that I've had an attack.
line 1291
line 1292 *Interviewer:* So you have been fairly well?
line 1293
line 1294 *Participant:* Yah.
line 1295
line 1296 *Interviewer:* Alright, is there any question that you want to ask me while we
line 1297 are talking now, any question you want to ask me?
line 1298
line 1299 *Participant:* You know that I am willing to answer your questions and
line 1300 you can phone me if you need any more information. Maybe you can give
line 1301 me advice you know, what to do whenever I need your help in the future
line 1302 when I have problems.
line 1303
line 1304 *Interviewer:* You're welcome.
line 1305
line 1306 *Participant:* Yah that's all.
line 1307
line 1308 I'll stop there.
line 1309

line 1317 **Interview No 5**

line 1318 Gender: Female Age: 54
line 1319
line 1320 *Interviewer:* Alright, can we start now?
line 1321
line 1322 *Participant:* OK.
line 1323
line 1324 *Interviewer:* Alright, when you say you care for your son, what do you do
line 1325 when you care for your son?
line 1326
line 1327 *Participant:* We give him food, we wash clothes, we see that he's neat.
line 1328
line 1329 *Interviewer:* Yes, When you say we who else helps you?
line 1330
line 1331 *Participant:* My daughter helps me when I go anywhere.
line 1332
line 1333 *Interviewer:* Yes, you mention here that you give him his food, who is the
line 1334 one that actually prepares his food?

line 1335
line 1336 *Participant:* I prepare it.
line 1337
line 1338 *Interviewer:* Everyday that's your responsibility?
line 1339
line 1340 *Participant:* Yes.
line 1341
line 1342 *Interviewer:* Alright, and about his clothes you mention that you see that
line 1343 he dressed properly?
line 1344
line 1345 *Participants:* Yah I wash every day.
line 1346
line 1347 *Interviewer:* Mm.
line 1348
line 1349 *Participant:* Sometimes the girls hardly wash.
line 1350
line 1351 *Interviewer:* Mm
line 1352
line 1353 *Participant:* When it happen I have to go to somewhere.
line 1354
line 1355 *Interviewer:* When you say the girls you mean your daughters?
line 1356
line 1357 *Participant:* Yes.
line 1358
line 1359 *Interviewer:* So they do care for him also?
line 1360
line 1361 *Participant:* Yes they care for him.
line 1362
line 1363 *Interviewer:* Alright what are things do you do for him besides the
line 1364 cooking and seeing to his clothes, his meals, do you watch over his safety
line 1365 and check where he goes, what he does? Do you go with him to the clinic?
line 1366
line 1367 *Participant:* Yes, I go with him.
line 1368
line 1369 *Interviewer:* Mm.
line 1370
line 1371 *Participant:* And he's home early, he don't go anywhere.
line 1372
line 1373 *Interviewer:* Yes, so you keep a check, he doesn't go out of the house in
line 1374 the night?
line 1375
line 1376 *Participant:* Yes.
line 1377
line 1378 *Interviewer:* Are there any time that things became difficult for you?
line 1379
line 1380 *Participant:* Yes it was.
line 1381

- line 1382 *Interviewer:* Did it involve your son and caring for him?
- line 1383
- line 1384 *Participant:* Yes it was.
- line 1385
- line 1386 *Interviewer:* What would you say those difficult times were?
- line 1387
- line 1388 *Participant:* Financial problems
- line 1389
- line 1390 Interviewer: Mm
- line 1391
- line 1392 *Participant:* He was demanding his money from me and his father.
- line 1393
- line 1394 *Interviewer:* How do you really manage when this happens?
- line 1395
- line 1396 *Participant:* We collect grant for my son and also collect every time for us.
- line 1397
- line 1398
- line 1399 *Interviewer:* You are collecting just for physical illnesses how did
- line 1400
- line 1401 *Participant:* Every month I go there to check my blood pressure.
- line 1402
- line 1403 *Interviewer:* The grant helps you with the financial problems.
- line 1404 and that helps you to cope. So remind me of times when you don't have
- line 1405 money. Does he take away his money from you?
- line 1406
- line 1407
- line 1408 *Participant:* It helps a lots, yes but...
- line 1409
- line 1410 *Interviewer:* So financially it is a problem for you to refuse him money?
- line 1411
- line 1412 Participant: Yes.
- line 1413
- line 1414 *Interviewer:* What are the difficult things that he does at home, any other
- line 1415 difficulties that you can't manage?
- line 1416
- line 1417 *Participant:* When he comes home he wants money, he eats and messes.
- line 1418
- line 1419 *Interviewer:* How do you cope with that?
- line 1420
- line 1421 *Participant:* He won't go so we had to give it to him and then he go.
- line 1422
- line 1423 Interviewer: Mm.
- line 1424
- line 1425 *Participant:* We give it to him to go out, calm himself, come back,
- line 1426
- line 1427 *Interviewer:* Mm, when you have this difficult moment, how do you
- line 1428 actually deal with it? Do you leave him, ignore him, what do you do?

