## MIDLANDS STATE UNIVERSITY



## **FACULTY OF SOCIAL SCIENCES**

## DEPARTMENT OF PSYCHOLOGY

# EXPERIENCES OF COMPASSION FATIGUE AND CAREGIVER BURDEN AMONG FAMILIAL CAREGIVERS OF RELATIVES WITH SCHIZOPHRENIA BY SITHANDEKILE MOYO

## R144128N

A DISSERTATION SUBMITTED TO THE FACULTY OF SOCIAL SCIENCES IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE BSc HONOURS DEGREE IN PSYCHOLOGY

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## APPROVAL FORM

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## **DEDICATION**

Dedicated to the memory of my father, Dr Phinot Moyo who always believed in my ability to be successful in the academic arena. You are gone but your belief in me has made this journey possible.

To my mother, Mrs Sibongile Moyo and to my siblings Gugulethu, Thobekile and Mthokozisi, this humble work is a sign of my love to you.

## **ACKNOWLEDGEMENTS**

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I acknowledgement and cherish the support that I received from my family, my mother Mrs Moyo and my siblings I would not have done this without them. I recognize the support of my friends and roommates, words cannot say it all may God richly bless you all. Appreciation also goes to all the participants who shared their experiences with me.

## **ABSTRACT**

The study sought to examine the experiences of compassion fatigue and caregiver burden among familial caregivers of relatives with schizophrenia. The objectives of the particular study were to understand familial caregivers lived experiences with compassion fatigue and caregiver burden, to identify the perceived predictors of caregiver burden, how caregivers cope with the challenges of caregiving and to recommend possible measures that could be implemented to assist caregivers and reduce family burden. A descriptive phenomenological research design was used to describe the experiences of compassion fatigue and caregiver burden encountered by familial caregivers and heterogeneous sampling was used to select study participants. The sample was made up of 7 participants who constituted of 4 females and 3 males. The age range of these participants was between 24-58 years. Data was collected using a qualitative approach were semi-structured interviews were used as the main tool to gather data. Data was analyzed using thematic analysis and Giorgi descriptive phenomenological analysis method was used. Findings from the interviews of the study concluded that caregivers experience stigma, fear and satisfaction due to the care process and they attributed lack of support, lack of adequate skills and financial problems as being causes of caregiver burden. Caregivers reported that they use alcohol and spiritual assistance as ways to cope with demands of caregiving. Caregivers reported that they need financial assistance, training and support groups in order to manage their tasks and the emotional demands of caregiving. The researcher recommended that the government and mental health stakeholders to decentralize mental health services, establish support groups, come up with initiatives to assist caregivers and patients financially and awareness campaigns to help curb stigma in communities. More so the most important element is that caregivers should have somebody to help share the burden with.

## **ACRONYMS**

DSM- Diagnostic and Statistical Manual of Mental Disorders

GHQ- General Health Questionnaire

MRCZ- Medical Research Council of Zimbabwe

NGO's- Non Governmental Organisations

NIMH- National Institute of Mental Health

PANSS- Positive and Negative Syndrome Scale

SES- Socioeconomic Status

SPSS- Statistical Package for Social Studies

WFMH- World Federation of Mental Health

WHO- World Health Organisation

ZBI- Zarit Burden Interview

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#### CHAPTER ONE

## INTRODUCTION

## 1.1 INTRODUCTION

This chapter will give a preview of the research on the experiences of compassion fatigue and caregiver burden among familial caregivers of relatives with schizophrenia. The chapter focused on the background of the study, statement of the problem, purpose of the study, research objectives and questions, significance of the study, delimitations limitations and assumptions of the study as well as definition of key terms.

