

**AN EXPLORATION OF THE COPING MECHANISMS OF  
CAREGIVERS OF PERSONS DIAGNOSED WITH SEVERE MENTAL  
ILLNESS, IN THE WESTERN CAPE, SOUTH AFRICA**

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This work has not been previously submitted in whole, or in 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.

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**Lynne Hogan, University of Cape Town, 2015**

**ABSTRACT**

This exploratory study on the coping mechanisms of caregivers in the Western Cape was undertaken in order to gain a better understanding of what caregivers experience and utilise in order to cope with their role as caregivers. Informal caregivers are the primary carers for people with a severe mental illness living within communities. They often carry a significant burden in this role and have many stresses which they need to deal with. It is therefore essential that a better understanding of their experience is gained in order to provide relevant support services and interventions. Hopefully the insights gained in this study will contribute to the formation of policies and interventions for caregivers which are appropriate and lead to further research in this field. This study was a qualitative study, conducted with 18 caregivers who participated in in-depth interviews. The results show that there is a large variety of both positive and negative coping mechanisms which caregivers employ dealing with the challenges and stresses they face. Positive coping mechanisms ranged from: making use of services and facilities available, working or keeping busy, knowledge of mental illness, support from family and friends, faith, finding the right doctor for the mentally ill person,

support from hospital or clinic staff, looking after self and using challenges to grow, having lots of patience, taking one day at a time and listening to others' stories. Some of the negative coping mechanisms were: ignoring the mentally ill person or cutting off emotions, taking on all responsibility for the mentally ill person or controlling them, using verbal threats or abuse, isolating themselves and using medication to cope. The carers interviewed were also able to identify and access a number of social support mechanisms and systems available to them. Some of these provided psychological and emotional support, others provided physical / practical help and many provided both. The predominant social support mechanisms and systems were: hospitals and clinics, family and friends, churches and faith, support groups, Cape Mental Health and various NGOs. Participants in the study spoke about challenges and barriers in their role as carers. The research indicates that there are two main divides: challenges tend to be concerned with the person they are caring for while barriers tend to be external factors which carers have to deal with. Common challenges which carers face are: drug or alcohol use by the mentally ill person, unpredictable and disturbed thinking and behaviour, issues with medication and non-compliance, lack of person's insight, isolation and withdrawal from family life, lack of understanding from family and friends, financial problems. Barriers which are more external to the family unit include: lack of adequate medical services and facilities for the mentally ill person, lack of support services for the carer, lack of suitable accommodation for mentally ill people, carers not included in the treatment team and plan, police not helpful when asked for assistance with a mentally ill person, negative perceptions of mental illness in society. Recommendations of the study are for further research in this field; that mental health care services provide more support and interventions for caregivers; and that clear policies are developed and implemented for caregivers.

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Lynne Hogan

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## **DEDICATION**

This research is dedicated to my very special friend and angel, Peppi, who has inspired me, encouraged and supported me every step of the way. There are no words....

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# CHAPTER 1: INTRODUCTION

## 1.1 Background and context

There is global growth in the burden of mental illness in society. According to Murray and Lopez (1996), in the year 2000 mental disorders comprised 12% of the global burden of disease and it is predicted that by the year 2020 this could increase to 15% (Flisher, Lund, Funk, Banda, Bhana, Doku, et al., 2007). In 2007 it was reported that four out of the 10 leading causes of health disability were due to mental illnesses and that by 2020 depression would be the second leading cause of health disability in the world (Flisher et al., 2007). This growing burden is exacerbated in poorer countries because of a projected increase in the number of young people entering the age of risk for the onset of certain mental disorders and these countries do not have the resources to deal with this increase in numbers (Flisher et al., 2007). Neuropsychiatric conditions were ranked third in their contribution to the burden of disease in South Africa and 16.5% of South Africans reported having suffered from mental disorders in the year 2006 / 2007 (Williams, Herman, Stein, Heeringa, Jackson, Moomal, Kessler, 2007).

A substantial gap is found between the burden caused by mental illnesses and the resources available to prevent and treat them. It is estimated that four out of five people with serious mental disorders living in low and middle income countries (South Africa included here) do not receive the mental health services that they need (World Health Organization (WHO), 2011).

A significant majority (77%) of individuals admitted to mental hospitals remain there less than one year (WHO, 2011). This is due to the global trend to deinstitutionalise the care of people diagnosed with a mental illness. The result is that families or caring individuals in the community now have the responsibility of caring for those who are diagnosed with a

mental illness (Rudnick, 2004). This responsibility of care causes many stresses and challenges for the person who is the primary caregiver and the family involved with the care (Solomon & Draine, 1995). It is estimated that 30% to 65% of people diagnosed with a mental illness live with their families (Solomon & Draine, 1995). South Africa over the past few decades has also gone the route of deinstitutionalisation resulting in many mentally ill people living at home with families or in the homes of caring community members rather than in institutions. It is important then to support and consider those caring for the mentally ill so that they too can continue in good health and provide the much needed care for those diagnosed with a severe mental illness.

As many as one in six South Africans suffer from anxiety, depression or substance-abuse problems (and this does not include more serious conditions such as bipolar disorder or schizophrenia), according to statistics released by the South African Depression and Anxiety Group (SADAG). Furthermore, research reveals that over 40% of people living with HIV in South Africa have a diagnosable mental disorder. A study done by UCT's Department of Psychiatry and Mental Health indicates that, in low-income and informal settlements surrounding Cape Town, one in three women suffers from postnatal depression, while research from rural KwaZulu-Natal shows that 41% of pregnant women are depressed – more than three times higher than the prevalence in developed countries ( South African College of Applied Psychology, 2014). The research done by Williams et al., (2007) indicates that there is an elevated risk of mental illness in South Africa compared to several middle to high-income countries, with some reasons being: political violence and victimisation during apartheid; high crime rate and violence against women; harsh economic circumstances; high risk of HIV/AIDS and threat of trauma or injury to those working in mines. In Cape Town the leading provider of non-governmental mental health services to communities, Cape Mental

Health, report they provide interventions to just over 16 000 people in one way or another. They have an index of just over 4 000 users who benefit from their services of which 51.3% are female and 48.7% are male. They predominantly provide services to ‘coloured’ and ‘black’ people in the greater Cape Town area (Cape Mental Health, 2014).

It is also evident that Africa has the least number of countries with mental health plans (only 67%) and legislation (only 44%). However it is pleasing that South Africa is among the few in Africa that have both dedicated mental health policy and legislation. Even so services are stretched and very limited as there are not enough resources to properly implement the policy or legislation that exists. Statistics released by WHO (2005; 2011) indicate that in Upper Middle Income Countries (according to the World Bank) such as South Africa there are two psychiatrists, six psychiatric nurses, four psychologists and 20 social workers per 100 000 population and these professionals are more prevalent in urban areas. Public health care services are least accessible to the most vulnerable and are found mainly in psychiatric hospitals (Flisher et al., 1999). WHO (2011) reports that globally 67% of financial resources available for mental health are used to finance mental hospitals. This is a high proportion seeing that many people are now being cared for out of hospital and in the community.

Information and research show mental illness and its effects are significantly contributing to the burden of disease in South Africa (Williams et al., 2007 & Flisher et al., 1999). The increasing prevalence and unmet need for treatment are cause for concern and need to be addressed by expanding health care resources (Williams et al., 2007). When looking at the well-being of a country mental health is a fundamental foundation from which a healthy society can grow (Williams et al., 2007). Those who care for the severely mentally ill play a major role in their relapse rate and continuing well-being, thus affecting the burden

on society. The caregiver's well-being and coping is an important aspect in the picture of mental illness and its impact on families and communities. A survey done by the Commonwealth Fund Biennial Health Insurance company in 2003 in the United States (USA) showed that there were about 16 million informal caregivers aged from 19 years to 64 years in the US and 2 million informal caregivers aged over 65 years (Ho, Collins, Davis and Doty, 2005). The survey also established that two-thirds of the caregiver population was female.

We currently lack a full picture of the extent of mental illness in South Africa, although continuing research is helping with this, and there is scant research done on those in the community caring for the severely mentally ill (Williams et al., 2007). Both these areas need further investigating so that policy, treatment / intervention and support can be relevant and effective to those affected by mental illness in whatever way.

## **1.2 Statement of the research problem**

Since the onset of deinstitutionalisation it has increasingly become the family and community's responsibility to take care of those diagnosed with a severe mental illness. This has an impact on both families and communities as the responsibility of care takes time, resources and often causes increased stress (Rudnick, 2004; Crowe & Lyness, 2013; Seloilwe, 2006). Mental health care professionals are now required to work with these families and community members who are providing care as it is recognised that they are often the main resource and support system for many severely mentally ill people (Seloilwe, 2006; Romi & Melamed, 2007). These caregivers carry a significant burden in their role as caregivers of the many mentally ill people living in our communities. The caregivers' own mental health and general well-being have now become areas of concern for mental health care professionals (Ho et al., 2005; Solomon & Draine, 1995).

Very often a family or community member will become the primary caregiver for a mentally ill person, but these caregivers often lack understanding, skills, resources and support to deal with the demands they face (Seloilwe, 2006; Bland & Foster, 2012; Johnson, 2000; Solomon & Draine, 1995; Ho et al., 2005). Many of them are not employed as caregivers but fulfil this role within the community. In 2011 the Department of Social Development gathered data on community caregivers in South Africa. The information collected indicates that 90.3% of community caregivers are women and that 50.4% of them are aged from 26 to 40 years (Department of Social Development 2011: 5). In South Africa many caregivers receive no compensation for the care they provide, but these numbers are unavailable. The information there is provides a picture of the typical caregiver in South Africa as being a middle aged female with a poor education level and low income. These caregivers have to develop coping mechanisms (positive and/or negative) in order to deal with the challenges and demands on them (Solomon & Draine, 1995). It is not always easy for health care professionals to identify these mechanisms, thus delaying effective intervention to help these caregivers cope. It is also often the case that the caregivers are overlooked because the person with the mental illness is given priority when treatment and intervention is concerned. Thus caregiver burden and problems are not dealt with until they become significant enough to need intervention or treatment by health care professionals – which caregivers also struggle to receive or afford (Ho et al., 2005; Solomon & Draine, 1995). This research hopes to identify some coping and support mechanisms caregivers find helpful in caring for persons with severe mental illness. It also hopes to identify barriers and perceptions around services provided for caregivers.

### **1.3 Aims and objectives**

The aim of the study will be to establish, through a qualitative research approach, what coping mechanisms caregivers are currently using while caring for a severely mentally ill family or community member. The findings will inform best practice for mental health care professionals working with caregivers living in the Cape Town surrounds.

The specific objectives of this study are to:

- Examine the coping mechanisms of caregivers of persons diagnosed with a severe mental illness.
- Identify the support mechanisms available to caregivers of persons diagnosed with a severe mental illness.
- Identify challenges and barriers to effectively providing care to persons with a severe mental illness diagnosis.
- Examine caregivers perceptions of the services provided to them in South Africa.

### **1.4 Research questions**

- What are the coping mechanisms caregivers use when caring for a person with a severe mental illness diagnosis?
- What support mechanisms / services are available to the caregivers?
- Which coping mechanisms do caregivers find most helpful?
- What are the challenges and barriers caregivers face when caring for a person with a severe mental illness?
- How do caregivers feel about the services provided to them in South Africa?

## **1.5 Rationale of the study**

Clinical social workers need to provide support and interventions that are appropriate and helpful to their clients. Understanding the coping mechanisms caregivers use when caring for a person with a severe mental illness diagnosis, will guide and inform best practice. Having worked in the mental health field the researcher has experienced first-hand how stressed and burdened caregivers often are when caring for a person diagnosed with a severe mental illness.

Some research has been done and cited on how important caregivers are to the well-being and relapse rate of persons diagnosed with a severe mental illness (Romi & Melamed, 2007; Crowe & Lyness, 2013; Bland & Foster, 2012; Johnson, 2000; Solomon & Draine, 1995; Williams et al., 2014). That is why it is important to provide support and interventions which are helpful and relevant to caregivers (Ho et al., 2005). There is scant research done (especially in South Africa) on how caregivers cope with the demands they face and due to the growing number of caregivers, resulting from deinstitutionalisation and a strain on services, this is an area which needs exploration.

This study hopes to add to a body of knowledge around how caregivers cope when caring for a person diagnosed with a severe mental illness. This knowledge will help inform mental health professionals as to how they can best intervene in order to provide relevant and effective support and services.

## **1.6 Significance of the study to social work policies and practice**

This study will contribute to a better understanding and knowledge of the coping mechanisms caregivers within families and communities employ and what challenges they face within our South African (specifically Cape Town) context. There is little research in

this area for practitioners to base their interventions on. It is important for best practice to be based on sound knowledge and understanding of the problem area being addressed.

Informal caregivers form a large group of people that social workers come into contact with and thus more accurate information as to their well-being and coping can help social workers in their work (Ho et al., 2005). It is also becoming evident from research that caregivers seem to come disproportionately from lower-income households and are predominantly women (Ho et al., 2005; Seloilwe, 2006; Cape Mental Health, 2014). Social workers work largely with these groups of people.

This study is important as there is little research being done in Cape Town (or South Africa) around these caregivers and so it will be of value to those helping families, communities and individuals affected by severe mental illness. A study done in America by Ho et al., (2005), found that there were over sixteen million working-age adults caring for sick or disabled family members (mental illness included) which indicates there are large numbers of caregivers in society, and this is almost certainly the case in South Africa. Caregivers' well-being in society is therefore an essential issue to address.

This study will add to a body of knowledge which can help policy makers implement effective services for those caregivers and families affected by severe mental illness. There is no policy as yet in South Africa around caregivers but it is an issue which requires government consideration.

### **1.7 Concept clarification / definition of terms**

*Coping mechanisms* – Bland and Foster (2012) put forward that coping mechanisms (and defence mechanisms) are critical to how individuals deal with the day-to-day challenges of adult life and to long-term developmental outcomes. Coping mechanisms tend to be

viewed as being conscious, intentional, and mostly adaptive, but can be unintentional, and potentially maladaptive ways of coping with life stressors (Costa Jr., Zonderman, McCrae, Cummings, Greene and Karraker, 1991; Reber & Reber, 2001). There is a large variety of physical, psychological, spiritual and behavioural coping mechanisms which individuals employ. Therefore, coping mechanisms are what a person does and thinks in response to an event or situation, thus dealing with events or situations with varying degrees of success (Huang, Sun, Yen & Fu, 2008). Coping mechanisms can be viewed as positive or negative, either improving a person's well-being or being harmful to a person's well-being (Costa et al., 1991).

*Caregivers* – For this study caregivers will be those family or community members who take the primary responsibility for the psychological and physical well-being of the person diagnosed with a severe mental illness. They are people not employed to do so but who provide such care voluntarily. They may either live with the person who is severely mentally ill or else be in close contact with that person.

