AN EXPLORATORY-DESCRIPTIVE STUDY OF PERCEIVED FAMILY BURDEN BY FAMILY MEMBERS OF INDIVIDUALS WITH A SERIOUS MENTAL ILLNESS IN THE UTHUKELA DISTRICT OF KWAZULU-NATAL

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Student: **Ms. Tholakele Maria Buthelezi**

Student Number: **205527408**

Supervisor: **Dr. Lyn Middleton**

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Dedication

This study is dedicated to my husband Jabulani, my children Nhlanhla, Mpume, Njabulo and Ntoko and to my ever supportive friend Busie for being my source of encouragement.

Declaration

I Tholakele Maria Buthelezi declare that the dissertation entitled - **an exploratory-descriptive study of perceived family burden by family members of individuals with a serious mental illness in the uThukela district of KwaZulu-Natal** is my own work and it has never been submitted to any other institution for degree purposes. Sources of information used in this study have been acknowledged and indicated in the reference list.

Tholakele Maria Buthelezi   Date
 (205527408)

Dr L Middleton   Date
(Research supervisor)

Abstract

The global change in the provision of mental health care services from long-term institutionalization to community-based care brought changes in the care giving responsibilities. This approach shifted the responsibility for the care of individuals with serious mental illness from psychiatric hospitals where health professionals were the primary care-givers, to community health care services where the family members are now the primary care-givers and the major sources of psychosocial support for the individuals with serious mental illness (Chamber, et al., 2001; Seloilwe, 2006).

The aim of this study was therefore to explore the care giving burden as perceived by family members of individuals with serious mental illness and the association between their coping strategies and the perceived burden.

Methodology: An exploratory-descriptive, non- experimental quantitative study was adopted to describe and explore perceptions of care giving burden by family members, and the association between the perceived burden and the family coping strategies. The Zarit Burden Interview (ZBI) was used to collect data on perceived family burden and the Carers Assessment of Management Index (CAMI) to collect data on coping strategies. The questionnaire was self- administered to 120 family members of the individuals with serious mental illness who accompanied their relatives at the clinic and who met the sample inclusion criteria.

Findings: The findings revealed that family members in the uThukela District were experiencing great burden while caring for their relative with serious mental illness. The most influencing factors were the worsened condition of a relative with unmanageable behaviour, poverty, lack of resources including knowledge, rehabilitation centres. Over dependency of a relative with serious mental illness on family members was one of the greatest worries of the participants. The situation negatively affects on the social lives of the family members and on their well being. In terms of coping strategies, family members were found to be using both problem-focused and emotional-focused strategies to balance their coping abilities.

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CHAPTER ONE

1.1 INTRODUCTION AND BACKGROUND TO THE STUDY

The changing philosophy in the provision of mental health care services in South Africa from long-term institutionalization to community-based care has significantly increased the role and responsibility of families in the management of family members with serious mental illness (Chambers, et al., 2001).

This deinstitutionalization process which began in the United States in the 1960's and in South Africa in the middle 1970's, marked the beginning of the transformation of mental health care (Kigozi, 2007). The philosophy of community and family-based mental health care is enshrined in the national health transformation policy guideline of 1994, and is an integral aspect of the primary health care approach in South Africa (Department of Health, 2000).

The deinstitutionalization process was followed by the decentralization of mental health care into lower administration units of districts and community clinics (Kigozi, 2007). This approach shifted the responsibility for the care of individuals with serious mental illness from psychiatric hospitals where health professionals were the primary care-givers, to community health care services where the family members are now the primary care-givers and the major sources of psychosocial support for individuals with serious mental illness (Chambers, et al., 2001; Seloilwe, 2006).

However, Michael (2001) and Seloilwe (2006) are of the opinion that the deinstitutionalization process mandated the discharge of the individuals with serious mental illness from public hospitals, before ensuring that the necessary infrastructure for survival outside the institution was available. Shortcomings in planning were evidenced by an irregular availability of medication in some health care facilities, lack of rehabilitation services, shortage of skilled health care workers, problems with

accommodation and lack of involvement of family members in education and support programmes (Chambers, et al., 2001; Chui & Chan, 2007; Huang, 2008; Michael 2001; Seloilwe, 2006; Ukpong, 2006).

The literature in the area of family care giving suggests that while family members have become the central source of support for their ill relatives, they experience a great deal of emotional, physical, social and financial strain in this expanded role which negatively impacts on their own quality of life and their capacity to adequately care for their ill family member (Chambers et al., 2001; Chui & Chan, 2007; Seloilwe, 2006).

The care giving demands encountered by family members living with individuals with serious mental illness are most frequently perceived as a burden by the family members.

Family burden is described as the emotional, physical and economical difficulties that caring for the individual with serious mental illness imposes on family members (Magliano, Fiorillo, De Rosa, Malangone, 2005; Ostacher,et al.,2008; Perlick, et al., 2007; Kam-Shing, 2005).

Prior studies on family burden have found that family members find themselves engaged in long term commitments for the provision of material resources for the relative that has became a dependent person (Magliano, et al., 2005; Seloilwe, 2006;Kam- Shing, 2005).

Nossek (2005) has found that some family members use about 29 -49% of their family income to cover the expenses incurred in the management of the family member with a serious mental illness.

According to Chambers et al., (2001); Magliano, et al., (2005) emotional   reactions of family members facing mental illness include feelings of anger, shame, worry, loss, towards mental illness.

Eakes, 1995 (as cited in Seloilwe, 2006, p.267) described this emotional situation for the family members as an "unresolved grief associated with an, on-going loss, and chronic sorrow because of its constant, endless and persistent nature."

Families need appropriate education in order to help them in understanding the condition itself, and to develop skills in assessing and dealing with these difficult symptoms and behaviours (Magliano, 2005).

According to various researchers (Perlick, et al., 2007; Van Der Voort, et al., 2007) the caring burden for the individuals with serious mental illness can be influenced by different variables including: gender, age, level of education, severity of illness/symptoms, duration of illness, coping strategies, social stigma and relationship between the family member as a caregiver and the individual with serious mental illness.

Stigmatization upon individuals with serious mental illness and their family members may result into intense guilty feelings, shame and reluctance in seeking resources that would increase their coping strategies (Chien, et al., 2005). According to Van Der Voort, et al., (2007); Chang & Horrocks, (2006) family members that are exposed to social stigmatization associated with serious mental illness reported social deprivation and high burden of care giving.

Ekwall, Sivberg and Hallman (2006) and Van Der Voort, et al., (2007) are of an opinion that the relationship between family members and the individual with serious mental illness influences the perception of burden. Positive relationships lessens the perceived burden of caring.

Although most of the researchers in care giving for people with serious mental illness dwelt much in the negative experiences of families, Rapanaro, (2007); Mak and Cheung,

(2008); Bolden and Wicks, (2009) are of an opinion that care giving is not all about negative experiences and that there are some positive and rewarding outcomes in care giving. In a study conducted by Rapanaro, (2007) on chronic care giving by parents, family members reported some positive outcomes which were beneficial to them. The benefits reported in the study were expanded social networks, family developing new social networks while caring for their relative, opportunity to acquire new coping skills for managing difficult situations, closer family ties, personal growth and maturity (Bolden and Wicks,2009; Rapanaro, 2007; Mak & Cheung, 2008).

Family members need to develop efficient coping strategies to adapt to the demands of caring. Lazarus and Folkman (1984), (as cited in Ekwall, 2006, p.585) discussed the family coping strategies as derived from internal and external resources. Internal resources for coping strategies have been identified by Lazarus and Folkman (1984) as the knowledge about the relative's condition and its management, while family support and social networks are classified as external resources of family coping strategies. The level of perceived burden is also influenced by the effective usage of coping strategies (Ekwall, 2006; Van Der Voort, et al., 2007).

Coping strategies of family members influences the perception of care giving burden. Emotion-focused coping strategy is associated with high levels of perceived care burden. Family members who adopt Problem-focused coping strategies reported fewer burdens in various studies (Chui and Chan, 2007; Huang, et al., 2008; and Van Der Voort, et al., 2007).

Families need appropriate education to help them in understanding the condition of an individual with serious mental illness. According to Ekwall, et al., (2006); Magliano, et al., (2006) psycho-education plays a vital function in the family care giving context by increasing the coping orientations of family members and assisting them to develop skills in dealing with care giving demands thus improving the quality of life in the family.

1.2 PROBLEM STATEMENT

As discussed in the section above, the shift in the locus of care for the individuals with serious mental illness from long term institutionalization to family-based community mental health care did not seem to be adequately planned for. While the community-based mental health care paradigm regards families as the central pillar of care and support for their relatives with serious mental illness, very little is known about how the families in the uThukela district perceive and cope with this burden and its influence on their capacity for fulfilling this central care-giving role.

Various studies have shown that education and support play a role in alleviating family burden and suggested that families and mental health care professionals need to form partnerships in order to maximize the families' capacity for effective management of the individuals with serious mental illness (Goossen &Van Der Bijl, 2007; Seloilwe, 2006; Van Der Voort, et al., 2008).

Anecdotal reports from some family members caring for mentally ill persons suggest that families are reluctant to have their family members return home after being discharged from hospital (F.Zama; G,Masimula and R,Willis, personal communication, March 9,2009). Although family members are typically concerned for the welfare of their ill members, the respite from the burden of care-giving is often a welcome relief.

The rate of re-admission of these patients is generally high, with 25% of patients being re-admitted within 30 days of discharge. There is very little information about how the families of mental patients perceive their care giving role and the kind of interventions they might need to support them in this role.

The current study is the first study within the uThukela district that seeks to describe the perceptions of care giving roles of family members of the persons with serious mental illness and to explore the coping strategies used by family members to adapt themselves to the demands arising from the care giving context.

1.3 PURPOSE OF THE STUDY

The purpose of the study is to explore how families caring for family members with serious mental illness within uThukela District perceive and coping with the burden of care giving and the association between their coping orientations and the perceived burden.

1.4 OBJECTIVES OF THE STUDY

The objectives of the study are to:

1.4.1 Describe the factors that influence the perceived burden of family members as caregivers of individuals with serious mental illness within uThukela District.

1.4.2 Explore the coping strategies that are used by family members in their care giving roles.

1.4.3 Explore the relationship between the perceived family burden and their coping strategies with socio-demographic characteristics of the participants.

1.5 RESEARCH QUESTIONS

1.5.1 What factors influence the perceived burden of family members as caregivers for the individuals with serious mental illness within uThukela district?

1.5.2 How do families of individuals with serious mental illness cope in their care giving roles?

1.5.3 What is the relationship between the perceived burden and their coping strategies with socio-demographic characteristics of the participants?

1.6 SIGNIFICANCE OF THE STUDY

The findings of this study will document the burden perceived by family members in a care giving context within the uThukela district and further identify their coping needs. It will formulate a number of recommendations for addressing these needs and thus, for reducing burden and increasing their capacity for care-giving. It is believed that the findings of this study will form a valuable reference for mental health care professionals seeking to improve the quality of care for the individuals with serious mental illness within this district.

The study will provide nurses with comprehensive knowledge of the family care giving burden and coping and in so doing, contribute to the development of effective intervention strategies aimed at increasing the coping strategies for family members caring for people with serious mental illness.

The information from the study will assist the uThukela health care managers, the nursing management and programme coordinators in developing policies and intervention programmes for increasing support to family members of the individuals with serious mental illness within the uThukela district. Since there is limited knowledge about the

family coping strategies and their perception of care giving role in the uThukela district, this study may serve as the foundation for the future research about the issues encountered by families in their care – giving role within this district.

1.7 DEFINITION OF KEY CONCEPTS

Family burden

The concept is defined by, Papastavrou, Kalokerinou, Papacostas, Tsangari & Sourtzi, 2007; Perlick, et al., 2006; Platt, 1985(as cited in Lowyk, 2004) as the presence of problems, difficulties and negative events that negatively influence the lives of the family members. It broadly involves the physical, psychological, social and financial experiences of care giving.

Family burden is further described by McCubbin and Patterson (1983) as stressors that include discrete events of change in the family environment of the individual with serious mental illness. In this study it can include: the objective stressors, such as financial strains, social stigma, and assistance with physical care. Subjective stressors often occur as consequences of objective stressors and include psychiatric relapse, ongoing family disruptions e.g. unpredictable behavior, and disruptions of daily life.

Family

Family members are a group of people who fall under biological and/or kinship rules. Kinship will be based on a combination of both mother's and father's biological line (Kirby, et al.2000; Matzo & Sherman, 2010). In this study a family will also include stepchildren, life partners and extended family members living with and giving care to a relative with serious mental illness.

Extended family is defined as multigenerational and includes all relatives by birth, marriage or adoption. The extended family group may consist of grandparents, aunts,

uncles, nieces, nephews, cousins and in –laws (Giger & Davidhizar, 1999; Kirby, et al.2000; Matzo & Sherman, 2010). This study will consider the family group living either within the same household and or in close proximity with a relative that has a serious mental illness serious mental illness

The definition adopted for this study is provided by the American Association of Psychiatric Services, definition for adults (18 and older).According to the definition, Serious mental illness is a mental condition or illness ranging from moderate, severe to extreme functional impairment in two to four of the following areas.

I. Impairment of thought processes including lack of concentration, delusions, and hallucinations.

II. Disruptions in self-care/basic needs which are characterized in an individual's inability to provide for his /her needs. Role performance disruptions characterized by inability to meet the expectations and limited conduct in conforming to laws and rules resulting in destruction of property and being a danger to self and others.

III. The criterion for the diagnosis of serious mental illness from the given definition excludes the primary diagnosis of substance abuse and developmental disorders.

IV. The definition focuses on diagnosis, functional and duration of illness which is a minimal duration of two years of functional impairment in adults of 18 years and above.

Coping strategies

In this study coping strategies will be defined as any attempt made by the family members of the individuals with serious mental illness to reduce, alleviate problems arising from a stressful situation Lazarus & Folkman (1984) (as cited in Knussen,et al. 2008).

Coping strategies are grouped and classified as problem-focused and emotion-focused coping strategies. The concept coping is defined as the process whereby family members engage themselves in managing the discrepancies between the demands of care giving and the available resources.

Care giving

Care giving is an act of providing unpaid assistance to a relative with serious mental illness by family members who often have no formal training in care giving roles. Care giving by family members can be in one or more forms of care giving, which includes instrumental, emotional and or informational care (Drentea, 2007).

1.8 CONCEPTUAL FRAMEWORK

The conceptual framework for this study is based on McCubbin and Patterson's (1983) and Patterson's (2002) descriptions of family stress, adjustment and adaptation. The authors' argument is that family members actively engage in processes to balance family demands or burdens with family capabilities in order to maintain, develop or restore family adaptability and stability.

