THE ROLE PLAYED BY FAMILIES IN SUPPORT OF THEIR MENTALLY ILL RELATIVES IN A RURAL COMMUNITY IN LIMPOPO PROVINCE

by

MAKUA LEAH MPHELANE

Submitted in partial fulfilment of the requirements

for the degree of

MASTER OF ARTS

in the subject

HEALTH STUDIES

at the

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: PROF TR MAVUNDLA

JUNE 2006

Student number: 817-510-1

DECLARATION

I declare that THE ROLE PLAYED BY FAMILIES IN SUPPORT OF THEIR MENTALLY ILL RELATIVES IN A RURAL COMMUNITY IN LIMPOPO PROVINCE is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

SIGNATURE (Makua Leah Mphelane) DATE

THE ROLE PLAYED BY FAMILIES IN SUPPORT OF THEIR MENTALLY ILL RELATIVES IN A RURAL COMMUNITY IN LIMPOPO PROVINCE

STUDENT NUMBER: STUDENT: DEGREE: DEPARTMENT: SUPERVISOR: 817-510-1 MAKUA LEAH MPHELANE MASTER OF ARTS HEALTH STUDIES, UNIVERSITY OF SOUTH AFRICA PROF TR MAVUNDLA

ABSTRACT

The purpose of this study was to explore the role of family members in support of their relatives who are mentally ill and to develop guidelines for the support of mentally ill relatives by their families in a rural community. The research design was qualitative, explorative, descriptive and contextual. The research population consisted of families of mentally ill relatives collecting their monthly medications at the Jane Furse Gateway Clinic. Purposive sampling was used to draw the sample. Data was collected by individual in-depth semi-structured interviews that were tape-recorded. The study revealed that families provide physical, psychosocial, financial and developmental support to their relatives. Furthermore, families are faced with frustrations when providing support to their mentally ill relatives

KEY CONCEPTS

Contextual, descriptive, explorative, family, mentally illness, relative, support, qualitative.

ACKNOWLEDGEMENTS

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

- Almighty God, my Lord and Creator, for giving me the opportunity to complete this study
- Professor TR Mavundla, my supervisor, for his continuous support and encouragement
- Malope, my husband, for his love and support and for always being there for me
- Khutso, Mahlatse and little Tshepho, my sons, for their love, encouragement and understanding and for the way they took responsibility for each other
- The Makhuduthamaga Primary Health Care Coordinator, for permission to conduct the study
- Christina, my aunt, without whose assistance and support this study would not have been completed, and I would not be what I am
- Sebolelo, my friend, for providing accommodation while I researched at Unisa
- The respondents in the study, for their participation, courage, dignity, and sharing
- Ms T Burger, Unisa librarian, for assisting me with the literature search
- Linky, our typist, for typing the manuscript so patiently and painstakingly
- Ms IM Cooper, for critically editing the manuscript

Thank you and God bless you all!

Chapter 1

Orientation to the study

1.1	INTRODUCTION	1
1.2	BACKGROUND OF THE PROBLEM	1
1.3	STATEMENT OF RESEARCH PROBLEM	6
1.4	RESEARCH QUESTION	7
1.5	RESEARCH OBJECTIVES	7
	PARADIGMATIC PERSPECTIVE	
1.6.1 1.6.2 1.6.3	Meta-theoretical concepts Meta-theoretical assumptions Methodological assumptions	3 3 9
1.7	OUTLINE OF THE STUDY	9
1.8	CONCLUSION	9

Chapter 2

Research design and methodology

2.1	INTRODUCTION	10
2.2	PURPOSE OF THE STUDY	10
2.3	RESEARCH DESIGN	10
2.3.1 2.3.2 2.3.3 2.3.4	Qualitative Explorative Descriptive Contextual	11
2.4	RESEARCH METHODOLOGY	13
2.4.1	Phase 1: Exploration of the family's role in support of their relatives who are mentally ill	13
2.4.1.1 2.4.1.2 2.4.1.3 2.4.1.5	Ethical consideration Population and sampling Sampling technique Data collection	14 15
2.4.1.5.1	In-depth phenomenological interview	16

2.4.1.6	Pilot study	18
2.4.1.7	Data analysis	18
	Literature review	

Table of contents

2.4.2	Phase 2: Development of guidelines for the support of mentally ill relatives by their families in a rural community	. 20
2.5	MEASURES TO ENSURE TRUSTWORTHINESS	. 20
2.5.1 2.5.2 2.5.3 2.5.4	Credibility Transferability Dependability Conformability	. 21 . 22
2.6	GUIDELINES	. 22
2.7	CONCLUSION	. 23

Chapter 3

Research findings and literature control

3.1	INTRODUCTION	
3.2	SAMPLE	
3.3	FIELD EXPERIENCE	25
3.4	THEMES ASSOCIATED WITH THE SUPPORT OF MENTALLY ILL RELATIVES BY THEIR FAMILIES	26
3.4.1	Physical support	27
3.4.2.1	Challenges of physical support	29
3.4.2	Psychosocial support	32
3.4.2.1	Challenges of psychosocial support	33
3.4.3	Financial support	
3.4.2.1	Challenges of financial support	35
3.4.4	Developmental support	
3.4.5	Frustration experienced by families	37
3.5	THEORY TO SUPPORT THE FINDINGS	39
3.6	CONCLUSION	41

Chapter 4

Guidelines for support of mentally ill relatives by their families

4.1	INTRODUCTION	42
4.2	GUIDELINES FOR HEALTH PROFESSIONALS TO EDUCATION FAMILIES OF MENTALLY ILL RELATIVES IN RURAL COMMUNITY CLINICS AND PUBLIC HOSPITALS	42
4.2.1 4.2.2 4.2.3	Mental illness Side effects of medications prescribed for mentally ill relatives Support needed by mentally ill clients	43
4.3	DEVELOPMENT OF SUPPORT MECHANISM FOR THE FAMILIES OF MENTALLY ILL RELATIVES	44
4.3.1 4.3.2	Joining support groups Rehabilitation of the mentally ill	45 45
4.4	MANAGEMENT OF DISTURBING BEHAVIOURS AS EXPERIENCED BY FAMILIES OF MENTALLY ILL RELATIVES	46
4.4.1 4.4.2 4.4.3	Refusal of treatment Management of aggressive and destructive behaviour Roaming around	46 46 47
4.5	CONCLUSION	47

Chapter 5

Conclusion, limitations and recommendations

5.1	INTRODUCTION	48
5.2	SUMMARY	48
5.3	LIMITATIONS	48
5.4	RECOMMENDATIONS	49
5.4.1 5.4.2 5.4.3 5.4.4	Education	49 49 50 50
5.5	CONCLUSION	50
BIBLIOGR	APHY	51

List of table	es Page	
Table 1.1	Monthly head count of mentally ill persons	,
Table 3.1	Sample distribution	
Table 3.2	Themes associated with the support of mentally ill relatives by their families	

List of annexures

Annexure 1	Request for permission to conduct a research study
Annexure 2	Consent letter for participants
Annexure 3	Permission letter
Annexure 4	Interview

Chapter 1

Orientation to the study

1.1 INTRODUCTION

After the democratisation of South Africa in 1994, one of the government's major challenges was to transform the services that were previously neglected as a result of apartheid. The majority of the population of South Africa had inadequate access to basic services, including health care, clean water and basic sanitation (South Africa (Republic) 1997:11). Mental health services were run as a vertical programme, ill equipped and lacked a comprehensive approach advocated by the primary health care (PHC) philosophy. With the implementation of the PHC approach, the mental health component was integrated into the rest of the PHC services, with the emphasis on the rehabilitation process, which should also include the family who care for the client in the absence of the health professionals (Sokhela & Uys 1998:9). As a result of this integration, mentally ill persons now collect their medication at the clinic in their communities. What families need to ensure is that the treatment collected is taken as prescribed. Families of mentally ill individuals have to realise that without their active participation and involvement in the care of their relatives, little progress can be made in improving the health status of these relatives.

In Australia, Jubb and Shanley (2002:48) found that family caregivers are often unsure or unclear about the nature of the therapy that their family member is receiving. This means families need to be involved in order to be able to offer support to their relatives who are mentally ill. This chapter presents the background, statement of the problem, research question and objectives. The aim of this qualitative study was to explore and describe the role played by families in the support of their mentally ill relatives at Jane Furse Gateway Clinic.

1.2 BACKGROUND TO THE PROBLEM

This study was conducted at Jane Furse Gateway Clinic, which is situated at Makhuduthamaga local municipality under the Sekhukhune district municipality in Limpopo. The clinic is attached to the Jane Furse Hospital. It renders services seven days per week and provides all services except deliveries. It has ten professional nurses, four nursing axillaries and one enrolled nurse. Its

monthly head count ranges from 4 000 to 6 000 per month, and about 400 mentally ill persons collect their monthly medication at the clinic. Table 1.1 reflects the monthly head count of mentally ill persons from 2001 to 2004. A visiting psychiatrist reviews the patients monthly.

MONTH	2001	2002	2003	2004
January	249	334	357	285
February	275	354	310	208
March	236	334	383	258
April	201	340	251	256
May	221	370	397	279
June	273	337	361	134
July	268	300	368	316
August	332	371	319	234
September	330	319	312	189
October	339	233	348	195
November	331	229	262	216
December	341	272	228	218

Table 1.1Monthly head count of mentally ill persons

The Jane Furse Hospital is a community hospital with no ward for mentally ill persons, who are mixed with physically ill patients and this leads to brief hospitalisation which results in a phenomenon known as "the revolving door syndrome", which refers to short hospital stays with rapid turnover and a pattern of continued re-admissions (Ntongana 1996:68). Since the clinic is attached to the hospital, newly diagnosed mentally ill persons collect their monthly medication at the clinic before they can be discharged to their local clinics.

There is a high defaulter and relapse rate due to inconsistency in collecting their medication at the clinic. Press (1990:22) states that most of the mentally ill persons are taken to mentally ill institutions for admission without understanding why they have been taken out of the community and put in hospital. This affects their follow-up care and taking their medication regularly.

According to Hatfield (1990:132), the world of the mentally ill often seems dangerous and frightening and efforts on their part to reach out, to try something new, bring on intolerable levels of anxiety. This contributes to high defaulter rates, as mentally ill persons are discharged to their local clinics for monthly collection of medication and because of lack of trust in nursing staff who are new to them, they do not collect their medication, hence the high relapse rate.

Efforts should be made to provide sufficient information and support for clients to understand the need for medication and to monitor their own administration. Because of lack of sufficient information, most mentally ill persons leave their medication when they develop side effects and again, the friendly hallucinations or feelings of power may be some of the things that make clients object to treatment (Tom 1992:90). The family need to know that the more chronic the disease, the more stressful it can be for family members to provide care (Nemecek 2004:149).

Mentally ill persons have rights like any other human beings; they need to be treated with respect and dignity, need freedom of movement and independence to a certain extent, though the ability to live independently depends on the ability to budget and manage money, hygiene, keep the surroundings safe, and do shopping (Hatfield 1990:132). Some mentally ill persons are unable to care for themselves and consequently need family support, as observed during home visits. In rural communities, the families make no future plans for the mentally ill relatives. When they have money and other property to leave, no plans are made so that their ill relatives profits maximally and do not lose entitlement. Caregivers have to make decisions regarding the patient's as well as their own future (Kritzinger & Magaqa 2000:301). This study explored guidelines for the support of family to their mentally ill relatives.

