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**CAREGIVERS' EXPERIENCE OF CARING FOR A FAMILY
MEMBER WITH SCHIZOPHRENIA IN CONDITIONS OF
POVERTY**

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DECLARATION

This work has not been previously submitted in whole, or part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: _____ Date: _____

University of Cape Town

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This thesis is dedicated to the ten men and women who agreed to talk to me and share their experiences of caregiving. They took the time to share honestly and openly their experiences and challenges.

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ABSTRACT

The aim of this study was to explore the experiences of South African caregivers caring for a family member with schizophrenia, living in conditions of poverty. Of particular interest in this research was to explore the factors that present challenges to their capacity to care and the factors that facilitate coping. A qualitative methodology was utilized, making use of semi-structured interviews which were conducted with ten caregivers caring for a family member with schizophrenia. Data were analysed using analytic techniques from grounded theory. Six broad themes emerged during analysis, namely: caregivers' assistance with activities of daily living; involvement with illness management; knowledge of illness; consequences of caregiving; coping with caregiving; and the impact of poverty on caregiving. While some themes reflect caregiver experiences described in the international literature, others may be more specific to the South African context. These findings have implications for future research and indicate a great need to further understand these caregivers' experience in order to identify appropriate interventions.

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CHAPTER ONE: INTRODUCTION

A large amount of research has examined the impact of caring for a family member with a mental or physical illness, given the shift in emphasis in most parts of the world from institutional to community-based care (Ohaeri, 2002). These studies have indicated a considerable burden experienced by caregivers. The extent of burden experienced is influenced by a number of factors such as severity of disorder, degree of disability and extent of behavioural disturbances, as well as caregiver gender, socioeconomic status and coping strategies (Baronet, 1999). Caregiving has been found to impact on caregivers' quality of life (Li, Lambert & Lambert, 2007) and mental and physical health status (Dyck, Short & Vitaliano, 1999; Provencher, Perreault, St-Onge & Rousseau, 2003).

Studies which have explored the experience of caring for a family member with schizophrenia, as opposed to other mental and physical disorders, have found that caregivers of people with schizophrenia experience higher subjective burden and lower social support compared to caregivers of people with physical conditions such as diabetes, heart, lung, renal and brain diseases (Magliano, Fiorillo, De Rosa, Malangone & Maj, 2005). This group of caregivers also score lower on measures of subjective quality of life than caregivers for members with major affective and anxiety disorders (Awadalla, Ohaeri, Salih & Tawfig, 2005).

Most studies assessing caregiver burden in patients with schizophrenia have been conducted in developed countries (Bibou-Nakou, Dikaiou & Bairactaris, 1997; Foldemo, Gullberg, Ek & Bogren, 2005; Magliano et al., 2005) and indicate that, even when comprehensive clinical case management is provided by community mental health services, the burden experienced by carers remains substantial. Studies from developing countries have also raised concerns regarding the increased burden on families who are caring for a member with a mental disorder, given challenges in the implementation of community services (Gutierrez-Maldonado, Caqueo-Urizar & Kavanagh, 2005).

In South Africa, the emphasis in mental health policy (Mental Health Care Act 17 of 2002) has shifted to advocate community-based care for people with severe and chronic mental disorders in an attempt to reduce reliance on long-term institutional care (Lazarus, 2005). There is, however, concern as to how effectively these policies are being implemented, given the under-resourced and under-developed services (Lazarus, 2005; Thom, 2004) and widespread unemployment and poverty in South Africa. Studies have indicated an increased burden on families who are now taking primary responsibility for family members with mental illnesses, without adequately developed community services (Freeman, Lee & Vivian, 1999; Hamber, 1997 cited in Thom, 2003). These studies have also indicated a need for an improvement in community based services to support these families, as well as for research to inform family interventions and support (Thom, 2003).

Schizophrenia is a chronic severe and debilitating mental illness and is associated with greater chronic disability than any other mental disorder (National Academies Press, 2001). Although no national data exist on the prevalence of mental disorders in South Africa (Seedat, Nyamai, Njenga, Vythilingum & Stein, 2004), prevalence studies that have been conducted in specific regions of South Africa (Bhagwanjee, Parekh, Paruk, Petersen & Subedar, 1998; Cooper et al., 1999; Robertson, Ensink, Parry, Chalton, 2001; Rumble, Swartz, Parry & Zwarenstein, 1996) suggest a prevalence at least as high as, and possibly higher than, internationally. A study conducted in 2005 to provide an estimate of the prevalence of selected mental disorders in order to assist in allocation of available resources (Kleintjes et al., 2006), suggested that the annual prevalence for schizophrenia for adults in the Western Cape, adjusted for co-morbidity, was one percent. For children and adolescents the prevalence was found to be 0.5%. This is comparable to data from the United States (Kaplan & Saddock, 2005).

The findings from other developing countries, where factors such as gender, education level, physical health and employment are associated with an increased burden of care, have implications for a country like South Africa with high levels of infectious illness such as HIV/AIDS and Tuberculosis and high levels of poverty and

unemployment, as well as a prevalence rate of schizophrenia as high if not higher than international prevalence rates.

The data for the current study was collected as part of a study conducted for the Municipal Services Project in 2005, which aimed to investigate the impact of municipal service restructuring on households coping with serious mental disorders (Breen, 2005). The first stage of data analysis focused on the impact of municipal services, such as water and electricity, on the families' experience of schizophrenia. A considerable amount of data was collected, which covered other areas, such as caregivers' experiences, challenges and factors facilitating coping, which will be presented in this thesis.

The aim of this research is to generate descriptive qualitative data on caregivers' experiences of caring for a family member with schizophrenia in South Africa, living in conditions of poverty. There is a paucity of data in this area and it is important in order to inform further research in the area, which can in turn inform policies and interventions, given current mental health policy implementation challenges.

This thesis is divided into five sections. Following this introduction, a review of the literature on caregiver experience is presented in Chapter two. In Chapter three the research aims, design, procedure, instrumentation and data analysis are outlined. Chapter four presents the results of the analysis and discusses these findings in relation to the literature. Lastly, Chapter five presents a summary of the main findings, considers the limitations of the study and makes recommendations for future research.

CHAPTER TWO: LITERATURE REVIEW

The literature review explores various aspects of caregiving, with a specific focus on the experience of caring for a family member with schizophrenia. The review strategy included a search for empirical studies and review papers on PsycInfo and Pubmed databases, and local databases SA ePublications and South African Studies. The aim of the review is to highlight the dominant issues and themes emerging in the caregiver literature, specific to the care of schizophrenia.

2.1 Definition of key concepts

Before an outline of the literature is presented, some pertinent terms used in the literature will be defined.

2.1.1 Caregiver

For the purposes of this study, family caregiver is defined as the person in the family who is the primary person involved in daily practical and emotional care and treatment decisions with the patient.

2.1.2 Burden

The term 'burden' is used in the caregiver literature as an all-encompassing term that refers to the totality of the experience of caring for an ill relative or friend, including effects on the caregiver's physical, psychological and socioeconomic well being, as well as their capacity to cope with and adjust to that circumstance (Ohaeri, 2002). The concept is separated into *objective* burden (e.g. financial loss, impairment of work efficiency, disruption of family routines) and *subjective* burden (e.g. attitudes to the patient, subjective feeling of difficulty coping with the illness, emotional climate at home) when these problems are attributable to the illness (Ohaeri, 2002). There has been criticism in the literature regarding the use of the term burden as it excludes any aspects of caregiving that caregivers may experience as positive. There is an argument

for the use of a more broad definition of the caregiver experience that includes both positive and negative aspects of the caregiver experience (Veltman, Cameron & Stewart, 2002).

2.1.3 Quality of life

The multidimensional nature of quality of life (QOL) makes it difficult to define (Glozman, 2004). The World Health Organisation has defined it as ‘the individual’s perception of his or her position in life, within the cultural context and value system within they live, and in relation to his goals, expectation, parameters and social relations’ (World Health Organisation, 2006). QOL has also been considered as an outcome of health status and a sign of functional disability, or a manifestation of social and environmental conditions, as well as a subjective evaluation of psychological well-being (Glozman, 2004).

2.1.4 Schizophrenia

As the focus of the study was on the caregiving experience for schizophrenia, the diagnostic criteria for schizophrenia according to the Diagnostic and Statistical Manual of Mental Disorders (4th edition revised) (APA, 2000) will be discussed as well as other issues relevant to the presentation of the disorder.

Schizophrenia is a chronic, severe and debilitating mental illness (National Institute for Mental Health, 2006). The DSM-IV-TR (APA, 2000) defines schizophrenia as the presence of a mixture of characteristic signs and symptoms including delusions, hallucinations, disorganised speech or behaviour as well as negative symptoms such as affective flattening, alogia (poverty of speech) and avolition (inability to initiate or persist in goal directed activities). These symptoms must be severe enough to cause social or occupational dysfunction and be present for at least 6 months. There are a number of schizophrenia subtypes which vary according to the clinical presentation including paranoid, disorganised, catatonic, undifferentiated and residual type. People

with schizophrenia are also known to have a high mortality rate from accidents and natural causes, and suicide is the leading cause of mortality among people with schizophrenia. Co-morbid substance use is also common.

Schizophrenia is associated with greater chronic disability than any other mental disorder (National Academies Press, 2001). Impairments in functioning occur in a number of different areas including interpersonal relations, occupation and self care (APA, 2000). In general, functioning in these areas is below that which was achieved before the onset of symptoms. Consequences often include the inability to complete schooling or hold down a job, limited social contacts and an inability to take care of activities of daily living and hygiene. Many people with schizophrenia also have poor insight into their illness, which may lead to poor medication compliance and help-seeking behaviour. Studies also indicate a high incidence of violence and assaultive behaviour in individual with schizophrenia. The above factors impact on the social support networks and quality of life of people with schizophrenia.

2.2 Mental health care

Over the past 40 years there has been a change internationally in the approach to mental health care. Treatment for people with chronic mental disorders no longer is provided within psychiatric institutions, but rather at the level of the community on an outpatient basis. This has resulted in a shift of responsibility for care from the institution to the family (Ricard, Bonin & Ezer, 1999).

Until recently, in the mental health field as in all others, South Africa expended resources on health and mental health unequally across races and provinces (Thom, 2004). Issues regarding poor care and even abuse of human rights, such as respect, dignity, privacy and consent to care, of people with psychiatric disorders remain (Freeman, 2002; Thom, 2004). In the context of political transformation in South Africa during the past decade, mental health and substance abuse have been prioritised on government agendas.

The new legislation on mental health care (Mental Health Care Act 17 of 2002) emphasises a community-based rehabilitative model of mental health care within a comprehensive integrated health service (Freeman, 2002; Thom, 2004). This policy to deinstitutionalise mental health care is in line with international trends, and focuses on developing comprehensive and integrated community-based services (Thom, 2004). The objective is to integrate mental health services into primary health care services, and thereby to avoid a separation of mental health from other health issues, in an attempt to destigmatise and normalise mental illness (Freeman, 2000).

These policies require that people with mental disorders (mental health care users) must primarily be treated, managed and rehabilitated at the level of primary health care, which for the most part takes place at the community health clinics and a number of non-governmental organisations (NGOs). Should an admission to a psychiatric facility be deemed necessary, the assessment would take place at the primary care level and a referral would then be made to the appropriate tertiary or specialised service. Following this admission, the mental health care user would be provided with follow up treatment once again at the primary health care level.

There is, however, concern as to how effectively these policies are being implemented, given the under-resourced and under-developed mental health services in South Africa (Lazarus, 2005; Thom, 2004). Research has played a vital role in the process of identifying problems but has lacked clear organised collection of findings and analysis of relevance or the impact of this information on the policy-implementation process (Thom, 2003). Internationally, deinstitutionalisation has led to a large number of people with schizophrenia being homeless due to lack of adequate follow up and care (Gutierrez-Maldonado et al., 2005).

A review of mental health literature, with particular emphasis on mental health services in South Africa, was conducted by the Health Systems Trust (Thom, 2003). Problems associated with implementation of policies were found to include shortages and inequitable distribution of mental health personnel relative to international settings (Freeman, 2000; Lund & Flisher, 2002). Other challenges to implementation

included limited resources and budget cuts, ineffective management of these resources and a lack of a broader mental health care approach due to a scarcity of trained mental health practitioners. This scarcity of human resources was found to lead to a lack of time to provide more than basic medical and nursing care.

Stigmatization of mental disorders which leads to difficulties in arranging community placements, as well as competing priorities on an already overburdened health care system, was also found to have implications for implementation (Lazarus, 2005).