- line 1429
line 1430 *Participant:* We can't ignore him because you know he just want it.
line 1431
line 1432 *Interviewer:* So he put a demand on you for his money?
line 1433
line 1434 *Participant:* Yes.
line 1435
line 1436 *Interviewer:* Alright, and so you just have to listen and be obliging?
line 1437
line 1438 *Participant:* Yes we have to do that.
line 1439
line 1440 *Interviewer:* Alright then what is a nice thing about having him at home,
line 1441 let me give you an example, sweep the floor or iron his clothes?
line 1442
line 1443 *Participant:* No he doesn't do all that.
line 1444
line 1445 *Interviewer:* Nothing at all?
line 1446
line 1447 *Participant:* Yes.
line 1448
line 1449 *Interviewer:* So you think there is really no benefit of having him at home?
line 1450
line 1451 *Participant:* No.
line 1452
line 1453 *Interviewer:* Does it worry you about his safety and what could happen to
line 1454 him?
line 1455
line 1456 *Participant:* I worry but what can I do he does not listen to us.
line 1457
line 1458 *Interviewer:* Okay, can I say that it has been really difficult looking
line 1459 after him.
line 1460
line 1461 *Participant:* What has made it easier to look after him, having company or
line 1462 the others helping you?
line 1463
line 1464 *Participant:* Others help. Like if he can, at least look after himself .
line 1465
line 1466 *Interviewer:* Yes.
line 1467
line 1468 *Participant:* Yah.
line 1469
line 1470 *Interviewer:* Yes.
line 1471
line 1472 *Participant:* You know all that stuff he's taking is not good.....!
line 1473
line 1474 *Interviewer:* So he's able to do things for himself, you are not looking after
line 1475 him 100%?

- line 1476
line 1477
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line 1520
line 1521
line 1522
- 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!

line 1523
line 1524
line 1525
line 1526
line 1527
Participant: To keep away from them because now with his condition he has to be at home.

line 1528
Interviewer: Is he taking any medication?

line 1529
Participant: He used to take one tablet in the evening.

line 1530
line 1531
Interviewer: How is he with that?

line 1532
Participant: One is not helping so they give him the injection.

line 1533
line 1534
line 1535
Interviewer: Has he stopped taking it or has he continued?

line 1536
line 1537
Participant: Yah every month he goes for the injection.

line 1538
line 1539
Interviewer: Taking one injection only per month now, and one tablet?

line 1540
line 1541
Participant: Yah.

line 1542
line 1543
Interviewer: Have you ever been to the clinic with him?

line 1544
line 1545
Participant: Yah when he goes I go with him

line 1546
line 1547
Interviewer: Have you told them about his behaviour?

line 1548
line 1549
Participant: Yes.

line 1550
line 1551
Interviewer: Did doctor explain to you what was wrong with him?

line 1552
line 1553
Participant: Yah it was the drugs.

line 1554
line 1555
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?

line 1556
line 1557
Participant: Yes they told us.....

line 1558
line 1559
Interviewer: Has he been to Town Hill and then discharged the clinic?

line 1560
line 1561
Participant: Yes, Ghandi Road.

line 1562
line 1563
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?

line 1564
line 1565
line 1566
line 1567
Participant: No nothing.

line 1568
line 1569

- line 1570 *Interviewer:* Have you discussed anything that you are concerned
line 1571 about with the sisters?
line 1572
line 1573 *Participant:* Yes every month they talk to us and him.
line 1574
line 1575 *Interviewer:* When you go there do they include you in the interview also?
line 1576
line 1577 *Participant:* If there is any problems they ask me you know, and go to talk
line 1578 to him also.
line 1579
line 1580 *Interviewer:* Mm, has the doctor been able to talk to you at any
line 1581 time?
line 1582 *Participant:* Yes he talk to us.
line 1584
line 1585 *Interviewer:* How often is that?
line 1586
line 1587 *Participant:* Every six months
line 1588
line 1589 *Interviewer:* Yes, so on the monthly visit the sisters speaks to you and
line 1590 then once in six months doctor speaks to you.
line 1591
line 1592 *Participant:* Yah.
line 1593
line 1594 *Interviewer:* Alright.
line 1595
line 1596 *Participant:* But if there is a problem before 6 months then they let
line 1597 him talk to the doctor, they let us even talk to the doctor.
line 1598
line 1599 *Interviewer:* Alright, has it ever happened that you needed to talk to the
line 1600 doctor before six months?
line 1601
line 1602 *Participant:* Yah it happened I think once.
line 1603
line 1604 *Interviewer:* What happened then, what was the situation?
line 1605
line 1606 *Participant:* He wasn't taking his tablet, he wanted to stop it.
line 1607
line 1608 *Interviewer:* OK.
line 1609
line 1610 *Participant:* He spoke to the doctor and he said no, he must carry on.
line 1611
line 1612 *Interviewer:* Alright, mum is there any question you want to ask
line 1613 me, anything you want to ask me?
line 1614
line 1615 *Participant:* If I think of anything I can call you
line 1616