According to the WHO (2001:2), persons experiencing mental problems are more vulnerable than others in their social dealings and, as a result, are at risk of having their human rights and freedom violated, including the

- right to liberty; for example, not to have restrictions automatically imposed on freedom of movement through measures such as detention
- right to integrity of the person; for example, not to be unduly subjected to mental or physical harm
- right to control their own resources; for example, they should not be automatically removed on the mere grounds of status as a mental patient, but should be judged on their actual ability to manage resources. The relatives of mentally ill persons need to ensure that the mentally ill persons' rights are not violated.

While caregivers protect patients from being abused, they are often abused themselves (Kritzinger & Magaqa 2000:302). They experience forms of exploitation by mentally ill patients, by other people as well as by the situation itself. They are often threatened, beaten or ill treated by patients; people sell goods to patients on credit with the intention of claiming the money from caregivers and in some instances patients break other people's belongings and owners demand to be compensated by caregivers (Kritzinger & Magaqa 2000:302). At times the family gets relief when the patient is removed from the home (Ngubane & Uys 1994:9).

Family members do not take an active part in the care of their mentally ill relatives. Certain factors contribute to this failure. According to Jubb and Shanley (2002:48), there are factors that militate against the caregivers' contribution to the recovery of their family member, such as:

- The use of the traditional medical model in patient settings, which focuses on the individual, paying little attention to the family and the person's social environment. There must be recognition of the interdependency of health status among family members as a central concept in mental health interventions.
- Failure of professional to recognise the therapeutic benefits of caregiver's involvement in treatment programmes. Families are not informed about the treatment being provided. They are often unsure or unclear about the type and nature of the therapy that their family members are receiving. Hospital staff ignores their own experiences and understanding of their family member. This lack of consideration leaves many families frustrated.
- Number of different health care professionals that families deal with during the patient's hospitalisation. These professionals may come from different disciplines and, as such, have different attitudes towards and perceptions of families, consequently families can feel isolated in terms of their dealings with professionals who can be separated and disjointed. Families are expected to take care of these patients without receiving the necessary training and support for this task (Kritzinger & Magaqa 2000:296).

Family care of clients with mental illness is an endless burden to family caregivers. Kam-Shing (2005:3) cites Lefley (1996), who identifies three types of burdens faced by family caregivers:

- Objective burdens in coping with the mental illness; for example, financial burden, time and effort in care giving, disruption of daily routine and social life.
- Subjective burdens in facing the mental illness; for example, feelings of loss, shame, worry, anger and hopelessness towards the client with mental illness.
- Burdens in management of problem behaviour of clients with mental illness; for example, assault, mood swings, unpredictability and negative symptoms.

Families of mentally ill relatives need to take care of themselves if they are to take care of their mentally ill relatives. They must be able to recognise the warning signs of stress. Nemecek (2004:150) suggests the following factors to restore equilibrium if there is a sign of stress to care givers.

- Get an adequate amount of rest. A good night's sleep is essential for caregivers.
- Avoid becoming isolated. Caregivers need to stay active in activities or hobbies that are important to them.
- Eat a healthy, balanced diet. Good nutrition can make a difference in the ability to cope with stress.
- Find activities that the family can share with their mentally ill relative; look for activities they can do together, depending on the level of illness. It might be as simple as reading a book or listening to music they both like.
- Take time for themselves. It is important to have time away from their loved one. Seek out day care or alternative housing.
- Seek out a support group where fellow members can provide information in lay terms, making it easier to understand. The support group plays an important role in the community, as there are few available professionals to meet the needs of carers in crisis, particularly in the initial stages of coping with psychosis in the family (Makhale & Uys 1997:47).

In South Africa, support groups are important as they share information amongst the members, encourage the families to support their ill member and members support each other (Makhale & Uys 1997:48). In South Carolina, USA, families identified a need for advocacy in communication with mental health professionals and a relatively weak need for support groups (Quidette Gasque-Carter & Curlee1999:523). Quidette Gasque-Carter and Curlee (1999:524) found that families of

lower socio-economics status do not participate in support groups, and mental health professionals must find alternative methods to ensure that families receive the needed services. Although families have experiential knowledge of their relatives' disorder, professionals give them little factual information about the disorder. Information provided by professionals is often inadequate and vague and not sufficient for family members to help ill relatives. Families need to be educated on the nature, course and effects of the illness on the day-to-day functioning. Education must also include treatment and its side effects (Sokhela & Uys 1998:9).

In South Africa, there is a shortage of resources in the communities for mentally ill persons because of financial constraints. The problem is exacerbated by the lack of policy on rehabilitation and the de-institutionalisation of mental health care (Sokhela & Uys 1998:9). In Europe, on the other hand, the policy of de-institutionalisation has created a positive move towards the provision of mental health care in the community (Hetherington & Baiston 2001:352). In rural Ethiopia, families are the sole care givers of their severely mentally ill relatives and the family network is strong and important (Shibre, Kebede, Alem, Negash, Deyassa, Fekadu, Fekadu, Jacobsson & Kullgren 2003:27). Families in Canada stress the need for training programmes for people who care for mentally ill persons, stating that mentally ill people need somebody who can listen to and talk to them (Piat, Perreault, Lacasse, Loannou, Pawlluk & Bloom 2004:231).

In Australia, Jubb and Shanley (2002:50) found that education for families in the form of information was inadequate. They were not satisfied with the level of emotional support they received from hospital staff. To overcome non-compliance with treatment schedules in chronic psychiatric patients, Ntongana (1996:70) states that, while patients are still in hospital, the patients and their families need educational programmes on the disease process that emphasise continuity of care and compliance with medication regimen.

1.3 STATEMENT OF THE RESEARCH PROBLEM

The researcher observed that relatives only brought mentally ill persons to the hospital to collect their medication and when they had problems. Even though they collected their medication regularly, they still relapsed. Some forgot the instructions for taking their medication; others had negative attitudes towards medication, and turned to faith healers and witchdoctors. Some felt they

6

could not be cured and used herbs instead of the medication (Ntongana 1996:69). Some mentally ill persons are malnourished and unkempt despite receiving a disability grant. The reason for this is that they do not allow the caregivers any say in how they spend their money, and most caregivers are dependent on the disability grant as they have no other source of income (Kritzinger & Magaqa 2000:304). Some families delay seeking medical advice when a member becomes mentally ill or shows signs of relapse. When mentally ill persons experience side effects, including libidinal changes in males, which give them a feeling of impotence, and lactation in the absence of pregnancy in females, they decide to stop taking the medication without informing the health professionals. Mentally ill persons are often returned home not fully recovered and in the expectation that the family and the community services will provide the necessary support for them (Jubb & Shanley 2002:47).

1.4 RESEARCH QUESTION

In the light of the rate of relapse among mentally ill patients in the area and the need for the families and the communities to care for these patients, the researcher wished to examine how families can be helped to support them. Therefore, the study wished to answer the question:

What is the role of families in support of their mentally ill relatives in a rural community?

1.5 RESEARCH OBJECTIVES

To answer the research question, the study had two objectives, namely to

- explore and describe the role of family members in support of their mentally ill relatives in rural community (Phase 1).
- develop and describe guidelines for the role of family members in the support of their relatives who are mentally ill in the rural community (Phase 2).

1.6 PARADIGMATIC PERSPECTIVE

Neuman (2000:65) describes a paradigm as "the whole system of thinking that includes basic assumptions, important questions to be answered, research techniques to be used and examples of what good scientific research looks like". Polit and Hungler (1997:463) refer to a paradigm as "a way of looking at natural phenomena that encompasses a set of philosophical assumptions and

that guides one's approach to inquiry". These assumptions are meta-theoretical, theoretical and methodological by nature. The researcher must therefore make her/his own assumptions explicit.

1.6.1 Meta-theoretical concepts

Meta-paradigm refers to the major concepts that identify the phenomena (ideas or observation) of interest to a discipline. They provide the boundaries for the subject matter of the discipline (Stanhope & Lancaster 2004:196). The meta-theoretical concepts of nursing are person, environment, health and nursing.

- **Client/person.** The families of mentally ill relatives that participated in the study including patients they cared for were referred to as clients.
- Environment. The environment refers to the physical and social settings in which the families stay with their relatives who are mentally ill. Families must ensure that the environment promotes the mental health of the relatives by providing their security.
- Health. Health refers to the state of health of both the families and the mentally ill relatives. Families need to care for themselves before they care for their mentally ill relatives. They also have basic human needs.
- Nursing. Nursing is the process of practice intervention used to care for the community (Stanhope & Lancaster 2004:196). In this study, families provide support to their mentally ill relatives in order to meet their needs.

1.6.2 Meta-theoretical assumptions

Qualitative researchers always "attempt to study human action from the insider's perspective (also referred to as emic perspective)" (Babbie & Mouton 2004:53). In this study the researcher adopted Maslow's hierarchy of needs theory as the paradigmatic perspective on which to reflect findings after data collection. Maslow's theory assumes that every human being has needs that must be satisfied. The needs are divided into five categories: physiological, security, love and acceptance, esteem and appreciation, and self-actualisation. The theory was applied to the major concepts of nursing, as they are interrelated in a holistic approach to caring. The theory of Maslow's formed the theoretical basis for this research.

1.6.3 Methodological assumptions

Apart from the statement of theoretical assumptions, the researcher also made her methodological assumptions known. Creswell (1998:77) states that from the distinctions about reality, the relationship between the researcher and that which is being researched, the role of values, emerges the methodological assumptions, how one conceptualises the entire research process. In qualitative methodology, the research starts inductively, that is, the initial inductive logic of generating open coding and generating a theory evolves into the deductive process of examining the theory against existing and new databases. Botes (1995:5) adds that research findings in qualitative studies should be functional and findings used to improve practice.

In this study the researcher inductively developed categories and themes only after the participants had given information. The participants were interviewed about the phenomenon under study without the researcher specifying categories. The methodological assumptions are discussed under the research design, data collection and analysis and presented in chapter 2.

1.7 OUTLINE OF THE STUDY

Chapter 1 introduced the study and outlined the problem, research design and methodology.

Chapter 2 discusses the research design and methodology.

Chapter 3 discusses the research findings.

Chapter 4 presents guidelines for the role of family members in the support of their relatives who are mentally ill.

Chapter 5 concludes the study, discusses its limitations, and makes recommendations for practice and further research.

1.8 CONCLUSION

This chapter introduced the problem to be investigated, the purpose and objectives of the study, and defined key terms.

Chapter 2 describes the research design and methodology.

Chapter 2

Research design and methodology

2.1 INTRODUCTION

Chapter 1 briefly outlined the background to, purpose and objectives of the study. This chapter deals with the research design and methodology. The study was carried out in two phases. Phase explored and described the role played by families in support of their relatives who are mentally ill in a rural community in Limpopo Province. Phase 2 developed guidelines for the support of mentally ill relatives by their families in rural community.