In particular, concerns were raised regarding the process of deinstitutionalisation, as government policy has attempted to decrease reliance on long term institutional care for people with severe and chronic mental disorders, in favour of the promotion of treatment at a primary health care level in the community (Dartnall, Porteus, Modiba & Schneider, 2000; Lazarus, 2005). These concerns echo those that have been raised internationally in response to deinstitutionalisation (Lovisi, Mann, Coutinho & Morgado, 2003). These include the fear that pressure to reduce hospital beds may result in indiscriminate discharges of patients, without careful consideration of their readiness for discharge, and that there may be inadequate family and community preparation and support around issues of obtaining chronic medication, disability grants and emergency assistance (Lazarus, 2005). Other concerns include inadequate community resources, such as day care centres, work shops and other forms of caregiver support, which are critical in reducing the burden of care for families caring for a member with a mental illness, as well as in preventing relapse of patients. Finally, a 'revolving door' phenomenon could occur, where patients are neither adequately treated in hospital nor effectively integrated into the community, with the final result being homelessness for many patients. Given the housing problems many South Africans face, people with chronic mental disorders are even more likely to be ejected or unable to access even the more basic shelters.

Family and caregiver burden is therefore a highly topical issue as it concerns an 'invisible healthcare system', which constitutes the core long-term care provider for people with chronic mental disorders in the community (Arno, Levine & Memmott, 1999).

2.3 Caregiver Literature

There has been a large amount of research conducted in economically developed and developing countries that explores the experience of caring for a family member with a chronic mental or physical illness, as a result of the above mentioned shift towards community and family based care for such conditions. In the United States, Switzerland and Germany, an estimated fifty to ninety per cent of the chronically mentally ill live with family members after being discharged from acute psychiatric hospitalisation (Dyck et al., 1999; Lauber, Eichenberger, Luginbuhl, Keller & Rossler, 2003). Research has studied the impact of caring for a family member with physical conditions such as a stroke (Wagner, Bigatti & Storniolo, 2006) and cancer (White, Mayo, Hanley & Wood-Dauphinee, 2006), and a range of mental disorders such as dementia, in particular Alzheimer's disease (Borrayo, Goldwaser, Vacha-Haase & Hepburn, 2007), mood disorders (van Wijngaarden et al., 2000) eating disorders (Perkins, Winn, Murray, Murphy & Schmidt, 2004), attention deficit hyperactivity disorder (Bjornstad & Montgomery, 2005) and schizophrenia (Jungbauer, Wittmund, Dietrich & Angermeyer, 2004; Magliano et al., 2005). These studies have indicated that caregivers experience considerable burden when caring for a family member with a chronic mental or physical condition, as a result of a number of different factors which will be explored in greater detail below.

Studies which have explored the experience of caring for a family member with schizophrenia, as opposed to other mental and physical disorders, have found that caregivers of people with schizophrenia experience higher subjective burden and lower social support compared to caregivers of people with physical conditions such as diabetes, heart, lung, renal and brain diseases (Magliano et al., 2005). This group of caregivers also score lower on measures of subjective quality of life than caregivers for members with major affective and anxiety disorders (Awadalla et al., 2005).

Empirical studies investigating caregiver experience with schizophrenia have been conducted in economically developed countries such as Sweden (Lowyck et al., 2004), Canada (Provencher et al., 2003; Ricard et al., 1999) and the United States (Dyck et al., 1999; McDonnell, Short, Berry & Dyck, 2003) and developing countries

such as China (Li et al., 2007), Chile (Caqueo-Urizar & Gutierrez-Maldonado, 2006), Malawi (Sefasi et al., 2007), Nigeria (Ohaeri, 2001), and Sudan (Awadalla et al., 2005). A number of reviews aimed at examining the factors associated with caregiver burden in mental illness (e.g. Baronet, 1999; Ohaeri, 2002; Schulze & Rössler, 2005) have highlighted methodological issues associated with the research to date, indicating inconsistent use of theoretical and operational definitions, reliability and validity issues in the measurement of burden, problems in sampling and a lack of theoretical frameworks. These methodological challenges may account for some of the inconsistency of research findings.

There appear to be three main constructs that have been explored in the caregiver literature regarding the consequences of caregiving (Schulze & Rössler, 2005). These are caregiver burden, distress, and quality of life, which are at times not clearly separated. There is also considerable disagreement regarding the consequences of caregiving, perhaps due to the wide range of instruments used to measure these various constructs. The majority of research studies have utilised quantitative methodology to explore the level and severity of caregiver burden. These approaches have been criticised as cross-sectional, preoccupied with statistical quantification and not driven by theory as well as limiting the caregiver experience to only negative aspects, whereas many caregivers describe positive parts to the experience (Ohaeri, 2002). This may be addressed by longitudinal, qualitative studies that focus on practical descriptions and theories that contextualise the caregiving experience (Ohaeri, 2002). Recently, there has been an increase in qualitative studies which attempt to provide a more thorough understanding of the caregiving experience (Schulze & Rössler, 2005).

2.3.2 Caregiver Burden

Most studies assessing burden in caregivers for people with schizophrenia have been conducted in developed countries. These studies indicate that even when comprehensive clinical case management is provided by community mental health services, the burden experienced by carers remains substantial. Studies from developing countries have also raised concerns regarding the increased burden on

families who are caring for a member with a mental disorder, given challenges in the implementation of community services (Gutierrez-Maldonado et al., 2005).

Although studies agree that many caregivers experience burden, there is a lack of consensus regarding the factors that influence burden (Lowyck, De Heert, Peeters, Gilis & Peuskens 2001). This may be associated with the diverse constructs investigated and the lack of consistency regarding measurement instruments. There also seems to be a lack of consistency in operationalising burden as well as measurement of one or few variables, for example, some studies focus only on objective burden while others focus only on subjective burden.

Quantitative studies from developed and developing countries such as Sweden (Lowyck et al, 2004), Canada (Provencher et al., 2003; Ricard et al., 1999), the United States (Dyck et al., 1999 & McDonell et al., 2003), and Nigeria (Ohaeri, 2001), which assessed the factors that influence burden, found that carers experience burden on a practical, emotional and financial level, and that the most consistent predictors of burden have broadly been found to be problematic behaviour, functional disability and severity of disease (Ohaeri, 2002). There are however, a number of other factors that appear to contribute to the experience of burden. These will be outlined below.

Predictors of burden have most commonly been separated into caregiver-related and patient-and illness-related factors (Baronet, 1999). Some studies have separated the investigation of burden into subjective and objective burden. Consistently across studies, activities related to objective burden include providing transport, help with money management and cleaning and cooking, constant supervision, restriction in caregivers' activities and financial restraint. Subjective burden is experienced as a result of disruptive behaviour in their ill relative. This burden was related to concerns regarding violence, excessive demands and dependency on the caregiver and embarrassing and uncooperative behaviours (Baronet, 1999).

Characteristics of caregivers that have been studied include age, unemployment, ethnicity, gender, relationship to ill family member, living arrangements, education level and psychosocial resources (Baronet, 1999; Ricard et al., 1999). Female caregivers have been shown to experience greater distress than male caregivers after controlling for other variables such as income and education (Li et al., 2007; Ricard et al., 1999). The increased experience of distress in female caregivers may be the result of their carrying a greater affective investment when caring for their family member (Ricard et al., 1999). Caregivers who are unemployed, have low levels of education (Li et al., 2007), and those who are divorced or separated have been shown to be at risk for greater burden than those that are in relationships, highly educated and employed (Li et al., 2007; Ohaeri, 2001). Satisfaction with social support networks and available family resources has been shown to be inversely related to subjective and objective burden (McDonnell et al., 2003), and subjective burden inversely related to perceived control on behalf of the caregiver (Bibou-Nakou et al., 1997). No consistent relationship has been found between burden and age and ethnicity of caregiver.

The type of caregiving relationship has also been explored in terms of predicting burden. Research findings indicate different experiences and factors contributing to burden, depending on the kinship relationship between caregiver and patient. Studies have examined caregivers who are mothers, spouses, siblings (Lively, Friedrich & Rubenstein, 2004; Stalberg, Ekerwald & Hultman, 2004) and children (Valiakalayil, Paulson & Tibbo, 2004). Similarities and differences have been observed when comparing the spouses' and parents' caregiving experience (Jungbauer, et al., 2004). Similarities include the change in caregiver experience depending on whether the family member is stable or in a state of relapse, enduring fears regarding this state of relapse and impact of changes in patient's personality. Differences were that spouses reported problems around marital intimacy and reassessing long term plans and expectations, whereas parents experienced guilt regarding the possibility of some responsibility for the illness and concerns about the impact of the potential lifelong dependency of the child. Despite these varying experiences, no clear difference has been found to be associated with the impact of the kind of relationship on burden (Lowyck et al., 2001). Spouses of people with schizophrenia have been found to have

an increased work load and have to adapt to different roles within the partnership and family (Wittmund, Wilms, Mory & Angermeyer, 2002).

Patient or illness related variables related to the caregiver's experience of burden have consistently been found to include disruptive behaviour, severe symptoms and disability (Ohaeri, 2002). Factors associated with the illness and patient include behavioural disturbances such as aggressive and abusive behaviour, refusal or inability to do household chores, making unreasonable demands, and general uncooperative behaviour (Ricard et al., 1999). There are mixed findings regarding the stressors associated with positive and negative symptoms in terms of contributing to caregiver burden. Many studies have found that negative symptoms (e.g. lack of conversation, under-activity, slowness, and few leisure interests) are experienced as more burdensome than the positive symptoms (Lowyck et al., 2001). Reasons for this have been postulated to be that negative symptoms are temporally more stable whereas positive symptoms more episodic. Negative symptoms and related cognitive and functional difficulties mean that family members have increased burden in assisting with activities of daily living and household chores. This finding may also be due to the possibility that positive symptoms are more easily viewed as part of the disorder, whereas negative symptoms may be viewed as within the patient's control (Lowyck et al., 2001). However, other studies have indicated that behaviour symptoms directed at family members, such as violence and rudeness, unpredictability, bizarre ideas, and parasuicide attempts, caused the most severe distress (Lowyck et al., 2001; Ricard et al., 1999). In one study, subjective burden was found to be related to the severity of both positive and negative symptoms, whereas objective burden was only related to severity of negative symptoms (Provencher & Mueser, 1997).

The impact of the duration of the illness on caregivers has yielded mixed findings; however there seems to be more evidence for a decline in caregiver burden over time (Lowyck et al., 2001). This decrease in experience of burden may occur because as the chronic nature of the illness becomes apparent, caregivers make more active attempts to draw on social supports and access appropriate treatments for their family

member (Rose, 1996). Caregivers may also worry more about the patient and their other family members during the initial phase of the illness (Lowyck et al., 2004). This worry appears to decrease as they find ways of coping and adjusting.

The relationship between caregiver stress and psychological resources and burden has also been investigated. Findings indicate that a sense of mastery, satisfaction with coping resources and sense of self-efficacy are negatively associated with subjective burden (Baronet, 1999), whereas caregivers' own health was not found to be related to subjective burden.

Other predictors of burden have been found to include the duration of the illness (shorter duration associated with higher burden), living arrangements (caregivers who live in the same dwelling experience higher burden), time spent in caregiving, stigma, type of contact with mental health services, ill family member's age (younger patients associated with greater burden), caregiver's awareness of suicidal ideation (McDonell et al., 2003), as well as medication compliance, patient's participation in rehabilitation programmes, psychosocial functioning of the family and the number of hours spent with the family member (Koukia & Madianos, 2005 cited in Li et al., 2007), and caregiver's level of education (Li et al., 2007). The association of burden with young age may be explained by caregivers experiencing greater feelings of grief or mourning (McDonell et al., 2003). Caregivers also describe a sense of experiencing 'stigma by association' as a result of having a family member with a mental illness (Ostman Kjellin, 2002; Phillips, Pearson, Li, Xu & Lawrence, 2002; Veltman et al., 2002). Contrary to hypotheses, in Malawi, caregiver knowledge of patient's illness was associated with an increased caregiver burden (Sefasi et al., 2007), which may suggest that cultural factors may mediate the relationship and care is needed when introducing caregiver education in new cultures.

In summary, with the exception of caregiver sex and behavioural disturbance of the patient, there are few patterns which consistently emerge to indicate which factors contribute to caregiver burden (Ricard et al., 1999). Many studies have not included

information regarding the living arrangements of the patient and caregiver, which are heavily influenced by socio-economic status.

The results of these studies raise questions regarding how much assistance family members can provide for members with schizophrenia, before they become overburdened and overwhelmed and require professional input (Jungbauer et al., 2004).

2.3.3 Consequences of caregiver burden

A number of studies have examined how caregiving impacts on the caregiver's quality of life and mental and physical health status.

2.3.3.1 Caregiver Quality of Life

Several studies have examined the impact of caregiving on caregiver's quality of life (QOL) (Awadalla et al., 2005; Chen et al., 2004; Foldemo et al., 2005; Li et al., 2007). Again there have been inconsistent findings regarding the relationship between QOL and experience of burden, as well as the factors that are related to caregiver QOL. A range of different instruments such as the World Health Organisation Quality of Life Instrument and Quality of Life Index have been used to measure QOL, which may in part explain the inconsistent findings.