## 1.2 BACKGROUND OF THE STUDY

Foremost, Compassion fatigue has been defined by Figley (1995) as a state of exhaustion due to prolonged exposure to compassion stress. While, burden is defined as the undesirable effects an individual's mental condition has on the whole family, Grandon, Jenaro & Lemos (2005). According to Chan (2011), there is objective and subjective burden. Chan (2011) explains that objective burden refers to the patient's symptoms, behavior and factors such as changes in household routines, family or social relations. Subjective burden on the other hand refers to emotional conflicts experienced by the caregiver. The World Health Organization (WHO) (1996) describes schizophrenia as a serious mental condition characterized by disturbances in thinking, impacting an individual's language, perception and the sense of self. This view is supported by National Institute of Mental Health (NIMH) (2006) which defines schizophrenia as an enduring and severe mental illness that affects how a person thinks, feels and behaves. Therefore, the study seeks to assess how taking care of a schizophrenic relative contributes to compassionate fatigue and caregiver burden.

Notable is that, there is an increasing number of mental illness cases around the world. The NIHM (2006) estimates that the frequency rate for schizophrenia is approximately 1.1% of the population over the age of 18. Mental illnesses which were not given much priority are now

manifesting into vast disorders which leave people hopeless and devastated. For long people have been ignoring psychotic symptoms and illness, having a perception that spiritual practices are the causative. Most people believe that mental illnesses are caused by being demon possessed or being bewitched, thus resorting to exorcism rituals and other traditional rituals to cast the 'demon' away, (Razali, Khan & Hasanah 1996). This has caused many people to suffer with the burden and fatigue of taking care of their loved ones.

For individuals staying with a relative with schizophrenia or any form of mental illness can be stressful. According to Chan (2011) the problem of family burden of caring for people with schizophrenia is a challenge in both developed and developing countries. The World Federation of Mental Health (WFMH) (2010), issued a report in agreement with the fact that providing care to those living with chronic condition entails tireless effort, energy and understanding and greatly affects the daily lives of caregivers. Chan (2011) states that family caregivers receive little recognition for their work and most countries do not provide financial support for the care services. As a result caregivers struggle to balance their day to day activities with caregiving and their physical and emotional health is often overlooked. Consequently all this combined leads to caregivers experiencing tremendous stress, depression or even anxiety.

To add on, given the fact that most people are ignorant about mental health issues Bjorkman, Angelman & Jonsson (2008), most countries do not have up to standard mental institutions let alone anti-psychotic medicine. The symptomatic patients are hospitalized for a short period and in most cases the treatment administered there is ineffective. That same mentally ill patient it forced to go back home mostly because of the unavailability of resources to cater for long periods of hospitalization and due to the family's financial constraint. The patient goes home with little or no anti-psychotic medication to help repress the symptoms. The caregiver and consequently the entire family is left to struggle with the patient for life.

Families nowadays provide care to family members with different mental conditions such as schizophrenia. As economic challenges worsen and push health care costs to be high, the

responsibility of the patient more commonly resides with families and the community Lynch (2012). As a result family members become the primary caregivers of such patients. The caregiver plays several roles in making sure that the patient is well taken care of. These roles include supervising medication, taking care of the patient's financial needs (hospital, medication, food bills) and mainly looking after the patients day to day needs.

The situation get worse as the family has no knowledge on how to handle or take care of a psychotic patient. It is left to transformative experiences for them to learn how the deal with the new demands. The caregiver is not trained or given basic knowledge about dealing with psychotic patients and the individual has to struggle with ideas on how best to be of help and value to the patient. The family is left to adapt to the new uncomfortable situation which is traumatizing and very stressful. The lack of knowledge causes people to trying to find impractical solutions. Some families, are robbed of their money and possess as they going around traditional and religious domain trying to find a solution. Thus causing more harm than good.

The caregiver is forced to let his or her own personal needs go so as to be effective in taking care of the patient. Their sociocultural life is scotched with the task at hand. In most cases the individual has to cut all friendship ties as the burden and fatigue do not give chance to interaction with others. This also affects the family in general because the family structure is disturbed thus causing imbalances with the family leading to family disintegrations and disputes. Instead of the family to unify and help each other, the case of the psychotic patient causes them to split and avoid each other. The caregiver being compassionate about the well-being of the patient might be isolated and left to deal with situation alone. For example, when a father of three adult children suddenly experiences a psychotic break down and is diagnosed with schizophrenia, the adult children are mostly likely to move out and disassociate themselves with the psychotic father expect for maybe one child who will be left to bare the burdens of taking care of the patient.