2.2 PURPOSE OF THE STUDY

The purpose of the study was to examine the role of family members in support of their relatives who are mentally ill and to develop guidelines for the support of the mentally ill relatives by their families in a rural community. To attain this purpose, the objectives were to

- explore and describe the role of family members in support of their relatives who are mentally ill in a rural community in Limpopo Province.
- develop guidelines for the support of the mentally ill relatives by their families in rural community.

2.3 RESEARCH DESIGN

A research design is "a plan of how the researcher intends conducting the research" (Mouton 2001:55). Mouton (1996:107) describes the research design as "a set of guidelines and instructions to be followed in addressing the research problem". This study used a qualitative, explorative, descriptive and contextual design.

2.3.1 Qualitative

According to Burns and Grove (1999:338), qualitative research is "a systematic, subjective approach used to describe life experiences and give them meaning". It is "a means of exploring the depth, richness and complexity inherent in phenomena, and is useful in understanding such human experience" (Burns & Grove 1999:339).

In this study the design was used in order to explore the role of family members who support their mentally ill relatives in a rural community. The design "is directed towards discovering insights, meanings and understandings of phenomenon under study" (Brink & Wood 1998:337). The design offers "the opportunity to focus on finding an answer to questions that centre on social experience, how it is created and how it gives meaning to human life" (Streubert & Carpenter 1995:36).

2.3.2 Exploratory

Exploratory design as one of the characteristics of qualitative research explores the phenomenon under study. This design is used when little is known about the phenomenon under study or when the topic of the study itself is relatively new in order to allow the researcher to discover new phenomena or to gain new insight into known phenomena (Brink & Wood 1998:309). In this study an exploratory design was used to explore the family's role in support of their mentally ill relatives in a rural community.

2.3.3 Descriptive

A descriptive study is designed "to gain more information about characteristics within a particular field of study. It provides a picture of a situation as it naturally happens. The researcher observes the behaviour of the participant, describes what was observed, and explores and documents aspects of the situation under study" (Burns & Grove 1999:339). In this study the design was used to describe the family's role in support of their relatives who are mentally ill in a rural community in Limpopo Province. According to Streubert and Carpenter (1995:36), there are three steps in descriptive studies: intuiting, analysing and describing.

> Intuiting

The researcher "begins to know about the phenomenon under study as described by the participants. He avoids all criticism, evaluation and opinions, and pays strict attention to the phenomenon under study as it is described" (Streubert & Carpenter 1995:36). In this study, the researcher was involved as a research instrument in the interviewing process and data collection. The information obtained was transcribed and reviewed repeatedly to determine the description.

Analysing

In this step, the researcher "identifies the essence of the phenomenon under study based on data obtained and how they are presented" (Streubert & Carpenter 1995:37). The researcher looked for categories and subcategories in the data. These will describe how families describe their role in support of their relatives who are mentally ill.

Describing

The aim here is to communicate, to bring written and verbal descriptions and critical elements of the phenomenon based on classification or grouping of the phenomenon. This is a continuous process until data collection is complete. In this study the researcher classified all the elements that were common to families of mentally ill relatives by describing their role in support of their mentally ill relatives. All the steps often occured simultaneously.

2.3.4 Contextual

The aim of qualitative research is "to describe and understand events within the concrete natural context in which they occur" (Babbie & Mouton 2004:272). After description and exploration of the family's role in support of their relatives who are mentally ill, the findings were understood within the context of families of mentally ill relatives collecting their monthly medication at Jane Furse Gateway Clinic. In this study, the families were interviewed in their homes, which is their natural environment.

2.4 RESEARCH METHODOLOGY

The study was conducted in two phases. Phase 1 dealt with the exploration of the role played by families in support of their relatives who are mentally ill in a rural community in Limpopo Province. Phase 2 with the development of guidelines for the support of mentally ill relatives by their families in a rural community.

2.4.1 Phase 1: Exploration of the family's role in support of their relatives who are mentally ill

The role of the researcher is to collect data and this is achieved through various steps, including fieldwork.

2.4.1.1 Ethical consideration

When "humans are used as the study participants, great care must be exercised in ensuring that the rights of those human beings are protected" (Polit & Hungler 1997:127). Before the study was conducted, a letter was written to the PHC coordinator of where the study was to be conducted to ask for permission to conduct the study in the sub-district (see annexure 1). Permission was also obtained from families of mentally ill relatives who volunteered to participate in the study after informed consent was given. The participants were informed of the following rights:

Principle of beneficence

This principle is about protecting the study participants from any physical and psychological harm that may arise during the study. The participants were informed that they could terminate their participation at any time if they felt that continuation would result in undue stress or injury (Polit & Hungler 1997:130). The researcher tried to avoid sensitive questions during data collection. The questions were phrased carefully in order to do good, not harm to the research participants.

Informed consent

According to Polit and Hungler (1997:134), informed consent means that participants have "adequate information regarding the research and are capable of comprehending the information and have the power of free choice enabling them to consent voluntarily to participate in the research or decline participation". The nature of the study was fully explained to the participants including risks and benefits (see annexure 2). The participants were informed from the beginning of the study and reminded throughout the investigation that they had the right to withdraw from the study at any time (Streubert & Carpenter 1999:36).

Principal of justice

This principle is about participants' right to fair and equitable treatment before, during and after their participation in the study (Polit & Hungler 1997:137). It entails maintaining privacy and confidentially in the treatment of data throughout the study process until completion of the study. The participants were assured that information given during interviews would be treated confidentially. No names would be disclosed or linked to the information given during data collection. The tape-recorded cassette used during data collection will be used for verification of findings. Only the researcher and an expert in qualitative research shared the tape. Information on the cassette was erased after completion of the study.

2.4.1.2 Population and sampling

Polit and Hungler (1997: 223) define a population as "the entire aggregation of cases that meets a designated set of criteria". In this study, the mentally ill relatives collecting their monthly medication at Jane Furse Gateway Clinic were the population. Once a population has been identified, a sample is selected.

2.4.1.3 Sampling criteria

According to Brink (1996:13), a sample is "a part or fraction of the whole or a subset of a larger set selected by the researcher to participate in a research project". Sampling criteria refers to "the

characteristics essential for inclusion in the target population (Burns & Grove 1999:227). Sampling criteria for this study were:

➢ Gender

Participants in this study were families of mentally ill relatives collecting their monthly medication at Jane Furse Gateway Clinic. Both males and females were accepted to participate in the study.

≻ Age

Participants had to be between 20 and 65 years old and directly caring for mentally ill clients.

Duration of care

Participants should have cared for the mentally ill person for at least six months and longer. This criterion was used because newly diagnosed clients are put on medication for six months before being discharged to their nearest clinic.

Language

The ability to speak Northern Sotho or English was a strong recommendation.

> Permission

Participants were required to give permission by signing the consent form prior to participation in the study for both interview and tape-recorded information.

2.4.1.4 Sampling technique

Once the sampling criteria had been defined, the researcher decided on sampling technique to be used to select a sample. A non-probability purposive sampling technique was used to select participants for the study. This technique was relevant in this study because the researcher knew the participants. This was done according to the needs of the study, their knowledge as carers, experience of caring for mentally ill persons, and the duration of care. The advantage of purposive sampling is that it allows the researcher to hand pick the sample based on knowledge of the phenomena under study (Brink 1996:141). The number of participants in the study was not important, sampling continued until data saturation occurred, meaning that no more new information emerged. The researcher did not know in advance how many participants were needed.

2.4.1.5 Data collection

Data was collected at the families' homes, using in-depth, semi-structured interviews, probing, and field notes. The home environment was conducive to collecting data as the families were relaxed in their natural setting. In-depth semi-structured interviews were the preferred method because interviewer was able to determine whether the questions had been understood (Polit & Hungler 1997:299). The interviewer was in a position to observe or judge the participants' level of understanding, degree of cooperativeness, and life style (Polit & Hungler 1997:259).

2.4.1.5.1 In-depth phenomenological interview

Phenomenology was used to guide the study. This approach was used as it focuses mainly on the lived experience (Streubert & Carpenter 1999:43). The families of mentally ill relatives described their lived experience of supporting the mentally ill relative in their everydays life. According to Marshall and Rossman (1995:80), an in-depth interview refers to "a conversation with a purpose". Families were interviewed using this method in order to explore their role in support of their relatives who are mentally ill in rural community in Limpopo Province. The researcher explored a few general topics to help the free flow of information. Open-ended questions that encouraged conversation were used. Some participants understood English better than Northern Sotho so English was used with them.

The participants were asked a common question, "What is your experience in supporting your mentally ill relatives?" Participants were encouraged to talk about their experiences, feelings about

caring for the mentally ill individuals and the support they offered their mentally ill relatives to keep them in the community.

• Probing

Probing is the technique used by interviewers to elicit more useful or detailed information from a participant than was volunteered in the initial reply (Polit & Hungler 1997:259). The researcher probed the participants by encouraging them to talk about their experience in supporting the mentally ill relatives. The questions were directed at exploring their role in support of their relatives who are mentally ill and follow-up questions were asked for clarity.

Reflecting

Reflecting is one of communication strategies that facilitate effective communication between individuals or group of people. According to Streubert and Carpenter (1999:260), reflexivity describes the belief that the language individuals use to describe an experience reflects that particular experience and also all other experiences in each individual's life. The researcher was involved in dialogue with participants to reveal each individual's influencing behaviour (Streubert & Carpenter 1995:317). The researcher probed the participants by using reflection as a communication strategy to encourage alternative explanations or interpretations of the phenomenon under study that could be relevant or important.

• Field notes

Field notes refer to the documents generated from the observation (Streubert & Carpenter 1995:99). These notes are recorded about people and places where the study is conducted. In this study the researcher documented whatever she heard, experienced and observed during the interviews. According to Polit and Hungler (1997:272), field notes are sometimes categorised according to the purpose they will serve during the analysis and integration of information, namely observational, theoretical, methodological and personal notes.

Observational notes

These are objective descriptions of events, conversations, and information, such as time, place and activity (Polit & Hungler 1997:273). This information is recorded as completely and objectively as possible.

Theoretical notes

These notes are interpretive attempts to attach meaning to observation (Polit & Hungler 1997:273).

Methodological notes

These are instructions about how subsequent observations will be made (Polit & Hungler 1997:273).

Personal notes

These are comments about the researcher's own feelings during the research process (Polit & Hungler 1997:273).

2.4.1.6 Pilot study

According to Polit and Hungler (1997:264), pilot study is a small scale, or trial run, done in preparation for the major study. Its function is to obtain information for improving the project or for assessing its feasibility. The researcher conducted a pilot study on four participants in order to identify problems with data-collection tool, to refine the design of choice and also to offer the researcher an opportunity to practise using the audiotape recorder.

2.4.1.7 Data analysis

In a qualitative study, data analysis starts during data collection. The researcher wrote down observations and field notes while conducting interviews. On completion of the data collection, the

researcher transcribed the tape recording together with the field notes, verbatim transcriptions immediately after interview in order not to miss some important information. Once data has been transcribed, data analysis procedure starts. According to Marshall and Rossman (1995:112), analysis falls into five modes, namely organizing data, generating categories, themes and patterns, testing the emergent hypothesis, searching for alternative explanations of data, and writing a report.