Despite this, the majority of studies have indicated that caring for a family member with schizophrenia is associated with decreased QOL, due to the time and energy spent in providing care. QOL has been found to be lower in caregivers of people with schizophrenia when compared to caregivers of people with major affective and anxiety disorders (Awadalla et al., 2005) and controls (Chen et al., 2004). Quality of life has been found to be positively associated with caregiver's knowledge about and beliefs regarding the cause of the illness (Chen et al., 2004), and inversely related to patient's negative symptoms (Rudnick & Kravetz, 2001), and caregivers' experiences of stigma (Katschnig, 2000). Social support was not found to impact on quality of life

(Rudnick & Kravetz, 2001). The most common finding is that QOL is related to gender, with women reporting lower scores, disease severity, subjective burden, relationship to patient (with parents reporting lower scores) and caregiver state of health (Awadalla et al., 2005; Li et al., 2007). Patient characteristics have been found to be unrelated to caregiver QOL. High QOL scores were associated with being married and with high levels of education. Other studies have indicated that patient and caregiver age are important indicators for quality of life, with younger caregivers and younger patients being associated with lower QOL in caregivers.

2.3.3.2 Caregiver mental health status

Caregiving also appears to impact on the mental health status of caregivers. High rates of depressive symptoms and psychological distress have been reported amongst caregivers, particularly caregivers who are younger in age and have lower levels of education, and those experiencing high levels of objective and subjective burden (Bibou-Nakou et al., 1997; Magaña, Ramírez García, Hernández & Cortez, 2007; Provencher et al., 2003). Depressive symptoms and poor psychological well-being are also associated with higher levels of patient positive symptoms (Chen et al., 2004; Magana et al., 2007), as well as caregivers' perceived experience of stigma. Experiences of mastery and coping strategies seem to mediate the relationship between burden and mental status; caregivers that were more passive in the role were found to experience more psychological distress.

2.3.3.3 Caregiver physical health

Exposure to chronic stress has been shown to impact on immune system functioning (Dyck et al., 1999). A study investigating the presence of infectious illness in caregivers found that patient positive symptoms (which typically accompany relapse) are predictive of the presence of infectious illness in caregivers, while increased social support predicts decreased episodes of infectious illness (Dyck et al., 1999). However, levels of caregiver burden were not found to be associated with infectious illness.

These findings have relevance for countries such as South Africa, where high rates of HIV/AIDS and TB result in a number of immuno-compromised caregivers.

2.3.4 Coping with caregiving

Factors that appear to be protective, and associated with greater QOL scores, include caregiver inner strength, extended family supports, positive appreciation of the patient and positive appraisal of the caregiver role. Other factors, such as experiences of mastery (the extent to which one sees one's life as under one's control as opposed to being externally controlled by factors such as fate and God) and active coping mechanisms such as seeking social support and being problem focused, have also been associated with greater coping (Bibou Nakou et al., 1997; McDonell et al., 2003). Strength of religious belief also appears to play an important role in helping family members to cope with the stress of caring for a mentally ill relative (Rammohan, Rao & Subbakrishna 2002) and provides a significant source of hope in challenging circumstances (Bland & Darlington, 2002).

A reduction of family burden over time has been found among relatives who adopted problem-focused strategies (such as seeking information and maintaining social interests) as opposed to emotion-focused coping strategies (including strategies such as avoidance of the patient, coercion and resignation), and among those who received more practical support from their social network (Magliano et al., 2000; Nehra, Chakrabarti, Kulhara & Sharma, 2005).

A qualitative study identified the role of hopefulness as a crucial part of the coping process, as it enabled caregivers to shift their view from the difficult present to a better future (Bland & Darlington, 2002). Hope also enables a balance against the loss experienced by families.

Other positive aspects of the caregiving experience have also been identified as important in coping with caregiving. These include a sense in the caregivers of learning life lessons, having feelings of love and care for the ill family member, feeling stronger as a result of the experience, feelings of fulfilment from duties, and increased self-knowledge (Bland & Darlington, 2002; Veltman et al., 2002). Perhaps the factor which has received the most support is the role of knowledge regarding the illness (Chen et al., 2004). Caregivers with knowledge of the illness, provided through

psychoeducation, have been shown to have better QOL and coping skills (Chen et al., 2004). This increase in knowledge is associated with decreased relapse and readmission rates, improved medication compliance and enhanced mental and physical health status of caregivers (Katschnig, 2000; Martens & Addington, 2001).

2.3.5 Caregiving in Sub – Saharan Africa.

The majority of countries in Sub-Saharan Africa face many challenges in terms of economic and social development (Wintersteen, Mupedziswa & Wintersteen, 1995), resulting in few community and social rehabilitation programs for people with psychiatric disabilities and their caregivers.

There are few studies examining the experience of caregivers in Sub-Saharan Africa. Those that have been conducted have taken place in Zimbabwe, Nigeria and South Africa. In Zimbabwe, families were found to bear the majority of the responsibility for family members with serious mental illness and were in need of more assistance from the government and NGOs in providing this care, such as information regarding the illness and how to manage behaviour, support groups and opportunities to discuss problems with professionals, (Wintersteen et al., 1995). Caregiving impacted on caregiver's health, emotional well-being, productivity and their standing in the community, perhaps as a result of stigma, discrimination and social isolation (Wintersteen et al., 1995). In Nigeria, caregivers of family members with schizophrenia reported significantly lower subjective quality of life than control participants (Abikoye, 2007).

There is a paucity of literature in the field of informal home based care in South Africa (Jeggels, 2006). A demographic report of caregivers in 2005 (Joubert, 2005 cited in Jeggels, 2006) indicated that 27% of the adult population provided informal home based care to a range of dependent persons, and that women were more likely to be the providers of this care. In South Africa, caregiving is gendered in that it is usually the women within the families who fulfil the role of caregiver (De la Rey & Eagle, 1997; Kritzinger & Magaqa, 2000). These women have been found to bear a

'double burden' of having to be the breadwinner as well as the caregiver (De la Rey & Eagle, 1997).

The HIV/AIDS pandemic in South Africa has led to an increase in literature regarding the impact on caregivers on caring for family members with HIV/AIDS (Akintola, 2006; Freeman & Nkomo, 2006). This literature has indicated that the informal caregivers are usually women who are poor, unemployed, and unmarried, who have to combine their caregiving role with homemaking and breadwinner roles (Akintola, 2006). These caregivers experience physical and emotional strain and are at risk for HIV and TB infection.

Although there has been little attention paid to psychiatric patients as a population vulnerable to HIV infection, many studies indicate high risk behaviour for contracting HIV/AIDS in psychiatric patients, especially patients with schizophrenia. The prevalence of HIV infection has also been found to be higher in psychiatric patients than in the general population. (Koen, Vuuren, Niehaus & Emsley, 2007; Grassi, 1996).

The concern of the burden of families due to lack of adequate services and support has been investigated in South Africa using qualitative and quantitative methodologies (Freeman et al., 1999; Hamber, 1997, cited in Thom, 2003). This burden includes financial strain, in some cases with a family member having to leave employment to care for the member with the mental illness, as well as a negative impact on social relationships with family members and friends (Freeman et al., 1999). Consequently, the task of care may be a particularly difficult one in households that are increasingly held responsible for monitoring the welfare of a psychiatrically impaired member, due to the policy of brief hospitalization and rapid deinstitutionalisation.

Finally, a qualitative study investigated caregiver experience of 25 carers living in rural areas in the Eastern Cape, the second largest province in South Africa and one of

the poorest (Kritzinger & Magaqa, 2000). Findings indicated that the majority of caregivers are women, either mothers or sisters of the mentally ill person. The impact the mental illness has on family relationships is disruptive and causes interpersonal problems. The behaviour of the person with the mental illness was described as violent and aggressive. Other problematic behaviours included being rude and wasteful, suicidal, monopolising their grant money, as well as the patient's withdrawing from social interaction. Caregivers also reported high levels of substance abuse, primarily cannabis and alcohol use. The role of the caregiver was found to include ensuring the patient's physical comfort and safety by observing their behaviour, problem solving and explaining their behaviour to others. Responsibilities included supervising medication and other forms of treatment including more traditional methods such as consultation with a traditional healer. Consequences of caregiving included exploitation of the caregiver by the patient as well as other people, social isolation, financial constraints and embarrassment when the patients engages in behaviours such as undressing and urinating in public. The research highlights the challenges and heavy burden faced by South African caregivers, and points out that these challenges are exacerbated by the context of extreme poverty that many of them live in. The importance of community based programs and support for these caregivers is highlighted.

The research that has been conducted in South Africa has indicated a considerable burden on family members caring for members with mental disorders and that this is a major obstacle to the effectiveness of the deinstitutionalisation process (Barnard, Gagiano & Joubert, 1998; Freeman et al., 1999; Hamber, 1997, cited in Thom, 2003). These studies have also indicated a need for an improvement in community based services to support families, as well as for research to inform family interventions and support programmes (Thom, 2003). The findings from other developing countries, where factors such as gender, education level, physical health and employment are associated with an increased burden of care, have implications for a country like South Africa with high levels of infectious illness such as HIV/AIDS and Tuberculosis and high levels of poverty and unemployment.

It is therefore important to explore the experiences of caregivers in South Africa in greater detail in order to understand the challenges they face in providing care, and to develop recommendations for addressing these.

University of Cape Town

CHAPTER THREE: METHODOLOGY

This chapter discusses the research aims and research design, as well as the sample, instruments, procedures, methods of analysis and ethical considerations.

3.1 Research aims

There is a paucity of data in South Africa regarding the experience of caring for a family member with schizophrenia, in the context of increased reliance on family members for care. The aim of the present exploratory study was to generate rich, descriptive data that explores the experiences of South African caregivers caring for a family member with schizophrenia, living in conditions of poverty. Of particular interest in this research was to explore the factors that present challenges to their capacity to care and the factors that facilitate coping. Given the lack of knowledge and data in this field, it is important to explore and generate themes in areas that will inform further study in the field. Exploratory and descriptive studies are useful when research is breaking new ground as they can yield new insights into a topic for research (Babbie, 1998).

3.2 Research design

A qualitative methodology was chosen to facilitate the emergence of data in this sparsely researched topic of caregiving for relatives with schizophrenia in South Africa. Although researchers accept 'burden' as an all-encompassing term, many caregivers in the literature reported positive and uplifting experiences, and hence the term 'care giving' is proposed. Qualitative research studies the subject's whole experience, relying on open questions and using inductive reasoning, whereas quantitative research measures only a part of a subject's experience, relying on closed questions and using deductive reasoning (Grant, 2001).

As mentioned previously, the research question was exploratory in nature. Therefore it was decided that a series of 10 qualitative case studies would be the most

appropriate method to address the research question and purpose. The reason for the selection of a case study design over other possible strategies was that case studies allow the collection of in-depth descriptive and exploratory data (Stake, 2000; Yin, 2003), and the establishment of rapport with participants. Case studies also allow flexibility to explore and uncover themes and issues related to the research question in depth and from multiple perspectives. This strategy also allows for flexibility in that theoretical propositions and hypotheses are developed at the beginning of the study to guide data collection and analysis, but the method also allows themes and areas to emerge that did not form part of the original propositions (Yin, 2003).

Case study methodology is utilised when the aim of the research is to provide an in-depth description of a small number of cases (less than 50) and the key research questions are exploratory or descriptive in nature (Mouton, 2001). In qualitative case studies, the researcher seeks a greater understanding of the case, and wants to appreciate the uniqueness and complexity of the case, including its embeddedness and interaction with its context. “We are interested in them [the cases] for both their uniqueness and their commonality. We seek to understand them. We would like to hear their stories” (Stake, 1995, p. 1).

There is some debate about whether case studies are a valid research design. Case study design has been criticised for being a weak method with insufficient precision, objectivity and rigour (Yin, 2003). Another criticism is that the method provides little basis for scientific generalisability (Mouton, 2001; Yin, 2003). Yin (2003) asserts that the case study method is a valid design in itself, provided rigorous procedures are followed throughout the process. These procedures must be followed from conceptualisation of the idea to reporting of the findings, in order to combat the above criticisms and minimise potential sources of error.

Stake (2005, p.443) refers to the use of case studies as “not a methodological choice but a choice of what is to be studied”. His view is that the case study should be used when the purpose of the research is to determine what can be learned from the case as opposed to generalising beyond it.

Although Yin (2003) believes that the findings from case studies may be generalised in certain circumstances, this was not the purpose of the present study but rather, as Stake (2005) asserts, to discover what can be learned from particular cases. The analysis of the descriptive case study design was based on the theory outlined in the literature review, which provides a framework against which similar or different patterns which emerge in the data can be compared. The findings were reported with the view of learning what was specific to the cases and identifying common themes within these cases as opposed to making an attempt to generalise from them. Although what is found is not generalisable to populations, it is generalisable to theory (Stake, 2000; Yin, 1994).