*Mental illness* – According to the Mental Health Care Act 2002: mental illness means a positive diagnosis of a mental health related illness in terms of acceptable diagnostic criteria made by a mental health care practitioner authorised to make such diagnosis. It can be considered in terms of 'impairment' of mental functioning which involves loss or abnormality of function. This concept is appropriate for the psychological impairments or dysfunctions that underlie the basic psychiatric symptoms (Wing, Thornicroft & Brewin, 2001).

*Severe mental illness* – For the purposes of this research severe mental illness or serious mental illness includes major depression, schizophrenia, bipolar disorder, obsessive

compulsive disorder (OCD), panic disorder, posttraumatic stress disorder (PTSD) and borderline personality disorder, all diagnosable in the DSM V (2013). (National Alliance of Mental Illness, 2012).

*Mental health* – The concept of mental health includes subjective well-being, perceived self-efficacy, autonomy, competence, intergenerational and self-actualisation of one's intellectual and emotional potential. It is broader than a lack of mental illness as it has a psychosocial underpinning and is fundamentally connected with physical and social functioning and health outcomes (WHO, 2001).

*Mental health services* – A system of care provided by medical institutions, government health facilities, non-government organisations and community health services helping people with a mental illness (WHO, 2001).

*Mental health policy* – This is a statement of intent, a set of principles which guide decisions and is implemented as procedures around mental health issues by the government. In South Africa in particular, government documents which embrace human rights, community-based mental health care, and the integration of mental health into primary health care (Mental Health Poverty Project, 2010).

*Social support* – Social support can generally be viewed as an interpersonal transaction that involves emotional concern, instrumental aid, information or appraisal. Social support can be divided into two categories: psychological support involving both appraisal and emotional dimensions and non-psychological support or tangible support which is seen in material aid (Cohen & McKay, 1984).

*Resilience* – This is 'the process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances' (Masten, Best & Garmezy, 1990, p.426).

Definitions of resilience seem to be based on two core concepts: positive adaptation and adversity. Both of these must be evident for resilience to occur (Fletcher & Sarkar, 2013).

### **1.8 Assumptions**

Working in the field of mental health has brought the researcher into contact with caregivers struggling to accept and adjust to the changes of having to care for a family or community member diagnosed with a severe mental illness. A number of issues have become apparent which this research hopes to explore further. In particular caregivers experience stress when caring for a person diagnosed with a severe mental illness and invariably a family or community member (caregiver) is given the primary responsibility for the welfare of the mentally ill person. This responsibility affects the caregivers in a variety of ways mostly negatively, assisting or hindering their role as caregivers, and this requires further investigation.

Previous research has pointed to the burden and stress that caregivers experience (Seloilwe, 2006; Rudnick, 2004; Huang et al., 2007; Crowe & Lyness, 2013; Solomon & Draine, 1995 and Bland & Foster, 2012). This research intends to explore which coping mechanisms caregivers use to manage this burden and stress, and thus help direct social work practice and interventions by mental health care professionals.

## **CHAPTER 2: LITERATURE REVIEW**

This literature review will highlight various studies, academic material and policy information which speak to the research topic of coping mechanisms of caregivers caring for people with a severe mental illness. It will also cover stress and coping including studies which have helped define the research question. Previous research in the field of caregivers and mental health, or caring for those who are ill is considered, including policy and legislation which impacts on this subject. When it comes to theory on the subject, this research will look at theories which influence how coping mechanisms are understood and how caregivers cope with caring for severely mentally ill family or community members.

### **2.1 Social welfare history of mental health services in South Africa**

Prior to 1994, Mental Health Services were available to South Africans but provided unfairly and unequally on the basis of race. This meant there was a huge gap between what was provided for 'white' South Africans and other race groups. Post-apartheid years have been spent trying to reduce that gap and provide equal health care services for all. This has created a fairly unique problem to South Africa which needs policy and legislation to help address closing this gap.

According to Mkise and Uys (2004), access to mental health care services continues to be a problem for the aged, the poor and rural black populations. This is largely due to financial affordability, location of services and transport costs to reach the required services. In a study done by Williams et al., (2007) the findings show that there is a high level of unmet need for Mental Health Services in South Africa. They found three out of four adults with a 12 month DSM IV / CIDI (Composite International Diagnostics Interview) disorder had received no treatment during the year of the interviews being done and questions around the quality of the little care that was received were raised (Williams et al., 2007).

Contrastingly, a relatively high proportion (even higher than that found in the USA) of people with no disorder received treatment for emotional problems. This could be because of non-optimal use of mental health services, or help seeking due to high levels of stress, people with disorders receiving successful aftercare or diagnostic errors in the CIDI (Williams et al., 2007).

Racial segregation in South Africa has also meant that families and caregivers of the mentally ill have been treated differently and have had access to different interventions and facilities. We would hope that the past 20 years have been spent bridging that gap but this is not always the case as can be seen in the little research done (Mkise & Uys, 2004).

With regard to the general theory behind services provided to help with mental health care, South Africa has also moved through the institutionalisation phase, where management of mental illness was done by an institution, to the community based care system, where families and communities are more responsible for the care of those diagnosed with a mental illness (Bland & Foster, 2012). Deinstitutionalisation in the past 30 years, in Western democracies and in South Africa, was given impetus by a series of social developments, including developments in medicine and pharmacology, and major policy reforms, which shifted management of mental illness from the institution to the community (Richmond & Savy, 2005).

While many policies emphasise the concept of decentralization and integrated care with other general health services especially at primary health care (PHC) level, little research output has been forthcoming in African countries to demonstrate the success of these strategies. Communities are having to provide care for those who are mentally ill, without adequate resources, support or understanding of mental health issues (Mkise & Uys, 2004;

Williams et al., 2007; Williams, Peckham, Watkins, Warrick, Tarn, Rudoler and Spalding, 2014). The burden of mental illness is compounded by the extensive human rights violations of people with mental disorders, plus the associated stigma and resultant discrimination against those with a mental illness (Flischer et al., 2007).

All of the above has placed the family unit under increased stress and as a result families and caregivers have had to find new ways of coping with the demands of caring for those who are mentally ill. Little research has been done in South Africa on how caregivers cope with these demands and the impact these demands have on their own well-being.

## **2.2 Overview of mental health policies and legislation in South Africa**

In South Africa, although post-apartheid “policy guidelines” were developed and approved in 1997, there is still no official mental health policy. Although the 1997 policy guideline was approved for implementation by MINMEC, “ due to capacity constraints within the national office, it was neither formally published nor widely circulated throughout the country, nor were the specific policy guidelines all completed or followed by the development of implementation guidelines” (Lund, Kleintjes, Campbell-Hall, Mjadu, Petersen, Bhana, Kakuma, Mlanjeni, Bird, Drew, Faydi, Funk, Green, Omar & Flisher, 2007). There is also no national strategic plan for mental health as planning is meant to occur at the provincial level. There was no official plan to accompany these policy guidelines but national targets with indicators were set to guide the realisation of selected priorities. New policy is still being developed which includes all ages and the promotion, prevention, treatment, rehabilitation of mental health disorders, but excludes substance abuse (except comorbidity) and intellectual disability (mild / moderate) which are included in other policies. It is evidence-based, takes resource constraints into account and provides specific guidance to the provinces (Mental Health and Poverty Project, 2010).

South Africa's 2002 Mental Health Care Act (Government of South Africa), developed through an extensive consultation process, has obtained strong support from government and other stakeholders, and has been praised for its human rights orientation and promotion of community-based care. The intention of this Act is to promote and protect the rights of people with mental disorders through a number of legal requirements and safeguards that dictate the procedural flow and clinical management of mental health service users. It requires the establishment of Provincial Review Boards that are to function as appropriately skilled and resourced bodies, and are able to act independently and autonomously in ensuring the proper implementation of the Act and its regulations. There is still however, a lack of a mandated national mental health policy supported by clear provincial implementation plans and budgets (Mental Health and Poverty Project, 2010). This has resulted in a wide gap between policy and practice in South Africa that needs to be urgently addressed so that people are provided with adequate mental health care services. (Mental Health and Poverty Project, 2010). In 2013, the National Health Council of South Africa adopted the Mental Health Policy Framework and Strategic Plan 2013-2020 for South Africa which was then adopted by parliament in October 2013. This is a combined provincial and national approach to mental health with many stakeholders. Hopefully with the adequate allocation of resources this policy framework and plan will work towards meeting the needs of those with mental disabilities (Cape Mental Health, 2014).

There still seems to be no policy or plan concerning how to best assist and support the caregivers voluntarily caring for those with severe mental illness. It is important that this area is not neglected as caregivers are vital in improving the outcomes of good health for those with severe mental illness.

### **2.3 Coping mechanisms of caregivers of mental health consumers**

Literature exists on coping and defence mechanisms studied primarily in the context of life stress (Diehl, Chui, Hay, Lumley, Gruhn, & Labouvie-Vief, 2014). Coping mechanisms are behavioural or cognitive responses made by any person contingent on a life event: thus coping is what a person does and thinks in response to an event, with varying degrees of success (Huang et al., 2008). This study hopes to highlight the variations in coping mechanisms used by caregivers in response to caring for family or community members who are severely mentally ill (Huang et al., 2008).

Huang et al. (2008) studied carers coping with those who suffer from schizophrenia in Taiwan and found that most carers were of low socio-economic status and low educational levels. This seemed to influence their coping mechanisms in that it delayed their seeking psychiatric help as they first went to traditional healers or tried Chinese medicine before going for psychiatric help (Huang et al., 2008). They also found that those from better educated classes would seek information about the illness and were members of support groups which helped them cope better (Huang et al., 2008).

In the literature that is available on coping mechanisms used by caregivers it seems that there are three most common coping mechanisms / strategies used. They are physical coping mechanisms which include caregivers using alcohol, smoking, medication, relaxation, sleeping, resting and overeating to help them cope; psychological coping mechanisms which include emotional (crying, denial, upset), cognitive (positive thinking, information, problem-solving) and behavioural (hobbies and action-orientated pursuits) responses; and finally, social coping mechanisms including social support, community resources, professional support, spiritual support, respite care and group / self-help groups (Huang et al., 2008).

Solomon and Draine (1995) looked at the difference between objective and subjective burdens / stressors which families have to deal with and how this can influence the kinds of coping mechanisms families and individuals use.

Research in this area is very scarce in South Africa. A thesis was done in 2002: 'An exploratory study on the needs of families with a relative with schizophrenia who are utilising services at Cape Mental Health Society (located in Cape Town)', by Paula Sellmeyer, speaks to the needs rather than the coping mechanisms of families. But the researcher hasn't yet found an exploratory study on the coping mechanisms caregivers in Cape Town (or South Africa) use when caring for a severely mentally ill family or community member.

Some research has been done around the fact that different family members interpret mental illness in a variety of ways and thus respond differently (Johnson, 2000). However, little attention has been given to how spouses cope (Johnson, 2000). In Huang et al.'s (2014) study often the first coping mechanism used by the predominantly low socio-economic sample involved traditional healers, shamans and traditional herbal medicine. We have a large section of our population in South Africa who may also make use of traditional medicine and healers when it comes to caring for those with a severe mental illness.

It has also been found that the family and caregivers of a person with a severe mental illness can affect the outcome of the illness and relapse rates, so it is important to consider how that person or family unit cope (Rudnick, 2004). Helping the caregiver cope and finding which support systems and coping mechanisms help caregivers, will not only improve family functioning and promote caregiver well-being but will ultimately help the person suffering from a severe mental illness (Crowe & Lyness, 2014).

A study done in America by Johnson (2000) found several significant areas emerged around caregivers' coping and it explored with special attention, differences based on gender, ethnic group, socio-economic status, and the role of the family member as far as coping mechanisms were concerned.

#### **2.4 Social support and mental health of caregivers**

Social support is seen as one of the mediating factors which help caregivers cope with the demands of caring for a person with a severe mental illness (Dunér, Nordström & Skärsäter, 2011).

The different sources of social support can be categorised as formal or informal. Formal sources of social support can be identified as: professionals from health and social organisations; informal sources of support can be divided into two subcategories – family and friends including neighbours, and fellow workers (Duner et al., 2011)

Five different types of support can be categorised: advice / guidance, emotional support / socialising, practical / personal assistance and financial assistance. All of these are part of the support systems caregivers of family or community members with severe mental illness issues may experience (Duner et al., 2011)

Solomon and Draine (1995), looking at the subjective burden of family caregivers, discovered personal and social resources of family member caregivers played a significant role in explaining subjective burden, more so than do the stressors of the person with the mental illness. Those with social support appeared to experience less subjective burden.

Other studies done by Cohen & Willis (1985), Kessler & McLeod (1985) and Berkman (1985) point to the fact that social support appears to mediate the effects of life stress on health and well-being (Dunkel-Schetter, Folkman & Lazarus, 1987). Social support

has also been linked to resilience and how the external factor of support can help people to cope during adverse times by improving resilience (Greene, Galambos & Lee, 2003).

Rudnick's (2004) study identified that around the world it seems that support for caregivers in the family is inadequate. This results in more burden on the caregivers, reducing their well-being and consequently the well-being of those with the mental illness whom they care for.

## **2.5 Theoretical framework**

There are three theories that underpin this study. These are the resilience theory, stress and coping theory, and social support theory.

### *2.5.1 Resilience theory*

Resilience theory puts forward that it is part of the human experience that we face challenges and difficulties during the course of a lifetime. These vary from daily difficulties to traumas which the human psyche is forced to deal with. Some individuals appear to be able to handle (even thrive on) these difficulties and traumas while others are too overwhelmed to cope and are affected adversely (Fletcher & Sarkar, 2013; Van Breda, 2001; Greene et al., 2003). An individual's resiliency is determined by the interaction of risk and protective factors (Greene et al., 2003; Van Breda, 2001). Resilience theory assumes that resilience is one way in which individuals overcome the adversities they experience in their lifetime and even become stronger, healthier people (Van Breda, 2001; Fletcher & Sarkar, 2013; Windall & Bennet, 2012). Resilience has been described as "the process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances" (Masten, Best, & Garmezy, 1990, p. 426). Definitions of resilience seem to be based on two core concepts: positive adaptation and adversity (Greene et al., 2003; Masten, Best & Garmezy, 1990).

According to Greene (2002), some basic assumptions of resilience theory include: that it is a biopsychosocial and spiritual phenomenon, involving transactional dynamic processes of person-environment exchanges. These encompass an adaptational process of goodness-of-fit, occurring across the life course with individuals, families, and communities experiencing unique paths of development. Resilience is linked to life stress and people's unique coping capacity, which involves competence in daily functioning and which may be interactive – having an effect in combination with risk factors, and being enhanced through connection or relatedness with others. It is influenced by diversity including ethnicity, race, gender, age, sexual orientation, economic status, religious affiliation, and physical and mental ability. It is expressed and affected by multilevel attachments, both distal and proximal, including family, school, peers, neighbourhood, community, and society. Consequently resilience is a function of micro-, exo-, mezzo-, and macro-factors and is affected by the availability of environmental resources and influenced by power differentials (Greene et al., 2003).