Organising data

The researcher read and re-read the transcripts in order to become familiar with the data.

> Generating categories, themes and patterns

As the researcher read through the data, she noted irregularities in the setting, developed a categorisation scheme, coded the data accordingly, and searched for relationships to code and recode the existing data.

> Testing emergent hypothesis

The researcher evaluated the data for their informational adequacy, credibility, usefulness and centrality.

Searching for alternative explanation

The researcher searched for links among the data, identified and described them. The report writing followed.

2.4.1.8 Literature review

In a qualitative study, a literature review is done after data analysis in order to confirm what was found in the study. The main reason for conducting a literature review is "to determine what is already known about the topic to be studied so that a comprehensive picture of the state of

knowledge on the topic can be obtained" (Brink 1996:76). The researcher reviewed literature for background information and also after data analysis.

2.4.2 Phase 2: Development of guidelines for the support of mentally ill relatives by their families in a rural community

After data analysis, the researcher used a deductive strategy to develop guidelines for the support of mentally ill relatives by their families.

2.5 MEASURES TO ENSURE TRUSTWORTHINESS

Trustworthiness refers to the ability of researchers to convince themselves and participants that the findings of the inquiry are trustworthy (Babbie & Mouton 2004:276). Qualitative research is trustworthy when "it accurately represents the experience of the study participants" (Streubert & Carpenter 1999:333). Trustworthiness is enhanced by credibility, transferability and conformability.

2.5.1 Credibility

According to Polit and Hungler (1997:305), credibility refers to "the confidence in the truth of the data". The truth value of this study was obtained from the experience of families in the support of their mentally ill relatives, the research design used, method of data collection and the context in which the study was conducted. The following strategies were used to ensure credibility.

Prolonged engagement

The researcher has 15 years experience as a mental health sister working with mentally ill patients at the clinic where the study was conducted. Her knowledge of mental health was also considered. The researcher stayed with the participants until data saturation occurred (Babbie & Mouton 2004:277). This enhanced credibility because the researcher understood the participants' culture and language. The researcher spent five months preparing for data collection. Field notes were collected during data collection.

> Triangulation

Polit and Hungler (1997:305) define triangulation as "the use of multiple referents to draw conclusions about what constitutes the truth". The researcher used a phenomenological approach that was qualitative, explorative, descriptive and contextual, in-depth semi-structured interviews, field notes and observation to collect quality data about the phenomenon under study. Non-probability purposive sampling was used to select a sample. The researcher worked with the supervisor and joint supervisor.

Referential adequacy

The tape-recorded information was transcribed verbatim. Experts in qualitative study assisted the researcher.

Member checking

Member checking refers to "providing feedback to the study participants regarding data findings and interpretations" (Polit & Hungler 1997:306). Literature was reviewed to link the results with previous studies. The researcher gave the participants contact numbers to give them the opportunity to review and discuss the final results to determine whether the descriptions reflected their experience (Streubert & Carpenter 1999:80).

2.5.2 Transferability

Transferability refers to "the extent to which the findings can be applied in other contexts or with other participants" (Babbie & Mouton 2004:277). The researcher was not interested in the generalization of the findings. All observations were defined in terms of the specific context in which they occurred. The findings of this study would be used by families of mentally ill relatives in rural areas but could not be transferred to other setting and yield the same results. The expectations for determining whether the findings fit or are transferable rest with users of the findings and not with the researcher (Streubert & Capenter 1999:29).

21

2.5.3 Dependability

Dependability refers to "the stability of data over time and over conditions" (Polit & Hungler 1997:306). Dependability is like reliability in a quantitative study. There can be no credibility in the absence of dependability (Polit & Hungler 1997:307). An inquiry "must also provide its audience with evidence that if it were to be repeated with the same or similar participants in the same context, its findings would be similar" (Babbie & Mouton 2004:278). In this study, the supervisor did an enquiry audit by scrutinizing the data and supporting documents, like field notes. The researcher reviewed literature to verify the findings. The tape-recorded information was also used as supporting information.

2.5.4 Conformability

This refers to "the degree to which the findings are the product of the focus of the inquiry and not the biases of the researcher" (Babbie & Mouton 2004:278). A conformability audit trial must ensure that conclusions, interpretations recommendations can be traced to their sources and if they are supported by the inquiry (Babbie & Mouton 2004:278). The following ensure conformability of data, when a trial is conducted:

- Field notes and tape-recorded information of raw data available
- Categorising data, using codes and summarising for data analysis
- Developing themes from the coded data
- Conducting a pilot study to refine the data-collection instrument

2.6 GUIDELINES

The researcher developed guidelines for the support of mentally ill relatives by their families in a rural community in Limpopo Province.

2.7 CONCLUSION

This chapter discussed the research design and methodology used in the study together with measures to ensure trustworthiness. Chapter 3 presents the findings.

Chapter 3

Research findings and literature control

3.1 INTRODUCTION

Chapter 2 discussed the research design and methodology and measures to ensure trustworthiness. This chapter presents the research findings with reference to the literature review in order to contextualise the findings. The main purpose of the study was to explore and describe the role played by families in support of their relatives who are mentally ill in a rural community and develop guidelines for the support of the mentally ill relatives by their families in a rural community.

During data collection and analysis the following themes emerged:

- Physical support
- Psychosocial support
- Financial support
- Developmental support
- Frustrations experienced by families

3.2 SAMPLE

For this study, the sample was drawn from the families of mentally ill relatives who collect their monthly medication at the Jane Furse Gateway Clinic. The sample comprised eight families, all of who provided support for their mentally ill relatives. The 8 participants consisted of 5 mothers, 1 father, 1 sister and 1 wife, aged between 41 and 65. All the families lived in the same household as the relatives. One mother was supporting two mentally ill sons. The families volunteered for indepth semi-structured interviews. During data collection, data saturation occurred in the fifth interview, but the researcher continued with the interviews until all eight families were interviewed. Table 3.1 depicts the sample distribution.

Table 3.1Sample distribution

SEX	AGE	RELATIONSHIP TO RELATIVE	LEVEL OF EDUCATION	DURATION OF SUPPORT
Female	54 years	Mother	Registered nurse	11 years
Female	56 years	Sister	Standard 8 (Gr 10)	25 years
Female	65 years	Mother	Standard 6 (Gr 8)	17 years
Male	58 years	Father	None	26 years
Female	63 years	Mother	Standard 5 (Gr 7)	2 years
Female	64 years	Mother	Retired nurse	12 years
Female	41 years	Wife	Standard 5 (Gr 7)	20 years
Female	54 years	Mother	Standard 8 (Gr 10)	6 years

3.3 FIELD EXPERIENCE

The researcher had some difficulty entering the research field. The researcher met with the research participants at their homes to arrange an appointment for the interviews. Even though the appointments had been arranged, the researcher found no one at home, and had to return another time. There was a lot of travelling as the participants stay far from where the researcher stays. The researcher had no difficulty obtaining permission from the authorities to conduct the study. The researcher is employed in the sub-district where the study was conducted. The authorities had no problem with granting permission for the study and expressed interest in the research topic and receiving the findings of the study.

The respondents had no problems with participating, despite having to tell the difficult experience of supporting their mentally ill relatives. Through the study the researcher learned that families also need support in the form of home visitation, especially by health professionals. All the participants were happy to see health professionals visiting them. The researcher explained the purpose of the study and what was expected of them from the participants. The researcher explained their rights to anonymity, confidentiality and respect as well as that participants was voluntary and that they could withdraw at any stage if they so wished. All the participants signed the letter giving informed consent (see annexure 2).

Pilot interviews were conducted on four participants, on different days. The aim of the pilot study was to refine the research instrument and sharpen the researcher's interviewing skills. However, because the researcher lacked sufficient experience of interviewing, some important concepts

were not properly explored. The pilot interviews were discussed with an expert in qualitative research, corrections were made and the researcher was taught proper facilitation of interviews. The researcher learned from the experience to ask probing questions to explore the phenomenon under study.

In-depth individual phenomenology semi-structured interviews were conducted for two months on different days, using audio tape recorder and the interviews lasted for 45 minutes to 1 hour. The researcher used effective facilitative communication skills to collect data from the participants.

Transcribing and coding the data for analysis was a time-consuming task. The researcher found it challenging to interview the respondents and listen to their painful experiences in supporting and caring for their mentally ill relatives.

3.4 THEMES ASSOCIATED WITH THE SUPPORT OF MENTALLY ILL RELATIVES BY THEIR FAMILIES

Five themes emerged from the data analysis, namely physical, psychosocial, financial and developmental support, and frustration experienced by the families. All the themes were about meeting human needs, therefore the researcher decided to reflect the findings within Maslow's theory of human needs. According to Maslow's theory, if a person lacks or needs something, for as long as the lack continues that person will have a need for whatever is lacking (Jordaan & Jordaan 1990:652). So, for example, if a mentally ill client needs food, for as long as family member does not provide food that need will remain unmet.

These needs are categorised into five groups: physiological needs, security needs, need for love and acceptance, need for self-esteem and appreciation, and the need for self-actualisation (Jordaan & Jordaan 1990:651). Every human being has these needs. Table 3.2 depicts the needs expressed by the respondents.

Table 3.2 Themes associated with the support of mentally ill relatives by their families

3.4.1	The experience of physical support provided by families
3.4.1.1	Physical support
•	Ensure that the client gets food
•	Build a shelter for the client
•	Supervise client taking medication
	Ensure maintenance of good hygiene
3.4.1.2	
J. T. T.Z	Eating too much
•	Refusal of medication
	Physical aggression
	Refusal to bath and change dirty clothes
	General body weakness and shivering
•	,
3.4.2	
3.4.2.1	
•	Lack of libido
•	Mood disturbance/swings
•	Substance abuse
3.4.3	Financial support
3.4.3.1	Challenges of financial support
•	Selling clothes and other household property
•	Financial constraints
3.4.4	Development support
3.4.5	Frustration experienced by families

3.4.1 Physical support

This theme dealt mainly with how the families provide their observable support to their relatives who are mentally ill in the rural community. Mentally ill relatives, because of their thought disturbance, experience problems in maintaining personal and environmental hygiene; they need to be assisted. According to Puskar (1996:6), psychiatric patients frequently suffer from thought disorder of depression and subsequently have impaired information processing or concentration. Their comprehension of treatment regimes may be inadequate and contribute to non-compliance, hence they need to be supervised when taking in medication. Some have problems with motor activity and are unable to do anything for themselves. The study revealed the following physical support given by families: ensuring that clients had food, building a shelter for the clients, supervising the client and taking of medication, and ensuring good hygiene.

• Ensure that the client gets food

According to Andrews and Boyle (1999:345), food is used to establish and maintain social and cultural relationships with relatives, friends, strangers and others. Food treats certain diseases, prevents illness, and fosters child growth and development (Andrews & Boyle 1999:346). In this study, families of mentally ill relatives experienced that their mentally ill clients need food therefore they ensure that they buy, cook and serve food to them every day:

"I try by all means to organize foods that he likes. If he needs bread and eggs, I must make sure that he gets them or else there will be problems."