Main sources of error include potential bias of the researcher and lack of rigour in analysis (Mouton, 2001). Ways in which the validity of case studies can be increased include the use of multiple case study design (Yin, 2003), as was the case in this design, in order to allow the research to identify commonalities across multiple cases (Stake, 2000). Furthermore, potential bias of the researcher was addressed by the use of two interviewers.

3.3 Sample

“Case study research is not sampling research” (Stake, 1995, p. 4). Given the research purpose, the researcher needs to decide which cases are likely to lead to understanding in order to maximise what can be learned. The aim of the study was to explore the experiences of caregivers caring for a family member with schizophrenia, dependent on state mental health services, and therefore purposive sampling was used in the selection of the cases, i.e. cases were selected based on the purpose of the study (Stake, 2005). Purposive sampling is a type of non-probability sampling (Babbie, 1998) in which cases are selected on the basis that they fulfil certain characteristics or in some instances to obtain maximum variation (Gobo, 2004). The cases were selected in such a way as to build in some variety to the sample and give the opportunity for intensive study (Stake, 2005).

In order to explore different experiences in different geographical areas, sampling occurred in two locations in the Western Cape:

- Klipheuwel, a peri-urban community 20km from Durbanville
- different areas in Khayelitsha (Makhaza, Harare and Site B).

Klipheuwel is a low socio-economic area that consists of two types of housing. The two housing types are separated by a railway line. The one side consists of 141 formal houses fitted with pre-paid water and electricity meters (Smith, 2005) and the other of informal housing. The majority of people living in the area are either current or ex-employees of farms in the area.

Khayelitsha is a settlement located 30km from the central business district of Cape Town. Population estimates range widely from 350 000 to 900 000 (Dyantyi & Frater 2001 cited in Tomlinson, Swartz, Cooper & Moltano, 2004). The vast majority are migrants from the Transkei and Ciskei. The area consists of a mixture of housing types, including low cost housing and shacks (Xali, 2002).

In Klipheuwel, households were identified through patient files at the Durbanville day clinic. Households that were identified as having a member with schizophrenia were asked by the interviewer if they would like to participate in the study. As none of the households had access to telephones, all interviews were set up via home visits. As Klipheuwel is approximately 20km from the nearest town, all participants elected to have the interviews take place in their homes. This was useful as it gave the interviewer an opportunity to observe the household.

Three households were selected from Klipheuwel, as only three patients were identified from clinic files. For this reason, a decision was made to include all three households even if the household income was slightly higher than the cut-off amount originally set out in the inclusion criteria (see below).

The second area from which cases were selected was Khayelitsha. Households were selected from three areas within Khayelitsha; namely Harare, Makhaza and Site B. In Khayelitsha, one of the interviewers had facilitated a support group for people with schizophrenia. If participants were being cared for by their families and if these households met the inclusion criteria, the families were asked if they would like to participate in the study. If they agreed, an interview was set up at a venue of their choice. Similarly to Klipheuwel, in all cases households chose for the interviews to be conducted at their homes.

In total 10 families were selected to participate (three from Klipheuwel, the rest from Khayelitsha) on the basis that they fulfilled the following inclusion criteria:

- have a combined household income of less than R4000 per month
- be caring for a member with schizophrenia
- the member with schizophrenia is being treated in the state mental health service

These inclusion criteria were chosen in order to select a sample that would be appropriate to the research question.

The table below outlines the demographics of the sample.

Table 1

Demographics of the Sample

Participant	Race	Relationship to patient	Age	Education Level	Marital status	Language	Occupation/source of income
F	Coloured	Wife	47	Std 4	Married	Afrikaans	Cook Disability grant
R	Coloured	Husband	45	Std 8	Married	Afrikaans	Driver
D	Coloured	Parent	70	Std 2	Married	Afrikaans	Unemployed Disability grant
N	Black	Niece	14	Std 7	Single	Xhosa	Unemployed Disability grant
P	Black	Wife	45	Std 5	Married	Xhosa	Domestic worker Disability grant
A*	Black	Aunt/uncle	51	Std 6	Married	Xhosa	Domestic worker/driver – unemployed Disability grant
C	Black	Mother	54	Std 4	Widow	Xhosa	Domestic worker
D	Black	Mother	68	Std 3	Widow	Xhosa	Unemployed Disability grant
R	Black	Mother	67	Std 5	Widow	Xhosa	Unemployed Disability grant
H	Black	Sister	38	Std 7	Single	Xhosa	Domestic worker Disability grant

*primary caregiver alternates depending on employment

Nine of the people with schizophrenia lived in the same house as the caregiver. The one that did not lived on the property in a small shack. Six of the caregivers were also taking care of other dependents. These included their own family members who needed extra care (one was caring for a son with epilepsy, another for a daughter who had suffered from TB meningitis as a child and suffered brain damage), as well as the children of other family members whose parents had passed away or were ill and unable to provide adequate care.

The clinics that were attended by the household members with mental disorders included Durbanville day clinic (N=3), Site B day hospital in Khayelitsha (N=2) and Michael Mapongwana clinic in Harare, Khayelitsha (N=5). Members visit the clinic once a month to collect their medication. Should they relapse they may be admitted to the state psychiatric hospital which serves the area. Lentegeur psychiatric hospital serves Khayelitsha and Stikland psychiatric hospital serves Klipheuwel.

Nine of the family members had been diagnosed with schizophrenia for just over six years, although in three cases the time they had been experiencing symptoms may have been longer but they were only diagnosed when arriving in the Western Cape. One had experienced his first psychotic episode just over a year ago at the time of the interviews.

3.4 Instrument

Data were collected by means of a series of semi-structured interviews which consisted of open-ended questions in order to obtain a large amount of in-depth data from each household. The open-ended questions also gave the opportunity for responses to arise that were unexpected and did not form part of the original hypotheses. This methodology also gave the interviewers the freedom to explore views and opinions in more depth if appropriate. Yin (2003) states that during an interview, the researcher will pursue a consistent line of enquiry but the actual questions are more fluid than rigid. The purpose of the research was to identify as

many themes as possible in relation to the topic at hand and therefore this methodology seemed the most appropriate in addressing this purpose.

The interview schedule consisted of a number of focused questions to elicit demographic information, followed by opened ended questions designed to encourage free expression and to generate responses related to psychosocial, financial, and coping issues. In order to allow caregiving experiences to emerge spontaneously, open ended questions were initially asked about the participants' experience, such as "tell me about your experience of caring for X." Caregivers were also asked more detailed and focused questions about challenges they faced in providing care, what enabled them to cope with caregiving, their experiences of mental health services, and the impact on the rest of the family. See Appendix A for the interview schedule.

3.5 Procedure

The first household identified in Klipheuwel served as a pilot study. The researcher (1st language English, 2nd language Afrikaans) and a co-interviewer (1st language Xhosa, 3rd language Afrikaans) visited the household and conducted interviews in Afrikaans (the household's first language). The interviews varied from half an hour to approximately one hour. Following this pilot case study, some changes to the interview format were made.

The remaining households in Klipheuwel were also interviewed for approximately one hour on average. The caregiver was identified as the member most involved in the care of the person with schizophrenia. This was established by asking family members who they thought the person that fulfilled this role was. The researcher then asked specific questions to clarify. At the beginning of the interview, the consent form was discussed with participants and signed. Any questions regarding the nature of the study and their involvement in it were answered. During the interviews, the data was captured using a digital recorder. During the interviews with participants whose first language was Xhosa, the co-interviewer provided translation between participants and

researcher. Both interviewers had experience and training in interviewing and data collection. The co-interviewer had experience as a translator and was a qualified auxiliary social worker. Observations were recorded using carefully dated and thorough field notes. The interviews were transcribed from the recorded voice files by experienced bilingual transcribers.

3.6 Method of analysis

The caregivers' interviews were analysed using analytic techniques from grounded theory (Corbin, 1986; Strauss & Corbin, 1998) in order to generate ideas and theory that are 'grounded' in the data. This inductive approach enables ideas or theories to be generated from the data rather than a process of testing already formed hypotheses, minimising the chance of the researcher just having their initial impressions confirmed (Mason, 1996).

The analysis consisted of coding the interview transcripts into categories. Initially four transcripts were analysed and each unit of analysis (phrase in the text) was assigned a code in order to assign meaning to the data (first-order categories). This list of codes was then used as a framework for coding the remaining six interviews, through the process of constant comparison of similarities and differences (Corbin, 1986). The first-order categories were then connected together conceptually into higher order categories (Swanson, 1986). These themes and patterns were then compared and contrasted with the related literature, thus making use of the literature inductively (Creswell, 1992).

3.7 Ethical considerations

Ethical clearance was granted by the Human Sciences Research Council's Ethics Committee and by the Ethics Committee of the University of Cape Town Psychology Department.

Issues of informed consent were dealt with by participants signing a consent form (see Appendix B) which was in their home language and it stated the nature of the study and what would be expected from them, should they agree to participate. The forms were read to participants who were not able to read the forms themselves and any questions were answered by the interviewers. Participants gave consent to participate in the interviews and for the interviews to be recorded. An awareness of the issues surrounding conducting research with disempowered participants ensured that extra care was taken when discussing with participants their decision to take part in the study. The lack of repercussions if they decided not to participate was emphasised.

Participants were informed that the material may be evocative, that they may choose not to answer questions that they did not feel comfortable answering and that they may stop the interview at any time. It was also agreed that any participant that was identified by the researcher as experiencing distress would be referred to the relevant mental health services, such as Cape Mental Health. Information was also given regarding other professional services where relevant.

Issues of confidentiality were addressed by the use of pseudonyms and the data were password protected.

Permission to conduct the studies was obtained from the relevant authorities, namely the Department of Health Director in charge of clinics in Khayelitsha and Durbanville.

CHAPTER FOUR: RESULTS AND DISCUSSION

This chapter presents the themes which emerged from the analysis of caregivers' interviews and relates these to the theory and empirical findings presented in the literature review. Twenty two high order categories emerged during analysis, which could be grouped into six broad themes (see Table 2 below). These were: assistance with activities of daily living, involvement with illness management, knowledge of illness, consequences of caregiving, coping with caregiving, and the impact of poverty on caregiving. Following the table will be a more in-depth discussion of the findings.

Table 2

Categories elicited from analysis

Category name	Sample quote
Assistance with activities of daily living	
1. Assisting with and supervising household chores	<p>"I have to help him make his bed and do his washing". (M)</p> <p>"I have to remind him and make sure that he keeps going and finishes what he started." (F)</p>
2. Assisting with financial management	<p>"I handle mine and M's [person with mental illness]." (M)</p> <p>"I take care of his disability money. I help him collect it and decide what should be done with it." (D)</p>
Involvement in managing illness	
3. Monitoring behaviour and attempts to prevent relapse	<p>"The thing is one has to check the progress, take note and notice such factors, on the unnaturalness of him to wake up and immediately go to sleep again." (M)</p> <p>"I watch to see that he keeps going ok. I know what to look for now to give me a clue that he</p>

	gets sick again.” (P)
4. Educating others regarding illness and behaviour	<p>“We told them what was happening to him and what to expect. At first they did not understand why he was behaving strangely. Now they accept it”. (A)</p> <p>“I try to tell the family everything I learn about his illness. They all seem to be ok with it now they understand why he sometimes does the things he does.” (P)</p>
5. Involvement in medication management and monitoring side effects	<p>“I used to give him myself before but now he takes them on his own. I’ll show him so that he makes sure on how many he should take.” (M)</p> <p>“He remembers most of the time but there are times I must remind him. I must say he’s much better this year in terms of taking care of himself.” (D)</p>
6. Involvement with traditional treatment methods	<p>“We take him to the witchdoctor at times. But when he is sick it is best for him to go to Lentegeur; that is how he gets better.” (A)</p> <p>“We sometimes give him traditional medicine but he also keeps taking the treatment from the day hospital.” (D)</p>
7. Supervising and attending clinic appointments	<p>“We go together to get the pills.” (M)</p> <p>“I go with her to get her pills every month. I worry that she will not be able to manage if I don’t go with her.” (N)</p>
8. Challenges accessing services	<p>“They freeze completely, and the psychiatric patients get nervous and leave.” (R)</p> <p>“Some people go there around 4 and 5 am, and wait outside the gate, in the rain and in the cold. They stand in long queues.” (A)</p>
9. Concerns regarding ability to protect against harm and stigma	<p>“I do often ask if anyone or perhaps the children hurt him when I’m not around and</p>