Family burdens are stressors which include objective and subjective burden. Objective stressors include disruptions of household activities, leisure time, social network and family relations due to the amount of care given to a relative with serious mental illness, social stigma and financial expenditures.

Subjective stressors occurring as the consequences of objective burden/stressors, this includes anxiety, anger, guilty feelings and despair (Van Der Voort, et al., 2008).

Any occurrence of a life event in the family, depending on the severity of the situation is associated with stressors that challenge the coping orientations of the family members.

A negative life event disturbs the family stability. In this study the life event is an illness where the presence of serious mental illness in a family demands a change in responsibilities within a family (Magliano, 2005).

According to McCubbin and Patterson, 1983 (cited in Dong et al.,"n. d") family members have existing resources that are utilized at the onset and during the process of a crisis in the family. These resources may be adequate or inadequate for the problem. Inadequate resources influence the family coping patterns and family stability.

A change in a family stability due to the presence of an illness is influenced by the availability of resources (coping orientations) and the effective usage of these resources by the family members.

The effective usage of coping strategies results in family stability by reducing the perceived family burden. Adequate resources tend to lessen the perception of care giving burden and promote family adaptation in the caring context. It has been indicated in different studies that family burden and coping strategies are major predictors of family adaptation (Ekwall, et al., 2006; Rakesh, et al., 2007; Van Der Voort, et al., 2008).

Coping orientations are classified into two broad coping strategies that is, the emotion-focused strategies which have no intentions of changing or reducing the threat but at changing the meaning of the situation such as a wishful thinking, crying over the situation or resorting to avoidance behaviors. Problem–focused strategies as defined by Ekwall, et al., (2006) are the ways of defining a problem and adopting measures of reducing or changing the problem, this includes family attempts of seeking support from friends, families with similar problems and professional help. Lack of coping orientations

and/or the ineffective use of these strategies are associated with disruptions in family stability and an increase in the perceived family burden.

According to Rakesh, et al., (2007) family members as caregivers perceive higher levels of burden when they have limited resources. The conceptual framework thus suggests that the perception of a caring burden by family members is influenced by their coping orientations in that, the more effectively a family member uses their coping strategies the lesser the perceived burden.

Diagram 1: Schematic Representation of a conceptual framework Adapted from (Ekwall, et al., 2006; MacCubbin & Petterson, 1985 (as cited in Dong et al.,"n.d); Maglino, 2005; Rakesh, et al., 2007; Van Der Voort, 2007).

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┌─────────────────────────────────────────────────────────────────────┐
│ Family burden (objective and subjective burden} from care giving     │
│ demands difficulties encountered in the care giving roles present as  │
│ stressors in the lives of family members.                            │
└─────────────────────────────────────────────────────────────────────┘
                                    │
                                    ▼
              ┌─────────────────────────────────────────────┐
              │ Challenges the availability of coping        │
              │ strategies (resources) and patterns of       │
              │ coping strategies.                           │
              └─────────────────────────────────────────────┘
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Inadequate resources and ineffective usage of coping

Increases the perceived burden of care giving

An increase in perceived burden decreases the coping strategies and is associated with family disruption and maladaptation

Coping resources
- Information about serious mental illness.
- Psycho- education
- Orientation on the available resources within the health care giving context.
- support including, social networking with: relevant professionals, families with similar problems, friends, family, support groups
- Destigmatisation
Availability of distigmatisation programmes
-Psychosocial Rehabilitation programmes
Coping strategies include: problem focused and emotion-focused strategies

Adequate resources and effective use of coping strategies

Decreases perceived burden of care giving

A decrease in perceived burden increases the coping strategies and is associated with family stability and adaptability

High burden (stress) _ less burden (stress)

1.9 CONCLUSION

This chapter provided a background of the study drawing information from literatures,
discussed the purpose, objectives and theoretical framework of the study. The next
chapter will discuss the literature review with respect to family burden and family coping
strategies.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

Literature review forms a linkage between the existing knowledge and the future research findings. As good research does not exist in a vacuum Polit & Hungler, (2002), a global review of literatures within the perception of care giving and family coping strategies will provide the foundation for this study.

The data bases-Medline-Pub Med, Medline-EBSCOhost, Health Source- Nursing editions, PsychINFO, Science Direct, Google Scholar were searched using the following terms:

Family burden, care giver's burden, coping strategies, stressors and stigma in the care giving context, family adaptation, interventions that reduces the burden of care giving.

The literature review is presented in the following sections:

2.1 The impact of deinstitutionalization in families of the individuals that have serious mental illness.

2.2 Burden of care giving perceived by family members

2.3 Impact of stigmatization on family members in a care giving context

2.4 Family coping strategies/mechanisms and nursing interventions for increasing family coping and reducing burden

2.2 Deinstitutionalization

Deinstitutionalization process in mental health care began with noble sentiments of releasing people to reside with their families where they could be treated in their

community settings and interact with the community members whom they familiar with the shared values, cultural background and norms (Lamb, et al., (2006).

This next session will briefly review the process of deinstitutionalization and its impact on the consumer, families and the service provision.

Deinstitutionalization is the process that begun in 1970s in South Africa and resulted into a shift from long institutional care of individual with serious mental illness into community care service.

According to Fisher, et al. (2001) deinstitutionalization brought along two processes in mental health care. The first process dealt with the transfer of the mental health care users from the state psychiatric hospitals to the community. The second process being the transfer of the psychiatric hospital functions to the community health care- based setting whereby the family forms the central pillars for the psychosocial support to the individual with serious mental illness.

Deinstitutionalization was believed to be a cost –effective approach that will be beneficial in all aspects but the implementation of it resulted into negative socio-economic consequences affecting the clients, family members and indirectly the government itself (Seloilwe, 2006; Sheth, 2009).

According to Lamb, et al. (2006) the implementation of the deinstitutionalization process lacked a third process in its process, which is the development of the various community resources. It has been pointed out by various researchers that, deinstitutionalization process lacked plans for the provision of funds for accommodation of the individuals with serious mental illness who are to released from the institutions, funds to implement psychosocial Rehabilitation programmes and for training and employment of staff that will provide support to family members whom the responsibility of care giving had been shifted to (Michael, 2001; Sheth, 2009).

Michael (2001) indicated that failure in the provision of resources for the individuals with serious illness resulted into the situation whereby the individuals with serious mental illness are seen walking aimlessly in the streets and being homeless.

Sheth (2009) is of an opinion that deinstitutionalization resulted into a shortage of psychiatric beds in the psychiatric public institutions. This created a negative impact on the rights of the clients for voluntary admissions and deprived them an opportunity to remain in the hospital at the end of their involuntary admission as voluntary patients even if the client still feels the need of being in hospital.

Discharged individuals are released to their family members who find it difficult to meet the demands of care-giving. This is mostly because of limited skills, lack resources resulting into care giving being perceived as a burden by family members (Perlick, et al., 2007; Van Der Voort, et al., 2007).

2.3 Family burden

A change in mental health care principles from long -term hospitalization of the individuals with serious mental illness into community health care services placed families as centre poles for the provision of care and support to their relatives who are affected with serious mental illness (Chambers, et al., 2001; Sheth, 2009; Seloiwe, 2006). The review will look at what is perceived as a burden and how does it termed a burden by family members.

Family burden refers to any emotional, physical and economic problems/difficulties encountered by family members of the individuals with serious mental illness (Lowyk, et al, 2004; Van Der Voort, 2007). The burden experienced by the family members is classified into three dimensions of burden by various researchers, that is, the objective, subjective burden and a burden of behavior management of the individuals with serious mental illness (Lowyk, et al.2004; Rakesh, et al., 2007; Kam-Shing, 2005; Wong, et al., 2008).

Objective burden being described as the practical problems, that include, financial expenditure, disruptions in family relationships, amount of physical care assistance compromising the social life of family members, (Rakesh, et al., 2007).

According to Mengdan, et al., (2007); Van Der Voort, et al.,(2007), Objective burden is more associated with duration of care giving, severity of symptoms and amount of care required which is influenced by a number of family members participating in care giving to an individual with serious mental illness.

Subjective burden is the psychological reactions resulting from the perception of objective burden. Psychological reactions include feelings of anger, shame, worry, guilt, loss towards mental illness (Chambers, et al., 2001; Mengdan, et al., 2007; Wong, et al., 2008).

Burden in management of problem behavior refers to the management of mood reaction of people with serious mental illness such as unpredictability of behaviour and management of negative symptoms.

There is a need to take a closer look on the impact of mental illness in rural areas. UThukela district is made up mostly of rural areas. Magliano (2005) indicated that the burden of mental illness in rural areas is higher due to access barriers including lack of mental health care facilities, qualified mental health care providers, poverty and the situation being magnified by lack of transport and or high transport fees

According to a study done by Magliano et.al (2005) in Northern Italy, mental illness in the family changes the family routines and their social living style. The unsettled conditions of persons with serious mental illness affect the social life of the family members, their work opportunities and relationships with community members.

It is reported that families find it difficult to leave the individual with serious mental illness alone and to freely attend to their social needs such as going out with friends and even going to work as continuous supervision is frequently a necessity in this care giving context (Rakesh et al., 2007).

Family members who often are the breadwinners in the families are sometimes obliged to leave their paying jobs to take care of the relative that is affected with serious mental illness with resultant into a decrease family income (Magliano, et.al, 2005).

The burden perceived by family members is influenced by many variables and varies from family to family, Ekwall, Sivberg &Hallman, (2006) stated that the relationship of the family members as the caregivers with that of the individual with serious mental illness has an influence on family burden. Care giving role to a parent differs from the care given to a spouse, child, sibling or and other relative with regard to cultural respect, intimacy, mutual relationships (Van Der Voort, et al., 2007).

The perceived burden varies with family member's demographics. According to Boldin &Wicks., (2009) caregivers attributes such as gender, age and educational levels, household income and severity of symptoms affects the caregivers perception of the intensity of care giving burden.

Age influences the caring burden in a sense that, the care giving burden is perceived differently by family members of different age categories.

Various research findings concur that older family caregivers perceive higher levels of care burden compared to the younger family members because of their poor health conditions (Chien, 2006; Van Der Voort, et al., 2008). A study done by Hi-Ching, 2009, exploring the experiences of older carers, indicated that, the elderly family members are the most affected family members as care givers as they traditionally accept the caring roles and have a tendency of developing physical problems because of their age.

Research studies by Croog, et al., (2006); Thomson, et al., (2004) (as cited in Papastavrou, 2007, p.452) showed that gender has a great influence on the burden of care giving and generalized that the caring role in most societies is ascribed to females as women are more frequently caregivers in the family compared to men.

Researchers have found that women perceive a higher burden of care giving in the caring role, than men. An increase in perceived burden among women has been associated with lack of resources and utilization of coping strategies (Papastavrou, 2007; Rakesh, et al., 2007). Chui & Chan (2007) and Papastavrou, et al., (2007) asserted that the general expectations from women in care giving role is the ability to fulfill the caring function even without any preparation or support because of their nurturing pre-disposition.

Various research findings associate the caregiver's level of education with the household income. (Caqueo-Urizar and Maldonado, 2006; Chien, et al., 2005; Li, et al., 2007; Ukpong, 2006). These studies hypothesize that the higher the level of education, the lesser the perceived economic burden since it is expected that a family member with a higher education level will earn a greater household income which thus lessens the perception of economic burden (Li, et al., 2007; Papastavrou, et al., 2007; Ukpong, 2006).

According to Caqueo-Urizar and Maldonado (2006), family members with higher education reported less burden than family members with lower level of education due to the fact that individuals with higher education access resources much easier as compared to the other group.

The severity and duration of illness also influences the perceived burden. According to Lowyk et al. (2004) the quantity of symptoms has an influence on the perceived burden, that is, the higher the quantity or severity of symptoms, the higher the perceived burden of care giving by the family member. The behavior of the individual with serious mental

illness influences the care burden (Etters, et al., 2007). Negative behaviors such as aggression and violence are associated with fear, despair, shame and anger contribute to emotional, physical and social burden perceived by family members as care givers (Etters, et al., 2007; Van Der Voort, et al.,2008).

Rakesh, et al., (2007) and Van Der Voort et al., (2007) discovered that the perceived amount of burden is not constant and changes with the course of the illness which is characterized by an improvement and or deterioration of the condition of the individual with serious mental illness.

According to various researchers Bolden and Wicks, (2009); Mak and Cheung, (2008); Rapanaro, (2007); family giving is not all about negative experiences, as there are some positive and rewarding outcomes in care giving. In a study conducted by Rapanaro, (2007) on chronic care giving by parents, family members reported some positive outcomes which were beneficial to them. The benefits reported in the study were expanded social networks, family developing new social networks while caring for their relative, opportunity to acquire new coping skills for managing difficult situations, closer family ties, personal growth and maturity.

Andréan & Elmstahl, (2005) reported women as the most affected group in the families as they are generally expected to be caregivers in many instances. Magliano, et.al (2005),is of an opinion that the burden perceived by family members is not always stable but decreases with time as the affected individual's functional skills improves and as coping strategies acquired by the family members increases over the period of time.

Prior research studies recommended the provision of psycho-educational programmes to assist family members in increasing their knowledge about the condition, and provide them with information, on the available community resources (Chang & Horrocks, 2006; Seloilwe, 2006).

The communities need to be involved in these education programmes about mental illness as they sometimes intensify the care giving burden by stigmatizing the individuals with serious mental illness and their families.

2.4 Stigmatization

Stigma is an undesired label, attribute that negatively impacts on the individual status and or reputation. (Whetten, et.al, 2008).This is further described by Corrigan & Watson 2002); WHO, (2001) as a phenomenon leading to disapproval and or discrimination of the individuals with mental illness in many aspects in the society by the society members.

The review of the literature will look at the magnitude, the effects of stigma and discrimination amongst the families of the individuals affected with serious mental illness.

Stigma and discrimination affect the individuals in different aspects of life that is, in social, economical and in psychological aspects.

According to Corrigan & Watson (2002) the negative impact of stigmatization does not only affect the individuals with serious mental illness but the whole family since stigmatization brings along discrimination with it.

Stigma is either directly experienced by the individuals or simple perceived by the individuals. Perceived stigmatization is termed self stigmatization of the family members resulting into a situation whereby family members decide to isolate themselves from community activities (Mak & Cheung, 2008).