In general, resilience theorists acknowledge that resilience is a dynamic process which changes over time. However the majority of resilience theories are specific to particular populations, e.g. adolescents, families (Fletcher & Sarkar, 2013).

The researcher found a generic resilience theory that can be applied across different groups of people and potentially stressful situations. This meta-theory of resilience and resiliency (Richardson, 2002; Richardson et al., 1990) can also be applied to different types of stressors, adversities, life events and at various levels of analysis (Fletcher & Sarkar, 2013). Caregivers often experience stressors and adversities and that is why this theory is relevant to this research.

Richardson and colleagues (1990) present the following theory: They start and then view as a process how resiliency can be identified and displayed. A person begins in a state of biopsychospiritual homeostasis; this is where a person is in balance. Disruption from this occurs when adversities come in a person's way which they do not have the protective resources to buffer themselves against. Over time a person does adjust and can begin the reintegration process. This process leads to four outcomes: "*resilient reintegration* (additional protective factors gained and higher level of homeostasis attained); *homeostatic reintegration* (people remain in a comfort zone to just 'get past' the disruption); *reintegration with loss* (loss of protective factors which leads to a lower level of homeostasis); and *dysfunctional reintegration* (disruption leads to people using destructive behaviours to cope, such as substance abuse)" (Fletcher & Sarkar, 2013, p.17).

For resilience to be demonstrated, both adversity and positive adaptation must be evident (Fletcher & Sarkar, 2013). For the purposes of this research the 'adversity' which a caregiver experiences will be that of caring for a mentally ill family member and all the challenges this may bring. Adaptations are needed in order to accommodate this caring role. This is not just seen in a negative light but also as a definite shift in the person's life circumstances, positive and negative. Next we look at what the 'positive adaptations' are. The indicators used to look at this must be relevant to the adversity being looked at (Fletcher & Sarkar, 2013). These are changes the person makes in response to the caregiving role they have. We must also take into account the socio-cultural context of the caregivers we are looking at, being mindful of the cultural context the caregivers find themselves in (Fletcher & Sarkar, 2013). This is especially important in our South African context where we have various cultural traditions which people live by. Some studies examining caregivers and caregiver burdens have also used this theory of resiliency to assist with understanding or to

gain more insight into resiliency (Musil, Warner, Zauszniewski, Wykle & Standing, 2009; Greene et al., 2003).

One limitation of this theory of resilience is that it is a linear model, considering just one event as it relates to an individual. As we know, life is often full of various events influencing us at the same time (Fletcher & Sarkar, 2013). Another drawback is that the theory does not look at how meta-cognition and emotion affect the reintegration process. Most importantly, the model has a bias towards coping orientated processes, which may draw researchers away from examining the true nature of resilience (Fletcher & Sarkar, 2013). All this considered, because this research is concerned with the nature of coping, this resilience theory is well suited to helping us understand caregivers' coping mechanisms when caring for the severely mentally ill.

#### *2.5.2 Stress and coping theory*

How individuals cope with stresses in life will be looked at in this research in terms of coping mechanisms; for this reason the stress and coping theory proves to be very helpful in understanding this process. This theory evolved through the 1950s to the 1980s through the work of Richard Lazarus, a psychologist, who started off looking at the general rules governing how stress impaired human functioning. His approach to stress and coping is explicitly cognitive-phenomenological (Eisdorfer, 1981).

The stress and coping theory and its basic assumptions can be viewed as follows. Initially, coping was looked at in two ways: one as a personality characteristic and another that emphasises process – that is, ways to manage stress that change over time and are shaped by the adaptational context out of which it is generated (Lazarus, 1993). Haan (1977) then proposed a tripartite hierarchy with coping as the healthiest and most developmentally advanced process of adaptation, defence as a neurotic process, and ego-failure as the most

severely regressed and perhaps psychotic adaptive process (Lazarus, 1993). The emphasis on coping style emerged out of an ego-psychology theoretical perspective, which was centred on inner psychodynamics rather than on external environmental forces. In the 1970s, the emphasis shifted for a time to the environment, especially environmental changes and life events. However the current emphasis is on both sets of factors – the person and the environment, which are said to interact. Person-environment relationships and especially relational meanings about them are an even more appropriate focus than the simple contrast between intra-psychic and environmental. This theory is well suited to the clinical approach of helping an individual and understanding them, as it focuses on the process of how a person appraises a situation and then identifies how they may cope if the situation is appraised as stressful (Lazarus, 1993).

What Lazarus puts forward in his stress and coping theory is as follows. In order to establish coping mechanisms it must first be established how the person has appraised a situation / transaction: Have they judged it as irrelevant, benign-positive or stressful? (Lazarus, 1970) or (Eisdorfer, 1981). This stress refers to the demands that tax or exceed the available resources of a person (in this case a caregiver); internal or external, as appraised by the person (Lazarus, 1970). If the person has appraised a transaction as stressful three subtypes are differentiated: those of (1) harm / loss, (2) threat or (3) challenge. These are called primary appraisals. This theory views stress and coping mostly as numerous specific encounters which stretch out over time. After the primary appraisal has occurred, secondary appraisal takes place which involves evaluating coping options and resources. These will then affect the coping process itself and the effectiveness of coping skills used by the person (Lazarus, 1970). One criticism of this concept of cognitive appraisal is that it appears circular; that is, what is known after the fact is by inference or self-report. However Lazarus

points out that cognitive appraisal is capable of cause-and-effect research on its determinants, thus the interaction of determinants will determine how a transaction is appraised (Lazarus, 1970).

This theory then puts forward that there are four main modes of coping, once appraisal has occurred, which can be identified as: (1) information seeking, (2) direct action, (3) inhibition of action, and (4) intrapsychic processes. (Lazarus, 1970). This research will use these coping modes as an indicator to help measure coping mechanisms of caregivers.

Difficulties in measuring coping must be considered a limitation of this theory and must be kept in mind when applying this theory in this study because of the following. Firstly, coping is a set of many acts and thoughts, not one single act or thought; thus accurate description of the process requires a series of interviews which is not possible in this research. Secondly, the process will be self-reported by the caregivers, not observational or from inferential sources of knowledge. Thirdly, ambiguities exist around coping because of faulty conceptualization; that is, the coping process is viewed as a static state of mind rather than a constant search for a way of comprehending and reacting to what is happening (Lazarus, 1970). These limitations will be taken into consideration in this research.

Studies done on caregivers have identified the burden and stress they often face and how they deal with this; thus this theory is relevant to a better understanding of how caregivers cope (Schock-Giordana, 2013; Huang et al., 2007; Rudnick, 2004; Johnson, 2000).

This research is basically interested in the study of human functioning: that of caregivers' coping mechanisms in the face of the demands of caring. Thus the stress and coping theory is relevant to our understanding of coping mechanisms.

### *2.5.3 Social support theory*

Basic assumptions around social support are that it is an interpersonal transaction that involves emotional concern, instrumental aid, information, or appraisal. Some studies show that the degree of social support an individual has in a situation may affect the entire stress process (Carlson & Perrewe, 1999). This will in turn influence caregivers' coping mechanisms; thus this theory has been used in other studies involving caregivers (Carlson & Perrewe, 1999; Berkman, 2008; Schock-Giordano, 2013).

Social support theory can be looked at from three different perspectives: the stress and coping perspective, the social constructionist perspective and the relationship perspective (Lakey & Cohen, 2000). For the purposes of this research social support will be looked at from a stress and coping perspective as this is a good link into the other theories in this research.

Social support theory as viewed by the stress and coping perspective hypothesises that support reduces the adverse effects of stressful life events on health (Lakey & Cohen, 2000). This is done through either the supportive actions of others, helping to enhance coping performance, or the belief that support is available. This leads to the appraising of stressful events as less stressful (Lakey & Cohen, 2000). This theory is linked closely with research and the theory on stress and coping.

The stress-support matching hypothesis is the most explicit statement of how supportive actions should promote coping. It hypothesises that social support will promote coping and reduce stress so long as the assistance matches the demands of the stressor (Lakey & Cohen, 2000). Thus it emphasises that appropriate support / assistance by others is essential in reducing stress and promoting coping which in turn promotes health and well-

being (Lakey & Cohen, 2000). Thus measures taken to assess coping mechanisms and styles will provide valuable information as to what the individual is doing to better cope with the situation. This research intends adding to this body of information.

There are still important research questions regarding the link between received social support and coping, as more studies have been done on perceived support and coping. For example, studies need to be done on what types of received support are more effective in positively influencing coping mechanisms and styles and which are not necessarily helpful (Lakey & Cohen, 2000; Dow & McDonald, 2003).

Another form social support takes is in helping protect people against the adverse effects of stressors by leading them to interpret stressful situations as less negative (Lakey & Cohen, 2000). How people interpret / appraise situations is very important in determining an event's stressfulness. Primary appraisals involve judgements as to whether an event is a threat; and secondary appraisals involve evaluations of personal and social resources available to cope with the event (Lakey & Cohen, 2000). It has been hypothesised that a person's belief that support is available reduces the effects of stress by contributing to less negative appraisals (Lakey & Cohen, 2000). Less negative appraisals should lead to less severe emotional reactions to an event. (Lakey & Cohen, 2000). This is something this research hopes to establish. There are relatively few studies that look at the beliefs of the availability of different types of support and how these are related to primary and secondary appraisals (Lakey & Cohen, 2000). In this research an understanding of the actual support there is for caregivers and what they perceive as their support will hopefully be established. This can help establish whether perceived support influences coping mechanisms. The prediction that perceived support influences appraisals will tie in with the stress and coping theory that predicts that appraisals directly influence coping. If so, perceived support should

influence coping (Lakey & Cohen, 2000). That is why the social support theory is relevant to this research.

Limitations of this theory include: measurement of supportive action involves self-reports, and such reports are often poor predictors of perceptions of available support and well-being (Lakey & Cohen, 2000). Behavioural observation may be a better way of measuring, but this is not possible in this research. Appraisals and perceived support are very subjective and are not easily measured in research (Lakey & Cohen, 2000). Hopefully through the use of qualitative research methods a clearer understanding can be gained of the link between social support and coping mechanisms. Secondly, there has been little actual research done in this field and so much of what is hypothesised is predicted but has not been rigorously tested (Lakey & Cohen, 2000; Dow & McDonald, 2003).

## **CHAPTER 3: METHODOLOGY**

This chapter examines the various factors involved in the methodological process of the research. The research design is outlined followed by a discussion of the population and sampling, methods of data collection and analysis used in qualitative research. Data verification is outlined and hindrances inherent in this research process are explored under potential limitations. Ethical considerations and reflexivity are also discussed.

### **3.1 Research design**

This research study employed a qualitative approach, as this allows research to adopt a person-centred and holistic perspective. It develops an understanding of people's opinions about their lives and the lives of others (Holloway, 2005). The original context of the experience is unique, and rich knowledge and insight can be generated in depth to present a picture of the participants' reality and social context. These events and circumstances will help the researcher answer the research questions being investigated (Holloway, 2005). This kind of design is used because this research aims to enquire at a deeper level which coping mechanisms caregivers use and why; thus an exploratory study will be conducted (Rubin & Babbie, 2011). The design is well suited to research where there is not a large body of information on a subject; which is the case regarding the coping mechanisms of caregivers of the severely mentally ill in Cape Town and even South Africa (Rubin & Babbie, 2011).

The findings of this research will, hopefully, build on the growing body of knowledge of coping mechanisms primary caregivers use (Grinnell, 1997) and encourage further and more conclusive research. Generation of knowledge in this design is thus developmental and dynamic, and does not use formal structured instruments (Holloway, 2005). It involves the systematic collection and analysis of subjective narrative data in an organised and intuitive fashion to identify the characteristics and the significance of human experience (Holloway,

2005). Qualitative research is suited to the subject of caregivers' coping mechanisms because it lends itself to the study of social processes and human experiences over time, which is also a way in which coping theory is viewed (Rubin & Babbie, 2011; Lazarus, 1993).

Qualitative research is flexible, so if needed for better outcomes changes can be made during the research process where appropriate and necessary (Rubin & Babbie, 2011). The researcher selected the exploratory method to gain new insights, discover new ideas and/or increase knowledge of the experience of caregivers of the severely mentally ill.

In order to establish rigour in research it needs to be trustworthy. The goal of rigour in qualitative research is to accurately represent in the study the participants' experiences / their subjective realities. Rigorous qualitative work engages in activities that assist in giving priority to the meanings of participants over those which are our own (Lietz, Langer & Furman, 2006).

Mechanisms were put into place to increase trustworthiness / rigour by reducing reactivity and researcher / respondent bias, thus helping to describe qualitative data in a way that is credible (Lietz et al., 2006). Other ways in which this was done was by writing field notes, keeping a journal and trying to leave an 'audit trail' so that others may reconstruct the thinking and test assumptions put forward in this research (Grinnell, 1997). The researcher was also involved with a supervisor who gave feedback and acted as a sounding board (Grinnell, 1997; Rubin & Babbie, 2011).

The paradigm which influences this study is the social constructivist perspective, which means steps taken to ensure trustworthiness were done by trying to capture multiple subjective realities (Rubin & Babbie, 2011). The social constructivist perspective acknowledges the subjective realities of participants and therefore does not strive for external

validity of the study but rather leaves the consumers of the study to judge the findings of the study's applicability elsewhere (Rubin & Babbie, 2011).

### **3.2 Population and sampling**

Individual caregivers who have a family member or look after a community member with a severe mental illness are the population of this study. These caregivers are not professionals but take on the role of caring in multiple ways for those diagnosed with a severe mental illness. A fairly diverse population was found in terms of population group and geographical location. However, only one third was of low socio-economic status. There were 18 participants interviewed, all female. Eight of the respondents were white, seven were coloured and three were black. Their age varied from 48 to 72 years old.

The sample was a non-probability sample, a portion of the population: this means the researcher does not know the population size or the members of the population, so the sample is based entirely on the researcher's judgement (De Vos, Strydom, Fouche & Delpont, 2005): a parent, spouse or other family / community member who is living with or closely involved in the life of a person with a severe mental illness (Rubin & Babbie, 2011). The sample was a purposive sample; that is, a sample with the characteristics and attributes of the population under consideration. The researcher sought out caregivers who were in contact with Cape Mental Health or support groups for caregivers (Grinnell, 1997). Permission had to be obtained from the organisation, so the researcher went and presented her research proposal to the staff at Cape Mental Health (Appendix A). Once permission was obtained from the organisation, the social workers there obtained permission from clients for the researcher to contact them and ask them if they would be willing to take part in the research (Appendix F & G). Cape Mental Health is a welfare organisation based in Cape Town catering for the mental health needs of those affected by mental illness and disability within the greater Cape

Town area. Initially the caregivers were contacted through the support groups run by social workers from Cape Mental Health (in Gugulethu and Mitchells Plain) and the Cape Support for Mental Health group (in Mowbray). After this, snowball sampling methods were used (Rubin & Babbie, 2011). The topic is sensitive so the researcher had to rely on people to volunteer to come for the interviews.