	<p>he'll say no." (H)</p> <p>"So that's what I fear the most because one could get severely injured when they get sick." (P)</p>
Knowledge of illness	
10. Beliefs regarding cause of illness	<p>"It's amafufufunyana. We know someone inflicted him with it because he would see them calling him." (D)</p> <p>"The doctors said he smoked dagga and his system could not handle it." (A)</p>
11. Beliefs regarding reasons for relapse	<p>"It is such substances like dagga that cause one not to have common sense, because the mind goes backwards." (D)</p> <p>"That's usually what bothers him the most because he really is a caring person. He gets sick when his grant gets stopped." (E)</p>
Consequences of caregiving	
12. Impact on physical and mental health	<p>"Because he would run away from taking his injection and stress me out to a point of getting asthma attacks. I ended up that way and am on treatment." (D)</p> <p>"I struggle and worry a lot about him. It distresses me and I am tired all the time. I am very overwhelmed." (H)</p>
13. Mourning and needing to adjust expectations after first psychotic episode	<p>"I was completely shocked because he was very clever at school. I was in a complete shock... I'm the one who was supposed to be in hospital from being shocked." (C)</p> <p>"That broke my heart. I was convinced I was going to get sick as well because I had nerves all the time. I dreamt that he was going to be somebody. I thought he would study and be successful at school, I worked so hard for his</p>

	success." (D).
Coping with caregiving	
14. Social support in coping and managing behaviours	<p>"I go to church on Sundays. I usually talk to other women at church." (A).</p> <p>"My sister's husband would come over to assist me, more especially problems that men particularly can deal with. He's able to show us how to handle problems such as when he [the patient] refuses to go to the witchdoctors." (D)</p>
15. Role of religion	<p>"If I think about it now, I can just say, thank you lord for giving us the strength to get through this. Thank you for helping us to get through every day." (R)</p> <p>"I said to the Lord, thank you for this child, I'm talking from my heart. I belong to the Apostolic faith." (E)</p>
16. Impact of knowledge	<p>"They do understand as well about his illness. In the beginning, when he started getting ill, they were very worried too. But they do understand now about his illness. They say nothing about it and they also don't ask any questions."(F)</p>
17. Burden decreases with time	<p>"In the beginning, I was under a lot more pressure because he was very sick a lot more than he is now. I had my hands full then and it gave me a lot of stress. But he is a little better now". (F)</p> <p>"No, he's not as aggressive as he was before. Once he gets aggressive I go to the clinic, there they call the police and ask them to talk to him nicely and let him know that he has to go to the day hospital, where he then gets referred to Lentergeur." (D)</p>

18. Patient experienced as valued and loved family member	
Impact of poverty on caregiving	
19. Decreased opportunities for supervision	<p>“Yes, I have to remind him. But often I’m not here, like I’ve worked night shift this week, and there are many evenings that he doesn’t take his tablets because he forgets.” (F)</p> <p>“I can’t hide the fact that he’s mentally ill within the community because I might not be around when he relapses.” (H)</p>
20. Impact on employment	<p>“At times I have to miss work to take him to the clinic when he gets sick. It is hard as my employer understands but I then get less money for the money. We struggle as it is.” (P)</p> <p>“Yes, there are times when I stay at home as I am worried to leave him like that. I worry that he will get hurt if he leaves the house and does something.” (H)</p>
21. Caregiver financial stress	<p>“The other worrying thing is my husband who does not work, because we have children whose school fees we cannot afford. When the month ends I always have to buy groceries because children are wasteful, by the time the month ends everything is finished and I have to start from scratch.’ (A)</p> <p>“Terrible because all the money goes there and leaves us with little to eat here at home. Having to pay for rent and services takes out a lot of money and leaves us with a shortage here at home.” (D)</p>
22. Role of the disability grant	<p>“We had no money. We had to go and ask other people for food. It’s not nice when the food cupboard is bare. We had to wait for his money [disability grant] to come so that we</p>

	<p>could go out and buy our own food again.” (E)</p> <p>“We struggled (when the grant was suspended) because the money that I earn on its own is very little. We struggled but we tried to make do with what was available.” (H)</p>
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Section 4.1 below presents an expanded discussion of the table, with reference to the findings in the literature.

4.1 Assistance with activities of daily living

Caregivers described a range of practical tasks that they were involved in to assist the family member with schizophrenia on a day to day basis.

4.1.1 Assisting with household chores

Eight of the ten caregivers reported that they assisted the person with mental illness in daily household chores, such as cooking, washing their clothes and tidying the house. The amount of input needed varied from needing to do the chores themselves, supervising and providing instruction while the person with mental illness completed their tasks, to reminding and motivating the family member. None of the households reported having difficulties with the person’s hygiene.

“He’s able to now [help with activities of daily living] at least. He prefers to get told what to do slowly because he takes his time to do anything, even with food, he does the same. He does his laundry but not thoroughly..... His meal must be ready made for him to warm up. I do most of the cleaning because I’m still training them [grandchildren] now.” (D)

“I have to help him make his bed and do his washing. Sometimes are better than others. For example, now he does his bed himself, before I had to help him. He would keep forgetting what he was doing and go back to bed”. (M)

“I do the bulk of the work. He needs to be reminded to do things sometimes.” (F)

“Ja, and this one doesn't help with the housework! I have do help him with everything.” (E)

The need for assistance with these activities was in most cases understood to be the result of the illness and not related to personality traits of the family member with schizophrenia.

“I have to remind him and make sure that he keeps going and finishes what he started. He never used to be this way.” (F)

“He is a helpful and caring guy. It is his illness that makes him struggle to do the things at times.” (A)

Six of these caregivers did not feel that assisting the person with mental illness in daily chores contributed to their overall level of burden. Three described feeling that it was part of their responsibility, as housewife or mother, to help with these tasks. The other two (of the eight) did not mention whether these tasks impacted on their level of burden.

“That part [assisting with activities of daily living] isn't the problem at all. I often just say to myself, you've got to do it because you are the housewife. I

must see to it that it gets done; it's my duty to do the housework. I must just do it." (F)

"He is my son. I must help take care of him. It doesn't make me stressed." (M)

"I don't feel stressed helping him with these things. He tries to do what he can." (D)

"It is not a problem for me to do these things to help my aunt." (N)

The caregivers had found many ways to alleviate the burden on themselves such as involving nuclear and extended family members in helping with household chores. Seven reported being helped with tasks by family members.

"They even fix food for him when I'm not around..... I never have to worry about him being taken care of, because they look after each other." (M)

"Yes they do [help with chores], the little one has to get followed though." (A)

"Ja, I really do the bulk of the work. But when I'm working night shift I'll ask A [daughter] to prepare the supper for them." (F)

"Yes, they have turns and days to wash dishes. Everyone has a task." (C)

These findings are contrary to those found consistently across previous studies, which indicate that assistance with activities such as cooking and cleaning contributed to the level of burden experienced by caregivers (Baronet, 1999). This difference may in

part be explained by the meaning making process caregivers engage in, such as being part of their role, as well as the presence of family support with daily activities.

4.1.2 Involvement in financial management

Six of the caregivers reported involvement in taking care of the patient's financial matters. In four cases, this involved collecting and administering the grant money, and in two cases this involved assistance with applying for, and the administration regarding, renewal of the grant. In all six cases, the patient gave their grant money to their caregivers for them to decide how this money was dispensed.

"I handle mine and M's [person with mental illness]." (M)

"I take care of his disability money. I help him collect it and decide what should be done with it." (D)

"I handle the money matters in the house. My husband gets his grant money and gives it to me. Then I have to make sure there is enough for school fees and other things." (P)

"I take my money and his (husband with schizophrenia) and organise our bills. It is stressful as there is never enough" (F)

"Every month when he receives his money from the government, he comes and he gives it to me. He gives me all the money." (E)

With the exception of one caregiver, all had control of the finances of the person with the mental illness. The one who did not was given a monthly amount by the patient to contribute to the household expenses.

The caregivers who were wives experienced this as stressful as it was not a role that they were accustomed to. They also felt that they needed to include their husbands in the decisions but not enough for him to become stressed. They needed to balance his involvement in an attempt to allow him to still feel like the man of the house.

“I’m the one who has to think ahead [with finances]. I’m really thinking for him as well. But he is the man of the home and I must make sure that he still feels that way.” (F)

“I struggle with doing the money, it is not something I was used to. But I also try to involve him a bit to make him still be like he is in charge.” (P)

These findings are contrary to previous research findings in South Africa (Kritzinger & Magaqa, 2000) and elsewhere (Veltman et al., 2002) where patients have been found to monopolise their grant money.

The majority of caregivers were therefore involved in some form of assistance with activities of daily living. This is consistent with findings reported in the literature, where people with schizophrenia struggle to cope with these kinds of activities and often require assistance with the most basic of tasks, such as self care and financial matters. The need to provide assistance in these kinds of tasks has been established in the literature and found to be related to the caregiver’s experience of objective burden (Baronet, 1999). However, the caregivers in the current study did not seem to find this burdensome. Factors that appear to alleviate their burden include enlisting assistance from family members with daily tasks as well as an understanding that the person’s difficulties were the result of their illness. This understanding of the negative symptoms as part of the illness stands in contrast to findings in the literature where positive symptoms are more easily understood as part of the illness and negative symptoms more likely to be attributed to personality characteristics (Lowyck et al., 2001).

4.2 Involvement in managing illness

4.2.1 Educating others regarding illness and behaviour

Three of the caregivers described how they had explained to their family members their understanding of schizophrenia and the meaning of their family member's symptoms and behaviour.

"They do understand as well about his illness. In the beginning, when he started getting ill, they were very worried too. But they do understand now about his illness. They say nothing about it and they also don't ask any questions." (F)

"We told them what was happening to him and what to expect. At first they did not understand why he was behaving strangely. Now they accept it". (A)

"I try to tell the family everything I learn about his illness. They all seem to be ok with it now they understand why he sometimes does the things he does." (P)

These caregivers had been given this information by the nursing staff at the day hospital which they attended. This played a role in containing the other family members and decreasing their levels of fear and worry, by understanding what was happening. The adoption of this role of educator by the caregiver has been found in other studies in South Africa (Kritzinger & Magaqa, 2000). Psychoeducation has been proved to be a valuable intervention in addressing family burden and to increase coping. This will be discussed further in the section on knowledge of illness.

4.2.2 Monitoring behaviour and attempts to prevent relapse

Eight caregivers described a heightened sense of awareness of the patient's behaviour and observed any changes in order to detect signs of relapse.

"This time around he said he won't eat meat because he doesn't want to abuse animals, so that day the food prepared was meat and rice, so he went to the kitchen and asked the person who was cooking not to give him meat with his meal. That's when I noticed that he was getting sick." (F)

"The thing is one has to check the progress, take note and notice such factors, on the unnaturalness of him to wake up and immediately go to sleep again." (M)

"I watch to see that he keeps going ok. I know what to look for now to give me a clue that he gets sick again." (P)

"At times I notice he doesn't sleep until 4 am in the morning. That usually happens when he doesn't take his treatment. He gets up and becomes restless." (D)

All caregivers described attempts to decrease the chances of relapse in their family members. There were a number of different ways in which they did this. Five caregivers described attempting to shield the patient from family problems, fights and financial worries in order to decrease the stress they experienced and therefore decrease the possibility of relapse.

"We never really disclose anything about water to him as it is my responsibility. We can't afford to make him stressed." (A)

“It really is stressful. I sometimes ask him not to let it get to him because I know that when he gets stressed, he’ll get sick. I usually try and find a solution and avoid asking him for help and involving him in such issues.” (P)

“We can’t afford to hurt her because she will end up going to Lentergeur and leave us here all alone.” (N)

“I don’t disclose everything to him because I know he easily gets hurt. For instance, I took him from Nyanga East to live here with me in order to ease him of his current burdens. He still has responsibilities back in Nyanga because he is responsible for the rent since the others don’t bother paying. So I relieve him of such duties here and encourage him to look after himself instead.” (H)

“It’s in his nature to get hurt when he can’t do something for someone in need. He’s been like this before he even got sick. When he can assist even in my bus fare, he’s capable of giving up all he has in order to rescue me. He’s naturally a very kind person, so I don’t like disclosing everything to him.” (F)

Two caregivers attempted to monitor their son’s involvement with people who were supplying him with cannabis. These caregivers noticed the impact that smoking cannabis had on the patient’s mental status.

“We try to keep him away from those skollies. They force him to smoke and that makes him ill.” (D)

“There are a lot of people that encourage him to smoke. When he hangs around with his friends and says he feels like smoking they encourage him and say it will make him better. He doesn’t know what to say because they swear

at him. I try to make him meet new friends and go to church so that he doesn't see those people.” (E)

The concern by caregivers regarding the use of substances and the implications of this on the person's mental status, particularly the increase of aggression, has been previously noted in the South African literature (Kritzinger & Magaqa, 2000). The concern in this study, however, did not relate to an increase in the patient's aggressive behaviour and the consequent fear of the caregiver for the safety of themselves and others, but rather their understanding of how this leads to relapse and disorganisation of their behaviour.

These caregivers therefore attempt to shield their family member from stress but in the process appear to absorb this stress and take on more responsibilities. Caregivers have been described in the international literature as having to be 'on duty' all the time in their efforts to monitor and manage their family member's symptoms (Ohaeri, 2002).

4.2.3 Involvement in medication management and monitoring side effects

Nine of the caregivers were involved in management of medication to various degrees. Their involvement also changed over time. Some needed to remind and supervise the medication routine while others only had to occasionally remind the person.