Families, respond to stigmatization by restricting the disclosure of illness and withdrawing from social networks to protect their social images. Social withdrawal results into loss of support from the significant members and increase care giving burden

(Mak & Cheung 2008).Seloilwe (2006) also pointed out that, family members social activities tend to decrease because of perceived stigmatization which impacts on their leisure activities and on their socialization needs

According to the findings of the study performed by Magliano, (2005), 17% of the relatives from the study conducted had problems in calling visitors in their living places because of the unpredictable behavior of a relative with serious mental illness.

Stigmatization affects the quality of care giving provided by family members to their relatives. Mak & Cheung, 2008, pointed out that, family members with high levels of affiliate stigma develop negative attitudes towards care giving.

Families need to be well informed about the disease and disease management to reduce the feelings of guilt, self- blame, discrimination and social isolation. Pitschel-Walz, et al. (2004) are of the opinion that family empowerment is a proper tool that can be considered by the mental health care team in preparing families to become partners in treatment and or to function as core workers in mental health care management.

 A study on stigmatization of mental illness in the Sub-Saharan African country identified the need for the incorporation of anti-stigma educational programmes into mental health Policies to ensure that the community is educated on mental illness related issues. The strategy was aiming at changing the negative attitudes of communities towards the individuals with serious mental illness, and at boosting the self image of family members (Abiodun, Adewuya, & Makanjuola, 2008).

Anti-stigmatization programmes have been found by various authors as the strategy that improves the negative attitudes thus contributing towards the improvement of family members' coping strategies (Abiodun, et al., 2008; Chien, et al., 2005).

2.5 Coping strategies.

Families provide a continuous emotional, physical, psychological and economic support to the individuals affected with serious mental illness.

Uys & Middleton (2004) described coping is defined as a cognitive or behavioral attempt adopted by a person and or family members experiencing a problem to reduce or prevent a stressful situation. Coping is also described as a family attempt to reduce or manage demands on the family system and to interact with all the resources coming at their disposal for management of the situation (Mengdan, et al., 2007).

Lazarus and Folkman (1984) (cited in Ekwall, 2006) discussed the family coping strategies as derived from internal and external resources. Internal resources for coping strategies have been identified as the knowledge about the relative's condition and its management. The positive relationship between the family members and the individual with mental illness lessens the burden of caring. Family support and social networks are classified as external resources of family coping strategies

According to (Mattei, Prunas, Novella, Marcone, Cappa& Sarno, 2008) there are two general coping strategies that are used by family members in a care giving context, identified as problem- solving and emotional –focused coping strategies. Problem-solving strategies are directed in active efforts made by family members to alleviate a family stressful situation. While the emotional –focused coping strategies involve the coping efforts that regulate the emotional consequences (Mattei, et al., 2008).

Various studies concur that coping experiences of family members tend to influence the perception of care giving burden. Emotion-focused coping strategies are associated with high levels of perceived care burden compared to problem-focused coping strategies (Chui and Chan, 2007; Huang, et al.2008; and Van Der Voort, et al.2007).

According to Papastavrou, et al., (2007) family members with high levels of care burden tend to adopt the emotional-focused strategies such as avoidance and escape strategies

which are often associated with high burden perceptions if not combined with problem – focused strategies. The findings of the study done by Papastavrou, et al., (2007) on family caregiver burden, women were found to use more emotion–focused strategies such as praying for the illness to go away, without active actions of seeking support. Men on the other hand, compared to women were more problem –focused and reported lesser levels of burden of care giving (Papastavrou, et al., 2007).

Huang, et al., (2008), also identified three coping methods that are mostly used by family members of the individuals with serious mental illness which include the physical, psychological and social strategies.

In various findings, family members reported the use of neuromuscular relaxations, getting enough rest, and using of comfort exercises (Van Der Voort, et al., 2007)

Psychological coping strategies include cognitive, behavioral and emotional coping strategies. Findings from a quantitative study performed by Huang, et al., (2008) on coping experiences of carers, in Taiwan, showed that cognitive coping strategies were the most strategies utilized by the family members which include seeking information for more knowledge, using personal experience in problem solving. Family members making efforts of solving their relative's related problems among themselves before seeking for professional help.

Behavioral coping strategies being more action –orientated were also found helpful by family members in trying to keep themselves busy all the time to think less about the problem.

 In a study performed by Huang, et al., (2008) three social coping strategies that emerged from the study were spiritual support, social support from friends and family members and professional support. Professional support was mentioned by the participants in the study as inadequate and not readily available as support to the family members

Families tend to alleviate their emotional stressors including feelings of shame resulting from the antisocial behavioral activities by refraining from the social gatherings (Chang & Horrock, 2006).

Magliano et.al (2005) from the study conducted in Europe pointed out that there is an existing relationship between the level of practical support, social network available for the family members and the family coping strategies. According to Magliano, et.al, (2005) any support received by the family increases the level of coping strategies and a reduction in the perceived burden. This is echoed by Chien, et al., (2007) who is also of an opinion that social support and social networking alleviate the stress of the perceived care giving burden. It can therefore be hypothesized that family members who receive social support report a less care giving burden than family members that have no support.

According to Huang, et al., (2008) family members with low social support tend to utilize spiritual coping strategies more than those who receive support in their care giving roles.

Provision of psycho education, self –help groups provide a platform for family members to discuss their problems with health professionals and share ideas with other family members who had similar problems (Uys & Middleton, 2004; Ekwall, et al., 2007)

2.6 Conclusion

The chapter summarized the impact of deinstitutionalization, explored the global perception care giving burden, family coping strategies and recommendations of various researchers. The next chapter discusses the research methodology of this study.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

This chapter describes the research approach, research design, setting and data analysis. It explains the sampling procedure, how data was collected from the participants and the data analysis. The chapter also addresses the ethical issues in the study.

A quantitative approach was used to explore and describe the perceived family burden and coping orientations of family members of individuals with serious mental illness within Thukela district. This approach is based on the positivistic paradigm which assumes that there is an orderly reality that can be objectivity observed. The approach also emphasizes objectivity in the collection and analysis of numeric information.

3.2 Research design

A descriptive, non-experimental design was used in this study. According to Polit and Hungler (2002), descriptive designs enable the researcher to describe the perceived reality and to identify the relationships between the phenomena and to categorize information.

3.3 Research setting

The study was situated in the uThukela Health District of KwaZulu-Natal. This is primarily a rural district in the north-east of the province. According to the District annual report, (2009)**.**The health district had a population of 553 671 and encompasses five municipalities. The regional hospital in the uThukela district has 452 beds and serves

an estimated population of 26 739 from two of these municipalities. The district-regional hospital is the only hospital in the district with a dedicated psychiatric unit and 72-hour admission facility for the district. There is a psychiatric clinic attached to the hospital which receives referrals from the psychiatric wards and other units within the hospital and from the fixed clinics, mobile clinics and local authority clinics situated within the two municipalities.

3.4 Research population

The study was conducted with family members whose psychiatrically ill family members attend the community psychiatric clinic attached to the district-regional hospital situated in the center of the uThukela District. According to Polit and Beck (2004), a population is the entire aggregation of cases in which the researcher is interested in studying. It was difficult to estimate the potential size of the population of the family members of clients attending the clinic from the clinic records since these are not a routinely monitored statistics.

The population for the study was therefore all family members accompanying their mentally ill relative to the clinic during a three-week data collection period. Anecdotal reports suggested that this population was relatively small. Approximately10% of the individuals with serious mental illness were accompanied to the clinic for their repeat treatments (V, Smith, personal communication, January 12, 2010); therefore, all those who met the inclusion criteria were targeted.

3.5. Sampling

3.5.1 Sample inclusion criteria

Family members who were 18 years and older and who were currently caring for/living with a family member with a serious mental illness on a continuous basis were included in the study.

3.5.2 Sample size

Quantitative studies work on the general rule that the larger the sample the more reliable the results. This study determined its research sample following the sample size selection guidelines offered by Stokes (1985) cited in De Vos (1998).

The sample size was determined by the response rate. The community psychiatric clinic in which the study was situated attends to an average number of 60 clients a day. The clinic offers a service for five days of the week and attends to approximately 1200 clients per month. If approximately 10% of these patients (i.e. 120) are accompanied by family members, then the total number of family members for inclusion is approximately 120.

3.5.3 Sampling procedure

Family members who accompanied their relatives to the clinic during the three-week data collection period constituted the population of the study. The study therefore adopted a non-probability, purposive and convenient sampling technique (Polit and Beck, 2004).

The researcher was present at the clinic each day for a three week period. The clinic sister was requested to assist the researcher in identifying from the people that accompanied clients to the clinic, those family members who were currently living with their relative with a serious mental illness. Data collection continued until the required sample size had been achieved.

3.6 Data collection instruments.

A structured self-report questionnaire formed the data collection instrument for this study (see Appendices, 1). The questionnaire consisted of three sections. Section A outlined the

demographic variables of gender, age, educational level, relationship with the patient and monthly household income. Section B covered the perception of care giving by family members of the individuals with serious mental illness and Section C explored ways in which family members cope with the care giving roles. The questionnaire was translated into isiZulu by a recognized transcribing and translating company and thoroughly checked by the researcher. The Zulu version and the original English version questionnaire were presented to a small sample of 5 family members to test its adaptability before using it in the study.

Family burden (section B) was measured using the Zarit family burden interview (ZBI). The instrument was developed by Zarit and his co-workers in 1985 It is comprised of 22 items (Taub, et al., 2004). The questions from the ZBI were administered to the participants to explore the perceived objective and subjective burden among family members caring for individuals with serious mental illness. Each question was evaluated on a five-point Likert scale. Family members were requested to indicate how often they had experienced the feelings by indicating with an x, on the scale from 0 (never) to 4 (nearly always). Evidence of content validity of the instrument has been published in many studies (Bolden & Wicks, 2009; Hanzawa et al 2008). The instrument is freely available for use for academic study purposes and for non-commercial users (see Appendix 2).

The coping strategies of family members (Section C) were measured using the Carer's Assessment of Management Index (CAMI) scale, also known as ways of coping. This study adopted the instrument developed by Nolan et al (1996) as cited in Knussen, Tolson, Brogan, Swan, Stott and Sullivan (2008). The instrument consists of 38 statements concerning the ways of handling difficulties in the care giving situation. According to Nolan et al. (1996), the statement items were based on three themes which are problem solving and coping skills, perception of events, and dealing with stress symptoms. The participants responded to the questions using the evaluations from "I do not use this" (0) to "I find this very helpful" (5) (Knussen et al., 2008). The instrument

requires permission before use; such permission was obtained from the author (see Appendix D).

3.7 Validity and reliability of the instruments.

Validity is the degree to which an instrument measures what it is supposed to measure (Polit, Beck & Hungler, 2005). Reliability is defined as the degree of consistency, dependability, and accuracy of the information of the study (Polit & Beck, 2004). The ZBI has been used in many studies to measure the care burden experienced by the caregivers, including studies on burden of care in families of patients with schizophrenia (caqueo- Urizar[1] & Gutie'rrez-Maldonado[2]), Dementia: Caregiver burden (Taub, et al.,2004) and yielded good results. It has been adapted to several languages and performed similarly in each language to the original version. A research study on burden of care in Spanish families (Spanish version of ZBI) showed an internal consistency of 0.91 and a test re-test reliability of 0.86. A study performed on Dementia care giver burden using a Brazilian version the ZBI showed a cronbach coefficient alpha of .77.

The CAMI instrument has been used in several studies and showed acceptable results. In a study on caring for a relative with dementia (Papastavrou, et al., 2007), the instrument showed a cronbach alpha of .85.

3.7.1 Content validity

According to Brink (2002), content validity assesses the validity of the instrument if it addresses all the variables and major concepts that are to be measured. Table 3.1 summarizes how the content validity of the questionnaire was established.

Table 3.1 Summary of content validity: Objectives and measurements

OBJECTIVE	QUESTIONNAIRE
1. To describe the factors that influence the perceived burden of family members as care givers for the individuals with serious mental illness within uThukela district.	Section B of the questionnaire, Zarit Burden interview
2. To explore the coping strategies that are used by family members in their care giving roles.	Section C of the questionnaire (CAMI) career's assessment of management index
3. To explore the association between the perceived family burden and their coping strategies with socio-demographic characteristics of the participants.	Section A Socio-demographic questionnaire

3.8 Data collection procedure

The researcher obtained ethical approval from the University of KwaZulu-Natal Research Ethics Committee approval number HSS/ 0449/2010.and gatekeeper's permission from the Department of Health (Knowledge Management and Production) and the district and clinic authorities before commencing data collection. The procedure followed is attached as Appendix 3.

All family members accompanying individuals with serious mental illness to the clinic during the data collection period were approached to participate in the study. The clinic sister was requested to assist the researcher in identifying the families of individuals with serious mental illness who met the inclusion criteria for the study. A private room was used as an interview room. . The questionnaire was given to each participant with an accompanying covering letter explaining the purpose of the study. The purpose and the

procedures of the study were further explained to the participants by the researcher. Family members who agreed to participate in the study were given a consent form to sign. The participants were informed that they were free to discontinue their participation at any point if they felt uncomfortable with the questions. Assistance was given to participants who were unable to read and or respond in writing. Completed forms were coded and kept safe in a locked drawer.

3.9 Data analysis

The data from the questionnaire was captured and subsequently analysed using the Statistical Package for Social Sciences (SPSS version 15). Descriptive statistics such as frequencies, median, mode and interquartile range were used to summarize the data. Bar charts and pie charts were used to present the results. The scores for perceived burden and coping strategies were worked out from the responses.

The Mann Whitney test was used to examine the difference in scores between males and females. Kruskal-Wallis test was used in testing the difference in scores by demographic data such as: age, education level, relationship with patient, income, marital status and condition of the patient in the past three months. Spearman rank correlation was used in examining if there was any linear relationship between perceived burden and coping strategies (Polit & Beck, 2004; Polit & Hungler, 2002).

3.10 Ethical considerations

The study adhered to ethical principles that served as standards against which the researcher's conduct during the research process (De Vos, 2001) was evaluated. These principles are briefly discussed below. The researcher first presented the proposal to the School of Nursing Ethics Committee for approval and thereafter, to the University of

KwaZulu-Natal's Ethics committee for ethical approval. Permission to undertake the study was simultaneously sought from the Provincial Department of Health's Health Research and Knowledge Management Unit, as well as from the Health institutional ethics committee prior to data collection.

3.10.1 Informed consent

Informed consent was obtained prior to the commencement of data collection and participants freely committed themselves to the study. According to Brink (2002), participants should sign the consent form having a full understanding about it. The researcher explained the purpose of the study and how the data would be collected, in a manner that the participants would understand. . The written information was presented in the participant's language (isiZulu). The researcher informed the participants that they were at liberty to withdraw from the study at any time if they felt uncomfortable (De Vos, 2001).