The caregiver also has to deal with a number of different negative emotions which include fear, guilt, anger and frustration. Not only that, the caregiver also has to deal with feelings of helplessness and worry about the stigma of schizophrenia that their relative is likely to endure. Chan (2011) further highlights that families often face regular stressors of unpredictable and peculiar behaviors of their family member with schizophrenia. External stressors of stigma and isolation upon the family, emotional frustrations like guilt and loneliness and family conflicts also affect the caregiving relationship.

Furthermore, living with a psychotic patient has a negative stereotype with the community, Sibitz (2009). Once the mentally ill family member comes from hospitalization the community around develops a negative attitude towards that family. The people residing with the schizophrenic individuals are labeled and people disassociate themselves from them. The affected family is left in isolation, without support. Thus intensifying the already stressing situation. The discrimination is also a form of burden associated with taking care of psychotic family member. The care giver thus feels abandoned and valueless. Which eventually develops as stress and depression.

Dealing with the burden of nursing and taking care of schizophrenic patient is not an easy task as it requires psychological, physical and emotional strength. Some people find it a challenge in dealing with such situations and thus adopt ill- behaviors (coping strategies) which are destructive to them and the patient. According to Lauber (2003) some care givers resort to alcohol and drug abuse so as to suppress the burden and fatigue they go through. Instead of being helpful, by taking care of themselves first, most caregivers are prone to putting self-needs on hold and focus of the needs of the patient. In some cases caregiver burden and fatigue can cause the caregiver to develop suicidal tendencies and self-harm. The caregiver can adopt pain as a source of therapy for themselves where there cut themselves in order to feel alive. Such behaviors are not healthy to the caregiver and the patient.

It is paramount to note that, some scholars believes that psychotic illness are learnt behaviors. According to (Bandura 1977) social cognitive learning, people can learn to act and behavior in a certain way through their immediate interactions. It should be observed that, prolonged burden and fatigue can contribute to the caregiver developing psychotic tendencies. The individual's behavior is modelled by the daily experiences of living with a schizophrenic patient. The learnt psychotic behavior is reinforce by the need to understand the patient at hand. Some care givers will thus adopt the same antisocial behaviors.

The burdens of being a care giver to a schizophrenic patient do not limit to psychological problems but can also be physical. Given that the caregiver is the closest person to the patient, there sometimes follow victim to the violent episodes that patients go through. Notable is that, schizophrenic symptoms are characterized with distorted and hallucinatory voices and visions, thus the patient can harm the caregiver as they perceive the caregiver as a threat Swanson (2006). The violent episode also leads to destruction of property and furniture as the patient struggles with controlling the emotions. Thus such an environment is very unhealthy for any one because eventually it will lead the caregiver having a psychologically breakdown due to the burden and fatigue.

However, there is recent studies that suggest that, compassionate fatigue and caregiver burden contribute to positive outcomes, (Lynch, Shuster & Lobo 2017). The study results show that taking care of someone with a psychotic mental illness can be a purpose for one's life. Every one struggles to find a purpose it their lives thus given the opportunity to take care of a sick relative, can be a form of 'calling' for some people. The compassion fatigue and caregiver burden can be motivating factors to them were the trying to improve and be of better service to the patient they are helping. Thus taking care of the schizophrenic patient becomes a source for self-actualization as the person feels that they have achieved holistically.

The study aims at assessing the experience of care givers compassion fatigue and burden when taking care of schizophrenic patients at home. The focus is on the effects of these experiences on

the psychological, emotional and social well-being. Thus how it has changed their lives either for the good or bad.