### **3.3 Data collection approach**

Individual participants were asked to participate in in-depth interviews (See Appendix B) of about 60 to 90 minutes. Interviews were conducted by the researcher who is fluent in English and Afrikaans. The instrument the researcher used to collect the data was a semi-structured interview schedule (Appendix D & E). This schedule or guide collected some basic personal information from the participants to establish their suitability for the research and then asked questions exploring the caregivers' coping mechanisms and available support. Other questions exploring barriers, challenges to care and services available were asked and discussed. Questions were mostly open-ended to get as much data rich information as possible. Interviews took place mostly in people's homes; three were done at a community centre and five in a quiet restaurant. Interviews were voice recorded using a recording device which participants were made aware of and agreed to. All data collected was securely saved on a password access only folder, available only to the researcher to ensure confidentiality.

A pilot study was conducted as it allows for the testing of the data collection tool. The researcher asked two caregivers, whom she has been in contact with in preparation for this research, to participate in this pilot study. No significant changes were made to the interview schedule.

### **3.4 Data analysis**

All of the interviews were tape recorded, then transcribed and analysed according to categories and themes that emerged. Thematic analysis was used to identify categories that are common throughout the different interviews (Rubin & Babbie, 2011). This process made use of Tesch's (1990) eight steps as a guideline for analysing the qualitative data. This process involved the following:

1. The researcher got a sense of all the data collected by reading carefully through all the transcriptions and jotting down ideas.
2. The researcher selected any one transcript and went through it, asking “What is this about?” and thought about the underlying meaning in the information. The researcher wrote in the margin thoughts that came to mind.
3. Once the researcher had completed this task for several transcripts, a list of all the topics was made, and similar topics were clustered and formed into columns so they could be arranged into major topics, unique topics, and leftovers.
4. The researcher took the list and returned to the data. The topics were abbreviated as codes and the codes written next to the appropriate segments of the text. The researcher tried out this preliminary organising scheme to see whether new categories and codes emerged.
5. The researcher found the most descriptive wording for the topics and then turned them into categories. The total list of categories was reduced by grouping related topics. Lines were drawn between the categories to show interrelationships.
6. A final decision on the abbreviation for each category was made and the codes were alphabetised.
7. The data material belonging to each category was assembled in one place and a preliminary analysis performed.

8. The researcher recoded existing data if it was necessary. (De Vos et al., 2005).

### **3.5 Data verification**

According to Guba and Lincoln (1985), in qualitative analysis the researcher should address the issue of ‘trustworthiness’ to test the rigour of findings. This research looked at the following four constructs laid out by Guba and Lincoln (1985) in order to increase trustworthiness:

#### *Credibility*

This is the consistency between participants’ realities and those attributed to them (Babbie & Mouton, 2007). This was achieved in this study by accurately defining and describing the participants in the study, voice recording interviews and using established methods of interpreting the data (Babbie & Mouton, 2007).

#### *Transferability*

This was looked at by clearly stating the theoretical parameters of the study and the extent to which the findings could be used in other settings and with other participants (Babbie & Mouton, 2007). In order to help achieve this, in-depth descriptions and purposive sampling were used.

#### *Dependability*

This refers to whether the study’s findings would remain the same (or similar) if it were repeated (Babbie & Mouton, 2007). Here the researcher attempted to account for any changes in conditions and/or changes in the design because of an increase in the understanding of the setting.

### *Confirmability*

This implies that the findings of the study can be confirmed by another and evaluation was based solely on the data collected by the researcher (De Vos et al., 2005). In order to comply with this the researcher kept all documentation, recordings, transcriptions and information collected during the study so they could be reviewed by another if needed.

This research also took into account biases which may appear – such as social desirability bias; cultural, class and gender bias. Social desirability bias can come up especially in face-to-face interviews: if questions are asked which could cause people to feel embarrassed, irresponsible, silly, etc., they may give an answer which is not the truth but rather what they think is more socially acceptable (Rubin & Babbie, 2011). Questions and answers between researcher and participants can reflect cultural, class or gender biases that must also be considered and as far as possible negated (Rubin & Babbie, 2011).

The researcher was also aware of the fact that first impressions or dramatic accounts given by a participant can sometimes distort data analysis. The data can also be skewed if more weight is given to some data and thus other data is missed which is relevant to the study. The researcher made use where possible of her creativity, sensitivity, flexibility and skill in using these verification strategies in order to improve the trustworthiness of this study (Morse, Barret, Mayan, Olson & Spiers, J., 2002).

### **3.6 Ethical considerations**

*Interviewees' protection:* Because human participants were interviewed for this research all the necessary approvals were obtained from the university and the organisation, Cape Mental Health, through which participants were first contacted, to make sure ethical

requirements were met. This was done to ensure that participants were protected (Rubin & Babbie, 2011).

*Voluntary participation and informed consent:* All participants in the study were assured that they were under no obligation to participate in the study – it was of their own free will. This was done in discussion with them when setting up the interviews. Agreeing or refusing to participate in the study would have no bearing on the services or support they receive from any organisation they may be affiliated to. The researcher developed a research overview and consent form (Appendix B) which explained to each participant what the researcher was researching, the purpose of the research, what would be required from the participant, what would happen to the information gathered, and that all information would remain confidential and anonymous. The form states that participants are participating freely, are free to withdraw at any time and if any problems come up they will be dealt with appropriately. It also states that the participant is aware that interviews will be recorded (See Appendix B). Participants were asked to sign the consent form if they agreed to and understood everything (Rubin & Babbie, 2011).

*Confidentiality and anonymity:* Participants were assured that information obtained would not be submitted to any case files of any organisation regarding their family. Information would at all times remain locked up and/or password controlled for only the researcher and her supervisor to access. The participants' identity and information would be protected, and their names would not be put on any transcriptions (Rubin & Babbie, 2011).

*Risks and benefits of the study:* Due to the sensitive nature of the research, the researcher was aware that participants might have an emotional reaction during the interviews. This did happen on a number of occasions so the researcher used her social

worker skills to contain the person and then once the person felt ready proceeded with the interview.

### **3.7 Potential limitations**

The following are limitations of this study:

The findings cannot be generalised to all caregivers who care for a severe mentally ill family or community member due to the qualitative nature of this research. The use of semi-structured interviews opens the research up to subjective interpretations by the researcher. There is the possibility of ambiguity or brevity in reportage thus limiting external validity (Rubin & Babbie, 2011).

The research interviews were conducted with those caregivers who spoke and understood English and Afrikaans as the researcher is fluent in these languages. This automatically excluded caregivers who speak other languages thus limiting this study.

By conducting some of the interviews in a public place, albeit as private as was possible, some of the participants may have felt they could not be completely honest and open at the risk of being overheard. This may also be true for those carers interviewed at home where there was a family member somewhere else in the house.

Only three of the eighteen participants were black. This limits the generalisation of findings as not all race groups were represented equally. All participants were female and thus male caregivers were not represented; therefore findings cannot be generalised across both genders. The sample in this study was limited to participants who were willing and available to participate on a completely voluntary basis during the time set aside for data collection by the researcher. The participants were also mostly from Cape Mental Health or

the Cape Support for Mental Health which also limits the generalisation of the findings to all caregivers.

The length of time the caregiver had been caring for the mentally ill person was not taken into consideration which is also a limitation, as this may make a difference to how caregivers cope. Some of the carers interviewed did indicate that the first five years were the hardest for them.

Lastly some of the participants were asked by Cape Mental Health if they would be willing to participate in this study. This connection to an organisation they received services from might have impacted the findings by virtue of the fact that they felt the organisation might have had some access to the information they provided during the interviews.

### **3.8 Reflexivity**

Reflexivity is an important part of qualitative inquiry because it is through this reflection that the researcher can think about the ways in which who they are may both assist and hinder the process of co-constructing meanings with participants in their research (Lietz et al., 2006).

The researcher has previously worked with families and the severely mentally ill which may mean that this research is approached with some preconceived ideas about what coping mechanisms caregivers use. The researcher had to keep these ideas in check and remain objective at all times. The researcher endeavoured to be open and accountable at all times in describing the choices made in implementing various approaches in the research.

Another important consideration is that the researcher has had a close family member diagnosed with a severe mental illness and has therefore witnessed very closely how a caregiver has had to cope in this situation. The researcher did not allow this experience to

cloud or hinder how other caregivers reported in the research their coping experiences. The researcher tried to reflect on how this might have influenced the interview process during this research and the perceptions the researcher has of carers and their coping mechanisms. Having professional and personal experience in this field made it difficult not to intervene at times when participants told of their struggles; being mindful of this, the researcher restricted interactions during interviews to those of data collection and containment.

The researcher also considered the setting in which the interviews were conducted as this might have influenced the results / information gathered. Preferably the interviews were conducted in a private space where participants felt free and comfortable enough to be open and honest (Rubin & Babbie, 2011).

During the data analysis and writing up of this research the researcher found herself feeling tired and there was a heaviness to this experience. The researcher feels this may be due to the caregivers' burdens and the situations they find themselves in. The researcher had to remain mindful of this during the research.

## CHAPTER FOUR: RESULTS

This chapter will present the findings of this research study both in written and tabular form.

Participants will be described and then the findings under headings which emerged as categories and subcategories in the data analysis. Quotes will be given from the interviews.

### 4.1 Description of study participants

All the participants were female. Otherwise the group was fairly diverse.

**Table 1: Socio-demographics of participants**

Population group of participants	
Number of participants	
Black	3
Coloured	7
White	8
Age of participants	
41 – 50	1
51 – 60	9
61 – 70	6
71 – 80	2
Residential suburb in greater Cape Town area	
Blouberg	1
Fish Hoek	1
Gugulethu	3
Kenilworth	1
Kommetjie	1
Marina da Gama	2
Meadowridge	1
Mitchells Plain	2
Mowbray	1
Pinelands	1
Retreat	1
Rondebosch	2
Wetton	1

Table 2 presents information about the relationship of the carer to the person who has been diagnosed with a mental illness, the diagnosis of the mentally ill person and whether they live together or apart, as this will make a difference to the nature of the caring relationship and the coping mechanisms employed by the carer. The majority of carers (13 out of 18) are permanently living together with the mentally ill person.

Eighteen interviews were conducted individually with the carers themselves. Due to the sensitive nature of the information and its reference to the mentally ill person being cared for, seven participants were interviewed away from their homes in a quiet public place, e.g. quiet corner of a restaurant or nursery. Two were interviewed in a private room attached to a library, one was interviewed in her office at work and the other eight were interviewed in their homes. Of the eight interviewed at home, two had the person who was being cared for at home, but they were somewhere else in the house.

**Table 2: Nature of relationship of carer to mentally ill person and living arrangements**

Nature of Relationship of carer to person diagnosed with severe mental illness	Numbers
Mother and daughter	4
Mother and son	8
Sister and brother	2
Sister and sister	2
Wife and husband	1
Wife and ex-husband	1
<b>Living Arrangements</b>	
Living together in same house	13
Living apart	5

## **4.2 Coping mechanisms of caregivers of persons with severe mental illness**

Having analysed the data collected from the participants in this study it is clear that carers face many challenges and stresses in their caring role. All employed various methods of coping; some methods were healthy and appropriate while others were inappropriate and caused more strain in the already strained situation in which they found themselves.

The positive coping mechanisms included: making use of services and facilities available, working or keeping busy, knowledge of mental illness, support from family and friends, faith, finding the right doctor for the mentally ill person, support from hospital or clinic staff, looking after self and using challenges to grow, having lots of patience, taking one day at a time and listening to others' stories. Some of the negative coping mechanisms were: ignoring the mentally ill person or cutting off emotions, taking on all responsibility for the mentally ill person or controlling them, using verbal threats or abuse, isolating themselves and using medication to cope.

### *Making use of services and facilities available*

The majority of participants used available services and facilities as a coping mechanism. These included 12 participants attending support groups and almost all making use of clinics / hospitals or mental health services of some kind. It seemed that those attending the support groups coped better and were more able to resolve difficulties than those who didn't. It was also evident that those carers who were better educated and in a middle to high socio-economic group were able to make use of more services and facilities and sought them out proactively.

A 72 year old mother put it this way:

I started going to a support group... I spoke to other people in the support group and most of them had been through this and survived it... it does help without a doubt.

Another said:

I have no one to offload on except the support group and the psychiatrist. – *64 year old mother.*

A 60 year old mother said the following when asked what helped her cope:

It was joining the support group which was probably the absolute best thing that happened because that's how I learnt, that's how I could speak to other people. I got onto the committee and I've probably been the chairperson for a long time – at least 12 years I think... the support group has been helpful because you can speak out and encourage other people to speak out and to understand the illness and things like that... a sense of giving back. That to me made a big difference.

It seemed that most participants felt their experience could only be truly understood by those who experienced the same thing and had an understanding of what they were going through. This was of great supportive value and gave them encouragement.

#### *Working and keeping busy*

Many participants also indicated that working or keeping busy by being involved in hobbies or other activities was of great value as a coping mechanism. This seemed to take their mind off the immediate problems and stress of caring which they may be dealing with and allowed them to cope better.

One mother of 70 years (now retired) put it this way:

I did work all along and that kept me busy and I think it helped. It helped take your mind off things that were happening.

Another mother of 59 years said:

And then I've got my work. I do work also a little bit... so I've got a nice balance so they know nothing. I don't talk to them at all about that (son's illness). We've got a good working relationship that helps me.

And:

I work mornings only. I realised I can do this, I must get out. I also need to do things for myself. – *56 year old mother*

Other carers who didn't have work expressed that keeping busy at home or being involved in activities outside of the home was also a good way to help cope.

I am fixing up my house and I have to keep it up... I try find things to do to occupy my time and mind. – *64 year old mother of daughter with schizoaffective disorder*

This sense of being busy and doing something outside of caring seemed to give the carers a better sense of well-being and the ability to cope better than those not working or busy.

### *Knowledge of the mental illness*

Those carers who took time and energy to find out about the person's illness and what to expect seemed to cope far better than those who were uninformed and perhaps unwilling to accept the person's mental illness diagnosis.

For example:

I educated myself enormously. Learning as much as possible (about the mental illness) makes all the difference. – *60 year old mother*

Another mother of 70 years said:

You will read anything and research anything you find, any sort of answer. It becomes your mission. Somewhere out there they might have or say something that is different, it is interesting, it is helpful.

Those carers who understood the person's mental illness and were aware of what to expect seemed to cope better in general.

One mother of 72 years whose son is now married and living independently reported coping better because:

I read all I could. I spoke to all I could. So I informed myself as much as I could.

### *Support from friends and family*

The support and help from friends and family was a significant coping mechanism for carers. Carers were able to cope much better by talking to and sharing problems with family and friends.

The sister of a person responds as follows:

Interviewer: Who can you go to, to ask for help, if you need help coping with her?