“I used to give him myself before but now he takes them on his own. I'll show him so that he makes sure on how many he should take.” (M)

“He remembers most of the time but there are times I must remind him. I must say he's much better this year in terms of taking care of himself.” (D)

“He needs to be reminded and told how many to take.” (F)

“She usually remembers but I always check and there are times she has forgotten.” (R)

Three caregivers described how their children would assist with supervision and reminding the patient to take their medication.

“.....and they [the children] make sure he takes his medication.” (M)

“When I’m at work the younger one will make sure that he takes his tablets.” (P)

Three caregivers described monitoring for the presence of side effects.

“During the day after he wakes up and after breakfast, he’d immediately go back to sleep. I thought something is happening with these pills! He used to take 3 in the morning, then I made him reduce them to 2..... They once said so at Site B, that often they fall asleep after taking the pills, in which case they should be reduced. The other one said they hold the tongue and make it difficult to speak.” (M)

“You see at times when the medication is too much there’s a lot of side effects, some get the shakes.” (R)

I must see that there is nothing wrong with him when he takes his tablets. If there is then he stops taking his pills and gets sick.” (E)

Only one caregiver was not involved in medication administration. This was the combined effect of the functional level of her son as well as long work hours which did not allow her to perform this supervisory role.

“At least he takes his own medication and goes to the clinic himself. He takes his medication with interest. I am glad of this because even if he didn't there is not much I could do to help as I am often not here.” (C)

Thus these caregivers play an important role in medication compliance, a role that has been well documented in the international literature (Ohaeri, 2002). The caregivers in this study are therefore involved directly in the treatment and management of their family member's illness.

4.2.4 Involvement with traditional treatment methods

Three caregivers from Khayelitsha reported having enlisted the assistance of traditional healers as part of their treatment plan. This was combined with more conventional methods such as medication and hospitalisation.

“We take him to the witchdoctor at times. But when he is sick it is best for him to go to Lentegur, that is how he gets better.” (A)

“We sometimes give him traditional medicine but he also keeps taking the treatment from the day hospital.” (D)

Thus caregivers seem to straddle two treatment modalities and understandings of treatment; both traditional and western. This use of a combination of treatments is consistent with previous findings in South Africa (Kritzinger & Magaqa, 2000).

4.2.5 Supervising and attending clinic appointments

Six participants reported attending their family member's monthly clinic appointments with them. The reasons for this ranged from their concern over the member's ability to manage, to needing to ensure that they did not become inpatient with the queues and leave before collecting their medication.

"We go together to get the pills." (M)

"I go with her to get her pills every month. I worry that she will not be able to manage if I don't go with her." (N)

"He needs to be supervised for his clinic visits, otherwise he just wanders off." (A)

"If he goes alone he gets impatient and leaves before he has collected his treatment." (D)

One caregiver described an elaborate strategy to ensure that her son collected his medication.

"When it's his date, I usually wake up early and put his folder there and say I've gone to look for him so that by the time he goes there he's first on the list." (D)

Again, this need to supervise treatment appointments has been described in the literature. This proves disruptive for employment, with many caregivers describing having to miss many days of work to be involved in treatment, something that can be distressing for caregivers (Ricard et al., 1999). This will be discussed further in the section regarding the impact of poverty.

4.2.6 Challenges accessing services

Six of the caregivers described challenges accessing state services and professional support at different points in the process. Four described the challenges they faced when collecting medication from the day hospitals on a monthly basis. These included long queues and waiting times, problems related to safety, and poor management. At one clinic it was reported that patients needed to queue outside from as early as 4am in order to be seen. Here they would be exposed to cold and risk being mugged and attacked.

“They freeze completely, and the psychiatric patients get nervous and leave.”
(R)

“Some people go there around 4 and 5 am, and wait outside the gate, in the rain and in the cold. They stand in long queues. The reason for that is to get medication early because sometimes people get sent back home and get told to come the next day. At 7 am they open the gates to get inside the yard, then at 8am the door to the clinic gets open. The problem is not opening the gates around 5am or 6 am. It would be better if people could be inside the premises because there’s a shelter there and one people would feel safe when it rains for instance. There is no safety outside.” (A)

“They sometimes have to go very early while it’s still dark and I don’t like that. Perhaps they should have their own section at the clinic, because sometimes they probably get tired of standing in the queue in the dark. At that time they leave home without having had a meal. Having to leave home to get to Harare or Michael Mapongwana by 5 o’clock is too early. So they stand there the whole day and come home around 3 o’clock.” (P)

“When I went to fetch your [person with schizophrenia] medication the other day, criminals were collecting jewellery from people because they were queuing outside the premises.” (N)

Two caregivers reported incidents where they had felt that their family member needed inpatient care in order to recover and had struggled to access the state support they needed for this to happen. For the one, the staff at the day hospital refused to have the family member admitted, reportedly as he was not behaving violently or aggressively.

“It was on his fifth day [of not eating] when I took him again to the day hospital. At the day hospital they said he is alright because he was not a threat to bodily harm [not aggressive]. He didn’t try to beat anyone up and committed no offence. I asked what they meant by he’s alright and whether his sickness was determined by being violent. They insisted it was only a matter of refusing to eat and therefore he is alright.” (A)

This caregiver felt that being admitted was the only way for the patient to recover once he had relapsed.

The second caregiver reported having difficulties getting the police to assist her with the patient when he relapsed.

“The other problem is that when these people start getting sick, they get violent and no one really wants to take action. The police don’t take action, these are the kinds of problems I have. It gets difficult for one to have control over him until someone he is able to listen to comes around; someone to tell him that he has to go to hospital. It’s really hard when the police and community members distance themselves in such situations.” (H)

This was the only caregiver who reported difficulties with the police; however she was the only participant who did not have access to other forms of assistance when

the person had relapsed and was refusing admission. One other caregiver reported receiving assistance from the police.

“He would run away and police would come fetch him and take him through to Lentergeur.” (D)

Others caregivers did not report having difficulties with their family members refusing admission and were therefore not in need of support from the police.

This sense of having to ‘fight the system’ in order to access care has been described in previous studies (Veltman et al., 2002). These challenges seem to add extra effort to the caregiving experience. However, the extent of difficulties described by some of these caregivers in accessing the most basic of services has not been cited as a significant contributor to the burden experienced in many studies. Thus this may be an added stressor for caregivers, in the context of mental health policy changes and poor community support structures.

4.2.7 Concerns regarding ability to protect against harm and stigma

Four caregivers reported concerns regarding their ability to protect their family member against being harmed as a consequence of their behavior being misinterpreted by others or against experiences of stigma. They expressed concerns about the way the family member was treated in the community. Two caregivers reported being selective regarding who they told about the patient’s illness in order to prevent them being stigmatized.

“Many people don’t know what illness he’s suffering from – but then there are many people who do know because I made them aware of it. It’s mainly the people from the church. Well, I didn’t tell everybody; it’s more his brother who is a pastor in the church. He knows about it – and so does his wife. But the rest of the people don’t really know about his illness.” (F)

I do often ask if anyone or perhaps the children hurt him when I'm not around and he'll say no." (H)

"The people around this community have never seen him sick before..... I can't hide the fact that he's mentally ill within the community because I might not be around when he relapses. Lately he has a tendency of taking his clothes off; he would for example leave his pants in the loo and stand at the gate or inside the house naked. Some people view him in a different manner and misinterpret his behaviour as him maybe wanting to rape their children." (H)

So that's what I fear the most because one could get severely injured when they get sick." (P)

"He took his pants off showed us his penis stating that he is a man and therefore had never been hospitalized. He may have misinterpreted our question because of his state and thought that we were asking if he was circumcised at the hospital or not. People would therefore misinterpret such situations." (H)

"Some people view him in a different manner and misinterpret his behaviour." (H)

Contrary to previous findings, these caregivers did not report experiences of 'stigma by association' (Ostman & Kjellin, 2002). The primary concern of these caregivers was attempting to limit their family members' exposure to teasing, ridicule and possible danger when their behaviour was misunderstood. Caregivers' lack of disclosure to family and friends has been described as a strategy to protect against this (Magana et al., 2007). Experience of stigma and misunderstanding of behaviour of

people with mental illnesses is well established as a common occurrence in the international literature (Phillips et al., 2002).

4.3 Knowledge of illness

4.3.1 Causative beliefs

Three of the caregivers reported traditional understandings of the cause of the behaviour. They felt that it was amafufunyana, which is a serious disorder described amongst Xhosa and Zulu countries which results from possession by evil spirits (Swartz, 1998).

“It’s amafufunyana. We know someone inflicted him with it because he would see them calling him.” (D)

“You see, this guy was alright until 1991. We were staying in Site B. He started by going to Site C with some other guy, when they came back, he said there’s something wrong with him. We thought perhaps he started seeing things and assumed it was the bad spirits. We then took him to a witchdoctor where it became evident that certain potions were excessively used on him as a result he was losing power.” (A)

Four caregivers reported more psychosocial explanations. Two of the caregivers made use of both traditional and psychosocial explanations in their understandings.

“The doctors said he smoked dagga and his system could not handle it. We also think this, but he has also been bewitched”. (A)

“It was the stress that made her sick because her husband left her and broke her heart.” (N)

“He became ill because there was too much for him to handle. His mind couldn’t take it anymore.” (F)

Four caregivers did not have causative explanations or reported vague explanations.

“But no one in this house can say what the illness is. I also don’t know what the illness is.” (E)

“I don’t understand why it happened to begin with.” (H)

“I don’t know what made him the way he is”. (C)

“I have no idea because there was nothing wrong with him when he left for Jo’burg, and came back sick and quite sleepy, he always covered himself and claimed to have flu or a headache. The doctor there said he had bumped his head onto something and that caused a disturbance, there’s no damage though. He asked if he ever got beaten up or something and I said I do not know. It may have happened in Jo’burg and no one may have noticed and he didn’t tell us anything.” (M)

Finally, one caregiver regarded the role of genes in the causation.

“I think it is in her genes as her aunt and grandfather also had what she has.” (R)

Thus caregivers reported a mixture of traditional, psychosocial and biological explanations for the symptoms their family member was displaying. These understandings impacted on the kinds of treatment caregivers initially sought. The

impact of knowledge for caregivers will be more fully discussed in a later section. However, as mentioned in the section regarding use of traditional treatments, caregivers who believed in traditional causes still made use of conventional treatment modalities in addition to traditional ones.

In the international literature, psychosocial stressors are the most commonly cited beliefs about causes with the exception of sub-Saharan Africa where supernatural causation predominates, followed by beliefs of heredity ranging from 9-17% across cultures (Ohaeri, 2002).

4.3.2 Beliefs regarding reasons for relapse

Two of the caregivers believed that smoking cannabis contributed to the patient relapsing as well as the experience of stress.

“Taking drugs, because such substances undermine one’s mind and make them believe they can do this and that. It is such substances like dagga that cause one not to have common sense, because the mind goes backwards.” (D)

Four described the role of stress in their beliefs around reasons for relapse.

“That’s usually what bothers him the most because he really is a caring person. He gets sick when his grant gets stopped.” (E)

“Yes, when she’s stressed then she gets sick.” (R)

Finally, medication was acknowledged by five caregivers to play an important role in preventing relapse.

“.....and if she stops the tablets. That is why she has to stay on the tablets.”

(R)

“Not getting treatment would cause a relapse, I noticed that when I went over to him in Transkei, as well as poverty, not knowing what to eat.” (M)

“I personally cannot put my finger on it, because at times he wakes up not being himself even if nothing had disturbed him, so it’s hard to say... But since he now takes his medication regularly, he’s fine, but as soon as the treatment gets finished he relapses.” (F)

All of these caregivers had their own understandings of the factors related to relapse, despite some of them not understanding the reasons for the development of the illness. Smoking cannabis, exposure to stressful circumstances and medication compliance have all be shown to play a role in relapse (Agarwal, Sharma, Kishore Kumar & Lowe, 1998; Bergen, Hunt, Armitage, & Bashir, 1998).

4.4 Consequences of caregiving

4.4.1 Impact on physical and mental health

Only three caregivers described experiencing either poor physical and poor mental health which they attributed to their caregiving role.

One of the three described experiencing poor physical health which she attributed to the stress of caring for the patient.

“Because he would run away from taking his injection and stress me out to a point of getting asthma attacks. I ended up that way and am on treatment.”

(D)

Two of the three became very tearful in the interview when speaking about the impact of caregiving. They expressed feeling alone in the task and feeling overwhelmed and overburdened. Both of these caregivers were single women who lacked an extended family and support system.

“It is terrible.....terrible. I feel I can not cope.” (C)

“I struggle and worry a lot about him. It distresses me and I am tired all the time. I am very overwhelmed.” (H)

Thus for these caregivers, their mental and physical health felt to be at stake as a result of their caregiving responsibilities. The two caregivers described depressive symptoms, a consequence of caregiving that has been well documented (Magana et al., 2007; Provencher et al., 2003). Therefore, in this study, the majority of caregivers did not report negative emotional or physical consequences of their role.