line 1617 *Interviewer:* You can tell your daughter to phone me and...

line 1618

line 1619 *Participant:* I'll phone you.

line 1620

line 1621 *Interviewer:* Alright.

line 1622

line 1623 *Participant:* I like someone to do a home visit cause he's not supposed to go out of the house.

line 1624

line 1625

line 1626 *Interviewer:* Has the sister ever suggest that he go to AA or SANCA?

line 1627

line 1628 *Participant:* SANCA he refused. I did try before he went to Town Hill and he was not willing...

line 1629

line 1630

line 1631 *Interviewer:* There's also a drug facility where they can go, ever thought of sending him there, the rehab centre?

line 1632

line 1633

line 1634 *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....

line 1635

line 1636

line 1637

line 1638 *Interviewer:* You look very tired, are you tired?

line 1639

line 1640 *Participant:* I am doing this room you know we had put in a new lino mat.

line 1641

line 1642 *Interviewer:* You must be tired, you and the girls did this?

line 1643

line 1644

line 1645 *Participant:* Yah we did that.

line 1646

line 1647

line 1648 *Interviewer:* They are very good, they help you a lot.

line 1649

line 1650 *Participant:* They are very helpful, Yah.

line 1651

line 1652 *Interviewer:* How do they help their brother do they talk to him?

line 1653

line 1654 *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

line 1655

line 1656 *Interviewer:* Are they both working?

line 1657

line 1658 *Participant:* Both working.

line 1659

line 1660 *Interviewer:* OK, so if anything happens to you so they will take responsibility for their brother

line 1661

line 1662 *Participant:* Yah?

line 1663

line 1664 *Interviewer:* And your husband, what are his thoughts? Is he
line 1665 supportive in looking after him?
line 1666
line 1667 *Participant:* Yah he looking after him at home.
line 1668
line 1669 *Interviewer:* So both of you are caring for him?
line 1670
line 1671 *Participant:* Yah because he's old he's 68.
line 1672
line 1673 *Interviewer:* 68 and well?
line 1674
line 1675 Participant: Yes.
line 1676
line 1677 *Interviewer:* So you got no questions to ask me, I can switch off the
line 1678 Recorder?
line 1679
line 1680 *Participant:* No questions.
line 1681

line 1686 **Interview No 6**

line 1687 Gender: Female Age: 56
line 1688
line 1689 *Interviewer:* Can we start?
line 1690
line 1691 Participant: Yes.
line 1692
line 1693 *Interviewer:* Alright, Mum you are living alone with your son and he goes
line 1694 to Ghandi Road clinic for treatment. Can you tell me what you do for your
line 1695 son at home?
line 1696
line 1697 *Participant:* I do quite a few things for him because he lives with me.
line 1698 I like to make sure that I cook his meals and he has proper meals.
line 1699 I make sure his cloths are always washed and they are clean.
line 1700 all the time and I like um to make sure that if he is not feeling so well I can
line 1701 take him to the doctor so that he's attending, in case he get the flu or
line 1702 anything and make sure that he get his treatment for that and also for
line 1703 treatment from the clinic. I make sure he is collecting his medication
line 1704 and goes on time for his injection, because the clinic sisters give the
line 1705 date you must come, so I take him on time for that and also his appointment
line 1706 at SANCA. He goes to SANCA for his appointment to the doctors
line 1707 appointments there. There the doctor makes appointment which he keeps.
line 1708
line 1709 *Interviewer:* So there's quite a lot that you are doing for him?
line 1710
line 1711 Participant: Yes.
line 1712

line 1713 *Interviewer*: You say that you cook for him and you see to his clothes, also
line 1714 supervise at home, you see to it that he has a good meal during the day and
line 1715 that he takes his tablets.

line 1716
line 1717 Participant: Mm.

line 1718
line 1719 *Interviewer*: Does he do any cooking or helping at home?