• Build a shelter for the client

The physical functions of the families are to provide food, clothing and shelter and to protect members against danger and provide health care (Giger & Davidhizar 1995:74). In this study, families ensured that they built shelters for their relatives to protect them:

"She stays alone there; her father built it with the money she gets."

• Supervise client taking medication

Educating people with mental illness about their illness, its symptoms and their medication is the best way to encourage cooperation with treatment (Casper 2003:264). The study revealed that families of mentally ill relatives supervise their relatives when taking medication to ensure that is taken correctly, collect the medication for them from the clinic, accompany clients for collection of medication at the clinic and educate them on how to take their medication:

"I take the medication to him because sometimes he wants to take the whole lot of tablets at once. I am trying to educate him on how to take his medication because you cannot predict the future, so that he can be acceptable in the community."

• Ensure maintenance of good hygiene

Most of the mentally ill clients neglected their personal hygiene and this led to the need for support in the maintenance of proper hygiene. In this study, families reported that their relatives' bath under supervision, they do the washing and buy clothes for them, and also educate the siblings to wash their clothes and cook food for them:

"It is really a problem. He sometimes refuses to bath and change his dirty clothes. Even if he is given warm water, he refuses. I always beg him to bath. He can spend a whole month without changing his clothes, especially the new clothes."

Another participant explained the situation like this:

"The support that we provide for her is to ensure that she has meals and she has washed herself clean and put on clean clothes. We also teach her siblings so that they can continue supporting her even when we are not at home because she is unable to take care of herself."

3.4.1.1 Challenges of physical support

Families are sometimes compelled to provide support to their mentally ill relatives even if they are not well physically. Their own health status can be a challenge to the provision of physical support because they also need to care for themselves to avoid burnout, isolation and stress, both physical and mental. They provide support while at the same time trying to function in other areas of life, like work, attending to the children and household demands and end up being exhausted (Nemecek 2004:149).

According to the respondents, some mentally ill relatives are wasteful, stingy, don't want to buy food for the house yet they eat too much and don't want to help with any household activities. They easily spend their money and expect the families to provide clean clothes and toiletry whereas they don't buy anything for themselves. They refuse to collect medication at the clinic yet they need to be supervised when taking medication.

The study found the following physical support challenges: eating too much, physical aggression, refusal of medication, refusal to bath and change dirty clothes, and general body weakness and shivering.

Eating too much

The more stressed and unhappy the person becomes, the more he or she is forced by inner need to comfort himself or herself with food (Fisher 1987:628). Andrews and Boyle (1999:346) maintain that compulsive eating and hoarding of food to relieve tension are largely learned and patterned from cultural practices. These physical support challenges cause some problems to families when they support their mentally ill relatives. One participant stated that:

"We try to give him what he wants. If he asks for food, we cook the type of food he likes for that day. Sometimes he just goes to the refrigerator and takes out whatever he wants to eat despite what the family is intending to cook that day. Sometimes he asks foods that he cannot afford. These types of people are troublesome because even if they have money, they do not want to use it in the house. They are greedy. Sometimes he will take out meat straight from refrigerator, put it in the micro-oven and cook it until well cooked."

Another one said:

"He eats a lot. He is out now, when he comes back he will eat and take medication."

Refusal of medication

Because of lack of sufficient information, most of mentally ill persons stop taking their medication when they develop side effects and because the condition is chronic, clients become discouraged when they don't get healed and decide to refuse medication. They look for alternative healing systems, like traditional medication. In this study, the participants indicated refusal of medication by relatives as a major problem that challenges their provision of support:

"The support we give is to ensure that he has taken his medication correctly because he often refuses to take in medication. I always beg him."

"He was not taking tablets from my hand, reporting that I want to kill him. I started to put the medication in his tea and food, and he is better now."

Physical aggression

According to Perko and Kreigh (1988:503), aggression is a destructive goal-directed behaviour closely associated with anger. It arises out of frustration or over-stimulation where an individual resorts to aggressive behaviour when he perceives there is no other form of adaptation available for him (Perko & Kreigh 1988:380). In this study, the participants stated physical aggression and destructive behaviour as challenges to provision of physical support to their relatives. One participant explained her situation:

"I am afraid of him because he frightens me with a spade, stones, hoes and knives. The other day I was in my neighbour's house, he came with a spade and with the other hand he made a sign of the cross on his chest. I could see that he was praying God to help him so that he could kill me."

• Refusal to bath and change dirty clothes

This was found to be a challenge to provision of support to their mentally ill relatives as follows:

"He is able to bath under my supervision and if I don't say bath, he won't."

• General body weakness and shivering

The major adverse reactions produced by the drugs prescribed for the mentally ill relatives include drowsiness, fatigue, ataxia, blurred vision, tremors and slurred speech (Perko & Kreigh 1988:422). In this study, this was found to be a problem:

"What causes this patient to shiver because he takes his medications regularly? Sometimes he shivers to the extent that he is unable to hold an object in his hand."

3.4.2 Psychosocial support

The amily has affectional function, which includes meeting the emotional needs of its members (Giger & Davidhizar 1995:74). The need for love is generally characterized by striving to establish and maintain loving relationships with other people like friends, relatives, spouses and children (Jordaan & Jordaan 1990:655). The mentally ill clients sometimes become lonely and because of their fluctuating moods, are sometimes unable to establish and maintain relationships with others. The participants interviewed explored their support for provision of psychosocial support by talking to their clients and drinking tea together:

"I stay with her, I joke with her the whole day. We stay together. It is just now that she has left to see a friend. I treat her like a normal person because there is nothing wrong with her when we are together."

The mentally ill relatives also need to belong to a group of people for interaction and an increased level of self-esteem and self-worth (Perko & Kreigh 1988:350). This can be achieved by encouraging them to be involved in group activities. The participants in this study revealed that they had joined a burial society for mentally ill relatives and they also attend funerals together. One participant related her situation:

"We decided to join a burial society for her because life is too short so that one day when I am no more, she will remain covered. Sometimes we attend the family funerals together."

Families of mentally ill relatives also need time for themselves. It is important that they become involved in other community activities so that they can mix with people and relieve stress. Mentally ill clients need to be exposed to people gradually and environmental changes (Perko & Kreigh 1988:379). In this study, the participants provide psychosocial support by taking clients for entertainment so that they can also get a rest. One of the participants explained:

"During December month his sister took him to town so that I could just get a rest and also to entertain him. He was very excited."

3.4.2.1 Challenges of psychosocial support

The families of mentally ill suffer social isolation; they cannot attend church services, funerals and other important traditional functions because of their involvement in the support of the client (Kritzinger & Magaqa 2000:303). This challenges the provision of psychosocial support and the fact that they adjust their social lives to the needs of their mentally ill relatives is a source of stress, as they no longer have time for themselves. Families offer support to their mentally ill relatives without being exposed to any teaching about the provision of proper support or coping mechanisms, these may challenge the provision of psychosocial support as they are always unsure of the quality of support they provide. This study revealed lack of libido, mood disturbance and substance abuses as the challenges of psychosocial support.

Lack of libido

According to Maslow's hierachy of needs, sexual needs and behaviour can be seen from a physiological point of view, but sexual behaviour is usually determined by more factors than just physiological need. Factors like love and acceptance are important (Jordaan & Jordaan 1990:655). In this study, participants indicated that lack of libido was one of their major challenges when trying to provide psychosocial support to their relatives by showing them love and acceptance. According to Perko and Kreigh (1988:418), impotence in males and menstrual irregularities in females are side effects of medication prescribed for mentally ill clients. One of the participants expressed her feelings:

"The other problem that we are encountering with these mentally ill people is lack of sexual desire, sometimes they can take 6 months or 3 months without any desire. We request the government to help us, maybe by giving them something like an injection so that they can be human beings again."

Mood disturbance

According to Rowe (1989:244), mood syndrome is a group of mood and associated symptoms that occur together for a minimal period of time. Mentally ill relatives experience this type of mood,

especially those with affective disorder, and pose psychosocial support challenges to families. One of the participants said:

"Yes I have experienced a lot. She can change just any minute, just become negative with anything you tell her."

Substance abuse

According to Uys and Middleton (1999:403), substances are taken to escape from personal and psychological problems and conformation to social values and norms is resisted. By smoking dagga, they avoid a problem situation and acceptance of responsibility. The participants found dagga smoking and alcohol intake a challenge for them when providing support:

"Sometimes after taking medication he goes outside to smoke dagga. He does not forget to take his medication."

Participants indicated their desire to provide psychosocial support to their relatives by arranging marriages for them to have wives and families. This was a challenge to them because that their clients refused. One participant reported her situation as follows:

"I was thinking of marry a woman for him. Even if she has two children it's ok, so that he can have a family. But he refused, he says he need somebody who does not have a child because he also does not have a child."

3.4.3 Financial support

The mentally ill clients monopolize their grant and do not allow caregivers to have any say in them on how to spend their money (Kritzinger & Magaqa 2000:305). The financial support that the families provide to their mentally ill relatives in this study included giving them money to buy tobacco, buying food and clothes for them, banking money for them and also paying insurance for them. Of all eight families interviewed, only 50% had access to the grant of their relatives and were able to utilise it effectively. Participants explained their situation:

"I don't know how can I convince him to bank money. I don't know, maybe if the Government can be able to bank a certain amount for him, it will be better. Since he started to receive a grant three years back, I have never been to a pay point because he has reported that if he sees me there, he will kill me."

Another participant said:

"Yes, he is not using his grant well. He is smoking too much. I tried to get him to quit smoking, but I failed. His money is used for smoking. We are afraid to talk to him about the grant, he uses a card and is quite friendly outside, but at home he will not be all right if we tell him to buy food with the grant.."

3.4.3.1 Challenges of financial support

The families of mentally ill experience problems in maintaining employment and supporting the mentally ill, therefore they rely on government assistance of the mentally ill, which sometimes becomes inadequate to cater for education of siblings, mentally ill needs and maintenance of the rest of the family. Mentally ill relatives destroy people's property and owners claim money from the families for repair. They also destroy household property and much is spent on repairing household property and buying new ones. Some mentally ill clients refuse to collect their disability grant at pay points, which means they depend on the family members for financial support. Some family members who do not take care of mentally ill relatives take control of the relatives' grants and that causes financial support challenge to the carer. This study revealed the following challenges of financial support: clients selling clothes and other household property, and financial constraints.

Selling clothes and other household property

Mentally ill patients demand food from caregivers every day; spend their money on items like dagga, cigarettes, and alcohol, and at times give their money to other people (Kritzinger and Magaqa 2000:304). In the study, the financial challenges the families meet when providing financial support were that relatives sold their clothes and other household property, and were destructive and aggressive when they had money:

35

"Sometimes he sells property from the house which does not belong to him. My cups are sold to people outside. Every time he goes out of the house, he has some parcel to sell. He is selling his clothes and brother's clothes, too. He can wash one item in the washing machine, spin dry it, and take it for sale. These are problems we are experiencing with mentally ill clients."