4.4.2 Mourning and needing to adjust expectations after first psychotic episode.

Six caregivers described their feelings of sadness, shock and heartbreak when their family member first became ill. Three spoke about mourning the loss of the expectations for their family member’s future and having to adjust these expectations.

“When he started getting sick we were heartbroken because we knew how nice this guy is.” (A)

“I was completely shocked because he was very clever at school. I was in a complete shock... I’m the one who was supposed to be in hospital from being shocked.” (C)

“That broke my heart. I was convinced I was going to get sick as well because I had nerves all the time. I dreamt that he was going to be somebody. It broke my heart so badly that I ultimately gave up on it. I thought he would study and be successful at school, I worked so hard for his success.” (D).

“It was very difficult when my wife was first in the hospital. I had to look after the children. They were very small. It was very difficult. It was very difficult for me to see the people in a place like that! It was not very nice and I was just so glad that my wife could come home again. It was so much better for us and I’m glad it’s now just part of history. We don’t really talk about it any more. We are just grateful that she’s at home again and that she’s okay.”(R)

These caregivers therefore experienced emotional distress and a sense of loss regarding their family member’s illness and the implications for future functioning, experiences which are commonly reported in the literature (Bland & Darlington, 2002; McDonnell et al., 2003).

4.5 Coping with caregiving

4.5.1 Social support in coping and managing behaviours

Eight of the caregivers identified various forms of social support as a crucial part of the coping process. The different forms this support took was the availability of extended family members to assist with taking the patient to hospital when they had relapsed, assistance with supervision, monitoring and household chores, financial and emotional support, as well as the role of professional support. Some of these factors have already been discussed in previous sections. Family members were also called upon to assist with problem-solving. Support was provided by extended family members, employers and people of the church.

“We usually call my brothers. I also have another brother who works at Shoprite. We usually call him as well, sit down and discuss what can be done. He also usually helps with funds for my children in school matters like money for trips and so on. So that eases out the stress levels.” (P)

“I go to church on Sundays. I usually talk to other women at church.” (A).

“My sister’s husband would come over to assist me, more especially problems that men particularly can deal with. He’s able to show us how to handle problems such as when he (the patient) refuses to go to the witchdoctors.” (D)

“There is a woman I work with, that I usually go to. She’s usually able to notice when I’m suffering emotionally and she’ll usually ask what’s wrong then I open up to her.” (A)

Consistent with previous findings from African countries (Ohaeri, 2001), these caregivers appear to have been active in drawing on available social supports to assist in care.

The tasks that caregivers most often need help managing include their ill relative’s refusal to attend the day hospital when relapsed, financial matters, activities of daily living, and aggressive and self destructive behaviour. Four caregivers described behaviours that were distressing and that they felt unable to manage on their own. Only two caregivers reported that the patients became aggressive when they relapsed.

“I was hurt, extremely hurt, badly hurt. It was so painful because he used to physically attack me to a point of getting swollen, whenever I took him to hospital. When coming back from hospital he would kick me and continue doing so until he goes back again.” (D)

One described how the patient would take his clothes off in the road. (H)

“Lately he has a tendency of taking his clothes off, he would for example leave his pants in the loo and stand at the gate or inside the house naked.” (H)

Finally, one caregiver spoke of how her nephew would undress and stare into the sun.

“Again he was naked, refused to wear clothes and underwear claiming that God instructed him not to wear clothes. We took him to Harare, forced him to get dressed. We noticed his sickness before he took off his clothes. He would look at the sun till his eyes got red and say God tells him to look. It was terrible. He would stand at the sunny side of the house and stare at the sun till his eyes were red and not listen when we told him not to.” (A)

Four caregivers described the support they received from the day hospitals and professional support.

“If it hadn’t been for the help we got from the doctors, I don’t know where we would have been today.” (E)

“He doesn’t wait because the sisters there know him. They attend to him immediately; give him his injection and medication, so he can go home. He doesn’t wait too long and the nurses there are friendly towards him.” (D)

“When he gets sick the only way he gets better is when he goes to Lentegeur. When he is there we know he is looked after and he will recover. We are very thankful for that.” (A)

Thus support was important for these caregivers, as has been reported for many others. Social support in the form of family, friends and professionals has been associated with the ability of these caregivers to maintain hope despite challenging circumstances (Bland & Darlington, 2002).

4.5.2 Role of religion

Three of the caregivers described the role their faith had played in helping them survive the days when things were hard.

“If I think about it now, I can just say, thank you Lord for giving us the strength to get through this. Thank you for helping us to get through every day.” (R)

“I said to the Lord, thank you for this child, I’m talking from my heart. I belong to the Apostolic faith. I believe that the Lord meant for this to happen and He gives me strength when things are hard.” (E)

“If I didn’t have my faith, I don’t know how I would have got through all this.” (N)

Religious beliefs have been identified as sources of hope as well as help caregivers cope with stress during difficult times (Bland & Darlington, 2002; Rammohan et al., 2002), as is the case with these three caregivers.

4.5.3 Impact of knowledge

The three caregivers who educated their family members regarding the illness spoke about the impact this had on the families’ ability to cope.

“They do understand as well about his illness. In the beginning, when he started getting ill, they were very worried too. But they do understand now about his illness. They say nothing about it and they also don’t ask any questions.” (F)

They described how this facilitated the family understanding and making sense of the patient’s behaviour, whereas this had previously been frightening for them. This enabled the family to have strategies to cope with the behaviour.

Caregivers themselves described a change in attitude and response to the patient’s behaviour once they were more aware of the illness.

“I used to get very angry when he gets stressed like that, because he was in the hospital for that schizophrenia of his. Now, he stresses a lot, and then I just keep quiet because I know it’s due to his illness.” (F)

This indicates that knowledge of the illnesses assisted in coping for these caregivers, something for which there is overwhelming evidence in the international literature (Chen et al., 2004).

4.5.4 Burden decreases with increase in time

Four of the participants reported managing to care for the patient better now than they had when the patient first became ill. This appeared to result from a combination of factors; namely that the patient’s disruptive behaviour was now better controlled, and the caregiver had discovered ways in which to prevent relapse.

“In the beginning, I was under a lot more pressure because he was very sick a lot more than he is now. I had my hands full then and it gave me a lot of stress. But he is a little better now”. (F)

“They do understand as well about his illness. In the beginning, when he started getting ill, they were very worried too. But they do understand now about his illness. They say nothing about it and they also don’t ask any questions.” (F)

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“In the beginning, I was under a lot more pressure because he was very sick a lot more than he is now. I had my hands full then and it gave me a lot of stress. But he is a little better now”. (F)

“No, he’s not as aggressive as he was before. Once he gets aggressive I go to the clinic, there they call the police and ask them to talk to him nicely and let him know that he has to go to the day hospital, where he then gets referred to Lentergeur. He’s much better this year, we talk and see eye to eye.” (D)

“I just believe that she won’t get like that again. The tablets are really helping her. I mean, it’s been many years now and she hasn’t been like that again. There are many times when I like lie in my bed and I think, what if my mother gets ill again? I don’t know if I’ll have the strength to go through that again. It caused a lot of stress.” (R)

“He remembers most of the time. I must say he’s much better this year in terms of taking care of himself.” (D)

Reasons for the increase in the ability to cope included better management of symptoms and medication compliance as well as caregivers identifying and managing signs of relapse as discussed earlier. Caregivers describe an increase in medication compliance but also a more suitable medication regime being established that either reduced side effects, or decreased the number of tablets that needed to be taken and supervised by the use of an injection.

“Yes he is better because now he takes that injection. He also takes his pills regularly.” (D)

“I used to cry and my neighbours would come over to assist me. They would assist to the extent of giving us their phone numbers so as to call when there’s a crisis. Some would help me watch if he has any friends that are of bad influence. Police would also come for an update on his behaviour so that friends with bad influence don’t come near him. If suspicious people come

looking for him I ask what they want from him, or what he has done, when they say they're just looking for him or for his company I tell them that I don't want them to come looking for his company." (D)

Therefore, consistent with findings in the literature, these caregivers seem to have been active over time in drawing on social supports and identifying appropriate treatment strategies in order to decrease their burden (Lowyck et al., 2004; Rose, 1996).

4.5.7 Patient experienced as valued and loved family member

In all of the households the person with the mental disorder appeared to be a valued family member, with family members actively involved in their care and supporting their treatment.

"When he's not sick he's a very nice guy who talks about love and peace all the time. The family knows him the way he is. We have to be sensitive and easygoing towards him as a family. They love him because he's a nice guy.....He has a good heart, he surpasses everyone in the family. He set a very good example within his family. We really adore him because he is such a nice person" (A)

"My husband is a good man. Although sometimes it is difficult when he is sick, I love him very much. This makes it easier when things are hard." (P)

"He is a very gentle and kind person with a big heart. It makes me want to help him more." (H)

"He is part of the family and it is better that he is home than away in the hospital. We are glad to have him here." (D)

These feelings of love and care for their family members seem to help caregivers with their tasks, particularly during periods of relapse. This positive appreciation of their family member has been related to a decreased experience of burden as well as improved quality of life amongst caregivers in the international literature (Awadalla et al., 2005).

Caregivers therefore drew on a number of internal and external resources in order to cope with the task of caregiving. It seems that the longer they have spent in caregiving, the more they have been able to identify and make use of factors that decrease their experience of burden.

4.6 Impact of poverty on caregiving

4.6.1 Decreased opportunities for supervision

Four caregivers described difficulties in supervising their family member due to the need to work in order to provide for the family. They also reported not having sufficient resources to pay someone to provide day care.

One of these caregivers described the importance of supervision in medication compliance and the implications when this was not possible.

“Yes, I have to remind him. But often I’m not here, like I’ve worked night shift this week, and there are many evenings that he doesn’t take his tablets because he forgets. When I’m around then I check with him to see whether he has taken his tablets before bedtime or not.” (F)

Another spoke of her concern of not being present to monitor the behaviour and protect against consequences.

“I can’t hide the fact that he’s mentally ill within the community because I might not be around when he relapses.”

A third spoke of the need to keep people, who were trying to sell her son cannabis, away from him.

“When I am not there he goes out to walk and they try to sell him dagga. I need to watch him as he can’t say no to them.” (D)

As mentioned in previous sections in this chapter, the need for supervision in patient’s daily activities as well as in medication compliance has been well established as important. One of the primary differences that seems to emerge in poor as opposed to well off households is the ability to secure alternative forms of supervision and care. In this sample, caregivers often had to rely on young children to supervise medication compliance and clinic visits, or miss a day of work to perform these tasks.

4.6.2 Impact on employment

Four of the caregivers that were employed described having to miss work and therefore forfeiting a day of pay in order to fulfil their caregiving role. Reasons for this would include needing to assist in visits to the clinic or monitor behaviour when the family member was relapsing and when there were no family members available to assist in these tasks. This was experienced as problematic by caregivers, as they all experienced financial stress.

“At times I have to miss work to take him to the clinic when he gets sick. It is hard as my employer understands but I then get less money. We struggle as it is.” (P)

Yes, there are times when I stay at home as I am worried to leave him like that. I worry that he will get hurt if he leaves the house and does something.”
(H)

“When he [my husband] was working, he or I would have to take a day from work to take him to the clinic. It makes it very hard as money is tight.” (A)

The majority of these caregivers were involved in casual labour which then has implications for their income. Again, missed work is a well known implication of caring for a family member with schizophrenia (Ricard et al., 1999). This has great implications when the person missing work is the primary breadwinner and caregiver.

4.6.3 Caregiver financial stress

All of the caregivers in this study reported experiencing financial stress. The ways their care was compromised by this stress included not being able to provide for their family member’s material needs, but also impacted on their ability to provide for emotional needs due to their own stress and burden as a result of difficulties with finances. Some of their concerns included not being able to supply blankets to keep them warm during winter, fear over home repossession and therefore inability to provide home environment, unable to provide extra supervision and at times unable to provide sufficient food. The caregivers in Klipheuwel described how their family member would sometimes not be able to attend the clinic to collect medication as they were unable to provide money for transport.

“If he doesn’t have money then he hitch-hikes. I worry as it is not safe and he may get hurt.” (E)

“I can’t even buy blankets for him to warm himself up at night when he sleeps. That really works on me.” (A)

“When you don’t have money and everything in the house is nearly finished. You are stressed because you don’t know where it’s going to come from. There is even no money to buy food. How was he going to get some food so that he could take his tablets? You can’t drink tablets on an empty stomach.” (E)

“It bothers me a lot, more especially regarding the uncertainty and possibility of having to losing my house. I wouldn’t know where to begin or what to have as surety if I were to ever get summons to go to court. I mean, where would he live if I lost the house? Let me just say. Things are really not easy for me.” (H)

The experience of financial stress therefore limits caregivers’ ability to access resources, at even the most basic levels at times. The stress experienced by having to make alternate arrangements depletes caregivers’ internal resources and as a result impacts on their caregiving ability. For these reasons, caregivers of low socioeconomic status have been described to be at high risk for experiencing burden when caring for a family member with a mental illness (Baronet, 1999).