Participant: I would be able to get help. No, I've got big support of my family and friends. I have a big support system. What helps me cope is that I've got help. – *caregiver aged 59 years*

Another quote was:

I've been open with my friends from the very start. I never hid it. And so my friends from the beginning, have

always been incredibly supportive. When I need to talk to anybody there are people I can talk to. – *mother of 60 years old*

Fourteen out of the eighteen participants expressed that support of family and friends made a significant difference to their ability to cope. They were able to share their difficulties and stresses in caring for the mentally ill person, as evidenced by the following:

Interviewer: And your husband?

Participant: He is wonderful and a great help. He is not so emotionally charged and can stand back and look at the situation and calm me if I am anxious about her (their daughter). – *mother aged 56 years*

### *Faith*

Almost half of the carers interviewed spoke openly about how their faith has given them strength to cope and a feeling that they have help from a higher power as evidenced in the following quotes:

Who looks after me? God looks after me. – *59 year old sister caring for her brother*

Another carer when asked what helps her cope said:

My faith, I have a very strong faith and am so thankful I can rely on Jesus to help me each day. – *63 year old wife of husband with bipolar disorder*

The ability to connect with a higher power seems to give carers strength and support which carries them in their role as carers.

### *Finding the right doctor for the mentally ill person*

Many carers spoke openly about how finding a doctor who they could speak to honestly about the person they were caring for and who included them as part of a team in

helping the mentally ill person, made it a lot easier to cope. They felt heard and supported in their role as carers.

For example, one mother said:

There's the family and there's the medical people and things will only work if they work together... I feel very strongly that it is a team. If someone doesn't want to hear what's going on at home – find another doctor. 'Cause things won't get better unless someone (doctor) is going to listen and work with the family and respect the family.  
– *60 year old mother whose son has schizophrenia*

A number of participants said the doctors and medical staff made them feel that they were part of their family member's mental illness problem. They were excluded from any treatment plan, which made them feel helpless and confused. Once they found a different doctor everything changed and they were better able to cope. One mother put her initial experience with doctors this way:

They think I'm being overbearing and want to know about everything. But with the person's permission there must be things they can discuss to help the person... I found the people at J2 (Groote Schuur Hospital) a huge support. I managed to find someone there who worked out for her. I try connect with her Dr. It's so positive and I don't know how it will be in the future but it's good now. – *mother of 56 years old*

#### *Support from hospital or clinic staff*

Many carers said that getting support and the right kind of help from the hospital or clinic for the mentally ill person made a big difference to their ability to cope. Those who had a positive experience at hospitals or clinics were in a better position to cope with the person who was mentally ill, as expressed in the following quote:

I found the people at J2 (Groote Schuur Hospital) a huge support, they are interested and have helped her (daughter). – *56 year old mother*

Another participant whose brother collects medication from a local clinic reports:

They talk, they tell me about him, how he must drinks his tablets. How in the morning when I drink mine but he doesn't because he is sleeping too late... no, they help him. – *71 year old sister*

### *Looking after self and using challenges to grow*

Two coping mechanisms which appeared to be closely linked were the carers' ability to continue doing things which nurtured themselves and looking at the challenges they faced in order to grow and develop as people. Two participants across different population groups explain their experience as:

Participant 1: I also need to go do things for myself and let her do it. I think I've been able to see the challenges and used them to actually grow in my life... So I've used the things to help me look at life differently and not be so inflexible.

Participant 2: I do think you've got to have your own interests. But I mean, it pushed me into areas that I would never have gone. I came onto the committee (of support group), I did public speaking – all things I found stressful. You become quite knowledgeable. I mean we wrote a book!! – *56 and 70 year old mothers*

The ex-wife of a person who was diagnosed with bipolar disorder did the following:

To be alone, I just recharge my batteries. I have a lovely little dog which I take for walks. And I eat very well... Meditation. I go for therapy. Sleep, can I say sleep? I go to bed early... I address things. I don't have a bottle of wine at night, even tho' it's painful. – *54 year old ex-wife*

### *Having lots of patience*

Nearly half the carers interviewed told the interviewer that they have lots of patience which makes the caring role more manageable, as evidenced through the following quote:

You have to be patient even if you are angry sometimes  
you've got to adjust yourself and then you think oh no,  
that's happening. And then you know how to carry on. –  
*59 year old sister*

Some of the participants reported that this was a skill they had to develop while others said that fortunately they were by nature patient people.

A 56 year old mother put it this way:

Often I said things that weren't helpful and I've had to  
learn to step back and be careful.

### *Taking one day at a time / living in the now*

An effective coping mechanism for seven out of the 18 participants was taking one day at a time. Living in the now and not worrying about the future or making plans for the future which may just add to the stress of getting through each day.

When asked by the interviewer 'What are the ways which you find / feel help you cope?' this is how two mothers responded:

You can only take one day at a time. – *66 year old mother*

... I was so worried about the future. You do learn to live  
differently and you learn to take one day at a time, a stress  
at a time and it's so true. It's the only way to go. – *60 year  
old mother*

It became clear during the interviews that those carers who could take one day at a time were more able to cope with the stresses caring brings.

*Listening to others' stories*

This was such an interesting coping mechanism which the interviewer came across in a third of participants in the study. Those carers who were able to listen to others' stories of adversity, even if not from others in the same situation, seemed to draw strength and encouragement for their own situations. Naturally the support groups were the primary place for this to happen and those who were engaged in helping others' carers. But a couple of participants found it helpful to listen to the stories of any others.

A wife of a husband with bipolar disorder said she didn't attend any groups for the support of mental illness carers but found it helpful going to AA. She said what helped her was:

Real stories. I was fascinated by their stories not only of staying sober but of their actual behaviour while they were alcoholics and the family support... For 2 years I used to go. – *63 year old wife*

Some participants did however also use negative coping mechanisms which were not particularly helpful in dealing with their situation in the long term. Some of these were not generally good for their well-being but were employed as an immediate way to cope in reaction to stressful situations they found themselves in. Some of the negative coping mechanisms included: Ignoring the person or cutting off emotions, taking on all the responsibilities for the mentally ill person or controlling them, using verbal threats or abuse, isolating themselves and using medication to cope.

*Ignoring the mentally ill person or cutting off emotions*

Many participants in the face of ongoing stress in their role as carers found that in order to cope they would just ignore the person or cut off emotional responses to the person. This is detrimental to their well-being and even though it helped them cope in the short term it caused emotional problems for them and those they are caring for in the long term.

One carer reported that:

...when he was psychotic I used to have to learn to walk away. Learn not to respond even if there are... bizarre things. – *60 year old mother*

Another participant said:

Sometimes at home when he starts really going off on a tangent, then I just go to my room. I just close it (the door). – *66 year old mother*

#### *Taking on all responsibilities for the mentally ill person or controlling them*

An overwhelming majority of the carers took on almost all the responsibilities for the mentally ill person's well-being. It was evident that in the early stages of the illness this was much more prevalent, e.g. in the first five years. After that some carers would have learnt to seek help from elsewhere or encouraged the mentally ill person to take back some of the responsibilities for themselves. However other carers took control of the situation and the mentally ill person as a way of coping. The responsibilities that a caregiver has are overwhelming at times, depending on how ill or well the person they are caring for is, as evidenced by the following quotes:

I've had to develop a sense of almost responsibility that I thought would have left a bit by now... It's almost like you are still caring for a baby... You prepare yourself as a mother for every stage. And I hadn't prepared myself for this stage. I thought that then (by now) I would have more freedom. – *59 year old mother*

Because you know when they are ill they become again very dependant, like children... people would intimate that I was controlling him. – *72 year old mother*

A sister aged 59 who cares for her sister put it this way;

When ... was staying here last year I could control her to a certain extent because she was on medication and under my care. I suppose I've always felt emotionally responsible for her... it's... \*sighs\* always it doesn't go away.

The feelings and practicalities of being responsible for the person and trying to control things is a huge burden which carers have to live with.

#### *Using verbal threats or abuse*

A few carers were open enough to speak about how they verbally threaten or abuse (verbally and physically) those in their care in order to cope. The stress of the caring role pushes some people into behaving in ways they would not typically behave. This situation is not healthy for the caregiver or the person with a mental illness, as described in the following quotes:

I need intervention. Because the way I'm... You know, I become... And I do shout, shout and I sometimes do swear. And he's going to have me up for abuse. – *66 year old mother*

If he doesn't listen you know what I say? I think he is scared of my big sister... then I say 'You know what? I am going to call Sheila (big sister), then you won't do this kind of thing. – *48 year old sister*

These negative coping mechanisms are used when caregivers feel stressed and are struggling to deal with the person they are caring for.

### *Isolating themselves*

Caregivers who felt overwhelmed and stressed by the demands of coping often isolated themselves as a coping mechanism. They had no energy to socialise or interact with others so they withdrew. This is evidenced through the following quotes:

No I don't have friends. It's only the street people. Ladies, they help me when he's wrong like that time... when I'm not feeling right, or stressing, I just go and sleep. – *71 year old mother of son diagnosed with schizophrenia*

So what I would do is, I wouldn't invite people round, I don't want to upset her but then I would get to a point when I think, no hang on a second... – *59 year old sister*

It seems that these coping mechanisms can lead to the caregiver feeling less able to cope and can make their caring role far more stressful in the long run.

### *Using medication to cope*

Only three participants openly admitted they used medication to cope. However this coping mechanism may be more widespread than reported in this study, and may include the taking of other substances such as alcohol or drugs. One mother explained her experience:

I take pills. I told the chemist, I can't sleep, I've got 3 children... just give me something to calm me. – *52 year old mother*

Another said the following:

Interviewer: If you need help coping, are there people you feel you can go to?

Participant: I've got a big support system... Oh yes, ya and I can go to my Dr and get happy pills when I need them.

#### **4.3 Social support mechanisms and systems available to caregivers**

The carers interviewed were able to identify and access a number of social support mechanisms and systems available to them. Some of these provided psychological and emotional support, others provided physical / practical help, and many provided both. The predominant social support mechanisms and systems were, hospitals and clinics, family and friends, churches and faith, support groups, Cape Mental Health and various NGOs.

##### *Hospitals and clinics*

All of the participants had at some stage been in contact with a local hospital and/or clinic while caring for the person with a mental illness. Even though these facilities did not always directly give support to the carer, by caring for the mentally ill person they provided support for the carer. This is explained in the following extract:

Interviewer: And do you feel though when he goes to the hospital or the clinic then they look after him properly and they help?

Participant: No they do help! Mmmm this time he's right because he's going to take injection and the tablets. – *71 year old mother*

Another participant put it this way:

We had a breakthrough at Victoria Hospital. We got the help we needed. – *51 year old sister*

##### *Family and friends*

A very important support system for caregivers are the interactions between family and friends and how they view these interactions. Most participants found that there were always certain family members and certain friends who were a valuable support system for them. They could talk freely and felt supported by these relationships, which helped them in their role as carers significantly. One mother said the following:

My family have also been helpful and they support me,  
even if they don't understand sometimes what is going on.  
– 63 year old wife

Another participant put it this way:

I have met a few people who I can talk to openly about  
my situation, (one lady), we have known each other for 4  
years now and only one day did we really share about our  
children... you can support and uplift each other. – 56  
year old mother

### *Churches and faith*

Another significant support system which carers spoke about was their faith and attending church. It seems that caregivers can draw strength and encouragement from their faith and from participation in religious activities. This is evidenced in the following quotes:

I go to church. I sing in the choir in church. I think the  
church plays a big role in my life, you know, I know there  
I get comfort, we sing, we pray and I forget about  
everything. – 59 year old sister of brother diagnosed with  
*schizophrenia*

I am a practicing Christian. I am sending prayers of love  
to... Let the healing power of their spirit run through your  
hands as you reach to touch another... I know the love of  
God, we are supporting each other and holding her up and  
faith is what we are giving her. – 63 year old mother

It was interesting that some caregivers had a strong faith and yet they found that often in the churches they were not supported as caregivers. The people and even leaders in the church were uninformed about mental illness and sometimes even made people feel guilty about having to take medication as evidenced in the following excerpt from an interview:

Participant: Some people in the new church they had never experienced this before, because in my opinion not at the time, retrospectively, they had an idea, they prayed and God heals and answers, that was the one school of thought the other school of thought is God can raise the dead therefore God can heal and not take pills, I understood that people taking medication is not believing.

Interviewer: So not having enough faith.

Participant: Ya ya, so I was in that, so I think what happened is that I needed to survive now, so I went into survival mode – *63 year old wife*

Therefore it is apparent that even though faith and religious ritual is very supportive, often religious people are ill informed about mental illness and not helpful or supportive of the caregiver.

### *Support groups*

It was very clear that almost all the participants (sixteen out of eighteen) interviewed had at some stage been to a support group or had been informed about where they could join a support group. Of those sixteen, fifteen said they found the support group very helpful and supportive. That being able to attend the support group had been beneficial to their ability to cope in their role as carers.

The support groups provide a place for psychological support, learning about mental illness and coping as a caregiver. Professional people giving talks, passing on valuable information and members just sharing their own experiences is a very supportive mechanism:

Well, I went to the bipolar support group, they are the most fantastic people, they are the loveliest people I have ever met. I value the relationship in that group and I value the collective of a whole lot of people who are working towards a generative outcome for all our health and well-being. – *63 year old mother*

It was however also evident that those carers from poorer socio-economic backgrounds, seven participants, did not feel as supported by the support groups and often had difficulty attending them due to financial or transport problems. A participant said the following about the support group she attended:

Interviewer: And the support group that you go to there... how does that work?

Participant: We go every month. I am using a taxi to go there... That is money and time.

Interviewer: And is this helpful? Do you find it helpful going there to talk?

Participant: I wouldn't say so... because other people there they don't communicate. It is good when they speak, like the social workers, then if you've got something to say then you can say... but I find out it is only 2 people who are talking only... – *59 year old sister of brother diagnosed with schizophrenia*

### *Cape Mental Health*

Special mention should be made of Cape Mental Health, the largest organisation dealing with mental health issues in the Cape Peninsula. Most participants have been or are in contact with this organisation and find it a wonderful support for themselves and the mentally ill person they are caring for.

Eleven of the participants interviewed said they felt Cape Mental Health was doing very good work in the field of mental health and were very appreciative of any involvement they had with them, as evidenced in the following quotes:

Cape Mental Health does a fantastic job you know, and they do have support groups for people when they need help. – *60 year old mother*

I think we are very fortunate to have Cape Mental Health here, they are very involved. I think their attitude to groups is very good. – *65 year old mother*

### *NGOs*

Participants reported a number of different NGOs which they made use of for support and assistance when they needed it. These ranged from places providing accommodation for mentally ill people such as Comcare, William Slater, Hope House and Abbeyfield House to those providing rehabilitation facilities such as Fountain House and the Rainbow Club.

A number of participants also went into private therapy for themselves or went to an organisation that has counselling facilities such as Hope House, as one such participant explained:

They actually just give you more tools to work with... For me now what she's doing is, for how to comfort me, how to not attack and how to not play their games. Try to withdraw and get me a quiet corner for myself. – *52 year old mother*

It is evident that there are a number of different support systems and mechanisms available to carers but some carers find them more easily accessible and more helpful than others.