## 1.3 STATEMENT OF THE PROBLEM

It was observed that there is an increasing number of patients forced to stay at home and be taken care of by their relatives. WHO (2010) has estimated that about 40-90% of patients with schizophrenia live with their families. However, the caregivers face compassion fatigue and caregiver burden due to such situations. It was noted that these people undergo through a lot of stress and depression as there try to cope with the intense situations. The caregivers do not have basic training or knowledge on how to take care of schizophrenic patients thus there are left to struggle with the situation alone. In most cases, the patient has no anti-psychotic medication to help ease the psychotic episode, thus adding to caregiver burden as there have to learn to live with this deteriorating situation thus resulting in fatigue. According to Chan (2011) families with poorer Socioeconomic Status (SES) experienced higher levels of burden. This being predisposed by the reason that some countries do not provide financial support for care-services that families deliver for their mentally ill-relatives, (Chan 2011). To add on, some studies argue that caregiver burden will decrease as the caregiver's level of knowledge on the disease increases (Yazic, et al. 2016).

Chan (2011), further supports this view by stating that if family caregivers do not have sufficient knowledge and backing there may not be able to fully take care of the ill persons. As a result this may lead to relapse and readmission. Hence, the problem is that care givers are left isolated to deal with such tough situations without prior educate on the welfare of schizophrenic patient. The care giver struggles with how to handle the overwhelming situation which eventually leads to their fatigue and burden. The problem is faced by the care givers and the community at large. The caregiver's lose themselves as they try to ensure the well-being of the psychotic patient thus negatively affecting their psychosocial system. Such situations has also seen to the rise of severe stress and depressed individual as there would have reached a breaking point. In some cases, it contributes to suicidal tendencies and self-harm. Therefore, this is a problem because the situation is causing increase in care compassionate fatigue and care giver burden. Thus at the end

of the day the problem affects the community as such situation rob people of their lives were they have to play the role of a full time care giver.

## 1.4 PURPOSE OF THE STUDY

The purpose of the research is to assess the experiences of compassion fatigue and caregiver burden among familial caregivers of relatives with schizophrenia

## 1.5 RESEARCH OBJECTIVES

- 1. To find out familial caregivers lived experiences with compassion fatigue.
- 2. To determine how familial caregivers experience caregiver burden.
- 3. To determine how these experiences encountered by caregivers affect the care process
- 4. To identify the perceived predictors of caregiver burden.
- 5. To help identify possible interventions that can be made to reduce family burden.

## 1.6 RESEARCH QUESTIONS

- 1. What is the nature of familial caregivers lived experiences with compassion fatigue
- 2. How do familial caregivers experiences caregiver burden?
- 3. How does this experience affect caregiver's ability to care for their relatives?
- 4. What are the perceived predictors of burden on familial caregivers of relatives with schizophrenia?
- 5. What involvements can be made to reduce family burden

## 1.7 SIGNIFICANCE OF THE STUDY

It is envisioned that the study findings were aimed at helping in the following:

## 1.7.1 Caregivers

The research findings would help caregivers get provided with psychological assistance to help them reduce burden levels. Caregivers would also be taught to employ positive coping strategies so that they come up with preventative measures that promote self. Thus ensuring positive psychological well-being. The care givers, will also be taught how to nurse psychotic patients. Therefor this will counter most of the care giver burden and fatigue.

## 1.7.2 Government

The research finding were meant to influence policy makers to come or put aside a budget to help caregivers of patients with mental conditions financially. More so, the research will help advice the government on the much needed mental health education throughout the country. This will foster social support to care giver living with psychotic patients and thus reduce care giver burden and social discrimination.

## 1.7.3 Community

The study findings would bring more awareness and insight about schizophrenia to the community. At the same time decreasing levels of stigma and discrimination of schizophrenic patients. The findings would also help communities come up with programs like support groups to assist those with schizophrenia.

## 1. 8 Assumptions

The study assumes that take care of schizophrenic patients at home gravely contribute to compassionate fatigue and care giver burden. When taking care of someone with schizophrenia, there is a lot of work involved and it required strong psychological aspect. The study also assumes that compassionate fatigue and care giver burden are negative outcomes of taking care of a schizophrenic patient because they contribute to increase in stress and depression which might lead to ill- behaviors as coping strategies.