line 1720
line 1721 Participant: He, yah, he comes to the kitchen while I'm in the kitchen. He
line 1722 helps me, with sometimes washing of the dishes you know, helps me
line 1723 with packing the dishes away and also when he's well, he also vacuums the
line 1724 house and mm, when he's well he does quite a bit of things because he can
line 1725 do the washing of the car so he doesn't have, we don't have to pay for this,
line 1726 also when he is well he can drive us to where ever I need to go.

line 1727
line 1728 *Interviewer*: Does he have his licence to drive?

line 1729
line 1730 Participant: Yah.

line 1731
line 1732 *Interviewer*: Is he not working?

line 1733
line 1734 Participant: Yah.

line 1735
line 1736 *Interviewer*: Alright so you've been looking after him and financially
line 1737 how has that been for you?

line 1738
line 1739 Participant: A little bit difficult.

line 1740
line 1741 *Interviewer*: Mm ... How do you manage?

line 1742
line 1743 Participant: Yah, a little bit difficult because he's like you know –
line 1744 everything is costly now because I'm supporting him with I'm getting a
line 1745 pension now, so supporting him and myself is financially a little bit difficult
line 1746 but –

line 1747
line 1748 *Interviewer*: Is he looking for a job?

line 1749
line 1750 Participant: Yah, at the moment yah, he's looking for a job and he's
line 1751 applying. He did his C.V. He did all his paper work.

line 1752
line 1753 *Interviewer*: He's taking his medication and is quite stable now?

line 1754
line 1755 Participant: He's yah, at the moment he's very stable.

line 1756
line 1757 *Interviewer*: Mm.

line 1758
line 1759 Participant: Yah, because he's now actually at this moment he's very

line 1760 stable and well, he goes to the clinic himself, he sees the sister there, the
line 1761 sisters are very good there, He goes and get his card out he sees one of the
line 1762 sisters there, Sister Anne and Sister Vani, one of them is always there.
line 1763

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

line 1764

Participant: Yah, and he... goes and takes his injection and they make sure
line 1765 that he get his return date to go back for his next injection.

line 1766

Interviewer: You said that sometimes you take him to the doctor
line 1767 does he often get sick?

line 1768

Participant: Not very often.

line 1769

Interviewer: Yah.

line 1770

Participant: You know this change of weather sometimes he get the flu so I
line 1771 take him for his you know, to make sure that he's on medication.

line 1772

Interviewer: At the moment is he well?

line 1773

Participant: Yah he's well.

line 1774

Interviewer: And you have generally been well also?

line 1775

Participant: Yah I'm well.

line 1776

Interviewer: What are the nice things about having him at home, as you
line 1777 also full time at home?

line 1778

Participant: Yes.

line 1779

Interviewer: What does, what is a nice things or experience you
line 1780 had you know with him being at home?

line 1781

Participant: Like at least you know that during the day or the evening
line 1782 always there is somebody at home with you and I always like you know,
line 1783 he's very caring and loving you know, when he is well he can come and talk
line 1784 to you and he find out what you need and what he can do to help me.

line 1785

Interviewer: Mm.

line 1786

Participant: And you know like if I want to watch anything you know, like
line 1787 TV or anything he can put a DVD on for us to watch, together spend time
line 1788 together and mm....

line 1789

Interviewer: And anybody else that he cares about?

- line 1807
line 1808
line 1809
line 1810
line 1811
line 1812
line 1813
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.
- line 1814
line 1815
line 1816
Participant: Um only when the time when he get sick is when he takes too much of this drugs.
- line 1817
line 1818
Interviewer: Mm.
- line 1819
line 1820
Participant: That's when you find that he's unstable.
- line 1821
line 1822
Interviewer: Then how do you cope?
- line 1823
line 1824
line 1825
line 1826
line 1827
line 1828
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.
- line 1829
line 1830
line 1831
Interviewer: What has been the most difficult thing for you so far? The most difficult thing to cope with?
- line 1832
line 1833
line 1834
line 1835
line 1836
line 1837
line 1838
line 1839
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.
- line 1840
line 1841
line 1842
Interviewer: Does he demand any attention that way?
- line 1843
Participant: Yah like he want me to notice something yah.
- line 1844
line 1845
Interviewer: OK.
- line 1846
line 1847
line 1848
Participant: Yah, yah, but not aggressive as such you know like violence to anybody but I haven't seen that kind of thing.
- line 1849
line 1850
line 1851
line 1852
line 1853
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.

line 1854

line 1855

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line 1900

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?