4.6.4 Role of disability grant in household economy

Seven of the members with schizophrenia received a disability grant¹. As mentioned previously, in six cases this money was managed by the caregiver and used to provide for the entire family.

“We struggled because the money that I earn on its own is very little. We struggled but we tried to make do with what was available.” (H)

¹ The disability grant is one of a number of social grants available in South Africa aimed at poverty alleviation. In order to qualify for the grant, the recipient must be 18 years or older and not able to work due to a mental or physical disability (Department of Social Services and Poverty Alleviation, Western Cap, 2005). The amount of the grant is currently R820 per month.

“We had no money. We had to go and ask other people for food. It’s not nice when the food cupboard is bare. We had to wait for his money [disability grant] to come so that we could go out and buy our own food again. I felt very unhappy. I asked the Lord everyday to help us. And the Lord has helped us because we are also going to get our little money from the government this month [pension].” (E)

Therefore the disability grant plays an important role in the household economy, supporting not only the recipient but also at times the entire family. The family member is able to play a part in contributing to the family survival, and is not only considered to be a financial burden, as is often the case in the international literature.

Similar to findings from previous studies, these caregivers indicate that living in conditions of poverty makes it harder to provide care for their family members. This may be the result of less resources available to them to assist in coping with challenging behaviours, as well as caregivers own experiences of other financial stressors (Magana et al., 2007).

4.7 Conclusion

The findings from this study indicate that this group of caregivers are involved in assisting in many aspects of their ill family member’s life, such as household chores, cooking and financial matters. For the most part, these caregivers also play an active role in the management of their family member’s illness. This involves monitoring their behaviour and making attempts to reduce chances of relapse, supervising medication and clinic visits and educating others regarding the illness. These areas of involvement have been described in the international literature. In order to cope caregivers enlist the support of nuclear and extended family, community and Church members and professionals. In particular, knowledge about the person’s behaviour appears to be an important part of the caregivers’ ability to cope. Living in conditions

of poverty pose an additional challenge to providing care in practical aspects, such as caregivers' inability to provide for material needs such as supervision, food and blankets. Living in these conditions also impacts on caregivers' ability to provide emotional care in that caregivers have other financial stressors to attend to. The disability grant plays an important role in these families' economies and has far reaching impacts when it is stopped or suspended as at times it is the sole means of family income. Although caregivers did describe painful feelings of grief and loss regarding the illness, as well as some consequences for their mental and physical health, their family member was regarded as a loved and valued part of the family. The final chapter discusses these findings in light of the international literature and makes recommendations for future research.

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CHAPTER FIVE: CONCLUSION

In this final chapter, the findings from the study are summarised and considered in the context of existing literature. Limitations are discussed and recommendations for future research and practise are offered.

5.1 Discussion of findings

Many of the experiences the caregivers in this study described are similar to those reported in the international literature. There are, however, some issues which may be contextually specific and need to be explored further in order to understand the specific challenges faced by caregivers living in South Africa.

This study provides insight into the range of experiences of these ten caregivers. Common themes which emerged that are also described in the international literature include the involvement of caregivers in a number of activities, over and above their usual family role, in order to support their family member cope with and adjust to daily living. Consistent with studies in other countries, caregivers also described their direct involvement in the management of their family members' treatment, including supervising medication and attending clinic appointment, as well as monitoring for side effects and responding to signs of relapse. The experience of this as burdensome appeared to be influenced by the amount of assistance caregivers received from family members and friends, as well as their attitude towards their family members. Caregivers also took on the role of protecting their family members from stigma and the possible consequences of their behaviour being misinterpreted, as well as containing their own family members and making sense of their family member's symptoms for them, a finding consistent with other studies.

The importance of support by family members and professionals, identified in the international literature, was also raised as important in this study in helping caregivers to cope. At times, caregivers were able to draw on this support when their family

members displayed challenging behaviours which they were unequipped to manage alone.

As found in other studies, the decrease in these caregivers' experience of burden over time, indicates that when caregivers find ways of accessing support and when their family member's behaviour is better managed, they are able to cope better and are under less stress. In this study, caregivers took many years to reach a state of feeling equipped to cope, and the earlier struggles impacted on some of the caregivers' mental status and quality of life. This has implications for the kinds of support caregivers are in need of when their family members first are diagnosed. It seems that perhaps caregivers need relatively less input once they have drawn on their available supports and developed their own strategies to manage their family member's illness. However, initially families may need extra support from professionals to assist in this process and provide psychoeducation.

Experiences that may be more specific to South Africa include the finding that the family member is not typically experienced as a financial burden. In fact, just the opposite seems to occur, where the family member may at times be the sole breadwinner, with the whole family relying on their disability grant. People with schizophrenia often do not do well in the labour market and are often either unemployed or require substantial support to maintain employment. This, together with the added costs related to the illness, can place considerable financial strains of caregivers. As poverty and unemployment are prevalent in South Africa, the lack of employment on the part of the ill family member was not unexpected, and the disability grant enabled them to provide a form of income that many family members relied on.

Another issue that is not specific but may raise different problems in South Africa is the gendered provision of informal care. In most cases it seems that it is the women who provide this care and are also the primary breadwinners. This strain and burden on women is a theme that is common in the literature, where women in poor conditions fulfil multiple and burdensome roles (WHO, 2001). In all 10 case studies,

the caregivers were women, again, a not unexpected finding in the light of the literature on care work (Higson-Smith, Richter & Altman, 2004), and the burden they carried could have implications for their own mental health.

Other experiences not commonly described in the international literature are the co-existence of two or more belief systems regarding the cause of the illness as well as a combination of modalities of treatments. Although the participants in this study combined their belief systems, many families who seek conventional treatment have more traditional understandings of the cause of the illness, but have not been able to treat the condition using traditional methods. Families' understandings of symptoms and meaning making systems need to be understood and engaged with during treatment in order to ensure adequate communication and compliance regarding treatment.

The extent of the challenges faced in accessing mental health services may also be specific to South Africa, given the change in policy and difficulties experienced in the implementation process. These challenges to optimal management and organisation of clinics, and under-resourced and underdeveloped services, may lead to increased burden on households in the form of time costs, waiting in long queues and having to get up early in the morning. This situation may necessitate supervision, and as employment of the caregiver in many cases is casual labour, that would mean losing a day's wage. When this is not possible, due to the caregiver's inability to miss work, problems at the clinic mean that family members do not collect their medication and therefore default on the treatment.

Three caregivers described consequences of caregiving for their mental and physical health. The two caregivers who displayed depressive symptoms and reported difficulties in coping with their caregiving role were noted to both be single, female, without adequate support structures, as well as lacking knowledge regarding the illness. These two women were trying to balance their roles as caregiver and breadwinner, as well as care for other vulnerable family members (one had a son with epilepsy; the other was caring for two grandchildren under the age of ten as their

mother was ill). The one whose physical health was suffering was an elderly woman who had been coping with her son's illness for a number of years. She was also taking care of two grandchildren. Although not the case in this sample, but an issue to be aware of in the context of high rates of HIV/AIDS and tuberculosis in South Africa, is that caregivers themselves or other family members may be physically unwell and in need of care.

The caregivers in this study are therefore directly involved in the treatment of their family members, which at times proved to be time consuming, and labour and energy intensive, and often at the expense of their employment stability. However, these caregivers demonstrate a commitment to caregiving despite the challenges, and appear to be resourceful in the way they cope with their task of providing care. When they are supported by professional services and are able to draw on family members for support, they seem to be able to cope for the most part. However there are times, when despite this resourcefulness, the demands exceed their capacity to cope and professional input is needed. However, there seem to be problems in their ability to access treatment at times, which adds to their experience of burden and stress. There appears to be a gap in professional support for times when their family member displays challenging behaviour that is not life threatening but beyond caregivers' capacity to cope. However the behaviour could have problematic consequences for patients safety and could also increase experiences of stigma, for example when patients run away from home or undress in public. As the new mental health care act aims to protect the rights of people with mental illness, it is important that caregivers are supported in achieving this aim.

5.2 Limitations

The study design imposed several limitations. First, the self-selection of participants from organizations such as family support groups may have biased the results because members of those groups who responded to the invitation to participate in the study may have been those who felt the greatest burden and distress in their caregiving role. Alternatively, they may also have been individuals who were better at finding support and resources. Second, the transferability of findings, or external validity, is limited

by the small sample size and further studies with caregivers are needed in order to establish whether the findings of this study reflect the experiences of other caregivers. Third, face-to-face interviews have many limitations, including possible interviewer bias. Although the interviewer tried to be as objective as possible, biases may have affected the quality of listening and reporting. The researcher as a white female researcher may have impacted on the information that was shared as well as how it was made sense of. The interviews were translated directly into English from Afrikaans and Xhosa, which may have resulted in some meaning being lost or distorted in translation. Measures were taken to minimise this. One of the interviewers for whom Xhosa was her first language, listened to selected recordings of the interviews which were conducted in Xhosa and compared these to the transcripts. The other interviewer, for whom Afrikaans was her second language, listened to the interviews that had been conducted in Afrikaans and compared these to the transcripts. However, the use of audiotapes and transcription analysis helped reduce this bias. Fourth, the majority of the interviewees were female. The greater willingness of women to volunteer for participation in this study is consistent with their generally greater involvement in caregiving roles of all sorts. However, it may have been beneficial to have included more male caregivers in this study for balance.

Despite the limitations inherent in this research, the present study provides a base of information from which future research can be conducted in order to better understand the needs and experiences of South African caregivers caring for a family member with schizophrenia in conditions of poverty.

5.3 Recommendations

The findings of this study have implications for future research as well as practice. The lack of research into caregivers' experience in South Africa, given the number of challenges which have emerged in this study, needs addressing. Given that families provide the bulk of care to people with schizophrenia in South Africa, it would be important to explore the challenges they face and factors that assist their coping further. Caregivers are noted to be resourceful and future research could benefit from exploring areas that caregivers identify as needs. Quantitative research could play a

role in exploring on a large scale the challenges caregivers face when attempting to access care and the areas where they feel they could benefit from more care. This study also explored experiences in a specific geographic and demographic sample. It would be important to expand this to compare caregivers' experiences in different areas and across socioeconomic and cultural groups.

Although the sample size was small, a few areas emerged that may be relevant to clinical practise and warrant further exploration. Psychoeducation was identified as an important part in caregivers' coping and has been identified in the literature as an important part of family interventions. However, there are few interventions in the Western Cape that offer this service. This is something that could be integrated fairly easily into interventions and the benefits have already been proven internationally. There is also a need for evaluative studies of intervention effectiveness.

A finding which emerged in this research is that single female caregivers may be at higher risk of physical and mental consequences. This could be further explored in research to determine whether specific interventions could be aimed at supporting this group of caregivers.

Finally, in the context of tuberculosis, HIV/AIDS and high levels of substance use, there is a need to explore the increasing phenomenon of having to care for people with both physical and mental health care needs, and the implications of this double burden on caregivers.

5.4 Conclusion

The experience of caregivers' caring for a family member with a mental illness, living in conditions of poverty, is an area that has been neglected in research. The high prevalence of risk factors for the experience of burden that have been identified in the literature, such as disease severity, caregiver gender, low socioeconomic status, and caregiver physical health, in South Africa together with changes in mental health

policy and associated challenges to implementation, make this an important area to investigate further. The findings from this study indicate that although caregivers are resourceful in the way they cope with caregiving, the numerous socioeconomic challenges they face make it difficult to cope. These caregivers are in need of support in order to strengthen their ability to cope and decrease the risk of development of their own mental health problems. Research that further explores caregivers' experiences and needs would be valuable in facilitating this process.

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APPENDIX A

Research Interview Schedule

Demographics:

Age:

Gender:

Highest level of education:

Income:

Employment/Occupation:

Language:

Dependents:

Marital status:

Other questions related to member with mental illness:

Living arrangements:

Duration of mental illness:

Clinic attended:

Age:

Research questions: (areas broadly covered)

1. Tell me about your experience of caring for X?
2. What tasks or activities do you find yourself involved in when providing care?
3. (If not spontaneously addressed followed up with more specific questions around medication, household chores and clinic visits)
4. What makes it difficult for you to care for X?
5. What helps you to cope?
6. Do you have family/friends that you are able to ask for help (emotional/financial)?
7. How does X's illness impact on your family members?
8. What is your understanding of why X experiences these symptoms/became ill?
9. What do you think causes X to relapse?
10. What are your experiences of mental health services/community clinic/psychiatric hospital?
11. How does providing care impact on you?

12. Tell me about your relationship with X?
13. Are there other things in your life that you experience as stressful which impact on caregiving?
14. In what ways does this impact on caregiving?
15. Anything else that you feel I haven't covered that is important in your experience of caregiving?

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