People sell goods to clients on credit with the intention of claiming the money from caregivers (Kritzinger & Magaqa 2000:302). In this study, participants viewed this as a challenge for providing financial support :

"I remember one time when the gentleman came to accuse me that I am going with him to the pay point and there are some shoes he bought but did not pay.'

• Financial constraints

Financial constraints were reported to be the major challenge to most of the participants in providing support to their mentally ill. Some depended on the grants of the relatives for survival as they had no source of income. Others left their employment to take care of their relatives. One explained her situation as follows:

"I was employed and forced to leave work because of his state of health."

3.4.4 Developmental support

Participants reported their plans to provide developmental support to their relatives. According to Jordaan and Jordaan (1990:655), the direction in which a person will grow depends to a large extent on his particular abilities, talents and potentials. Even if they are mentally ill, they need to be developed to the best of their abilities. One participant said:

"I talked to his sister to save a little amount in the bank because he wants to continue with his schooling but because he is not yet 100% right he would not go now. He left school in Grade 10."

According to Sadler (2000:3), rehabilitation is the process by which mentally ill individuals become people again. The disease still exists, but it occupies only a fraction of their lives, and the rest of their existence is devoted to family, community, friends and work. Participants indicated their desire to take their clients for rehabilitation:

"I want to take him for rehabilitation even if he cannot be 100%, but he will be better."

3.4.5 Frustration experienced by the families

Rejection of people with mental illness also affects the family and caretakers of the mentally ill person and leads to isolation and humiliation. These clients are not rejected only by the community, but also by some health professionals because of the stigma attached to mental illness. According to the WHO (2001:1), stigma is "a mark of shame, disgrace or disapproval which results in an individual being shunned or rejected by others". The misconception that when a person is mentally ill it is associated with witchcraft also affects the family so that when a client does not respond to medication, they become frustrated. The inactivity of the mentally ill clients also frustrates the family members, as they just eat and sleep without being involved in household activities. Other factors that frustrate families include lack of health education from health professionals to the clients about the illness, medication and its side effects, attitudes of health professionals, and clients not responding to medication.

According to Jubb and Shanley (2002:48), identified factors that militate against the caregivers' contribution to the recovery of their family member include failure of professionals to recognise the therapeutic benefits of caregivers' involvement in the treatment programme. Most of the participants were not given any education about the clients' illness including their medication. Participants explained their situation as follows:

"No education was given except the interview that they normally conduct about when the illness started. I sometimes read books about the illness and learn now to care for these patients."

• Lack of interest from nurses to mentally ill clients as perceived by families

The study revealed that nurses seemed not interested in assisting families of mentally ill relatives while their clients were admitted in the hospital. Mavundla and Uys (1997:6) found that most nurses were negative about the care of the mentally ill in a hospital setting. People who have a mentally ill relative in the family may have more knowledge and understanding and therefore be more positive towards mentally ill people. Other factors that could contribute to positive attitudes of nurses to mentally ill relatives include in-service training to all categories of nurse, orientation programmes for newly employed nurses to mentally ill units to help them adjust, and inclusion of a module on psychiatric nursing in training for enrolled nurse, who are studying for the bridging course in enrolled nurses training and enrolled nursing assistance (Mavundla & Uys 1997:6). If nurses had knowledge of mental health, they might have positive attitude towards mentally ill clients. One participant said.

"I did not know whether I should say nurses did not care or what, because they did not give us health talks. By the time he was admitted in the ward, there was a problem that nurses reported that they are not employed to care for mentally ill patients."

• Families perceive health professionals' attitudes as a problem

Lack of sufficient knowledge about mental health is a problem faced by many health professionals, not only nurses. Sadler (2000:121) recommends the establishment of a mental health team, which would be instructed on how to work with patients as well as with the family and its environment, using available treatment resources in that geographic area. The inactive mental health forum, which includes all the multidisciplinary team members that will address the mental health problem, contributes to the negative attitude of health professionals. The study found that other health professionals, like social workers, do not assist much in the support of families of mentally ill relatives. One participant said:

"I need help. Twelve years is not child's play. To tell you the honest fact, social workers did not do anything for me."

Families in this study reported the frustrations when supporting these clients:

"We even go to the extent of handcuffing her because she has developed a tendency of going to the main road. We are aware that that is wrong, but it is the only way of keeping her safe. The assistance I am asking for is what can we do instead of handcuffing her to keep her at home?"

It was found that some participants experienced a problem of their relatives not responding to medication, even if taken correctly:

"What surprises me, is that in August and September his condition became worse. Even if he takes his medication regularly, he still does odd things."

3.5 THEORY TO SUPPORT THE FINDINGS

The study was based on Maslow's theory of human needs. This theory was relevant in this study as it focuses on meeting basic human needs. Its assumption is that every human being has needs that should be met; as long as the need is not met, it will remain. Maslow thought that an individual's behaviour is motivated by universal needs that range from the most basic needs (food, sleep, safety) to the highest need for self-actualisation (Stanhope & Lancaster 2004:704). These needs are categorised into five groups: physiological needs, security needs, the need for love and belonging, need for self-esteem and need for self-actualisation. According to Maslow's hierarchy of needs, people must fulfil the lower level needs before they can move to the higher needs.

• Physiological needs

These are the most basic needs. If not satisfied, they affect all other needs. These include food, water and ventilation. The study found that families meet the physiological needs when they provide physical support to their relatives by buying, cooking and giving food to their relatives.

• Need for security

According to Jordaan and Jordaan (1990:651), the need for security includes stability, order, freedom from fear and anxiety. Most of the mentally ill clients live in fear and anxiety and their world is unpredictable, so they need medication to be stable and feel secure. In this study, the families supervised clients while taking medication. They also built shelters for them to ensure security. The need for security includes financial security, which was ensured by taking out insurance for the mentally ill relatives.

• Need for love and belonging

This need is characterised by loving relationships with people. In the study, this entailed the provision of psychosocial support to the mentally ill relatives by showing them love and acceptance. The families communicated with mentally ill and gave financial support. This need also means creating and maintaining relationships with others by interacting with them.

Need for esteem

This entails a need for appreciation and respect by other people. Mentally ill clients need to be respected and accepted. The participants met this while providing support to these clients by supervising them when they bathed so that they could be clean and accepted by other people. They also took the clients out for entertainment and attended funerals with them.

• Need for self-actualisation

This entails an individual's ability to develop, which depend on his potential and the involvement of the client in his treatment plan that will help to meet this need. One of the participants wanted to send her relative back to school so that he could develop further; another wanted to take her mentally ill relative for rehabilitation so that his self-actualisation need could be met.

3.6 CONCLUSION

This chapter discussed the findings with reference to the literature reviewed. The physical support, psychosocial support, financial support, developmental support, challenges and dilemmas faced by the families of mentally ill relatives emerged as themes during data analysis.

Chapter 4 presents the guidelines for the support of mentally ill relatives by their families.

Chapter 4

Guidelines for support of mentally ill relatives by their families

4.1 INTRODUCTION

Chapter 3 described the findings on how families met the needs of mentally ill relatives in their care and the challenges, problems and dilemmas these caregivers face. The literature review supported the findings and also referred to the need to assist these caregivers as well as train health care professionals in this aspect of health care. This chapter describes the guidelines developed by the researcher to educate and assist families in rural communities who support and care for mentally ill relatives. The guidelines cover three areas, namely

- Development of educational programmes for families of mentally ill relatives
- Development of support mechanisms for the families of mentally ill relatives
- Management of disturbing behaviours experienced by families of mentally ill relatives

4.2 GUIDELINES FOR HEALTH PROFESSIONALS TO EDUCATE FAMILIES OF MENTALLY ILL RELATIVES IN RURAL COMMUNITY CLINICS AND PUBLIC HOSPITALS

These guidelines resulted from the findings of this study (see chapter 3) and act as a guide for health professionals to educate the families of mentally ill relatives in rural communities and public hospitals. According to Sokhela and Uys (1998:9), it is stated that families need to be educated on the nature, course and the effects of the illness on the day-to-day functioning of the affected person. Quidette Gasque-Carter and Curlee (1999:520) found that information provided by professionals is often inadequate and vague and not sufficient for family members to help their ill relatives. Health professionals can use psycho-education as an approach with patients and families. Psycho-education emphasizes the goals of decreased client vulnerability to environmental stimulation through educated psychopharmacology, and increasing family stability by increasing both knowledge and coping strategies (Uys & Middleton 1999:748). Education can be given to

individual patients in in-patient settings and on occasion to patients and their families together on an outpatient basis on the following:

- Mental illness
- Side effects of prescribed medication
- Support needed by mentally ill relatives

4.2.1 Mental illness

Uys and Middleton (1999:218) state that teaching patients and their families about the condition from which patients are suffering, its treatment and management is one of the most empowering interventions nurses can implement. In this study participants reported a lack of knowledge about the illness. For intervention purposes, they need to be taught about the nature of the illness and its management.

4.2.2 Side effects of medication prescribed for mentally ill relatives

Sokhela and Uys (1998:9) emphasise that if the client is on medication, it is also important to educate the family on the effects of the medication to prevent relapse. The families in this study indicated a lack of information about the side effects of the medication taken by their relatives. There are side effects that occur frequently, especially when the client has just started taking medication. These need to be observed by health professionals and the families educated about them (Perko & Kreigh 1988:418), including:

- drowsiness
- dizziness
- dryness of the mouth
- constipation
- blurred vision
- urine retention
- impotence in males
- menstrual irregularities in females

4.2.3 Support needed by mentally ill clients

The study revealed the problems of clients who still behaved in an abnormal way even after taking the medication and some who needed to be handcuffed while taking medication regularly. Health professional needs to educate the families about the following:

- Creation of an environment for recovery from mental illness. Families must supervise clients who abuse substances not to take medication and substances so that medication can take effect. They must also discourage the clients from having relationships with people who use substances.
- Proper communication skills, to establish a conductive environment where all family members will respect each other. Mentally ill clients need someone who speaks simply and clearly.
- Ensuring that patients comply with medication; in other words, direct supervision of client taking medication.
- Families need to ensure that treatment taken by the mentally ill clients is reviewed periodically by checking their referral forms regularly. Periodical reviews are usually done every six months as some medications reach tolerance at six months (Uys & Middleton 1999:316).
- Families are not allowed to alter clients' medication without doctors' knowledge.

4.3 DEVELOPMENT OF SUPPORT MECHANISMS FOR THE FAMILIES OF MENTALLY ILL RELATIVES

In this study, the participants revealed that supporting mentally ill relatives is a problem to them. Some even mentioned that they no longer worked in order to care for the client who is mentally ill. The following guidelines indicate support mechanisms for families who support mentally ill relatives.

The families of mentally ill relatives need to take care of themselves first if they are to take care of their mentally ill relatives. Nemecek (2004:150) emphasises the following activities to restore equilibrium if there is sign of stress in families:

- Get an adequate amount of rest. A good night's sleep is essential for caregivers.
- Avoid becoming isolated. Caregivers need to stay active in activities or hobbies that are important for them.
- Eat a healthy, balanced diet. Good nutrition can make a difference in the ability to cope with stress.
- Find activities that the family can share with the mentally ill relatives. Look for activities the family and the mentally ill relatives can do together, depending on the level of illness. It might be something as simple as reading a book or listening to music.
- Take time for themselves. It is important to have time away from their loved ones, seek out day care or alternative housing.
- Seek out a support group where fellow members can provide information in lay terms, making it easier to understand.