## 1.9 DELIMITATIONS

The study is geographically located at Ingutsheni Central Hospital which is one of the biggest psychiatric hospital in Zimbabwe. The hospital is located in Bulawayo. The research utilized semi-structured interview guide to attain research findings. The study targeted people living with schizophrenic patients. The research is of a sensitive matter, thus only information relevant was

needed and it targets people who have experiences in the research area. Thematic analysis will be applied to analyze the raw data.

## 1.10 LIMITATIONS

Some participants were not willing enough to fully articulate their experiences of compassion fatigue and caregiver burden because of culturally and religious beliefs that say sick people should be well taken care of. More so the study was carried out on caregivers who take care of patients in the community setup, hence the findings are not conclusive to caregivers in the hospital setup. Furthermore some participants did not want to take part in the study because no monetary incentive was being offered.

## 1.11 DEFINITION OF KEY TERMS

Compassion fatigue –a secondary traumatic stress reaction resulting from helping or desiring to help a person suffering from traumatic events Figley (2002)

**Schizophrenia**- an intense and chronic mental disorder that impacts how a person thinks, feels and behaves.

**Caregiver**: a person who is involved with the everyday care of an ill person without any form of remuneration being exchanged.

#### 1.12 CHAPTER SUMMARY

The introductory chapter focused and gave an overview of the background to the study, statement of the problem, purpose of the study, research questions, assumptions and delimitations of the study, limitations and definition of key terms. The following chapter will focus on literature review.

## **CHAPTER TWO**

## LITERATURE REVIEW

## 2.1. INTRODUCTION

This chapter basically focused on the available literature on the subject matter of the study. According to Polit and Beck (2010), a literature review delivers a background of present knowledge on a topic. Thus the main purpose of undertaking a literature review was to summarise current knowledge that had so far been done, identify any strengths and weaknesses in the previous studies and identify the knowledge gap. In order to give a perspective to this study, scholarly views on the following would be discussed: schizophrenia, compassion fatigue and caregiver burden together with the causes and effects of these phenomena's

## 2.2. SCHIZOPHRENIA

According to Burton (2012), the word schizophrenia is taken from the Greek words schizo (split) and phren (mind) and was created in 1910 by Swiss psychiatrist Paul Eugen Bleuler. A review of literature has shown that Emil Kraepelin who was a German psychiatrist separated off schizophrenia (which he called dementia praecox or dementia of early life) from what he called manic depressive insanity.

An all-encompassing definition of schizophrenia was given by Miller, Schmidt, Angermeyer, Chauhan, Murthy, Toumi and Cadi- Soussi (2014), who defined it as a condition of brain function that disturbs one's thoughts, feelings and act. Thus it can be said that it is a mental condition that distorts an individual's capacity to interpret reality and respond appropriately. The Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5) 2013, describes schizophrenia

as a disorder that is characterized by negative and positive symptoms signs that have been present for a significant portion of time.

According to the DSM-5 (2013), positive symptoms include the manifestation of delusions, hallucinations and disorganized speech and grossly disorganized or catatonic behaviour. Negative symptoms are characterized by diminished emotional expression or lack of willpower.

## 2.2.1 Diagnostic Criteria (DSM-5(2013)

- A. *Characteristic symptoms:* Two (or more) of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated):
  - 1. Delusions
  - 2. Hallucinations
  - 3. Disorganized speech (e.g. frequent derailment or incoherence).
  - 4. Grossly disorganized or catatonic behaviour
  - 5. Negative symptoms (i.e. diminished emotional expression or lack of willpower).
- B. *Social/occupational dysfunction:* For a significant portion of the time since the onset of disturbance, one or more major areas of functioning such as work, interpersonal relations, or self-care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).
- C. *Duration:* Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1-month of symptoms (or less if successfully treated) that meet Criterion A (i.e., active phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in Criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).