3.10.2 Rights to self–determination and confidentiality

According to De Vos (2001), privacy and confidentiality are interrelated. Confidentiality indicates the handling of information in a confidential manner. The researcher used pseudo names when referring to participants.

3.11 Data management

Data were stored in a locked cupboard in a safe place. Data will only be available to the researcher and her supervisor and will be destroyed by shredding after five years.

3.12 Dissemination of findings

The final research report will be bound and submitted to the library of the University of KwaZulu-Natal. A hard copy of the completed study will be submitted to the uThukela District. An article will be prepared and submitted for publication in the African Journal of Nursing and Midwifery.

3.13 Limitations of the study

A purposive and convenient sampling method was used to select respondents from one geographic region. One health care facility was utilized as the research setting for this study. Consequently, the results may not be generalisable to all families caring for mentally ill persons in the district. However, since this psychiatric clinic is at the regional hospital in the district, it is likely that a variety of responses were achieved**.**

3.14 Conclusion

The chapter discussed the methods and procedures that were used in data collection. It highlighted the ethical principles observed during the process and data measurements intended to be used in analyzing data. The next chapter will discuss the research findings.

CHAPTER FOUR

DATA ANALYSIS AND FINDINGS

4.1 Introduction

This chapter presents the results of the study. The aim of the study was to explore the care giving burden as perceived by family members of individuals with serious mental illness and the association between their coping strategies and the perceived burden. A total of 120 questionnaires were collected from the study population and the data were analyzed using SPSS version 15. Descriptive statistics were used to describe the variables of interest (demographic factors and perceptions of burden) while non-parametric tests (Kruskal Wallis Test and Fisher's Exact Test) were used to explore associations between these variables. Tables, graphs and frequencies were used to describe the findings.

The findings in this chapter will be presented according to the study objectives. The chapter is structured as follows: the first section presents a description of the sample with respect to the demographic variables and perceived burden; the second section presents the coping strategies used by the sample; the final section presents the associations between perceived burden, coping strategies and socio-demographic variables.

4.2 Sample description

In this study, demographic data included gender, age, education, relationship with the client, household monthly income and condition of the client in the past three months. Although 120 questionnaires were returned, one question item on family burden, question no.18 was omitted by one participant and the questionnaire was found incomplete. Therefore the calculations on this question item was marked down by .08, bringing down the response on this question from 100% to 92% based on a sample of n=119

4.2.1**Gender Distribution**

As can be seen in Figure 4.1 below, female caregivers outnumbered the male caregivers, with females comprising n= 92(76.7%) and males comprising n=28 (23.3%) of the study sample

Figure 4.1.Gender
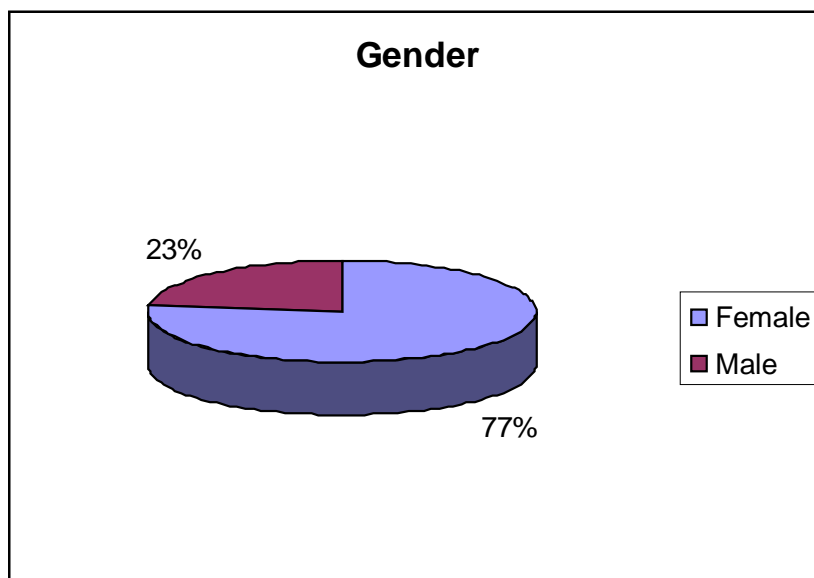
4.2.2**Age Distribution of Participants**

Figure 4.2 represents the differences in age distribution of family members who participated in the study. The majority of the sample n=81 (70%) was 41 years and above. The group aged between 30-40 years formed (13%) of the sample. There was a slight difference in number between the age groups 18-25 and 26-30 years. The age group 18-25 comprised of n=10 (8.0%) of the sample, while the 26-30 age group comprised n=11 (9.0%) of the sample.

Figure 4.2 Age Distribution
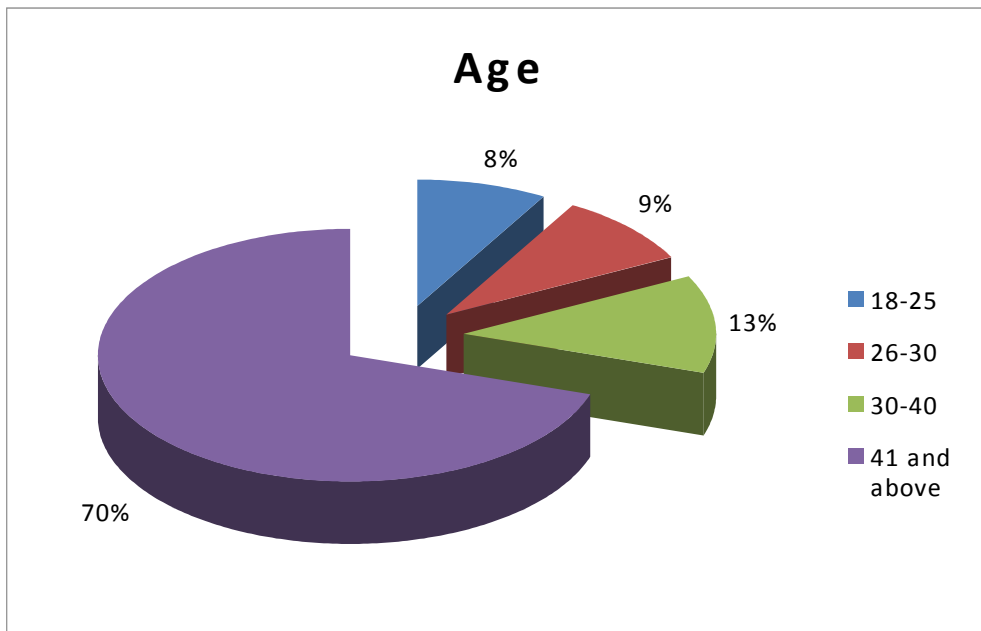
4.2.3   Education Level

The largest percentage n=82 (68, 3%) of the respondents had only a primary school education or had no formal education at all. n=32 (26, 7%) received a secondary school education and only n=6 (5%) received a tertiary education. Figure 4.3 represents differences in educational levels of the family members who participated in the study.

Figure 4.3 Participants educational levels
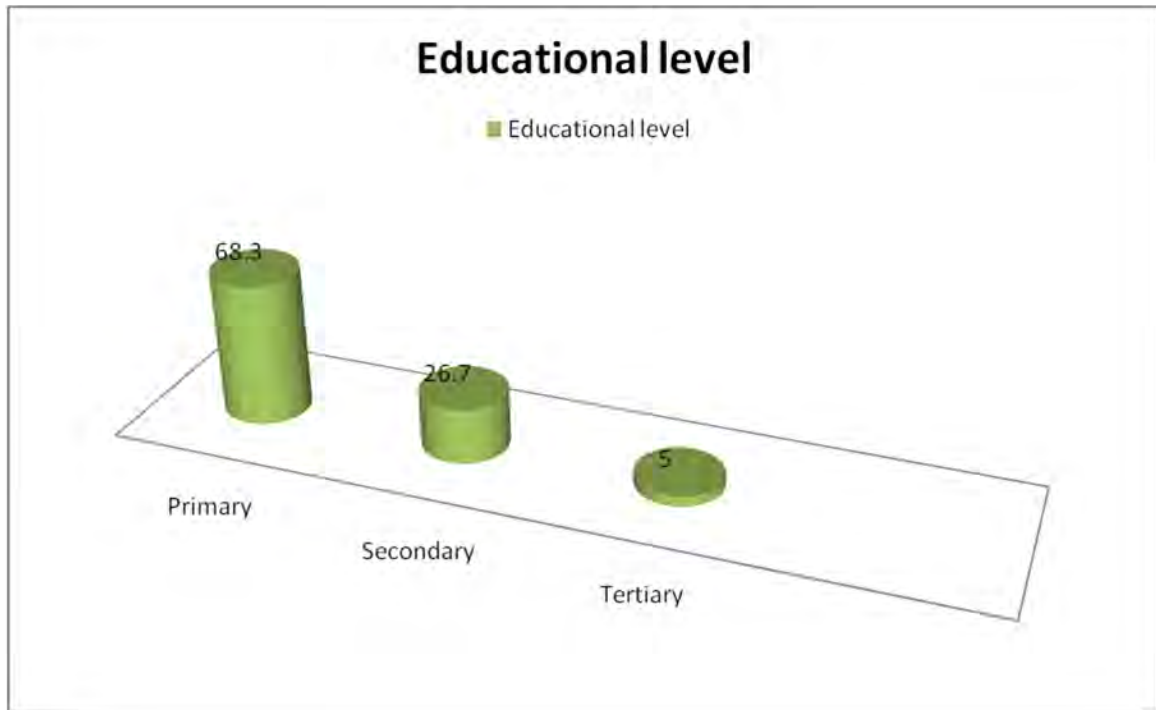
4.2.4   Relationship with an individual with serious mental illness

Figure 4.4 represents various relationships of participants to the client. Participants who brought their siblings to the clinic formed the greatest percentage of the study n=51 (42.5%), followed by other significant related family members including those who were aunts, uncles and grandparents n=40 (33.3%). Participants n=18 who brought their parents formed (15%) of the study. Eleven individuals participated as spouses (9.2%).

Figure 4.4 shows the distribution of different relationships.
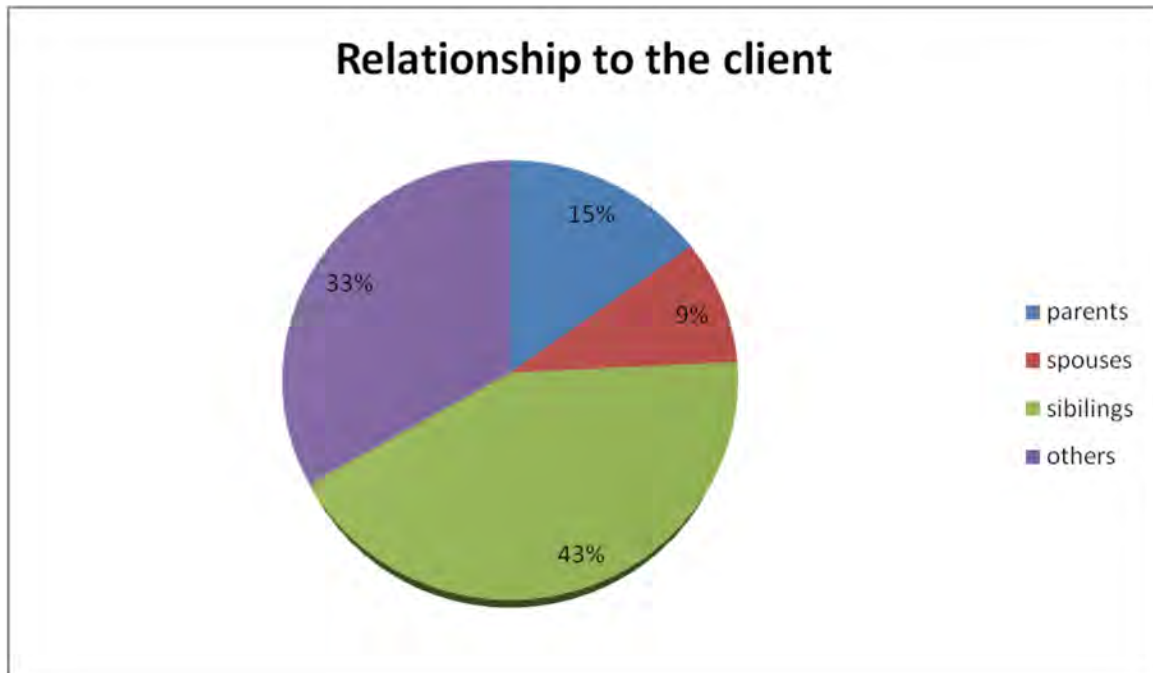
4.2.5 Monthly household income in ZAR

Just under half of the sample in this study were living under the poverty line. In other words, n=52 (43.3%) live on an income of between R1000.00 –R2000.00 per month, while almost one third n=38 (31.7%) live on an income of R1000.00 a month and below. The fact that the highest percentage of participants in the study were 41years and above suggests the income might be a combination of a pension grant of an elderly family member as well as the disability grant of an individual with serious mental illness. n=4 (3.3%) of the sample earned more than R2100-R2500 per month while n=26 (21.7%) of the sample had a household monthly income of R2600 and more.