4.3.1 Joining support groups

Support groups play an important role in the community, as there are few available professionals to meet the needs of the carers in crises, particularly in the initial stages of coping with psychosis in the family (Makhale & Uys 1997:47). According to Nemecek (2004:150), the benefits of belonging to a support group include:

- Fellow members can provide information in lay terms, making it easier to understand.
- Talking with people facing similar problems promotes a sense of belonging.
- Listening to others' experiences can foster a sense of hope.
- Participants help themselves by helping others in a group.
- Support groups can offer role models for coping with problems.
- Participants can express their feelings without shame.

4.3.2 Rehabilitation of the mentally ill

In the study, a participant stated that she needed her son to go for rehabilitation. According to Sokhela and Uys (1998:9), rehabilitation is an approach in which clients take an active part in the provision of health care aimed at the prevention of relapse. As the process of rehabilitation starts

immediately the client enters the institution and continues until he is discharged back to the community, health professionals need to inform the families of existing rehabilitation centres available in the community.

A multi-disciplinary team must implement a community assertive treatment programme that will provide clinical service and teaches coping skills to mentally ill relatives (Aubrey, Flynn, Gerber & Dostaler 2005:346).

4.4 MANAGEMENT OF DISTURBING BEHAVIOURS EXPERIENCED BY FAMILIES OF MENTALLY ILL RELATIVES

Families reported refusal of treatment, aggressive and destructive behaviour, and roaming around as major challenges they faced in providing support to their mentally ill relatives, which indicates that guidelines are needed that will assist families of mentally ill relatives.

4.4.1 Refusal of treatment

According to Uys and Middleton (1999:86), it may be very difficult for families to intervene when a patient who is obviously in need of treatment refuses either to go to the clinic or to take the medication. The following actions can be taken:

- Discussion with the treatment team may be useful, as they may be able to initiate and maintain medication treatment through home visits.
- Change to intramuscularly medication instead of oral tablets.
- Education of family and patient by the treatment team.

4.4.2 Management of aggressive and destructive behaviour

Uys and Middleton (1999:86) point out that aggressive behaviour can be very difficult to handle and is very disruptive of home life, and recommend the following steps to manage the behaviour:

- Analyse the circumstance of violence because sometimes a person may have a valid reason for being angry.
- If the violence is due to relapse, the client will display other symptoms, which indicate an acute phase of the illness.
- Perhaps the client is using threats or aggression to get his/her own way.

4.4.3 Roaming around

The mentally ill client, who roams, needs to be occupied by giving him tasks to perform, such as gardening.

4.5 CONCLUSION

This chapter described the policy guideline for support of mentally ill relatives by their families in rural community clinics and public hospitals. The study found that educational programmes are needed for both families and clients.

Chapter 5 concludes the study, discusses its limitations, and makes recommendations for practice and further research.

Chapter 5

Conclusion, limitations and recommendations

5.1 INTRODUCTION

This chapter concludes the study, discusses its limitations and makes recommendations for practice and further research.

5.2 SUMMARY

The main aim of the study was to understand the support that family members provide to their mentally ill relatives in rural communities. The participants were probed to give more information on their experience of supporting their mentally ill relatives. There was a high relapse rate at the clinic where the study was conducted and it was found that clients relapsed even if they took their medication regularly at the clinic. So the researcher considered it important to study the role of the families in support of their relatives who are mentally ill. The researcher chose an exploratory research design with the use of in-depth phenomenological interviews in order to gain an insight into the family's experience in support of relatives who are mentally ill. The themes that emerged from the data collection and analysis concerned human needs, specifically satisfying human needs when providing support to mentally ill relatives. The findings led to the development of guidelines for the support of mentally ill relatives by their families in rural communities.

5.3 LIMITATIONS

The researcher identified the following limitations in this study:

- Literacy level of participants might have influenced the response to questions or support they provide to their mentally ill relatives.
- The quality of data collected from the participants might be affected by the fact that it was for a research purpose and answers might not have been provided in an open manner. The respondents' knowledge of the researcher might have affected their answers.

5.4 RECOMMENDATIONS

Based on the findings, the researcher wishes to make the following recommendations for practice and further research.

5.4.1 Education

The study emphasised the importance of education for mentally ill relatives and their families together with health professionals. Families are expected to provide support to their relatives who are mentally ill in the community without being exposed to relevant educational programmes or workshops that will empower them to provide support to mentally ill relative. Sokhela and Uys (1998:9) emphasise that families need to be educated on the nature, course and effects of illness on the day-to-day functioning of the affected person. The teaching programme must include side effects of prescribed medication for mentally ill relative, signs and symptoms of relapse, and coping mechanisms.

The study found the attitudes of nurses towards mental illness being negative. Therefore, the researcher recommends in-service education for all categories of nurses. The content must include the attitude of health professionals towards mental illness and also the stigma attached to mental illness.

5.4.2 Support groups

There is a need for support groups in the community for families of mentally ill relatives. The support groups will assist families as they share information, support each other as they have common problems. Support groups would also facilitate health professionals' task of educating the families and other caregivers as well as invite experts to address the families.

5.4.3 Rehabilitation of the mentally ill

The researcher recommends the establishment of rehabilitation centres in the community in which clients take an active part in the provision of health care aimed at the prevention of relapse as explained by Sokhela and Uys (1998:9).

It is recommended that a multi-disciplinary team present a community assertive programme as an outreach programme to provide clinical service and teach coping skills. This would eliminate the problem raised by one of the participants that social workers did not help her.

5.4.4 Further research

It is recommended that a qualitative study be conducted in the same area on the community's perception of mental illness, with special reference to the problem of rejection and the stigma attached to mental illness. The aim would be to improve the support and acceptance of the clients when they are discharged and returned to the community.

5.5 CONCLUSION

This chapter concluded the study and made recommendations for practice and further research. The findings should contribute to the education of nurses, who provide health care at PHC level and are the primary contact for mentally ill patients and their family caregivers in rural communities. Implementation of the guidelines developed in the study should also contribute significantly to helping support the caregivers and eventually break down the negative attitudes towards and rejection of the mentally ill in our society.

BIBLIOGRAPHY

Andrews, MM & Boyle, JS. 1999. *Transcultural concepts in nursing care*. 3rd edition. Philadelphia: Lippincott.

Aubrey, TD, Flynn, RJ, Gerber, G & Dostaler, T. 2005. Identifying the care competence of community support providers working with people with psychiatric disabilities. *Psychiatric Rehabilitation Journal* 28:346-354.

Babbie, E & Mouton, J. 2004. *The practice of social research*. Oxford: Oxford University Presstte.

Botes, A. 1995. A model for research in nursing. Unpublished doctoral thesis. Johannesburg: Rand Afrikaans University.

Brink, HL. 1996. *Fundamentals of research methodology for health care professionals*. Kenwyn: Juta.

Brink, PJ & Wood, MJ. 1998. *Advanced designs in nursing research*. 2nd edition. Thousand Oaks: Sage.

Burns, N & Grove, SK. 1999. *Understanding nursing research*. 2nd edition. Philadelphia: Saunders.

Casper, ES. 2003. The latent variable model of the psychiatric rehabilitation beliefs, goals and practices scale. *Psychiatric Rehabilitation Journal* 28(3):260-266.

Creswell, JW. 1998. Qualitative inquiry and research design: choosing among five traditions. Thousand Oaks: Sage.

Debbie, I. 1990. *Community occupational therapy with mentally handicapped adults*. New York: Chapman & Hall.

Diaz-Caneja, A & Johnson, S. 2004. The views and experiences of severely mentally ill mothers: a qualitative study. *Psychiatry Epidemiol* 39:472-482.

Fisher, EE. 1987. *Psychology for nurses and the health team*. Kenwyn: Juta.

Giger, JN & Davidhizar, RE. 1995. *Transcultural nursing*. 2nd edition. St Louis: Mosby.

Hatfield, AB. 1990. Family education in mental illness. New York: Guilford.

Hetherington, R & Baistow, K. 2001. Supporting families with a mentally ill parent: European perspectives on interagency cooperation. *Child Abuse Review* 10:351-365.

Jordaan, WJ & Jordaan, JJ. 1990. *Man in context*. 2nd edition. Johannesburg: Lexicon.

Jubb, M & Shanley, E. 2002. Family involvement: the key to opening locked wards and closed minds. *International Journal of Mental Health Nursing* 11:47-53.

Kam-Shing, Y, 2005. Family care giving of clients with mental illness in the people's Republic of China. *International Journal of Psychosocial Rehabilitation* 8(5):1-8.

Kaung, SK & Mowbray, CT. 2005. What affects self-esteem of persons with psychiatric disabilities: the role of casual attributions of mental illness. *Psychiatric Rehabilitation Journal* 4(28):354-361.

Kirsh, B, Kruoa, T, Horgan, S, Kelly, D & Carr, S. 2005. Making it better building evaluation capacity in community mental health. *Psychiatric Rehabilitation Journal* 28:234-241.

Kritzinger, A & Magaqa, V. 2000. De-institutionalizing the mentally ill in rural areas: a case study of the official caregiver. *Social Work* 36(3):296-309.

Makhale, MS & Uys, LR. 1997. An analysis of support groups for the mentally ill as a psychiatric intervention strategy in South Africa. *Curationis* 20(1):44-47.

Manamela, KE. 2001. A needs assessment of persons suffering from schizophrenia in the Mogoto Village, Zebediela district. Unpublished dissertation. Pretoria: University of South Africa.

Marshall, C & Rossman, GB. 1995. *Designing qualitative research*. 2nd edition. Beverly Hills: Sage.

Mavundla, TR & Uys, LR. 1997. The attitudes of nurses towards mentally people in a general hospital setting in Durban. *Curationis* 20(2):3-7.

Mays, GD. 1999. Male caregivers of mentally ill relatives. *Perspectives in Psychiatric Care* 5:1-8.

Mead, S, Hilton, D & Curtis, I. 2001. Peer support: a theoretical perspective. *Psychiatric Rehabilitation Journal* 25:134-141.

Mouton, J. 1996. Understanding social research. 1st edition. Pretoria: Van Schaik.

Mouton, J. 2001. *How to succeed in your master's and doctoral studies: a South African guide and resource book.* Pretoria: Van Schaik.

Mulholland, C, Wilson, C, McCrum, B & MacFlynn, G. 1999. Factors influencing the support offered to the seriously mentally ill by a community rehabilitation service. *Journal of Mental Health* 8(6):639-647.

Nemecek, MD. 2004. Caring for the caregiver. *Health Care News* 2(10):149-150.

Neuman, WL. 2000. *Social research methods: qualitative and quantitative approaches.* 4th edition. Boston: Allyn & Bacon.

Ngoma, MC, Prince, M & Mann, A. 2003. Common mental disorders among those attending primary health care: clinic and traditional healer in urban Tanzania. *Journal of Mental Science* 183:349-355.