- D. Schizoaffective and Mood Disorder exclusion: Schizoaffective Disorder and Mood Disorder With Psychotic Features have been ruled out because either (1) no Major Depressive, Manic, or Mixed Episodes have occurred during active-phase symptoms; or (2) if mood episodes have occurred during active-phase symptoms, their total duration has been brief relative to the duration of the active and residual periods.
- E. Substance/general medical condition exclusion: The disturbance is not attributable to the physiological effects of a substance (e.g., drug of abuse, a medication) or a general medical condition.
- F. Relationship to a Pervasive Developmental Disorder: If there is a history of autism spectrum disorder or a communication disorder of childhood onset, the additional diagnosis of Schizophrenia is made only if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated).

According to Miller et al (2014), 1% of the population is affected by the mental condition of schizophrenia and has considerable impact not only on patient's health but also on their surrounding environment. Schultz, North, Cleveland and Shields (2007), further on state that schizophrenia is a devastating mental condition which impacts one percent of the population. Available statistics shows that the condition is equally shared in both sexes. According to Schultz et al (2007), men present with the disease in their late teenage years or early 20's, women on the other hand late 20's or early 30's.

Research has shown that schizophrenia also has an impact on patient's surrounding environment, family included. The shift from mental hospital to community care for schizophrenic patients burdens caregivers. Panayiotopulus, Paviakis, Apostolou (2013), conducted a study to look at the burden that familial caregivers experience by caring for individuals with schizophrenia. The conclusion of the study were that families face great stress due to the caregiving role. Thus this possibly leads to compassion fatigue and caregiver burden.

## **2.2.2 Causes**

One of the causal factors of schizophrenia is inheritance, which is genetic factors. Several studies have indicated that schizophrenia runs in families. According to Ayano (2016), the danger of schizophrenia in families of persons with schizophrenia is 10%, and when the child is born to schizophrenic parents the risk of the child developing the condition is 40%. According to Gross (2010), twin and adoption also support the notion that schizophrenia is genetic, as there is a high correlation. The biochemical theory of schizophrenia is likely to contribute to schizophrenia. The dopamine hypothesis states that the direct source of schizophrenia symptoms is a surplus of the neurotransmitter dopamine. The evidence of this has been seen in post-mortems on schizophrenics which show excess levels of dopamine and anti-schizophrenic drugs such as chlorpromazine (CPZ) which are believed to work by binding to dopamine receptor sites.

Family caregivers of individuals with schizophrenia also require support and education about the mental condition, so as to prevent the likelihood of the family caregiver developing compassion fatigue and caregiver burden. Awareness and education of coping strategies and problem solving skills may help in shielding the affected family member against a possible relapse. That is, family members should build an environment that may be therapeutic for a relative who has schizophrenia. Support groups, community awareness programs may be important tools for those looking for intervention techniques.

## 2.3 COMPASSION FATIGUE

According to Hunsaker, Maughan & Heaston (2015), the term compassion fatigue was introduced by Joinson in 1992 and he called it a unique form of burnout. The concept was later on developed by Fidley and since then multiple definitions have been used by different scholars to describe this concept. Lynch and Lobo (2012), stated that compassion fatigue was a term common used with professional caregivers like doctors, social workers and nurses due to their exposure to traumatizing events.