#### **4.4 Challenges and barriers caregivers face in their role as carers**

All participants in the study spoke about challenges and barriers in their role as carers. The research indicates that there are two main divides: challenges tend to be concerned with the person they are caring for while barriers tend to be external factors which caregivers have

to deal with. Common challenges which carers face are: drug or alcohol use by the mentally ill person, unpredictable and disturbed thinking and behaviour, issues with medication and non-compliance, lack of person's insight, isolation and withdrawal from family life, lack of understanding from family and friends, financial problems.

Barriers, which are more external to the family unit, include: a lack of adequate medical services and facilities for the mentally ill person, a lack of support services for the caregiver, lack of suitable accommodation for mentally ill people, carers not included in the treatment team and plan, police not helpful when asked for assistance with the mentally ill person, negative perceptions of mental illness in society.

## **Challenges**

### *Drug and alcohol use by the mentally ill person*

One of the challenges ten out of the eighteen participants faced was dealing with the drug or alcohol use of the person they were caring for as this interfered with their treatment and behaviour. This was a cause of great concern and distress to many carers as evidenced in the following quotes:

It is not that bad, only when he has a drink he loses it. My problem is his alcohol. He drinks and he's mixing medication with alcohol – that is not good. That's the thing I need help for... – *59 year old sister*

He started smoking dope... then for quite awhile he stayed off everything... but then during the course of the year he was not coping, he started to smoke dope again. He said he wanted to relax, I could see he was totally stressed out! – *70 year old mother*

He actually self-medicates on dagga – *55 year old ex-wife*

### *Unpredictable and disturbed thinking and behaviour*

By its very nature, mental illness affects people's thought processes and behaviours. Caregivers found the unpredictable nature of mental illness and the often accompanying disturbed thoughts and behaviour a huge challenge to deal with. One 63 year old wife reported the following:

...then he would leave the doors open, take the car keys and drive off at high speeds. I had to learn to call the police... I knew and hoped maybe giving him extra medication, maybe calm him down, maybe do this, maybe do that, that's the time you need instant help... I tried to contain him many times...

Another caregiver told of her experience:

The big thing is actually his thinking and how he feels about people, so getting rid of that... He's very dogged. He will push and push no matter how much it hurts. So it's almost... I'll show you, if I am going to compete with you at everything then you must be my enemy... so then there was his total withdrawal. – *59 year old mother*

### *Issues with medication and non-compliance*

Thirteen of the participants spoke at some point during their interview about the challenges they face with regard to the mentally ill person finding the right medication that works for them and their struggles with the person taking their medication. Many times medication needs to be switched or adjusted before it works effectively and even once this is achieved the mentally ill person is often non-compliant. These situations involve many challenges which the carer has to deal with. This is evidenced in the following quotes:

He doesn't manage his medication and maybe if he went on, there is a lovely drug called Seroquel which is a mood stabiliser and tranquiliser at night, if he went on that, I

have tried to get him on but he said he hated it. If he was on that the down would not be so great. – *55 year old wife*

She doesn't always take medication. In fact I am never really sure if she is as she won't let me into her room. One day after a long time, she was very guarded of her room... she went to the shops and I could look in her room and I found all her medication, all neatly wrapped in bundles – 3 years of medication!! – *64 year old mother of daughter diagnosed with schizoaffective disorder*

The wellness of the mentally ill person plays such a big role in the caregiver's ability to cope that sorting out medication plays a major role in the challenges caregivers face. One mother of 70 years old explained her experience:

... And if you lucky enough to have a child or whatever that responds to the medication. But if not you know the problem is in the brain... the brain is telling them (mentally ill person) one thing and you're saying another and they don't believe you. Well they don't believe the doctor either... It just goes round and round...

#### *Lack of person's insight*

Another challenge which eight of the participants pointed out was the mentally ill person's lack of insight into their own illness and how to cope with and manage it. This causes a significant amount of stress for caregivers in their interactions with the person, as evidenced in the following quote:

They don't accept it (the illness). I told her the doctor wants to book her in for 2 weeks for depression, she say 'no!' she say she's not going to go. – *52 year old mother*

And:

Interviewer: And insight into his illness? How is that?

Participant: He has never, never understood it, nor sought to understand it... got a book and that was one of the things I over a four year period of time, maybe 2 years was trying to get him to read it... but he has never recognised or admitted to any of the symptoms that was coming on, he can't identify them. – *63 year old wife*

### *Isolation and withdrawal from family life*

A number of participants expressed their concern about the person's isolation and how they try to get the person out and at least interacting with the family. Another challenge was the mentally ill person's withdrawal from participating in family life and the general practical contributions that family members make when living together for those staying at home. This withdrawal made the carer's task considerably more demanding and exhausting. One mother explained the following:

I feel it's not working because she's crying all week and she just wants to sit and sit there... she was sitting the whole day doing nothing. She didn't even wash a cup, nothing... and now it's draining. It's draining. – *52 year old mother*

And another explained:

The other day was her father's birthday and we were having family around. She went to her room before and cried as she said she didn't want them. I said what can I do to help? She said she didn't want them to come. I said that wouldn't be possible, what else could I do? She said she wants to go to her room, yes, so she took her tablets and went to bed early. She finds lots of these things with people stressful. – *56 year old mother*

### *Lack of understanding from family and friends*

Of the eighteen participants interviewed, eleven spoke about how challenging it was managing the family and friends' lack of understanding when it came to mental illness and the issues around caring for someone who is mental ill. Some said that it was often a balancing act trying to keep everyone happy – as this mother, aged 72, of a son diagnosed with schizophrenia explained:

I think it's the worst one, not the worst (challenges or barriers), but one of them is keeping the other people in the family happy. Some people would intimate that I was controlling him. Especially family members. And I'm not one who talks to friends about such things because I feel I'm a bit of a pain.

Another caregiver said the following in this regard:

Interviewer: And what about the family? Do you think you got support from them?

Participant: No, I don't think they understand what Bipolar is... apparently his father is just pushing him down all the time and that's the thing you least need with Bipolar. – *55 year old ex-wife*

### *Financial problems*

Two thirds of the participants encountered financial problems in caring for the person with a diagnosed mental illness. This was clearly a result of the fact that of the mentally ill people being cared for only five of them were able to work and this was only in a part-time capacity. Mental illness, some more than others, is so devastating that a large number of people diagnosed struggle to work or can't work at all. This means that they are reliant on family and/or friends for financial support or receive a government disability grant which is only R1 400 per month. This small amount of money does not go very far and needs to be

added to by family and friends for people to survive. Financial problems are a major cause of increased stress for many carers as evidenced in the following quotes:

You know in a normal situation he would probably be married or in a relationship, earning his own living. There's always going to be, you know, the financial support required... – *60 year old mother*

He gets a grant and he gets his pocket money... and what does he do with that money is the problem but he goes to buy liquor. – *59 year old sister*

Think of her financially... she has never had money... my family say how can you go on and on supporting her financially, but I say if she knows that I am here and she needs money then she knows that she can ask. But it's still hard, it's terrible for her to ask. – *59 year old sister*

The impact of financial problems is a burden many caregivers have to live with and try to manage as best they can. This causes added stress on an already stressful situation.

## **Barriers**

*A lack of adequate medical services and facilities for the mentally ill person*

One of the major barriers carers face is the lack of adequate services and facilities for the person they are caring for. Linked to this is the issue of access as many of the poorer socio-economic groups find access to the already limited services difficult. This has a large impact on their ability to cope and care for the person. One participant said the following:

Interviewer: And what about your experience in terms of finding help or places for her?

Participant: Extremely frustrating, you always see different Drs or you never knew what was going on... They wouldn't tell me what was going on because I'm not the patient. You are just the sister. You've got nothing to do with her. It's confidential. And then you try and sort

something out and then you get onto a path and she would be okay for a while and then she'd go off the rails again. And then you start on the treadmill again and there would be different people there... And there's no follow-up. – *52 year old sister*

Two other caregivers reported:

The doctor actually said to me, she said, 'take him out of here, the place is not fit for humans. I said okay I will take him out. But I did follow up to see medical people coz I'm not one to leave things. They actually gave me 4 ward rounds. They organised them to put my mind at rest but it was actually worse than I had even thought. – *65 year old mother*

So we did go to J2. I found that not very helpful because its like a revolving door and every time I talk to someone else and we just went through the motions. Got the medication. – *66 year old mother*

#### *A lack of support services for the caregiver*

When asking about services for the carers themselves ten of the eighteen participants expressed a need for services which would help them to cope in their role as carers. It seemed that apart from the groups run by Cape Mental Health there was little else supporting the carers themselves. This was evidenced in the following quotes:

The social system we have is very limited. Not many services available to people. Especially the carers themselves... nothing much to support or help the carers. I didn't really find the group I went to very helpful or appropriate. – *63 year old wife*

And:

And from there I said 'it's all very well but what about me? You're not giving me any help!' And then the Dr said 'Oh, didn't they tell you...' so nobody had even told

me about mental things. – *66 year old mother of son diagnosed with schizophrenia*

It appears that not even the hospitals and clinics provide adequate support for carers.

*Lack of suitable accommodation for mentally ill people*

Half of the carers interviewed reported a serious lack of adequate accommodation for mentally ill people. Of the participants interviewed 13 had the mentally ill person they cared for permanently living with them, mostly because of financial constraints and the lack of appropriate accommodation available for those suffering from mental illness. This is evidenced in the following quote:

I think the worst part was looking for accommodation because it was so terrible. Then we went to look at other places and I said to him; “okay, you choose where you want to live. Because you know I didn’t know how we were going to finance it but anyway we found private accommodation in Wynberg. – *72 year old mother*

Another mother said the following:

I want him to stay on his own. So that if he stays on his own he can see the value of that money. I can’t anymore... The social worker she say it’s full. There’s no place. That’s what she said. But only if somebody dies or when somebody moves or when a family member decides okay we are not going to have you in this place or whatever the case may be and then it’s like a waiting list. That is the thing! – *51 year old mother*

Participants also expressed great concern about where their charges would stay if something happened to them, the caregiver, and they were no longer around or able to care for the mentally ill person. A lack of appropriate accommodation made this even more overwhelming for carers to consider.

### *Carers not included in the treatment team and plan*

Almost half the carers felt very frustrated and powerless over the well-being of the person they were caring for because they were not included in the person's treatment plan. This was regarded as counter-productive by those carers who actually wanted to play an active part in the mentally ill person's recovery or well-being.

One of the participants, a mother aged 56 years, explained the following:

It's true the care giver does need to know, okay I know there is patient doctor confidentiality but at some stage you need to be filled in after an issue... Okay how is she doing? At least something... It needn't be a breach. She didn't know what medication she was taking, and why, and yet I was the one giving her the medication. And yet I wasn't included.

Another carer reported the following:

I wrote to the psychologist and I wrote to the doctor to appeal to them, please speak to me, I need to know what is going on, please... They didn't come back to me. I don't want to know every detail of what she says. If only we could come together to help her ... – *64 year old mother*

It is clear that very often caregivers are excluded from and not even informed about the cared for person's treatment plan.

### *Police not helpful when asked for assistance with the mentally ill person*

This was a barrier a quarter of participants pointed out. Often when the carer needed help with a psychotic person and had to call the police for assistance, they found the police to be totally inefficient and unprepared or ill prepared to give appropriate help.

A mother (aged 64 years) who called the police to help her get her psychotic daughter to hospital explained the following:

...another thing with the police. I had to call them to come... They were totally uninterested and they weren't very helpful or supportive. They came to the house, a woman and a man and they tried to talk to her. But didn't help so they thought of calling the paramedics but she wouldn't go with them but said okay she would go with me... and they then decided to just leave. I said to the guys, don't go, just go a bit further down the road because it's a long way to the hospital. She might just open the door and jump out. So please follow me... They said they would wait but they didn't – they just left me and I thank God that I got there (to hospital) okay.

Another said:

It was so stressful. We actually had to go to the police station to the district surgeon, he was in the van and we were driving behind and when we got to the trauma unit he was sitting in the back of the van. The police were nowhere and he was in this locked van. They came back ages later. – *65 year old mother*

#### *Negative perceptions of mental illness in society*

One of the other barriers mentioned quite frequently was the negative perceptions people have of those with mental illness and how this often became an obstacle for carers in their caring role. This is evidenced by the following quotes:

One of the major challenges or barriers is the limited understanding of mental health. People hear bi-polar, schizophrenia and they totally shut down. You would think they have now gone into Dante's Hell, they are so frightened. – *63 year old mother*

And:

You know the problem with this issue (mental illness) is... the first thing people think of is that the person is going to murder him. You know, this is a lunatic that is going to harm you. – *59 year old mother*

These perceptions become barriers which prevent the carer from trying to function as typically as possible with a mentally ill person in their care.

#### **4.5 Perceptions of services available to carers**

The perceptions carers had of the services available to them seemed to overwhelmingly concur: there are not enough services to meet the needs of carers. The services that are available are of an acceptable standard but often one has to wait a long time for them. However carers who made use of NGOs reported some availability of helpful services which they have access to.

##### *Poor availability of services*

Almost all participants except one reported a poor availability of services but those at the hospitals and clinics were of an acceptable standard. These services are those offered by the government to people with mental illness and thus indirectly to the carers themselves. The carers interviewed did not find any support for themselves at the government institutions but had to go to NGOs in order to receive any form of help for themselves. Two carers said the following in this regard:

These organisations who are meant to help don't really. I feel I am fighting to get any help... its tiring always fighting, The social services are not good and to get things done takes a long time, it can go on and on. – *51 year old mother*

There are not many services available to people.  
Especially the carers themselves... not much to support or  
help the carers. – *63 year old wife.*

Another mother spoke of how only after her daughter had renal failure due to high lithium levels, which had not been checked, did they get the help they needed:

After not getting the help we needed we moved on at  
Groot Schuur J2 and found a good Dr for her. I found the  
people at J2 a huge support, they are interested and have  
helped her. – *56 year old mother*

### *Quality of government services and facilities*

The perceptions in this regard seemed to vary quite widely. Most participants did express concern about the conditions of hospitals but said medical care was generally good.

Carer: They organised a tour for me. The doors had big holes in them, toilet doors because the people kicked them in and whatever. They had half done plumbing up in the corner, in the shower area. They all had different mattresses, every single one, as if all the condemned mattresses from other hospitals had landed up there. Can you imagine? The reception area of solitary wards and the passage way had holes in it and it was up on the first floor!

Interviewer: Well, I see now at last they are doing some renovations at Valkenberg.

Carer: Oh a great deal is needed. – *65 year old mother*

Another participant reported the following:

The worst part about Valkenberg was, it was not the people, the doctors and staff were fantastic, but it was the old wards, the facilities... – *60 year old mother*

And regarding the care that patients received:

Sometimes they (clinic nurses) go by the house and see him there, they give him the injection there, they go back by his flat, at the back and give him injection there. – *48 year old sister.*

#### *Helpful support and services from NGOs*

Almost all participants reported that they had at some stage made use of services to help them in their role as caregivers from an NGO. They had mostly asked for the help or been directed to seek help by others at these NGOs. In particular and worth noting was the valuable help eleven of the participants received from Cape Mental Health. Cape Mental Health runs support groups for carers and helps administer grant money to those diagnosed with mental disabilities who need assistance.