Ngubane, G & Uys, LR. 1994. The social support network for Black psychiatric in patients. *Curationis* 17(2):6-9.

Ntongana, ES. 1996. Non-compliance with treatment schedules in chronic psychiatric patients. *Curationis* 19(1):68-70.

Orem, DE, Taylor, SG & Renpenning, KM. 2001. *Nursing concepts of practice*. 6th edition. Philadelphia: Saunders.

Patel, V, Todd, C, Winston, M, Gwanzura, F, Simunyu, E, Acuda, W & Mann, A. 1997. Common mental disorders in primary care in Harare, Zimbabwe: associations and risk factors. *Journal of Mental Science* 171:60-64.

Perko, JE & Kreigh, HZ. 1988. *Psychiatric and mental health nursing*. 3rd edition. Mexico: Prentice Hall.

Piat, M, Perreault, M, Lacasse, D, Loannou, S, Pawlluk, N & Bloom, D. 2004. Stakeholder perspectives on psychiatric foster homes: residents, families, caregivers and professionals. *Psychiatric Rehabilitation Journal* 27(3):228-234.

Polit, DF & Hungler, BP. 1997. *Nursing research: principals and methods.* 4th edition. Philadelphia: Lippincott.

Press, H. 1990. Defining madness. Sydney: Hawkins.

Puskar, KR. 1996. The nurse practitioner's role in psychiatric nursing. *Online Journal of Issues in Nursing* 5:2-10.

Quidette Gasque-Carter, K & Curlee, MB. 1999. The educational needs of families of mentally ill adults: the South Carolina experience. *Psychiatric Services* 50(4):520-523.

Rowe, CJ. 1989. An outline of psychiatric care. Dubuque: Brown.

Sadler, P. 2000. Update on psychosocial rehabilitation for the severely and persistently mentally *ill*. Institute of Psychiatric Services: American Psychiatric Association.

Shibre, T, Kebede, D, Alem, A, Negash, A, Deyassa, N, Fekadu, A, Fekadu, D, Jacobsson, L & Kullgren, G. 2003. Schizophrenia: illness impact on family members in a traditional society – rural Ethiopia. *Psychiatry Epidemiology* 38:27-34.

Sokhela, NE & Uys, LR. 1998. The integration of the rehabilitation of psychiatric patients into the primary health care system. *Curationis*:8-13.

South Africa (Republic). 1997. *White Paper on the Transformation of the Health System in South Africa.* (No 17910). Pretoria: Government Printer.

Stanhope, M & Lancaster, J. 2004. *Community and public health nursing.* 6th edition. Philadelphia: Mosby.

Streubert, HJ & Carpenter, DR. 1995. *Qualitative research in nursing: advancing the humanistic imperative*. Philadelphia: Lippincott.

Streubert, HJ & Carpenter, DR. 1999. *Qualitative research in nursing: advancing the humanistic imperative*. 2nd edition. Philadelphia: Lippincott.

Tom, B. 1992. *Changing mental health services: the politics and policy*. New York: Chapman & Hall.

Uys, L & Middleton, L. 1999. *Mental health nursing*. 3rd edition. Kenwyn: Juta.

WHO – World Health Organization.

World Health Organization. 2001. *Mental health problems: the undefined and hidden burden.* Geneva: WHO.

Annexure 1

PO Box 383 GLEN COWIE 1061 3 October 2005

The Primary Health Care Coordinator Makhudu Thamaga Subdistrict Private Bag X431 Jane Furse Hospital 1085

Dear Madam

REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY

I hereby request permission to conduct a research project entitled "The role played by families in support of their mentally ill relatives in a rural community in Limpopo Province".

I am currently an MA Cur student doing research dissertation at Unisa. My supervisor is Professor TR Mavundla of the Department of Health Studies at the university.

The main purpose of this study is to explore and describe the role of family members in the support of their relatives who are mentally ill and to develop guidelines for the role of family members in the support of their relatives who are mentally ill in the rural community.

To complete this study, I need to conduct interviews of approximately 45 to 60 minutes duration with the families of the mentally ill persons. The interviews will be audiotaped for verification of findings. Only the researcher and an independent expert in qualitative research who will assist with the analysis of data will share the tape-recorded interviews.

The direct benefit of this study to the subdistrict is that a summary of the research findings will be made available to the PHC Office. The long-term benefits are that the research findings will be used to formulate guidelines for the support of mentally ill relatives by their families in the community.

Hoping that this request will receive your favourable consideration.

Yours faithfully

Mphelane Makua Leah MA CUR STUDENT, UNISA

Prof TR Mavundla SUPERVISOR (RN PHD)

CONSENT LETTER FOR PARTICIPANT

Dear Research Participant

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

I am an MA (Cur) student currently enrolled with the University of South Africa (Unisa). I am engaged in a research dissertation titled "The role played by families in support of their mentally ill relatives in a rural community in Limpopo Province".

The purpose of the study is to explore and describe the role played by families in support of their mentally ill relatives.

To complete this study, I need to conduct an interview of approximately 45 to 60 minutes' duration, which will be audio-taped for verification of findings by an independent qualitative research expert. In this study, I undertake to safeguard your anonymity by omitting the use of names and places. Confidentiality will be assured by erasing the taped material after transcribing the tapes.

Only an independent expert in qualitative research and I will share the transcribed tape material. It should be understood that you are under no obligation to participate in this study. You are free to terminate your participation even when the interview has begun.

The direct benefit to you of participating in this study is that you will have the opportunity to verbalise your experience of supporting the mentally ill relatives in a rural community to the researcher. Another benefit is that the researcher will use your experience to develop guidelines for the support of the mentally ill relatives by their families in a rural community.

A summary of the research findings will be made available to you on request. Should you wish to contact the researcher for any enquiries feel free to do so at the following postal address:

Mrs ML Mphelane Glen Cowie Stand No 982 PO Box 383 GLEN COWIE 1061			
Cell: 0827170037			
Thank you			
ML Mphelane Makua MA CUR STUDENT, UNISA	DATE:		
Prof TR Mavundla SUPERVISOR (RN PHD)			
PARTICIPANT'S SIGNATURE	DATE		

INTERVIEW[°]

Interviewer:

Hello. We are now going to start with our interview. Which language do you prefer?

Participant:

I prefer English.

Interviewer:

What is your experience in the support of your mentally ill relative? What is that, that you do to keep him in the community?

Participant:

Since I had this mentally ill client in the house, what I have experienced is that we, the family members, must not be short tempered because there are many things that he does in the house that could lead to either one of the family members being injured or dead. We always try to give him support by giving him what he wants, like if he asks for food we try to cook the type of food he likes for that day. Sometimes he just go to the refrigerator and took out what ever he wants to eat, despite what the family is intending to cook that day. Sometimes he asks for foods that he cannot afford. These type of people are troublesome because even if they have money they do not want to use it in the house. They are greedy, sometimes he can take out meat straight from the refrigerator, put it in the micro-oven, cook until is well-cooked. When they have their grants they are very aggressive. Now that he gets his grant from the shop he only spent R60 that the owner of the shop needs. Then, for him is okay, this are the problems we are experiencing with this people.

Interviewer:

I heard you saying that he is doing many things. What are those things that he does?

Participant:

Sometimes he sells property from the house which does not belong to him. My cups are sold to outside people. Every time he went out of the house, he has some parcel to sell. He is selling his

clothes and brother's clothes too. He can wash one item in the washing machine, spin and took it for sale. These are problems we are experiencing with mentally ill clients.

Since he started to receive grants he has only two trousers, although he had about ten trousers. He likes labels. One time he nearly sold my music system. He also sold my urn. Only two doors are closing. They are destroyed because he sometimes uses a spade to open the door even if that door is locked. If you can just leave him alone in the house only a minute, when you come back you will find him searching for things that he can sell.

Interviewer:

Is he doing all this things all the time?

Participant:

Sometimes I am afraid of him because he frightens me with spades, stones, hoes and knives. The other day I was in my neighbour's house, he came with a spade and with the other hand he made a cross on his chest. I could see that he was praying God to help him so that he can kill me. I become more afraid when I am alone in the house because sometimes when he enters home he has smoked dagga he thinks of bad things.

Interviewer:

Can you explore more on the support hat you give him?

Participant:

Sometimes if I see that he is happy, I sit with him, talk to him about banking account so that he can have a family one day, because sometimes God may take me first. I don't know may be his brothers and sisters wouldn't have tolerance like I have as a mother. If he has a family they will take care of him. Another support is that sometimes he stays with untidy clothes not being aware that he is untidy. I usually wash his clothes so that he can be presentable just like any other children. Sometimes, the mentally ill are not looking well after themselves, may be it is because of mental illness or they are lazy.

Interviewer:

What did you do when he was having dangerous weapons?

Participant:

Usually I call the police and they come after a long time and take him to the hospital. He is able to approach the police and tell them that he is not doing anything harmful. The police assists me though they say it is not their duty, it is the nurse's duty. They have assisted me four times. This mentally ill client is unpredictable because every time he gets relapsed his behaviour differs from the previous episode. He has just started to be aggressive last year; previously he was shifting objects in the house, moving table to the bedroom and beds to the kitchen trying to re-arrange the house.

Interviewer:

How often was he admitted in the hospital?

Participant:

I can say every year. He has been hospitalized in Thabamoopoo, Groothoek and Jane Furse hospital.

Interviewer:

While he was an in-patient, is there any education received in the hospital about him/his condition?

Participant:

No, education was given except the interview that they normally conduct about when illness started. I sometimes read books about the illness and learn how to care for these patients. I don't know whether I can say nurses did not care or what because they did not give us health talks. By the time he was admitted in the ward there was a problem that nurses reported that they are not employed to care for mentally ill patients.

Interviewer:

What information would you love to get from nurses?

Participant:

I would like to know the causes of mental illness because some people says it is caused by dagga and some says it is caused by home environment and the care of mentally ill clients at home. *Interviewer:*

Was he given medication from the hospital?

Participant:

Yes, I gave myself a task of counting his tablets every day to ensure that he takes them correctly. Sometimes he refuse and say I must also take that tablets. I was having a record for monitoring the tablets, then he said he doesn't want them anymore. I started to crush the tablets and put them in his meal until one day when his brother came home earlier and eat the meals with tablets. He slept for two days reporting body weakness, then I decided to stop. Nowadays he is on injections and he is fine.

Interviewer:

Is it possible for the mentally ill to get an injection only?

Participant:

Yes, it is possible and others get injections and tablets.

Interviewer:

Any other things?

Participant:

I don't know how can I convince him to bank money. I don't know, may be if the government can be able to bank a certain amount for him, it will be better. Since he started to receive the grant three years back, I have never been to the pay point, because he has reported that if he can see me there, he will kill me. I remember one time when a gentleman came to accuse me that I am going with him to the pay point and there are shoes he bought, but did not pay. Sometimes we attend family funerals together and we assist him with money for transport because even if he receives a grant, he does not have money.

Interviewer:

Do you still have anything to say?

Participant:

No, I think that is all what I do to this client.

Interviewer:

Thank you very much.