Figure 4.5 Household income
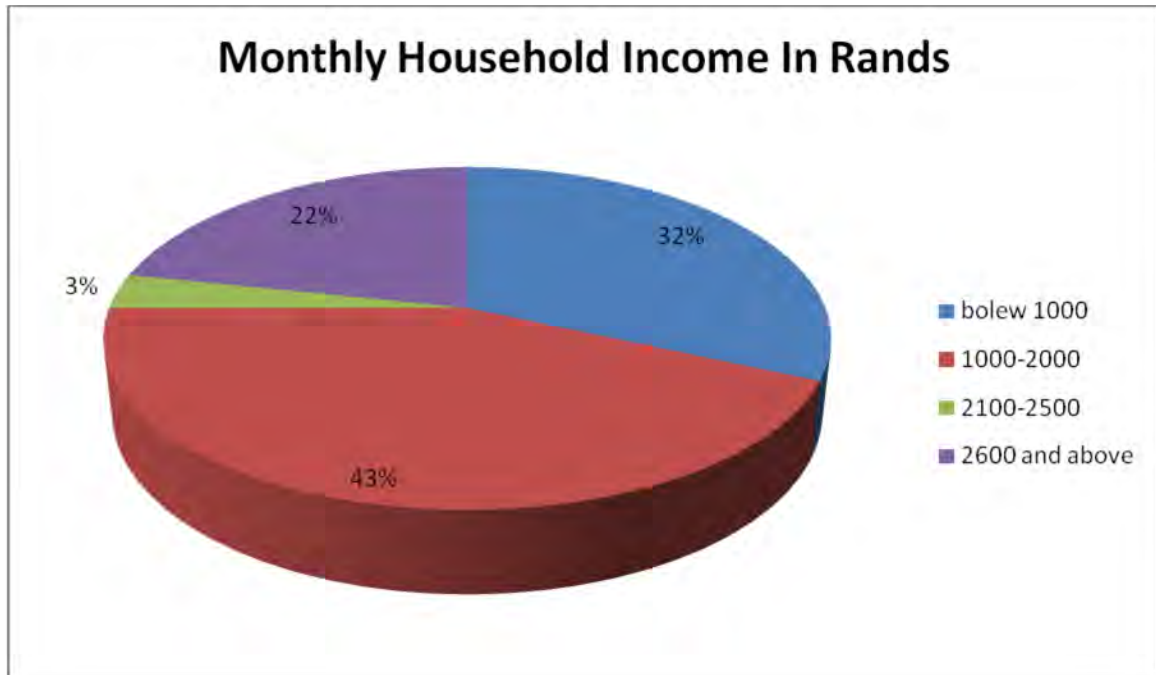
4.2.6 Condition of the individual with serious mental illness in the past three months

According to Figure 4.6, n=52 (44.%) of the participants reported the condition of their relatives with serious mental illness as improved over the past three months, which is equal to the number of family members who reported their relatives condition as worsened over the past three months. A small percentage of n=15 (12.5%) reported the condition of a relative with serious mental illness as being stable over the past three months.

Figure 4.6 Condition of a relative with serious mental illness in the past three months.

condition of the relative in three months

12%

44%

44%

- improved
- worsened
- stable
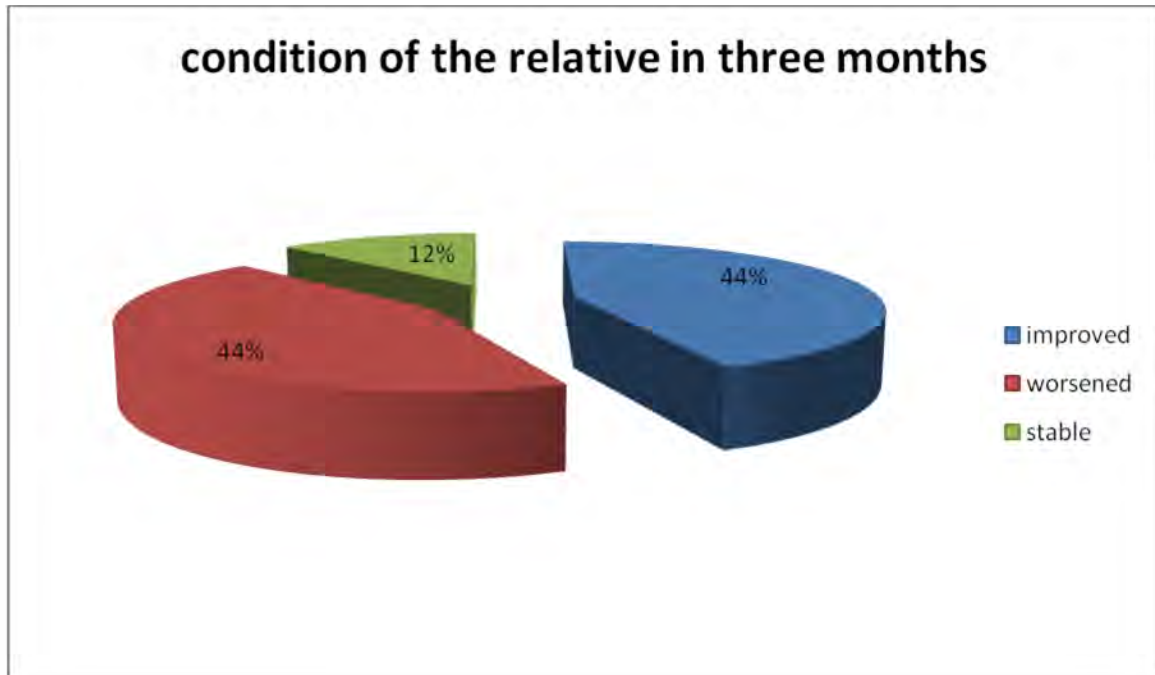
4.2.7 ZBI: Respondents' perceptions of the burden of care giving

The ZBI, consisting of 22 items, was used as a measurement of burden of care giving as perceived by family members. The responses were rated on a five-point Likert Scale.

The cronbach Alpha of the ZBI -22 items in this study is .86, which indicates good reliability of the instrument used in this study as a measurement of the perceived burden of care giving.

Participants' responses on their perceptions of burden using the ZBI -22 items are presented in Table 4.1 as appendix 5.Responses rated under 'sometimes' fell under moderately burdened, 'frequently' as severely burdened and 'nearly always' as extremely burdened. Scores from sometimes to nearly always for this study are identified as highly burdened. The burden scores are tabled in the order of intensity of burden as perceived by the family members.

The ZBI also includes psychological burden not only the practical burden this is evidenced in the family members concerns about the future of their relative. Table 4.2 shows responses of the family members in order of the degree of concern in percentages. The participants showed great concerns about what the future holds for their relative and ongoing questions as whether they are doing enough for their relative.

Table 4.2 Degree of concerns about a relative's future

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1. Are you afraid what the future holds for your relative?	(4) 3.3%	(6) 5.0%	(9) 7.5%	(97) 80.8%	(4) 3.3%
2. Do you feel uncertain about what to do about your relative?	(3) 2.5%	(7) 5.8%	(14) 11.7%	(95) 79.2%	(1) .8%
3. Do you feel you should be doing more for your relative?	(6) 5.0%	(3) 2.5%	(18) 15.0%	(91) 75.8%	(2) 1.7%
4. Do you feel you could do more for your relative?	(53) 44.2%	(15) 12.5%	(14) 11.7%	(35) 29.2%	(3) 2.5%

4.3 CAMI: Family coping strategies

The 38-item CAMI instrument was used to collect data to explore the coping strategies that are used by family members of individuals with serious mental illness. The statement items are based on three themes, namely problem solving strategies, reframing the meaning of events, and managing and alleviating stress. The items were rated on a 3-point scale, where a family member had to respond to a coping strategy whether they find it helpful, not really helpful or not using it. Table 4.3 shows only the most commonly used coping strategies that were found helpful by the family members of the individuals with serious mental illness at percentages above 90%.

Table 4.3 CAMI displaying the high scores on commonly used coping strategies that were found helpful by family members and scored above 90%.

Coping strategies	Helpful %
Managing Events /Problem solving	
Relying on your own experience and the expertise you have built up.	90.8
Thinking about the problem and finding a way to overcome it.	92.5
Keeping one step ahead of things by planning in advance	94.2
Establishing priorities and concentrating on them.	95.0
Being firm and pointing out to the person you care for what you expect of her.	92.5
Trying out a number of solutions until you find one that works.	93.3
Managing meanings (Reframing).	
Taking life one day at a time.	92.5
Realizing that the person you care for is not to blame for the way they are.	92.5
Drawing on strong personal or religious beliefs.	93.3
Keeping your emotion and feelings tightly under control.	92.5
Managing/alleviating and avoiding stress.	
Maintaining interests outside caring.	91.7
Taking your mind off things in some way by reading, watching TV or the like.	91.7

Family members use both problem-focused and emotional focused coping strategies (mostly drawn from the person's internal resources) to deal with encountered stressful situations. Coping strategies that promote social support for individuals (external resources) were less used by the participants and scored below 80%. The problem – focused coping strategy of talking over your problems with someone you trust was only used and found helpful by 68% of the sample. Getting as much practical help as you can

from your family was used by 70% of the sample while getting as much help as you can from professionals and other service providers was used by 60.8% of the sample. Only 17.5% of the sample attended self help groups.

Less commonly used coping strategies were the emotional- stress alleviating /avoidance strategies such as letting off steam in some way (e.g. shouting, yelling and the like). This was used by 46.7% of the participants while 40.8% found ignoring the problem and hoping it would go away, helpful. Almost half of the sample found the coping strategy of trying to cheer you up by eating, having a drink, smoking or the like, helpful (50.8%).

4.4 Association between perceived burden, coping strategies and demographic variables

4.4.1 Association between perceived burden and demographic variables

A nonparametric Mann -Whitney test was used to examine the difference in burden scores between males and females. No statistical significance found between the burden perceived and gender (P =.225). Kruskal-Wallis test was used to test the difference in scores by demographic variables such as: age (P = .794), education level (P=.409), relationship with patient (P= .406), monthly household Income (P =.054) and condition of the patient in the past three months (P =.000). No statistical significance found between age, education, relationship to the client and the perceived burden (p –values were > 0.05).

Positive associations were found between the condition of the patient and the perceived burden. (P=.000). The severity and quantity of the client's symptoms influences the perception of burden, that is, the higher the quantity or severity of symptoms, the higher the perceived burden of care giving by the family member (Lowyk et al., 2004).

Positive associations between the condition of client with serious mental illness in the past three months and the perceived burden were further explored using cross tabulations

and Fisher's exact test. Significant associations were observed between three differentiated groups of conditions, that is, improved, worsened and stable condition when compared with different burden factors from the burden scale measurement (ZBI instrument). Associations that will be reported on are only those with the statistical association of (P < 0.05). Only high rating scales that will be reported on, that is scores on quite frequently and nearly always.

The condition reported as worsened over the past three months was the most significant factor to increase burden in the care giving context; the higher the quantity or severity of symptoms, the higher the perceived burden of care giving by the family member. For example two-thirds of family members reported that perceived burden increased when the relative's condition worsened and decreased when the condition became more stable. Family members experienced increased demands on their time, increased social embarrassment and a negative impact on their health. The worse the condition the less time the relative has for him/herself and the greater the perceived burden of care giving.

Table 4.4 Association between perceived burden and the condition of the client in the past three months

Perceived Burden	P=value	Worsened		Improved		Stable	
		Quite frequently	Nearly always	Quite frequently	Nearly always	Quite frequently	Nearly always
Do you feel that your relative asks for more help than he/she needs	.005	53,3%	66,7%	37, 7%	33,3%	4.9%	0%
Do you feel that because of the time you spend with your relative that	.001	61.2 %	80,0%	30, 6%	20, 0%	8.2%	0%

you don't have enough time for yourself						
Do you feel that your relative currently affect your relationships with other family members or friends in a negative way	.022	57,9%	80%	26, 3%	0%	5, 3%	0%
Do you feel embarrassed over your relative's behavior	.009	63, 3 %	66,7%	23, 3%	33, 3%	33, 3%	0%
Do you feel your health has suffered because of your involvement with your relative	.006	59, 0%	66, 7%	36, 1%	33, 3%	4, 9%	0%

4.4.2 Associations between coping strategies and socio-demographic variables

This section explores the associations between perceived burden, coping strategies and socio-demographic data using Fisher's Exact Test. Associations that will be reported on are only those with the statistical association of ($P < 0.05$).

4.4.2.1 Gender and coping strategies

Problem-focused solving strategies such as being firm and pointing out to the person you care for what you expect of her showed a significant association with gender (p =.015). Female participants tended to use this coping strategy more (79.3%) than males (20.7%)

Significant statistical association were also found between gender and getting as much practical help as you can from your family (P =.033). Females had 82% and males 17, 9% responses on this coping strategy. Managing meanings strategies such as realizing that the person you care for is not to blame for the way they are and gender showed significant association (P =.023). Again, 79.3% females found this strategy helpful, compared to 20, 7% of males who found it helpful.

Drawing on strong personal or religious beliefs and gender showed a significant association (P= .001). Females found this emotional coping strategy to be more helpful to them (80, 4%) than males (19.6%).

4.4.2.2 Age and coping strategies

There were positive associations between age and some coping strategies. The older aged group used the coping strategies that showed significant association P =value of less than <0, 05. Finding out as much information as you can about the problem showed a significant association (P = .018) .Age group of 41years and above formed 72, 1% of the family members who found this coping strategy helpful. Finding out as much information as you can about the problem had a (P =.011).Participants of the age group 41 and above formed 73, 9% of family members in the study who found this coping strategy helpful in coping with the care giving demands.

Table 4.5 Associations between age groups and coping strategies

Coping strategy	P=Value	Age groups	Percentage
Being firm and pointing out to the person you care for what you expect of her	.018	18-25	7.2
		26-30	8.1
		30-40	10.8
		41 and above	73.9

		18-25	8.2
Realizing that the person you care for is not to blame for the way they	.011	26-30	7.3
		30-40	11.8
		41 and above	72.7
Maintaining interests outside caring		18-25	5.4
	.039	26-30	3.6
		30-40	21.4
		41 and above	69.6
		18-25	5.4
Letting off steam in some way (e.g. shouting, yelling and the like	.008	26-30	3.6
		30-40	21.4
		41 and above	69.6

4.4.2.3 Education and coping strategies

Association was identified between the level of education and only two coping strategies. Thinking about the problem and finding a way to overcome it showed association with educational levels (P = .018). Family members with primary or no formal education (71.2%) followed by those with secondary education (25.2%) were the groups who found this strategy helpful. Realizing there's always someone worse off than yourself showed a significant association with educational level (P =.006). Participants with primary or no formal education (63, 5%) and those with secondary education (31%) who used this strategy and found it helpful.

4.4.2.4 Relationship to the client

Remembering all the good times you used to have with the person you care for showed a positive association with demographic variable, which is relationship to the client (P = .020 < 0, 05). Siblings of the individuals with serious mental illness 44% and other related family members 29% were found to be the most groups who find this alleviating stress coping strategy helpful.

4.4.2.5 Monthly household income and coping strategies.

Comparing monthly household income and some coping strategies using Fisher's exact test, some coping strategies showed Significant associations with the household income and had a p=value of less than 0.05 Positive associations were found on the following coping strategies.

Talking over your problems with someone you trust showed a significant association with household income (P= .034). Family members with household income, between R1000-2000 formed 42, 7% and participants with a household income of below R1000 formed 36% of the participants who found this strategy helpful in meeting their caregiving demands. Significant associations were observed between active coping strategy of being firm and pointing out to the person you care for, what you expect of her and socio-demographic factor household income had a (P=.037). Participants with a household income between R 1000 – R2000 formed 43, 2% and participants with household income below R1000 formed 32, 4% of the participants who found this coping strategy helpful in their care giving demands.