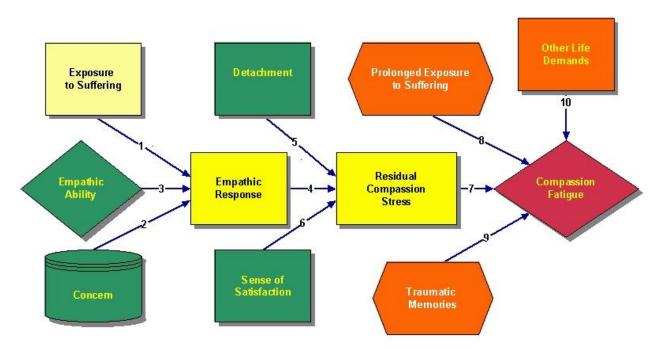
According to Lynch et al (2012), various meanings have been offered for compassion fatigue. As cited in Lynch et al (2012), Keidel (2002) defined compassion fatigue as a less harsh word for burnout. Sabo (2006), stated that the existence of burnout increased one's chances of having compassion fatigue. Abendroth and Flanney (2016), supported this view by stating that caregiving stress can result in burnout and eventually lead to compassion fatigue. Hunsaker et al (2015), argued that compassion fatigue and burnout are often linked to one another. According to Ledoux (2005) compassion fatigue has been categorised as vicarious trauma, secondary trauma syndrome, occasionally post-traumatic stress syndrome and as a variant of burnout. Ward- Griffrin, St Amant, Brown (2011), defined it as a condition impacting physical, emotional and social health and wellbeing, where anticipations surpass resources. Schulz, Monin and Czaja (2010), explained it as the stress, strain and wariness that arises from caring for a person suffering from a medical or psychological problem. McHolm (2006), stated that it was exhaustion that comes with an individual's decrease in the willingness to care for others and loss of fulfilment and pleasure in personal life.

Fidley (1995, 2002), described compassion fatigue as a state of tiredness and dysfunction biologically, psychologically and socially due continued contact to compassion stress and encompasses symptoms such as lowered concentration, anxiety, guilt, irritability and withdrawal. Through these various definitions it can be seen that compassion fatigue affects one's emotions, cognition, behavior, work performance and personal relations.

A review of literature has shown that the concept of compassion fatigue hasn't been particularly researched in informal caregivers, especially those caring for relatives with schizophrenia. Few information have been developed about its existence in family members caregivers, which is one of the weaknesses the researcher identified and the gap would be covered through this research study. According to Lynch et al (2012), compassion fatigue in familial caregivers is due to the fact that they offer daily care and support to serious ill family members and are at the same time experiencing their own emotional pain. The defining characteristic of compassion fatigue

included empathy, stress, shared experience and relationship between caregiver and patient. The consequences of compassion fatigue as highlighted by Lynch et al (2012) include social, spiritual, psychological and physical symptoms. For example a person may experience either of the following symptoms weight changes, exhaustion, loss of interest and withdrawal from family and friends.

However to note is features of compassion fatigue which exist in formal caregivers have also been found in informal caregivers, hence there are at risk of developing compassion fatigue Day and Anderson (2011). The various definitions of compassion fatigue combined with Fidley's model of compassion fatigue process offers an explanatory outline for understanding compassion fatigue in informal caregivers. Figley developed a model that explains some of the predictors to the development of compassion fatigue.



The Compassion Fatigue Process (Figley, 2001)

Figley's model is aimed at explaining emotional and situational factors that can result in one having compassion fatigue. The model postulates that a caregiver exposure to suffering triggers an emphatic concern from a caregiver that results in an emphatic response to help the person suffering. According to Schulz et al (2010), an increase in caregiver compassion was correlated

to family member suffering but the worst situation occurs when the suffering is long-lasting and severe. Family caregivers often take care of their relatives for longer periods hence this constant exposure to the suffering places them at higher risk for developing compassion fatigue.

According to Lynch et al (2010), there has to be empathy for compassion fatigue to occur in caregivers. Empathy being the understanding of the thoughts, feelings or emotional state of another person. The ability of the caregiver to empathize and help the patient who is a relative in this case put ones at a risk of developing compassion fatigue. Lynch et al. (2010), postulated that the caregiver must be able to identify and concentrate on what the patient is feeling and be able to realise this understanding.

According to Figley (1995) the caregiver's exposure to suffering, emphatic concern, emphatic ability and emphatic response are important attributes for caregivers and at the same time are risk factors for compassion fatigue.

Figley's model also highlighted that detachment and sense of satisfaction are measures used to prevent compassion fatigue. A caregiver develops a sense of satisfaction by being able to help their relative. Day and Anderson (2011), postulated that without a sense of gratification in care giving, the caregiver is at danger for developing compassion fatigue. Lynch et al (2017) conducted a study that was aimed at examining compassion fatigue and compassion satisfaction in family caregivers. They postulated that caregiving results in both encouraging and undesirable outcomes. The findings of the study revealed that in spite of high caregiver burden and reasonable compassion fatigue, family caregivers were able to care and find satisfaction in this caregiving role. Receiving appreciation for the caregiving they are providing also increases their sense satisfaction.