I think we are very fortunate to have Cape Mental Health here, they are very involved. I think their attitude to groups are very good. – *65 year old mother*

I say they are helping me there by Cape Mental Health with the money. Then what they do at Cape Mental Health is give him the money on different days. – *71 year old mother*

At Cape Mental Health they said everybody must go first to Valkenberg to get the injection and his tablets then he can go from Valkenberg to Cape Mental Health to get his money. He gets his money twice a month. That is why, how they help me. And the group, I think it's alright to come here and talk with people, then I can just relax and forget about my problems at home. – *48 year old sister*

Other carers did make use of other organisations such as Hope House, the Drug Counselling Centre and private psychologists to help them cope.

### *Shortage of suitable accommodation*

Half the participants perceived the accommodation available to mentally ill people to be inadequate and in huge demand. In some cases where private accommodation is available it is very costly and too expensive for most people to afford. This is problematic as caregivers have no relief or end in sight in their caring role if the person lives with them. They feel that the possibility of the person being able to live elsewhere is almost non-existent. The experience of two mothers when looking for accommodation was as follows:

We had to get accommodation for him. I contacted Comcare and they didn't have anything. And I went to all sorts of horrible places... and you discover these hell-holes of accommodation... and I couldn't do that to him. That took a while (finding accommodation) I think he went into Rosebank Court about 3 years into his illness. I think the worst part was looking for accommodation because it was terrible. – *72 year old mother*

The lack of, you know, accommodation, different types, because you know there should be! There should be much more infrastructure. We have gone the whole route of him living somewhere else. It can work well, then towards in the end he wasn't really participating anymore... And it was costing an arm and a leg so we took him out. It was not a great idea because what of the future? We keep thinking of the future, we have to look for alternatives. – *70 year old mother*

And another carer whose sister lived in a group home said:

A nurse, I think she could see the look of desperation on my face and she helped... I told her that I have to get my sister in somewhere safe and she gave me places names. I went to Comcare, they said my sister was too old but they maybe had a space for her. I didn't hear from them. I kept phoning them. After quite a while she got in... a place she can afford as how am I going to support her without it affecting our income of the family.

Comcare take a percentage of her income... she also  
needs to house sit and make cards and things for extra  
money – *52 year old sister*

It is evident that the shortage of adequate, affordable accommodation is an added  
burden which caregivers face.

## CHAPTER 5: DISCUSSION AND CONCLUSION

### 5.1 Discussion

The findings in this research study show that caregivers experience large amounts of stress and have to cope with many challenges in their role as carers. As a result they employ a variety of coping mechanisms. They also come across a number of barriers which make their task as caregivers even more difficult.

It should firstly be noted that in this study all participants were female and of those women 17 were over 50 years old. The findings that an overwhelming majority of caregivers are women and over the age of 50 years is consistent with studies done by Ho et al., (2005), Seloilwe, (2006) and Solomon & Draine, (1995). All the caregivers in this study cared for a family member diagnosed with either schizophrenia, bipolar disorder and/or schizoaffective disorder.

A number of coping mechanisms which carers use are: making use of services and facilities available, working or keeping busy, taking time out for themselves, listening to others' experiences, educating themselves about the illness, relying on family and friends, using the challenges to grow and taking one day at a time. Some of the negative coping mechanisms were: taking complete control of the situation, ignoring the person, verbal or physical abuse, isolating themselves, using medication.

In this study one of the overwhelming coping mechanisms which carers used was making use of services and facilities available to them, especially attending support groups. This was particularly true for those who were better educated and from middle to upper socio-economic groups. This finding is consistent with the study done by Huang et al.,

(2008), which also found carers from better educated classes would seek information about mental illness and join support groups. The use of services and facilities include a variety of options from finding the right doctor for the person they are caring for, talking to helpful staff at facilities, to attending groups.

In this research, social supports can be seen as significant mediating factors in helping carers cope in their caregiving role. Both informal social support – such as friends and family, faith or religious affiliations and listening to other people’s stories – and formal social support – such as groups and help from mental health care professionals – played a significant role in the carers’ ability to cope. These findings are also consistent with those of Huang et al., (2008) and Solomon & Draine, (1995) where use of social support is shown to be an effective coping mechanism.

The physical and behavioural coping mechanisms of keeping busy, using medication and taking time out for themselves were also mechanisms consistent with Huang et al.,’s (2008) study where they found these to be common coping mechanisms. Cognitive coping mechanisms which that study and this one also have in common are positive thinking (using challenges to grow) and information seeking. Psychological coping mechanisms such as denial were evident in this study but not significantly; more significant was the evidence that taking one day at a time and being patient helped carers cope in their caring role. Those caregivers who used more control in the relationship and had intense emotional reactions such as cutting off emotions or resorting to verbal abuse were those who were not coping as well as the others. This is also consistent with finding in studies done by Huang et al., (2008) and Solomon & Daine, (1995) where it was evident that reactions with an emotional focus were not effective coping mechanisms. Two other negative coping mechanisms which were

fairly common were ignoring the mentally ill person and the caregivers isolating themselves. These findings will add to the body of knowledge of caregiver coping mechanisms.

In the study only three carers admitted to taking medication in order to help them cope. This number could be more as not all participants may have felt comfortable enough to share such information; this links with the study done by Huang et al., (2008) and Magliano et al., (1998) where they found carers used a variety of substances to help them cope.

One coping mechanism which Huang et al., (2008) found in their study was how many carers from low socio-economic groups took those they cared for to traditional healers first before going for psychiatric help. In this study only one of the three black carers who came from a traditional low socio-economic background went the same route. However this may be more prevalent and further research should be done in this area.

Also worth noting in this study are the coping mechanisms of ignoring the person who is mentally ill and the carers isolating themselves, which were reported by carers who found themselves struggling to cope. There is a gap in the literature around coping mechanisms positive and negative, in the South African context. These findings therefore add to the body of knowledge in this area and can help improve mental health care professionals' awareness in their work with carers.

This study found that social support was an overwhelming mediator in the caregiver's ability to cope in their caring role.

In terms of formal social support all participants had at some stage connected with formal social support systems, such as hospitals, clinics and/or mental health organisations. Although not always satisfied with the support they got, most found that the support they had received had been helpful. Informal social support such as family and friends, community

members, and religious affiliations were also viewed as a positive source of support for carers. This is consistent with the studies done by Duner et al., (2012), Dunkel-Schetter, Folkman & Lazarus (1987) and Greene et al., (2003) where social support was found to assist those caring to cope.

In this study those carers involved in the Cape Support for Mental Health group (six participants) all reported significant benefits from belonging to this support group. Not only did they receive emotional support but also valuable information about mental illness, helping them feel better equipped and supported in their role as carer. This is linked to research done by Duner et al., (2012) and Solomon & Draine, (1995) where social support including group membership helped reduce the subjective burden of caregivers.

Another significant social support reported in this study was the role Cape Mental Health played in assisting carers in a variety of ways from support groups in local communities, mostly low socio-economic groups, to helping administer disability grants – which carers found very helpful. This organisation's help to carers highlighted the lack of help from other organisations and the need for additional assistance as they themselves have limited resources. Carers in general felt that there was not enough support for them. This finding is consistent with the findings of Rudnick (2004) and Williams et al., (2007) where a lack of adequate resources and support for carers was recorded.

Other areas which this study investigated were challenges and barriers carers face in their role as carers. This study found a number of challenges that caregivers face, the most common being: drug or alcohol use by the mentally ill person, unpredictable and disturbed thinking and behaviour, issues with medication and non-compliance, lack of mentally ill person's insight, isolation and withdrawal of the mentally ill person from family life, lack of

understanding from family and friends, financial problems. In general these challenges place a strain on the carers' ability to manage the consequences of their relative's mental illness. These findings link with those in a study done by Solomon & Draine (1995). The financial challenges are consistent with studies done by Ho et al., (2005) and Rudnick (2004). A number of barriers were also identified, which were: a lack of adequate medical services and facilities for the mentally ill person, a lack of support services for the carer, lack of suitable accommodation for mentally ill people, carers not included in the treatment team and plan, police not helpful when asked for assistance with the mentally ill person, negative perceptions of mental illness in society. These barriers make caring harder and more stressful for the caregiver. Some of them are also consistent with difficulties experienced by carers in studies done by Crowe & Lyness, (2014), Huang et al., (2008) and Seloilwe, (2005).

Another area which was investigated in this research included the perceptions carers have of services and/or facilities available to them. This is an important area to consider as it will directly affect the carers' ability to cope and influence which coping mechanisms they use. With regard to the carers' perception of available services and facilities, this study found that carers reported there are not enough services to meet their needs. The services that are available are generally of an acceptable standard, but are scarce and often have long waiting lists before they become accessible. A problem which was expressed by caregivers was the conditions of some facilities. They found them to be in a poor condition; however in general the staff were well trained and professional. Carers did report that most times mental health care workers were more concerned with the mentally ill person than the carer. It seemed that a positive perception of services and facilities correlated with an increased ability to cope. This is consistent with a study done by Crowe & Lyness, (2013) and reported by Williams et al., (2014) and therefore warrants further investigation. In particular participants in this study

who attended the Cape Support for Mental Health Group seemed to have a better perception of services and facilities and in turn coped better. This may be because they obtained valuable information about services from the group and felt more supported in their interactions with services and facilities. This would be consistent with findings by Huang et al., (2007) and Solomon & Draine (1995) who found that psychoeducation helped carers cope.

In terms of theory linked to this research, the findings show that the process of caregivers looking after mentally ill family members can be viewed from a resilience theory perspective. Most carers experience disruptions on and off when caring for a mentally ill person; they have to adapt and adjust over time and if this is done successfully they manage to adapt positively using positive coping mechanisms (Fletcher & Sarkar, 2013). In this research this was evident in carers' use of coping mechanisms such as: making use of services and facilities available, working or keeping busy, knowledge of mental illness, support from family and friends, faith, finding the right doctor for the mentally ill person, support from hospital or clinic staff, looking after self and using challenges to grow, having lots of patience, taking one day at a time, listening to others' stories. These carers were able to overcome and handle the difficulties they faced, showing resilience as put forward by Fletcher & Sarkar (2013); Greene et al., (2003) and Van Breda (2001).

Caregivers who were not coping tended to use negative coping mechanisms, leading to lower level functioning. They used destructive behaviours which in this study were: ignoring the mentally ill person or cutting off emotions, taking on all responsibility for the mentally ill person or controlling them, using verbal threats or abuse, isolating themselves and using medication to cope. These findings are consistent with the resilience theory put forward by Richardson and colleagues as outlined in Fletcher and Sarkar (2013), where both adversity and positive adaptation indicate resilience. These findings link to the stress and

coping theory proposed by Lazarus (1993) where the way in which a person appraised a situation would depend on how they coped with the situation. In this study, carers whose primary appraisal led to coping by information seeking and direct action, tended to cope better; while those who did not felt incapacitated and more stressed trying to cope. These findings link to studies done by Huang et al., (2007), Rudnick (2004) and Johnson (2000) which connect perceived burden and stress to modes of coping.

This research was also able to determine that social support plays an integral role in the carers' ability to cope with their caring role. Social supports which carers in this study found valuable were: hospitals and clinics, family and friends, churches and faith, support groups, Cape Mental Health and various NGOs. The degree to which these social support systems were perceived or actual could not be measured in this study but it was apparent that those carers who spoke positively about their social support systems appeared to be coping better. These findings are consistent with the theory of social support put forward by Lakey & Cohen (2000) where they propose that appropriate social support reduces stress and helps people cope in response to adversity. These findings link to studies which also support this theory done by Duner et al., (2011), Schock-Giordano (2013), Solomon & Draine (1995) and Dunkel-Schetter, Folkman & Lazarus, (1987).

Limitations of this study should also be kept in mind due to the fact that sampling was not representative of all the caregivers in the greater Cape Town area and because of the qualitative nature of the research.

## **5.2 Conclusion**

This research has highlighted the many coping mechanisms carers use in their role as carers and the challenges they face. What was of particular interest was the important role social support plays in the carers' ability to cope and in the way they frame their situation. Those who connected with social support systems were coping better with their situation than those who remained isolated. It was also clear that those carers who were in contact with social support systems used more positive coping mechanisms and felt they had support in their caring role. Those carers from poorer socio-economic communities seemed less able to connect with social support systems, used more negative coping mechanisms and seemed to struggle more with caring. These carers are in need of a variety of formal systems which provide healthcare and social support to both the person in need of care and the caregiver. The role Cape Mental Health and local clinics play in these poorer communities is very valuable and helpful to carers; however there is a serious lack of services to support carers themselves.

Overall, caregivers face many challenges and the stress of caring for a mentally ill person is often overwhelming. The challenges and stress carers face makes it harder for them to cope. Further research into the carer's own health, both physical and psychological, is needed in order to provide essential services for their well-being. A growing body of evidence shows that these caregivers play a crucial role in the mentally ill person's general well-being, functional independence and relapse rate (Williams et al., 2014) – thus looking after caregivers is essential. The evidence that carers are more likely than non-carers to have health problems has started to be reported (Ho et al., 2005) but needs further investigation, especially in the South African context.

This study was limited in a sense by the fact that most participants were members of some support group. Due to the snowballing sampling method group members generally gave the researcher other group members' contact details. Further study therefore needs to be done with carers who are not members of a support group as it would seem that these carers will be experiencing more stress, and struggling more, than carers in support groups. In order for mental health workers to adequately address caregivers' needs, the carers who are more isolated need to be considered.

There is a growing awareness, worldwide, that carers are a valuable and essential part of the mental health care system. Carers play an essential role in a mentally ill person's ability to live within a community and yet the focus of care is mostly on the mentally ill person. Therefore further research needs to be done around caregivers' needs and ways that would help support their well-being. It is hoped that those in the mental health care field would gain insight from the findings in this study with regard to carers' coping mechanisms and challenges, as well as their perceptions of services and facilities, in order to provide appropriate support. The researcher would suggest that further research with the family unit as a whole should be done in order to provide a broader understanding of the family's experience of caring for a mentally ill person.

As there is no clear policy for carers in South Africa this research would also recommend that this area is looked into by policy makers and that they develop a clear policy around the issue of family or informal carers. To develop such policies further research is needed around carers' roles, needs and experiences. This research contributes to the body of knowledge required to do this and will provide the evidence for mental health care workers to effectively provide appropriate interventions and support to persons with mental illness.

Further research is needed into the area of carers' coping mechanisms and effective support systems as this will help mental health care workers implement effective interventions. It will also help direct policy making which is becoming more essential in this field. A clear health care plan or policy for carers will ensure that services to them are more effectively provided and that there is a level of accountability in providing these services.

Research into the carers' experience will also help direct health care professionals' attention towards the importance of carer well-being and not only towards the person diagnosed with a severe mental illness. Research is also recommended within organisations who provide mental health care services, focusing on services to carers, in order to help advance the implementation of further carer support and interventions.