Associations between managing meanings strategy ,looking for the positive things in each situation and socio demographic factor, household income had a (P = .040)

Participants of household income between R1000- R2000 formed 47,2% and those with household income that falls below R1000.00 formed 29,2% of the participants in the study who found this strategy helpful to them.

4.4.2.6 Condition of a client in the past three months and coping strategies

There was positive significant association between active problem solving coping strategy finding out as much information as you can about the problem and condition of a client (P= .040). Participants who reported the client's condition as worsened (47, 0%) was the group that found this coping strategy as the most helpful strategy.

Positive significant associations were observed between keeping the person you care for as active as possible and the condition of the client (P = .023). Participants who reported the client's condition as improved (48%) was the group who found this strategy most helpful. The improved condition of a client enhanced the opportunities of training the individual with serious mental illness.

There were no other significant associations across socio-demographic characteristics and different burden factors. However, significant associations were found between the perceived burden and the coping strategies used by family members of the individuals with serious mental illness.

4.4.3 Association between perceived burden and coping strategies.

Fisher's exact test was used to compare items from the subscales of coping strategies from the CAMI and items from the ZBI to identify the associations between the coping strategies utilized by family members in their daily living situations and the burden perceived from the care giving responsibilities.

The association on variables will be determined on each subscale of the CAMI which includes problem-focused coping strategy, managing meanings and alleviating stress coping strategies.

The use of an active problem-focused coping strategy which is, finding as much information as you can about the problem, showed a significant association with the burden factors including feeling that your relative asks for more help than he/she needs, that you don't have enough time for yourself because of the time you spend with your relative, stressed between caring for your relative and trying to meet other responsibilities for your family or work, and feeling that you could leave the care of your relative to someone else (P =.000 - .025) were obtained and found significant.

Use of managing meanings coping strategy, which is realizing that there is someone worse off than yourself, showed a positive association with many burden factors such as feeling that your health has suffered because of your involvement with your relative, that your social life has suffered because you are caring for your relative, that you don't have enough money to take care of your relative in addition to the rest of your expense, feeling uncomfortable about having friends over because of your relative and feeling that your relative is dependent on you. Observed significant values were (P = .000 - .018).

Drawing on strong personal or religious belief which falls on the management of the meanings about the situation and falls under emotional –focused , showed negative association with many of the burden factors including feeling like your relative seems to expect you to take care of him/her as you were the only one he/she could depend on, that you don't have enough money to take care of your relative in addition to the rest of your expense and feeling uncomfortable about having friends over because of your relative. The observed significant values of association were (P = .001 -.012).

Use of managing / alleviating stress coping strategy such as taking your mind off things in some way, by reading, watching TV or the like, showed positive association with some burden factors such as feeling you could leave the care of your relative to someone else and feeling stressed between caring for your relative and trying to meet other responsibilities for your family or work. The values of (P = .000 -.020) were observed.

Letting steam off in some way (e.g. shouting, yelling and the like), showed a significant association with burden factors such as feeling that your social life has suffered because you are caring for your relative, that your relative seems to expect you to take care of him/her as you were the only one he/she could depend on, that you could leave the care of your relative to someone else and feeling that your relative asks for more help than he/she needs. The significant values of (P = .000 - .010) were obtained.

Table 4.6 Fisher's Exact Test. Associations between Perceived Burden and Coping Strategies

Burden of Care Giving	P=Value	Coping Strategy
1. Do you feel that your relative asks for more help than he/she needs?	.015	Managing Events/Problem Solving. Finding out as much information as you can about the problem.
2. Do you feel that because 0f the time you spend with your relative that you don't have enough time for yourself	.004	
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	.025	
4. Do you feel you could leave the care of your relative to someone else?	.000	
5. Do you feel your health has suffered because of your involvement with your relative?	.007	Managing Meanings Realizing that there is someone worse off than yourself.

6. Do you feel that your social life has suffered because you are caring for your relative?	.004	
7. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expense?	.018	
8. Do you feel uncomfortable about having friends over because of your relative?	.010	
9. Do you feel that your relative is dependent on you?	.000	
10. Do you feel like your relative seems to expect you to take care of him/her as you were the only one he/she could depend on?	.008 .012	Drawing on strong Personal or Religious belief
11. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expense?	.001	
12. Do you feel uncomfortable about having friends over because of your relative?	.003	
13. Do you feel you could leave the care of your relative to someone else?	.000	Managing/Alleviating stress Taking your mind off things in some way ,by reading ,watching
14. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	.020	

		TV or the like
15. Do you feel that your social life has suffered because you are caring for your relative?	.000	Letting steam off in some way (e.g.shouting,yelling and the like
16. Do you feel like your relative seems to expect you to take care of him/her as you were the only one he/she could depend on?	.002	
17. Do you feel you could leave the care of your relative to someone else?	.003	
18. Do you feel that your relative asks for more help than he/she needs?	.010	

4.5 Conclusion

This chapter presented the findings of the study. Overall, the findings suggest that family members of the individuals with serious mental illness are faced with high burdens of care giving in different situations. Females being the highest group in the sample were identified as highly burdened when comparing gender with overall perceived family burden. Cross tabulations and Fishers exact test were used to identify the associations between the socio-demographic factors and burden factors. There were no significant associations found between gender, age, and education, household income, relationship to the client and perceived burden. Significant associations were found between perceived burden and the condition of a client. A worsened condition of a relative significantly influenced the perception of family burden. The worse the condition of the patient, the more the burden perceived by the family members.

Family members were found to use problem-focused and emotional-focused coping strategies to balance their coping orientations. External resources such as seeking support from friends, health professionals and from other family members were less utilized and or found not helpful by a higher percentage of the participants. The next chapter will discuss the findings, limitations of the study and make relevant recommendations.

CHAPTER 5

DISCUSSION OF FINDINGS, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY

5.1 Introduction

This chapter discusses the findings of the study, limitations and the researcher's recommendations. The purpose of this study was to explore and describe the perceived burden by family members of individuals with serious mental illness in the uThukela District and the association between the perceived burden and their coping strategies. The discussions of the findings of this study are based on the objectives and research questions of this study and will be discussed in the context of the relevant literature and conceptual framework of the study.

5.2 Discussion

5.2.1 Factors that influence the perception of care giving burden by family members

According to the family adjustment and adaptation model an occurrence of a negative life event in the family depending on the severity of the situation is associated with stressors (perceived burden). Stressors challenge the coping orientations of the family members and disturbs the family stability. An increase in perceived burden decreases the coping strategies of the family members and is associated with family disruption.

The study revealed that the condition of the client with serious mental illness seemed to be the most influencing factor for the perceived burden. Analysis showed significant association between the condition of the individual with serious mental illness (i.e. worsened condition) and the perceived burden. The findings concur with the findings of other reserchers Etters, et al., (2007); Lowyk et al. (2004) who pointed out that the higher

the quantity or severity of symptoms, the higher the perceived burden of care giving by the family member.

 The findings showed that family members' health and social life tend to suffer because of their involvement and the time they spend taking care of their relative. This was evidenced by the participant's high responses on the question item, do you feel your health has suffered because of your involvement with your relative, 50% of the response was quite frequently and 30% of participants felt like that sometimes. The findings concurred with Etters, et al., (2007); Lowyk et al. (2004) studies that showed associations between the condition of the individual with serious mental illness and the amount of care giving burden perceived by family members.

The level of dependency of an individual with serious mental illness for assistance and more especially for daily activities put more strain on family members. The findings revealed that individuals with serious mental illness tend to rely on one person for help. The majority of participants responded "quite frequently" to the item regarding whether they felt that their relative is dependent on them in this study. The problem of dependency further extends itself to the level where it is reported by the participants that they frequently 40, 8% and sometimes 30, 8% feel that because of the time spend on their relative they do not have enough time for themselves. The care-giving situation affects the social life of the family members. The findings of this study confirm the findings of the previous research on emotional support needs and coping strategies of family members by Chambers et al. (2001). In this study, care givers revealed that constant care and supervision needed by the relative caused them deprivation in their social life.

The results of this study confirm some of the findings of previous researchers on stigmatization as the contributory factor on the perceived family burden (Magliano, et al, 2007; Seloilwe, 2006). In this study 25% of family members responded that they felt embarrassed over their relative's behavior; the problem intensified to the level whereby

family members seemed to feel uncomfortable about bringing their friends over because of the behavior of their relative. According to Magliano et al. (2005) the disruptive behavior of the individual with serious mental illness leave the family uncertain about what the relative might do and say in front of visitors and friends thus increasing their social embarrassment.

The findings of this study indicated that poverty and lack of resources add a lot of stress to family members. Nearly half of the family members involved in the study lived below the poverty line. Nossek (2005) found that some family members use about 29 -49% of their family income to cover the expenses incurred in the management of the family member with a serious mental illness. According to Rakesh, et al., (2007) family members as caregivers perceive higher levels of burden when they have limited resources.

The present study also found that family members tend to suffer emotionally worrying about the future of their relative with serious mental illness and about who will continue supporting a relative when they are no longer there for him/her. Participants' responses are displayed in table 4.2. The majority of participants felt "quite frequently" uncertain about what the future holds for their relative. The findings of this study were similar to the findings of a qualitative study done by Chambers (2001) exploring the emotional support needs and coping strategies of family carers which reported that the main concern of the family members was the future welfare of their relative.

5.2.2 Coping strategies used by family members in their care giving roles

Coping in this study is described as an attempt to reduce or manage demands on the family system and to interact with all the resources at their disposal for management of the situation (Liu, et al., 2007).

From the conceptual framework point of view McCubbin and Patterson, 1983 (cited in Dong et al.,"n. d") family members have existing resources that are being utilized at the onset and during the process of a crisis in the family. These resources may be adequate or inadequate for the problem. The findings of this study revealed that family members utilize both internal resources and external resources to increase their coping orientations. Coping strategies drawn from internal resources were found more helpful by the participants than strategies drawn from external resources. Internal problem-solving coping strategies used by family members in this study include, relying on personal experiences and expertise which was utilized by 90, 8% of participants and 90, 2% think about a problem and find a way to overcome it.

Coping strategies drawn from external resources which include seeking support from friends, families and from professional members, (Ekwall, et al., 2006) were less used or were found less helpful by a greater percentage of the participants. Enforcement of social networking and psycho-education programs is essentials to increase the family coping orientations. According to McCubbin and Patterson, (1983) adequate resources tend to lessen the perception of care giving burden and promote family adaptation in the caring context.

There are two general coping strategies that are used by family members in a care giving context, that is, the problem-solving and emotional-focused coping strategies (Mattei, et al.., 2008).According to the conceptual framework of this study, family members keep themselves in active engagement with coping processes to balance the family demands or burdens with family capabilities in order to maintain, or restore family adaptability and stability.

The findings of this study revealed that family members combine Problem-focused and emotional –focused strategies to balance their coping abilities in dealing with difficulties encountered in their care giving responsibilities. Active coping behaviors which involve reaching out for help and through active problem –solving strategies and emotional –

focused coping strategies that involve, avoidant, seeking spiritual help and coercion behaviors (Mattei, et al.., 2008; Van Der Voort, et al., 2007).

5.2.3 Relationship between perceived family burden, coping strategies and socio-demographic characteristics

In contrast with the findings of this study, other researchers Chien, (2006); Papastavrou, (2007) Van Der Voort, et al., (2008) who reported about the associations between gender, age, education, household income and the perceived burden. There were no association found between these demographic characters and perceived burden except for the condition of the client (worsened condition) and perceived burden which was significantly high.

5.2.3.1 Gender and coping strategies

Earlier studies already reported that the caring role in most societies is ascribed to females as women are more frequently caregivers in the family compared to men (Croog et al., 2006; Thomas et al., 2004) (as cited in Papastavrou, 2007). The majority of the participants in this study were females. The findings showed positive significant association between gender and certain coping strategies such as getting as much practical help as you can from your family. Females had 82% and males 17, 9% responses on this coping strategy.

Besides seeking support from other people, the results of the current study highlighted that females are able to utilize their internal coping strategies in the care giving context. A significant association existed between gender and the problem-focused coping strategy of being firm and pointing out to the person you care for what you expect of her. Participants who found this strategy helpful were females, 79, 3% and only 20, 7% males who utilized this strategy and find it helpful.

The present findings are in contrast with the findings of the study performed by Papastavrou, et al.2007) who pointed out that men compared to women were more problem –focused and reported lesser levels of burden of care giving. In this study gender cannot be generalized as problem-focused or emotional focused as this differs with certain coping strategies.

Analysis of this study also showed positive significant association between the emotional –focused coping strategy of drawing on strong personal or religious beliefs and gender. The findings revealed that females adopt more emotional-focused strategies than males to balance their coping orientations and therefore confirming the findings of the study performed by Papastavrou, et al.2007) that men compared to women were more problem –focused than fwomen.

5.2.3.2 Age and coping strategies

The older age group in the study (41years and above) was found to be the highly burdened age group. This group formed the greatest percentage of the family members who participated in the study. The present study suggested that there is a negative association between age and coping strategies. Older family members in this study was the most group that utilized problem- focused coping strategies and the alleviating coping strategies such as being firm and pointing out to the person they care for what they expect of her, maintaining interests outside caring, letting off steam in some way (e.g. shouting, yelling and the like) which is expected to reduce stress and the perceived burden and yet were found to be the most burdened age group. According to Chien (2006) and Van Der Voort et al., (2008), an increase in perceived family burden in older family members is also associated with general deceleration of health condition.

The findings are in line with the findings of other researchers Chien (2006) and Van Der Voort et al., (2008) who reported that older family caregivers perceive higher levels of care burden compared to younger family members**.**

5.2.3.3 Education and coping strategies

Previous researchers   suggested that the higher the level of education, the lesser the perceived family burden due to the fact that individuals with higher education have easier access to resources compared to other groups (Caqueo-Urizar & Maldonado, 2006; Chien et al., 2005; Li et al., 2007; Ukpong, 2006). In the present study participants with low educational levels were more problem-focused compared to participants with higher educational levels. It has been indicated by various researchers that family burden is influenced by the availability of resources and the effective usage of these resources by the family members (Ekwall, et al., 2006; McCubbin & Patterson's, 1983; Rakesh, et al., 2007; Van Der Voort, et al., 2007).According to the aforementioned researchers, effective usage of resources restores family stability by reducing the perceived family burden. Assessment of family members on the use of coping strategies is essential to promote family adaptation.