- line 1901 *Participant:* Yah, very, at the moment.
- line 1902
- line 1903 *Interviewer:* Is there anything that worries you that you want to ask me about his treatment or anything about his management?
- line 1904
- line 1905
- line 1906 *Participant:* Well at the moment now you, I don't know for
- line 1907 him to get a job because at the moment you see he's been applying for jobs,
- line 1908 now he is not getting any replies like any respond from them, at this
- line 1909 moment I can see he' getting a little bit quiet and then he's looking
- line 1910 like you know what, "will I ever get a job" you know like with his condition.
- line 1911
- line 1912 *Interviewer:* What are you doing about that? Are you giving him hope?
- line 1913
- line 1914 *Participant:* Yah.
- line 1915
- line 1916 *Interviewer:* You are encouraging him to carry on?
- line 1917
- line 1918 *Participant:* I told him to continue applying, looking at the papers. I give
- line 1919 him money to buy papers so that he get to look at the vacancies there so he
- line 1920 can apply for the jobs like he want which is suitable for him.
- line 1921
- line 1922 *Interviewer:* This is worrying to you and him very much?
- line 1923
- line 1924 *Participant:* Yah, that he must get into a job so that he can keep himself
- line 1925 occupied.
- line 1926
- line 1927 *Interviewer:* Especially that now he's functioning well.
- line 1928
- line 1929 *Participant:* Yah that he can cope you can see that he can cope you know
- line 1930 with a job.
- line 1931
- line 1932 *Interviewer:* So far there's no problem with his treatment or side-effects?
- line 1933
- line 1934 *Participant:* No, he's doing very well with the treatment she put him on.
- line 1935
- line 1936 *Interviewer:* No side-effects or anything with the drugs he was taking?
- line 1937
- line 1938 *Participant:* No.
- line 1939
- line 1940 *Interviewer:* So he's doing quite well on the injection and tablets?
- line 1941
- line 1942 *Participant:* Yah he's doing very well.
- line 1943
- line 1944 *Interviewer:* And are you happy with his progress.?
- line 1945
- line 1946 *Participant:* Yah, I'm very happy with his progress, what I've seen of him
- line 1947 what he is like now you know, he has progressed very well, I mean he took

line 1948 time for him he look the way he is now. Something like six months like you
line 1949 know, to reach this point now where he is, like, he can be independent
line 1950 you know, I can leave him because he is responsible he shows me he's
line 1951 responsible and the he keeps motivated, wanting to do things or helps me,
line 1952 Yah.
line 1953
line 1954 *Interviewer*: What, what did he do to keep him occupied at home?
line 1955
line 1956 *Participant*: At home apart from the chores that he does, he does the dishes,
line 1957 reading and he does music on the computer, and he looks for
line 1958 something that he can you know like apply for jobs on the computer I think,
line 1959 e-mails all that he sends he can apply through that and he read a lot---oh! he
line 1960 loves books. Just the other day when he, yesterday I think, he bought a book.
line 1961
line 1962 *Interviewer*: Mm.
line 1963
line 1964 *Participant*: There's a nice book shop here that he went and bought a book.
line 1965 He loves reading.
line 1966
line 1967 *Interviewer*: You mentioned that, in our conversation just now that he
line 1968 has a brother? Does he, is he supportive of him?
line 1969
line 1970 *Participant*: Yah very supportive of him you know.
line 1971
line 1972 *Interviewer*: Yeah, and also helps him.....
line 1973
line 1974 *Participant*: Also helps him very much, he's helping to find a job.
line 1975
line 1976 *Interviewer*: If you need to go somewhere who do you leave him with, do
line 1977 leave him with anybody?
line 1978
line 1979 *Participant*: Oh at the moment no. I don't have to leave him with somebody
line 1980 if I have like go anywhere only when he worries me.
line 1981
line 1982 *Interviewer*: So he stays on his own.
line 1983
line 1984 *Participant*: Yeah, then with his father and brother. Not now.
line 1985 He cares about the brother.
line 1986
line 1987 *Interviewer*: And then what about friends, does he have friends?
line 1988
line 1989 *Participant*: Yah he's got friends he's got a few friends that he visits.
line 1990
line 1991 *Interviewer*: And they've been supportive?
line 1992
line 1993 *Participant*: They've been very supportive of him, yah.
line 1994

line 1995 *Interviewer:* Excellent.
line 1996
line 1997 Participant: Yah.
line 1998
line 1999 *Interviewer:* Thank you so much for that, if there's any other question I can
line 2000 call you, because now our interview is over.
line 2001
line 2002 *Participant:* Yes, you can call me, yah you can call me.
line 2003
line 2004 *Interviewer:* Thank you very, very much.
line 2005