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## APPENDICES

### APPENDIX A:

#### PRESENTATION TO CAPE MENTAL HEALTH

Lynne Hogan: Clinical Masters Social Work student at UCT

#### **Research Topic: An Exploration of the Coping Mechanisms of Carers caring for persons diagnosed with a severe mental illness.**

#### **Key terms:**

*Coping mechanisms:* are what a person does and thinks in response to an event or situation, thus dealing with events or situations with varying degrees of success (Haung, et al., 2008).

*Carers:* those family or community members who take the primary responsibility for the psychological and physical wellbeing of the person diagnosed with a mental illness.

*Severe mental illness:* for the purposes of this research severe mental illness or serious mental illness includes major depression, schizophrenia, bipolar disorder, obsessive compulsive disorder (OCD), panic disorder, posttraumatic stress disorder (PTSD) and borderline personality disorder, all diagnosable in the DSM V (2013).

(Taken from the National Alliance of Mental Illness, 2012)

#### **Background:**

Social workers need to provide support and interventions that are appropriate and helpful to their clients. In the Mental Health Care field this means all those affected with Mental Disability and those involved in their care and management.

Having worked in the mental health field (Fountain House and schools/private counsellor) I have seen how stressed, confused and exhausted caregivers often are when caring for a person with a severe mental illness. The mental health of caregivers is critical to the wellbeing, care and relapse rate of those diagnosed with a severe mental illness.

Understanding the coping mechanisms caregivers use when caring for a person with a severe mental illness diagnosis, will guide and inform best practice. There is little research in this area for practitioners to base their interventions on.

This study hopes to contribute to a better understanding and knowledge of the coping mechanisms caregivers employ and provide significant information to guide intervention within our South African context.

It will also add to a body of knowledge which can help policy makers implement effective services for those carers and families affected by severe mental illness.

**Specific objectives:**

- Examine the coping mechanisms of persons caring for people diagnosed with a severe mental illness
- Identify the support mechanisms / services available to caregivers of persons diagnosed with a severe mental illness.
- Explore what coping mechanisms caregivers find most helpful.
- Identify harmful/maladaptive coping mechanisms caregivers use to cope when caring for a person who has a severe mental illness diagnosis.
- Identify challenges/barriers to providing care to people with a severe mental illness diagnosis.

**Research Design:**

This will be a qualitative and exploratory research.

Qualitative research is suited to the subject of caregivers coping mechanisms because it lends itself to the study of social processes over time which is a way in which coping theory is viewed.

The population needed will be a sample of individual caregivers who care for a person/s with a severe mental illness (specified by the DSM V). A sample of about 15 people is needed to engage with in face-to-face interviews and focus groups to help improve the reliability and validity of the findings. Both methods of data collection will involve the use of semi-structured or guided question schedules. Interviews will be conducted by the researcher who is fluent in English and Afrikaans. For Xhosa or Zulu caregivers an assistant interviewer will

need to be trained (See Appendix C) to conduct the interviews, in order to improve translation validity and minimise interviewer bias. The researcher will provide and train an assistant for this. One or two focus groups will be conducted by the researcher (or assistant) in order to add to data collection and clarification of the information from the face-to-face interviews.

All data collected will be securely saved on a password access only folder which only the researcher and her supervisor will know, to ensure confidentiality.

### **Ethical considerations:**

All the necessary approvals will be obtained from the University and the Organisation to make sure ethical requirements are met. This will ensure that participants are protected and data can only be collected once approval has been received.

*Voluntary participation and Informed consent:* The researcher will develop a consent form which explains to each participant what the researcher is researching. It will state that participants are participating freely, will not be harmed in any way and what will be done with all the information. Participants will be asked to sign the consent form or if they cannot write they can put their thumb print on the form.

*Confidentiality:* Any information obtained will not be submitted to any case files the organisation may have regarding that family or person the carer cares for. Participant's identity and personal information (except gender, age and general area where they reside) will be protected, their names will not be put on any transcriptions. The only information needed about the person the carer cares for will be their mental illness diagnosis, relationship to the person, gender and age.

*No harm:* Due to the sensitive nature of the research, painful material may surface during the interviews, follow-up counselling will be provided by someone organised by the researcher. If the person is disturbed by something that has come up during the interview the interview will be terminated and appropriate counselling organised for the participant.

I wish to undertake this research from July to September 2014 if everything is approved and ready for implementation. The research findings will be made available to your organisation so that social workers can use them to inform best practice.

Thank you for your consideration.

## APPENDIX B

### *INFORMED CONSENT*

*The aim of this form is to facilitate informed consent by communicating with participants in language that they can understand.*

#### **Information Sheet**

**Purpose of the Study.** As part of the requirements for my Clinical Masters in Social Work, I have to carry out a research study. The study is concerned with how caregivers, of severely mentally ill people cope in different ways with the all the demands and challenges they face.

**What will the study involve?** The study will involve a 60 to 90 min interview and a follow up focus group session.

**Why have you been asked to take part?** You have been asked because you are specifically or generally suitable to provide the information I am looking for in my study.

**Do you have to take part?** No, participation is voluntary. *(I will explain about signing a consent form. Ideally they get to keep the information sheet and a copy of the consent form. Participants will be told that they have the option of withdrawing before the study commences (even if they have agreed to participate) or discontinuing after data collection has started. Where data are identifiable (e.g. from interviews yielding qualitative data), it's useful to allow for afterthoughts by letting them withdraw within two weeks of participation and ask to have their data destroyed. This will all be explained and will be put in writing in the consent form.)*

**Will your participation in the study be kept confidential?** Yes. I will ensure that no clues to your identity appear in the thesis. Any extracts from what you say that are quoted in the thesis will be entirely anonymous.

**What will happen to the information which you give?** The data will be kept confidential for the duration of the study. On completion of the thesis, they will be retained for a further six months and then destroyed.

**What will happen to the results?** The results will be presented in the thesis. They will be seen by my supervisor, a second marker and the external examiner. The thesis may be read by future students on the course or students studying similar topics. The study may be published in a research journal.

**Focus groups:** These provide a particular challenge to confidentiality because once something is said in the group it becomes common knowledge. I will encourage group participants to respect confidentiality, but that I cannot guarantee it.

*(For example: We will ask you and others in the group not to talk to people outside the group about what was said in the group. We will, in other words, ask each of you to keep what was said in the group confidential. You should know, however, that the researcher cannot stop or prevent participants who were in the group from sharing things that should be confidential.)*

*Example of question to elucidate understanding: Did you understand the procedures that we will be using to make sure that any information that we as researchers collect about you will remain confidential? Do you understand that the researcher cannot guarantee complete confidentiality of information that you share with us in a group discussion. Do you have any more questions?*

**What are the possible disadvantages of taking part?** I don't envisage any negative consequences for you in taking part. It is possible that talking about your experience in this way may cause some distress.

**What if there is a problem?** At the end of the interview, I will discuss with you how you found the experience and how you are feeling. If you subsequently feel distressed, you should

contact.....[e.g. *the investigator, Cape Mental Health – give contact details - or their GP*].

**Who has reviewed this study?** Approval must be given by the Department of Social Development before studies like this can take place. I have also had approval from the organization you are associated with.

**Any further queries?** If you need any further information, you can contact me: [*Name, mobile number, email address. To protect my own privacy, this information will be deleted from the finished thesis*].

If you agree to take part in the study, please sign the consent form below:

**APPENDIX C**

**Consent Form** (available in English and Afrikaans)

I.....agree to participate in Lynne Hogan's research study.

The purpose and nature of the study has been explained to me in full.

I am participating voluntarily.

I give permission for my interview / focus group with .....to be tape-recorded.

I understand that I can withdraw from the study, without repercussions or negative consequences, at any time, whether before it starts or while I am participating.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by not using my name

I understand that disguised extracts (as my name will never be used) from my interview may be quoted in the thesis and any subsequent publications if I give permission below:

(Please tick one box :)

I agree to quotation/publication of extracts from my interview

I do not agree to quotation/publication of extracts from my interview

Signed.....

Date.....

## APPENDIX D

### Interview schedule:

Date:

Introduction of interviewer: I am ..... from.....

Male / Female:

Age:

Address:

Relationship to mentally ill person:

Diagnosed illness of person being cared for:

Thank you for agreeing to have this interview.

a). Explanation of study to participant:

We are conducting research into the coping mechanisms of caregivers caring for persons diagnosed with a mental illness. This study is being done in Cape Town.

b). Explanation of consent form and signing thereof. Any questions a participant has must be answered fully.

c) Please feel free to talk openly. If you feel uncomfortable talking about something, or would rather not answer a question, please tell me. You do not have to answer questions if you do not want to.

d) Time: The interview will take up to an hour and a half... If you are tired, or need to stop and do something else, please tell me and we can take a break.

e) Confidentiality: Everything said in this interview will be treated as confidentially as possible by the researcher. When reporting is done on the interviews no names will be used so that everybody remains anonymous.

f) **Recording:** Do you mind if I record this interview? It's only for research purposes. That way I don't have to write down lots of notes while we talk. Nobody except the researchers will listen to the recording. [Wait for the participant's response.] Please speak clearly so that we can hear what was said on the tape.

g) **Test recording:** Before we start, I would like to make sure that the tape recorder is working properly. (Interviewer: start recording: say your name and the date, and say something light-hearted – like an observation about the weather today. Ask the respondent an innocuous question to get their voice –or ask about their age and occupation sitting in their natural position where they will sit for the interview. Stop the recording and play back to make sure it is working and that we can hear both your voices.)

Start recording

(Make sure that you position the tape recorder so that your voices are still audible, even if you are looking down at the paper. Make notes of the answers as much as possible in the spaces provided)

## INTERVIEW GUIDE

1. How long have you been looking after the person with a severe mental illness?
2. How would you describe the way you deal with or manage looking after the person diagnosed with a severe mental illness?
3. How would you describe your experience as a caregiver? Give examples.
4. Do you consider your role as caregiver stressful or difficult in any way?
5. What do you find rewarding or satisfying about your role as caregiver?
6. Does anyone help you with the caring? How does this affect how you feel about and manage your role as caregiver?
7. What do you use as or for support in your role as caregiver?
8. Which of these supports do you find most helpful and why?
9. Which coping strategies do you find most helpful in your role as caregiver?

10. What are the challenges / barriers you often face when caring for this person?

11. Do you feel there are adequate services provided to support you?

Conclusion:

We have come to the end of the interview. Is there anything you would like to add which you feel may benefit this research?

Thank you for your time and participation.

Observations:

After the interview, write up your notes and observations:

Interview process

- What was the dynamics of this interview? Was it an easy or a difficult interview? Why?
- Was there anyone else present during the interview? If so, what effect did you think this had?
- Was there anything else that should be taken into account in the analysis?

## APPENDIX E

### Onderhoud skedule:

Datum:

Bekendstelling van onderhoudvoerder: Ek is ..... van .....

Manlik / Vroulik:

Ouderdom:

Adres:

Verhouding tot geestesongestelde persoon:

Gediagnoseerde siekte van persoon versorg:

Dankie dat u ingestem het om hierdie onderhoud te hê.

a). Verduideliking van studie aan deelnemer:

Ons is besig met 'n ondersoek na die hanteringsmeganismes van versorgers wat versorging verskaf aan persone gediagnoseer met 'n geestelike siekte. Hierdie studie word in Kaapstad gedoen.

b). Ondertekening en verduideliking van toestemmings vorm. Enige vrae van 'n deelnemer moet ten volle beantwoord word.

c) Voel asseblief vry om openlik te praat. As jy ongemaklik voel om oor iets te praat, of liewer nie 'n vraag wil beantwoord, vertel my asseblief. Jy hoef nie vrae te beantwoord as jy nie wil nie.

d) Tydsduur: Die onderhoud sal tot 'n uur en 'n half duur ... As jy moeg is, of nodig het om te stop en iets anders doen, sê asseblief vir my en ons kan 'n blaaskans neem.

e) Vertroulikheid: Alle inligting in hierdie onderhoud sal vertroulik as moontlik behandel word deur die navorser. Wanneer rapportering gedoen word oor die onderhoudsal geen name gebruik word sodat

almal anonym bly.

f) Opnames: Gee jy om as ek hierdie onderhoud opneem? Dit is net vir navorsing doeleindes. Op dié manier hoef ek het nie baie notas neer te skryf terwyl ons praat. Niemand behalwe die navorsers sal na

die opname luister. [Wag vir die deelnemer se reaksie.] Praat asseblief duidelik sodat ons kan hoor wat gesê is op die band.

g) Toets-opname: Voordat ons begin, wil ek graag seker maak dat die bandopnemer reg werk. (Onderhoudvoerder: begin opneem: sê jou naam en die datum, en sê iets lighartige - soos 'n waarneming oor die weer vandag, of vra die respondent 'n onskadelike vraag om hul stem te kry, of vra oor hul ouderdom en beroep terwyl hulle in hul natuurlike posisie sit waar hulle sal sit vir die onderhoud. Stop die opname en speel dit terug om seker te maak dit werk en dat jy albei steme kan hoor.).

Begin opname

(Maak seker dat jy bandopnemer plaas sodat julle stemme nog hoorbaar is, selfs as jy neerkyk op die papier. Maak aantekeninge van so veel as moontlik van die antwoorde in die spasies)

## ONDERHOUD GIDS

1. Hoe lank versorg jy al die persoon met 'n ernstige geestelike siekte?
2. Hoe sal jy beskryf hoe jy aangepas het om na die persoon wat gediagnoseer is met 'n ernstige geestelike siekte te versorg?
3. Hoe sal jy jou ondervinding as 'n versorger beskryf? Gee voorbeelde.
4. Dink jy jou rol as versorger is stresvolle of moeilik?
5. Wat vind jy lonend of bevredigend in jou rol as versorger?
6. Is daar iemand wat jou help met die versorging? Hoe raak dit hoe jy voel oor jou rol as versorger?
7. Wat gebruik jy as of vir ondersteuning in jou rol as versorger?
8. Watter van hierdie steun vind jy die mees nuttigste en hoekom?
9. Watter strategieë doen jy die meeste nuttig in jou rol as versorger?
10. Wat is die uitdagings / struikelblokke wat jou dikwels in die gesig staar wanneer jy die persoon versorg?
11. Voel jy daar is voldoende dienste verskaf om jou te ondersteun?

Slot:

Ons het aan die einde van die onderhoud gekom. Is daar enige iets wat jy wil byvoeg wat jy voel kan hierdie navorsing baat?

Dankie vir jou tyd en deelname.

Waarnemings:

Na afloop van die onderhoud, skryf op jou notas en waarnemings:

Onderhoud prosess.

- Wat was die dinamika van hierdie onderhoud? Was dit 'n maklike of 'n moeilike onderhoud? Hoekom?
- Was daar enige iemand anders tydens die onderhoud teenwoordig? Indien wel watter effek dink jy dit het?
- Was daar enigiets anders wat in ag geneem moet word in die ontleding?