5.2.3.4 Relationship to the client and coping strategies

The findings of this study showed that there is a positive association between the relationship to the client and some coping strategies. An alleviating coping strategy, of remembering all the good times which the family member used to have with the care recipient showed a positive association with relationship to the client. Siblings and other related family members of the individuals with serious mental were found to be the most groups who found this alleviating stress coping strategy helpful, compared to spouses and parents.

5.2.3.5 Monthly household income and coping strategies

According to previous researchers, adequate resources tend to lessen the perception of care giving burden and promote family adaptation in the caring context (Ekwall et al., 2006; Rakesh, et al., 2007; Van Der Voort, et al., 2008). The findings of this study showed that there is a negative association between household income and some coping strategies.

Active problem-solving and managing meanings strategies were mostly adopted by family members with a low household income of between R1000-R2000, 00 which is in contrast with the findings of prior researchers (Li, et al., 2007; Papastavrou, et al., 2007; Ukpong, 2006).The aforementioned researchers are of an opinion that the greater the household income the lesser the perceived of economic burden. According to the conceptual framework family stability is influenced by the availability of resources (coping orientations) and the effective usage of these resources by the family members. It is the effective usage of coping strategies that lessens the perception of family burden and promotes family stability (Ekwall, et al., 2006; Rakesh, et al., 2007; Van Der Voort, et al., 2008).

5.3 Recommendations of the study

The recommendations from this study are directed at policy makers, clinical practice, education and nursing research.

5.3.1 Policy Makers

It has been identified from the findings of this study that families are overburdened by continuous daily supervision and care giving to relatives with serious mental illness.

Creation of psychosocial rehabilitation centres within the communities may assist in scaling down the amount of perceived burden in different ways. Psychosocial rehabilitation could assist in increasing the skills of individuals with serious mental illness in general life skills to reduce dependency and improve the social network for the family members (Uys & Middleton, 2004).

It has been reported that in some instances breadwinners in the families are forced to leave their paying jobs to look after their relative who requires continous supervision because of unpredictable disruptive behaviour and needs for physical assistance (Magliano et.al, 2005; Rakesh et al., 2007). Psychosocial rehabilitation centres will not only provide skills to individuals with serious mental illness but will also offer opportunities to the family members to engage in paying jobs during the day thus increasing their household income. Funding for this programme will be of great significance in mental health care.

It is recommended that policy makers should look at housing and accommodation problem for Individuals with serious mental illness as they are mostly unemployed and only earning a disability grant and some do not even enjoy that privilege, as the findings have indicated that there are families that live on an income that is below R1000, 00.

5.3.2 District health management team

Deinstitutionalization of individuals with serious mental illness has created a situation whereby they are only hospitalized for a short period that is, only for acute episodes and released back to their families. This created a situation whereby family members, living below poverty line as indicated by this study, have to deal with transport expenses returning their relative to the hospital for reassessment and treatment review. In most instances, individuals with serious mental illness need to be accompanied by a family member which doubles the transport cost. Adequate staffing levels, in this instance

doctors to visit the clients' local clinics on monthly bases, has been identified as the mediating factor that will reduce economic stress on family members and scale down treatment defaulters.

According to a study performed by Nossek (2005) some family members use about 29 - 49% of their family income to cover the expenses incurred in the management of the family member with a serious mental illness. Availability and access to resources tend to lessen the perception of care giving burden and restore family adaptability to the stressors of care giving demands (McCubbin (1983) & Patterson (2002).

The findings of the study revealed that there is over-dependency of individuals with serious mental illness on their family members. 73% were concerned about overdependence on them which affect their health, social life and increasing the family burden. An increase in the staffing levels of psychiatric trained nurses in the facilities could enable the implementation of psycho education and empowerment interventions for families with information on the management of their relatives.

The findings of this study revealed that families are not adequately equipped by the professional category with the relevant information resources to cope with the care giving stresses. Programmes such as psychosocial rehabilitation and outreach programmes are essential for the district to reach out the families in the rural areas who are desperate for help in handling their relative's behaviors when considering the household incomes and their general level of education.

There is a need to develop the community health workers and the NGOs in mental health issues, that is mental health to be included in their training since they are groups that know the community members well and are always with them in the community. As mentioned earlier, professional help is not readily available to the family members in terms of counseling and support. . The findings of the current study revealed that family

members of the individuals with serious mental illness feel embarrassed to invite their friends over because of the behaviour of their relative. It is recommended that the district give support to awareness campaigns on mental illness, making the community aware of the real facts about mental illness and minimizing the stigma about mental illness.

5.3.4 Nursing Practice

Nurses as mental health care providers should be able to assess the coping strategies adopted by family members and assist in strengthening effective coping strategies and change the existing ones if not effective. The effective usage of coping strategies results in family stability by reducing the perceived family burden (Ekwall, et al., 2006; Rakesh, et al., 2007; Van Der Voort, et al., 2008).

Effective communication between the discharging hospital and the health care worker who will be receiving the client and his/her family is essential to maximize the quality of client management and to ensure that family members get supported in their care giving demands and promote family stability. It is important that nurses strengthen the psycho education and skills training programmes to wean off the individuals with serious mental illness from being over dependent thus minimizing the care giving burden for family members.

Proper assessment and maximized treatment regimes for clients with serious mental illness will assist in keeping the condition of the client in a stable condition. The findings of this study showed that the perceived family burden is increased by the worsened condition of a relative characterized by abusive and aggressive behaviours. The establishment of support groups needs attention to enable the family members a platform to benchmark ideas and support from other family members who have experienced and managed the same problem.

5.3.5 Nursing Education

There is a great need for all the professional nurses to come out of the college having received psychiatric training. Nowadays enrolled nurses are sent for bridging courses to study for their general diplomas. These nurses come out without the knowledge in mental health. It is recommended that such training be included in the period of training or extending their period of training in months to accommodate the training need in mental health nursing. There should also be scheduled in-service trainings and workshops on mental health care issues for other non-professional workers to increase their knowledge on the support needs of family members as partners in the care giving context.

5.3.6 Nursing Research

Future research is needed in the area of family burden and mental illness to adopt a qualitative approach to obtain in-depth information on the experiences of family members in the whole district and assess the existing coping strategies of the family members. Knowledge about the coping strategies is important for the planning of support programmes. A comparative study is recommended to look at differences and commonalities in the burden perceived by family members in rural areas and those living in sub-urban to urban areas.

5.4 Limitations of the study

The study used a convenience sample to collect data, which involved only family members who accompanied the client to the clinic. The information obtained during data collection may be biased depending on positive and negative relationships between the client and the family member (personal attitudes).

The study used two structured questionnaire to collect data which might have limited the depth of the information given by family members. The results of this study may not be generalizable to the entire district since it has been restricted to two municipalities out of five municipalities that make up uThukela district. Inequality of gender in the sample composition could have an impact on the results obtained; in this study females outnumbered the male participants by 53, 3%.

5.5 Conclusion

The purpose of the study was to explore the perceptions on burden of care giving by family members of individuals with serious mental illness within uThukela District and the association existing between their coping orientations and the perceived burden.

The results of the study confirmed that families are severely burdened by care giving demands. This affects them physically, emotionally, socially and economically. The results further revealed that families have very limited resources including knowledge and material resources. The study also highlighted that a great percentage of families caring for individuals with serious mental illness within this district are impoverished, and live below the poverty line.

Findings also revealed that families receive less support from professionals and do no meet with other family members with similar problems. It is of great importance that support groups be established to improve the social networking for family members and for the individuals with serious mental illness. The study showed that family members use different coping skills to balance family demands within their capabilities in order to maintain, or restore family adaptability and stability. Family members' coping skills need to be strengthened to promote positive attitudes towards care giving and reduce the burden perceived by family members.

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Appendices

Appendix 1: Data collection instruments

Study Title: Exploring the perceptions of family members on care giving burden and association between the perceived burden and their coping strategies.

Instructions: The questionnaire consists of three sections. Section A is about your personal information. Section B, asks about your perception of care giving responsibilities. Section C, is about your coping strategies

Section A Demographic Information

The first section asks for basic information about you as the family member and a care giver to a relative with serious mental illness.

Kindly indicate with an X in the appropriate spaces provided below.

Gender	
Male	
Female	

Age and Age range	
18 -25	
26-30	
30-40	
41 and above	

Education Level	
Primary School or none	
Secondary School	

Tertiary or university level	

Relationship with an individual with serious mental illness	
Parent	
Spouse	
Sibling	
Others (e.g. grandparent, niece, nephew etc.)	
Monthly Household Income in Rands	
Below 1000	
1000 -2000	
2100- 2500	
2600 and above	
Condition of the individual with serious mental illness in the past three months	
Improved	
Worsened	
Stable	

IMIBUZO NEZIMPENDULO

ISIHLOKO SOCWANINGO

Ukuhlola imicabango yemindeni enomthwalo wokubheka ilunga eligula ngomqondo ngokwedlulele eMkhandlwini waso Thukela, eSifundazweni sa KwaZulu-Natal

Imibuzo yehlukaniswe izigaba ezintathu.Uyacelwa ukuba uphendule yonke imibuzo.Usizo luyatholakala kumcwaningi uma kukhona lapho udinga khona usizo.

ISIGATSHANA: A

Isigaba sokuqala simayelana nemininingwane yakho njengelunga lomndeni elihlala/elinakekela ilunga eligula ngomgqondo.

Faka uphawu x maqondana nempendulo yakho.

Ubulili	
Owesilisa	
Owesifazane	

Iminyaka	
18 - 25	
26 - 30	
30 - 40	
41 nangaphezulu	

Izinga lemfundo onalo	
Imfundo yamabanga aphansi	
Imfundo yamabanga aphezulu	
Esikhungweni sezemfundo ephakeme (Enyuvesi)	

Ubudlelwane nomuntu ogula ngokwengqondo	
Umzali	
Owakwakho	
umntanakho	
Abanye (ugogo , umkhulu, abashana, nabanye)	

Imali engena nyanga zonke ekhaya uma ibalwa ngamarandi	
Ingaphansi kuka 1000	
1000 - 2000	
2100 - 2500	
2600 nangaphezulu	

Isimo somuntu ogula ngokwengqondo ezinyangeni ezintathu ezedlule	

Sesingcono	
Siyaqhubeka	
Sikahle nje	

Section B Zarit Burden Interview Scale

Please indicate how often you experience the feelings listed by putting a cross in the box that correspond with the frequency of these feelings.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1. Do you feel that your relative asks for more help than he/she needs?					
2. Do you feel that because 0f the time you spend with your relative that you don't have enough time for yourself?					
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?					
4. Do you feel embarrassed over your relative's behavior?					
5. Do you feel anger when you are around your relative?					
6. Do you feel that your relative currently affect your relationships with other family members or friends in a negative way?					
7. Are you afraid what the future holds for your relative?					
8. Do you feel that your relative is dependent on you?					
9. Do you feel strained when you are around your relative?					

10. Do you feel your health has suffered because of your involvement with your relative?					
11. Do you feel that you don't have as much privacy as you would like because of your relative?					
12. Do you feel that your social life has suffered because you are caring for your relative?					
13. Do you feel uncomfortable about having friends over because of your relative?					
14. Do you feel like your relative seems to expect you to take care of him/her as you were the only one he/she could depend on?					
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expense?					
16. Do you feel that you will be unable to take care of your relative much longer?					
17. Do you feel you have lost control of your life since your relative's illness?					
18. Do you feel you could leave the care of your relative to someone else?					
19. Do you feel uncertain about what to do about your relative?					
20. Do you feel you should be doing					

more for your relative?					
21. Do you feel you could do more for your relative?					
22. Overall, how burdened do you feel in caring for your relative?					

ISIGABA: B isipiliyoni sokuthwala kanzima

Phendula imibuzo ngokufaka uphawu (x) ebhokisini ukubonisa indlela okwenzeka ngayo uma uzwa lemizwa.

	Ngeke/ akwenzeki	Akujwayele	Ngesinye isikhathi	Kaningi	Kucishe kube njalo
1. Uzizwa noma ubona sengathi umhlobo wakho ucela usizo oluningi kunalolu aludingayo?					
2. Ngenxa yokuchitha isikhathi esiningi nomhlobo wakho, uzwa noma ubona sengathi wena awusenaso isikhathi esanele okungesakho nje?					
3. Uzizwa unencindezi ngokunakekela isihlobo sakho ube uzama nokubhekana nezinye izidingo zomndeni noma zemisebenzi yakho?					
4. Uzizwa unamahloni ngokuziphatha noma ngezenzo zesihlobo sakho esigula					

ngomqondo?				
5. Uzizwa unolaka noma unokudinwa uma unesihlobo sakho?				
6. Uzwa sengathi isihlobo sakho siyabulimaza ubudlelwane onabo nomndeni noma nabangani bakho?				
7. Unovalo noma unokwesaba ngokungenzeka kwi kusasa noma ingomuso lesihlobo sakho?				
8. Uzwa sengathi isihlobo sakho sithembele kuwena?				
9. Uzizwa ukhathazekile noma ungakhululekile uma unesihlobo sakho?				
10. Uzwa impilo yakho ihlukumezekile noma igqilazekile ngenxa yokunakekela isihlobo sakho?				
11. Uzwa sengathi awusanazo izimfihlo ngokwanele ngenxa yesihlobo sakho?				

12. Uzwa impilo yakho yokuzithokozisa ihlukumezekile ngenxa yokunakekela isihlobo sakho?				
13. Uzizwa ungaphatheki kahle uma uvakashelwa abangani bakho ekhaya ngenxa yesihlobo sakho.				
14. Uzizwa sengathi isihlobo sakho silindele ukuthi kube nguwena osinakekelayo sengathi uwena kuphela/ wedwa esingathembela kuye?				
15. Uzizwa sengathi awunayo imali eyanele ukunakekela isihlobo sakho uma uhlanganisa noma ubheka izidingo zakho onazo ezidinga imali?				
16. Uzizwa sengathi angeke usakwazi ukuqhubeka nokunakekela isihlobo sakho?				
17. Uzizwa sengathi				

impilo yakho iyashabalala ngenxa yokugulelwa isihlobo sakho?					
18. Uzizwa sengathi ukunakekela isihlobo sakho kungake kuthathwe omunye?					
19. Uzizwa unokudideka ngokumele ukwenze ngesihlobo sakho?					
20. Uzizwa sengathi isihlobo sakho bekufanele usenzele okungcono noma okuthe – xaxa?					
21. Uzizwa sengathi ungakwazi ukwenzela isihlobo sakho okungcono noma okuthe- xaxa kunalokhu?					
22. Kukonke nje , uzizwa uthwele ubunzima obungakanani ngokunakekela isihlobo sakho?	Anginabunzima	Kunzima kancane	Kunzima ngokulingene	Kunzima kakhudlwana	Kunzima Kakhulu impela

Section C Ways of coping using the Carers Assessment Management Index (CAMI)

Kindly read the statement below and place a tick where you feel it applies to you.

Coping strategies	Helpful	Not really helpful	Don't use
Managing Events/ Problem solving.			
1. Relying on your own experience and the expertise you have built up.			
2.Finding out as much information as you can about the Problem.			
3.Establishing a regular routine and sticking to it			
4. Thinking about the problem and finding a way to overcome it.			
5. Keeping one step ahead of things by planning in advance.			
6. Keeping the person you care for as active as possible.			
7. Establishing priorities and concentrating on them.			
8. Talking over your problems with someone you trust.			
9. Being firm and pointing out to the person you care for what you expect of her.			
10. Prevent problems before they happen.			
11. Getting as much help as you can from professionals and other service providers.			
12. Trying out a number of solutions until you find one that works.			
13. Getting as much practical help as you can from your family.			
14. Altering your home environment to make things as easy as possible.			
Managing meanings			
15. Believing in yourself and your ability to handle the situation.			

16. Realizing there's always someone worse off than yourself.			
17. Taking life one day at a time.			
18. Seeing the funny side of the situation.			
19. Realizing that the person you care for is not to blame for the way they are.			
20. Looking for the positive things in each situation.			
21. Gritting your teeth and just getting on with it.			
22. Accepting the situation as it is.			
23. Drawing on strong personal or religious beliefs.			
24. Realizing that no one is to blame for things.			
25. Realizing that things are better now than they use to be.			
26. Keeping your emotion and feelings tightly under control.			
27. Forgetting about your problems for a short while by day-dreaming or the like.			
28. Ignoring the problem and hoping it will go away.			
Managing/alleviating stress.			
29. Maintaining interests outside caring.			
30. Keeping a little free time for yourself.			
31. Remembering all the good times you used to have with the person you care for.			
32. Taking your mind off things in some way, by reading, watching TV or the like.			
33.Getting rid of excess energy and feeling by walking, swimming or other exercise.			
34. By having a good cry.			
35. Using relaxation techniques, meditation or the like.			
36.Letting off steam in some way(e.g. shouting, yelling and the like).			

37.Trying to cheer yourself up by eating, having a drink, smoking or the like.			
38. Attending a self-help group.			

APPENDIX 2

APPENDIX 2.1 Permission to use the instruments: ZBI and CAMI instruments.

1. Zarit burden interview general permission for non-commercial studies.
     ZBI (Zarit Burden Interview)
Developed by: Steven H. Zarit
Objective:
To assess the level of burden experienced by the principal caregivers of older persons with senile dementia and disabled persons.
Copyright: Copyright 1980, 1983, 1990 Steven H Zarit and Judy M Zarit
Reference publication:
Zarit SH, Reever KE, Bach-Peterson J. Relatives of the Impaired Elderly: Correlates of Feelings of Burden. The Gerontologist.1980; 20(6):649-55

Conditions of use:
1. User-Agreement:
User is required to complete and sign a User Agreement in which specific conditions required by the author are detailed.
2. Access fees:
Author's royalty fee: the use of the ZBI in commercial studies will be subject to Prof. Steven H. Zarit's royalty fees of an amount of 1,000 (one thousand) Euros per protocol/application plus an additional charge of 500 (five hundred) Euros per existing translation to be used in the protocol/application.
Other specific conditions requested by the author are detailed in the User Agreement .
Distribution fees are requested according to the study design and context of use of the questionnaire:
1. Access is free of charge in the framework of not-funded academic research (1) and individual clinical practice,
2. Access to the ZBI for a use in funded academic research (2) is subject to a distribution fee payable to MAPI Research Trust, of an amount of 300 (three hundred) Euro* per study plus an additional 50 (fifty) Euro per language version requested.
3. Access to the ZBI for a use in commercial studies (3) involving "for-profit" organizations is subject to a distribution fee payable to MAPI Research Trust , of an amount of 500 (five hundred) Euro* per study plus an additional 150 (one hundred and fifty) Euro per language version requested.
 (1) Not funded academic research: if the project is not explicitly funded, but funding comes from overall departmental funds or from the University or individual funds then fees are waived.
(2) Funded academic research: projects receiving funding from commerce, government, EU should anticipate paying the corresponding fees.
(3) Commercial studies (industry, CRO, any for-profit companies).

APPENDIX 2.2 Permission to use the CAMI

Subject:	Re: Permision to use a (CAMI) Instrument
From:	"mike Nolan" <m.r.nolan@sheffield.ac.uk>
Date:	Mon, July 12, 2010 9:52 am
To:	"tholakele buthelezi" <thola62@mailbox.co.za>
Priority:	Normal
Allow Sender:	Allow Sender | Allow Domain | Block Sender | Block Domain
Options:	View Full Header | View Printable Version | Download this as a file | Add to Address Book

```
I would be very happy for you to use CAMI in your study, subject to the
usual acknowledgements. There is no charge for this. Good luck with your
study.

Regards,

Mike
tholakele buthelezi said the following on 09/07/2010 17:45:
> Good Afternoon
> Iam Tholakele Maria Buthelezi a masters student at the university of
> kwaZulu-Natal at the KZN Province, in South Africa.
>
> I would like to use the (Cami) instrument in my study, investigating the
> perception of caregiving burden by families of the individuals with
> Serious mental illness and their coping strategies.
> Iam requesting your assistance  to access the permission to use this
> instrument in my study.
>
> Thank you.
> From
> T.M.BUTHELEZI


--
Mike Nolan
Professor of Gerontological Nursing
Sheffield Institute for Studies on Ageing
School of Medicine and Biomedical Sciences
University of Sheffield
Samuel Fox House
Northern General Hospital
Herries Road
Sheffield
S5 7AU

Tel:  (0114) 22 66851/66849
Fax:  (0114) 2715915
Email: m.r.nolan@sheffield.ac.uk
http://www.shef.ac.uk/medicine
_____
```

APPENDIX 3.1 Ethical clearance for study from the University of KwaZulu-Natal.

09 July 2010

Mrs T M Buthelezi
P O Box 4040
LADYSMITH
3370

Dear Mrs Buthelezi

PROTOCOL: An exploratory descriptive study of perceived family burden of family members caring for individuals with a serious mental illness in the uThukela district, KwaZulu-Natal
ETHICAL APPROVAL NUMBER: HSS/0449/2010 M: Faculty of Health Sciences

In response to your application dated 30 June 2010, Student Number: 205527408 the Humanities & Social Sciences Ethics Committee has considered the abovementioned application and the protocol has been given FULL APPROVAL.

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

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

Yours faithfully

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

SC/sn

cc: Dr. L Middleton (Supervisor)
cc: Mr. S Reddy

APPENDIX 3.1 Ethical clearance for study from the health care institution in the

UThukela District

LADYSMITH PROVINCIAL HOSPITAL/NURSING /NURSING COMPONENT
Postal address: Private Bag 9928, Ladysmith, 3370
Physical address: 36 Malcom Street, Ladysmith, 3370
Tel: 063 637 2111 ext. 337, Fax 036 637 7052
E-mail.:www.kznhealth.gov.za

Enquiries Dr M.S.H. Khan
Ext:

30 July 2010

Mrs T.M Buthelezi
P.O. Box 4040
LADYSMITH
3370

Dear Mrs Buthelezi

RE: REQUEST TO CONDUCT RESEARCH

RESEARCH TITLE: An exploratory descriptive study of perceived family burden of
family members caring for individuals with a serious mental illness in the UThukela
district, KwaZulu-Natal.

ETHICAL APPROVAL: Ladysmith Provincial Hospital Ethics Committee

In response to your application dated 22 July 2010, Student Number: 205527408 the
Ethics Committee of Ladysmith Provincial Hospital has considered the above mentioned
application and the research has been given full approval.

Wishing you everything of the best with your studies.

Yours faithfully

Chairperson of Ladysmith Provincial Hospital Ethics Committee

uMnyango Wezempilo. Department van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope

Appendix 3.3: Letter of approval from the Department of Health of KwaZulu-Natal

Health Research & Knowledge Management sub-component
10 – 103 Natalia Building, 330 Langalibalele Street
Private Bag x9051
Pietermaritzburg
3200
Tel.: 033 – 3953189
Fax.: 033 – 394 3782
Email.: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

HEALTH
KwaZulu-Natal

Reference	: HRKM119/10
Enquiries	: Mrs G Khumalo
Telephone	: 033 – 3953189

02 August 2010

Dear Mrs TM Buthelezi

<u>Subject: Approval of a Research Proposal</u>

1. The research proposal titled **'An exploratory-descriptive study of perceived family burden by family members of individuals with a serious mental illness in the Uthukela district of KwaZulu-Natal'** was reviewed by the KwaZulu-Natal Department of Health.

   The proposal is hereby **approved** for research to be undertaken at **Ladysmith Hospital**.

2. You are requested to take note of the following:
   a. Make the necessary arrangement with the identified facility before commencing with your research project.
   b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.

3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

For any additional information please contact Mrs G Khumalo on 033-3953189.

Yours Sincerely

Dr S.S.S. Buthelezi
Date: 3 /8/ 2010
Chairperson, Health Research Committee
KwaZulu-Natal Department of Health

uMnyango Wezempilo . Departement van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope

APPENDIX 4: Patient information document and declaration of consent to participate in the study

RESEARCH TITLE: An exploration-Descriptive study of perceived family burden by family members of individuals with a serious mental illness in the uThukela district of KwaZulu-Natal

INVESTIGATOR: Tholakele Buthelezi: Masters Student (University of KwaZulu – Natal) CONTACT NO: 0781469058

RESEARCH SUPERVISOR: Dr L. Middleton (University of KwaZulu –Natal, South Africa)

 CONTACT NO: 031 2601655 or Dr Lyn Middleton at middletonl@ukzn.ac.za

Informed consent for participation in the study.

As a family member you are hereby requested to participate in the study. The purpose of the study is to find out about family member's perceptions of care giving burden and the ways of coping with the situation while living and taking care of the individual with serious mental illness. This will help the health care professionals and the District health management team to understand your needs as family members and to plan for the appropriate programmes that will assist the family members to cope with the care giving responsibilities.

You will participate in this study by completing a structured questionnaire with three sections. Section A will be your personal information. Section B, you will give us information on perceived family burden. Section C is about your coping strategies.

The intention is to meet once in a private area at the clinic and it will take you approximately 20 minutes of your time to complete the form. Assistance with the completion of the questionnaire will be provided where it is needed. The completed questionnaire will be kept for five years in a safe place and your name as a participant will not be written on it.. Confidentiality and anonymity will be maintained at all cost. It will be only the researcher and her supervisor who will have access to your completed questionnaire. Your participation in the study is voluntary. You are not obliged to participate. You have a right to withdraw from the study at any time if you feel

uncomfortable about it even in the middle of an interview without any penalty imposed on you. If you have any questions about the study after the interviews, please feel free to contact me and or my supervisor at the given contact numbers.

Your participation will be appreciated.

Thank you

 --   Date: -------------------

Research investigator: Tholakele Buthelezi

DECLARATION OF CONSENT TO PARTICIPATE IN THE RESEARCHSTUDY

I hereby freely give consent to participate in the research project

I understand that my participation in the study is voluntary and I may refuse to participate or withdraw my consent and stop taking part at any time without penalty.

Signature of a participant………………..

Date …………………

APPENDIX 5. Table 4.1

Table 4.1(ZBI) INSTRUMENT showing the burden perception scores in percentages in their descending order.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1. Do you feel that your relative is dependent on you?	(5) 4.2%	(10) 8.3%	(13) 10.8%	(88) 73%	(4) 3.3%
2. Do you feel like your relative seems to expect you to take care of him/her as you were the only one he/she could depend on?	(2) 1.7%	(9) 7.5%	(25) 20.8%	(81) 67.5%	(3) 2.5%
3. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	(11)9.2	(7) 5.8%	(12) 10.0%	(81) 67.5%	(9) 7.5%
4. Do you feel your health has suffered because of your involvement with your relative?	(8) 6.7%	(12) 10.0%	(36) 30.0%	(61) 50.8%	(3) 2.5%
5. Do you feel that your relative asks for more help than he/she needs?	(6) 5%	(13) 10%	(37) 30.8%	(61)50.8%	(3) 2.5%
6. Do you feel you have lost control of your life since your relative's illness?	(10) 8.3%	(11) 9.2%	(39) 32.5%	(58) 48.3%	(2) 1.7%
7. Overall, how burdened do you feel in caring for your relative?	(7) 5.8%	(5) 4.2%	(27) 22.5%	(58) 48.3%	(23) 19.2%
8. Do you feel that your social life has suffered because you are caring for your relative?	(9) 7.5%	(21) 17.5%	(29) 24.2%	(56) 46.7%	(5) 4.2%
9. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	(8) 6.7%	(14) 11.7%	(41) 34.2%	(53) 44.2%	(4) 3.3%
10. Do you feel that because of the time you spend with your relative that you don't have enough time for	(4) 3.3%	(25) 20.8%	(37) 30.8%	(49) 40.8%	(5) 4.2%

yourself?					
11. Do you feel anger when you are around your relative?	(11) 9.2%	(23) 19.2%	(43) 35.8%	(39) 32.5%	(4) 3.3%
12. Do you feel uncomfortable about having friends over because of your relative?	(27) 22.5%	(38) 31.7%	(21) 17.5%	(33) 27.5%	(1) .8%
13. Do you feel embarrassed over your relative's behavior?	(19) 15.8%	(37) 30.8%	(31) 25.8%	(30) 25.0%	(3) 2.5%
14. Do you feel strained when you are around your relative?	(34) 28.3%	(31) 25.8%	(24) 20.0%	(29) 24.2%	(2) 1.7%
15. Do you feel you could leave the care of your relative to someone else?	(51) 42.5%	(12) 10.0%	(24) 20.0%	(28) 23,3%	(4) 3.3%
16. Do you feel that you don't have as much privacy as you would like because of your relative?	(39) 32.5%	(44) 36.7%	(13) 10.8%	(22) 18.3%	(2) 1.7%
17. Do you feel that your relative currently affect your relationships with other family members or friends in a negative way?	(34) 28.3%	(45) 37.5%	(22) 18.3%	(19) 15.8%	(0)
18. Do you feel that you will be unable to take care of your relative much longer?	(76) 63%	(18) 15,0%	(10) 8,3%	(15) 12,5%	(1) .8%