The models also explains that compassion stress then develops when the caregiver coping strategies fail to work. Figley (1995) defined compassion stress as the remainder of emotional

energy from the emphatic responses. Traumatic memories that would have been trigged by the continued stress of lengthy contact to suffering and other life demands such as work, school, and relationships perpetuate one's likelihood of developing compassion fatigue.

In summation, the literature review highlighted a variety of symptoms associated with compassion fatigue and various definitions that have been put forward by scholars in explaining this concept. Fildey model clearly explains that compassion fatigue is a process and the end results may lead to caregiver burden, depression, anxiety. Consequences of compassion fatigue may also lead to patient relapses and multiple admissions to psychiatry hospitals. More investigations in this area would be fruitful to explore this possibility.

## 2.4 CAREGIVER BURDEN

According to Unson, Flynn, Haymes, Sancho & Glendon (2016), caregivers encounter different types of burden depending on their kinship roles, gender and levels of involvement in the care. Urson et al (2016), defined caregiver burden also known as distress, strain, or stress as a multidimensional concept that refers problems experienced by caregivers. Thommessen, Aarsland, Braeskhus, Oksengaard, Engedol, Laaker (2002), defined caregiver burden as problems that family members taking care of an ill person might experience. Adelmon, Tmanoua, Delgado, Dion and Lach (2014), defined caregiver burden as resulting from providing care for patients with chronic illness.

A review of studies on caregivers and factors responsible for their burden, identified that the family was the primary caregiver of an individual with a mental illness. According to Zahid, Ohaeri, Basiony, Hamada, Vargnese (2010), family burden is a non- mediated effect on relatives living with and caring for a family member affected by a mental illness. Research studies have shown that there is objective and subjective burden. According to Alzahrani, Fallata and Bashwari (2017), objective burden is defined as the noticeable costs to the family that result from the mental condition, whereas subjective burden refers to the individual's sensitivity of the situation as burdensome. According to Martens and Addington (2001), in objective burden there is disruption of family or household daily routines as a result of the individual's illness for

example relationships and finances. Subjective burden includes the psychological effects of the illness for the family for example health problems and distress.

The burden of caring for individuals suffering from mental illness include disruption of everyday life routine, stigma, blame, financial problems, displeasure with family and relatives and troubles with compliance of patient to treatment Alzahrani (2017),.

## 2.5 RELATED LITERATURE

## 2.5.1 Caregivers experiences of caregiver burden

In addition, a study was conducted by Shamsaei, Cheraghi and Bashiran (2015) to determine the prevalence of caregiver burden reported by family caregivers for individuals with schizophrenia. The study involved face to face interviews with 225 caregivers who were selected from a psychiatry hospital in Iran. The ZBI was used to assess caregiver burden and information collected was analyzed using the Statistical Package for Social Studies (SPSS) with Pearson correlation and t- test. In this study convenience sampling was used because the researchers did not have access to patients' files, address or telephone number hence through convenience sampling participants were easy to locate. Caregivers had to be 18 years or older, living with the patient. Patients who had a diagnosis other than schizophrenia, who was not on medication and caregivers not living with the patient were excluded for taking part in the study. The results of the study revealed that familial caregivers of patients with schizophrenia experience enormous amount of caregiver burden as seen in the other reviewed studies. More so, educational status, relation to care recipient, age and duration of illness were also factors affecting caregiver burden. The study also emphasized the need for the provision of psychosocial provisions for both patients and family caregivers to ease caregiver burden levels.

Another study was done by Hsiao and Tsai (2014), which aimed at assessing family functioning in Taiwan family caregivers and testing its relationship with family demands, sense of coherence

and demographic characteristics. A sample of 137 caregivers was used and levels of burden were measured using Family Strains Index, Family Adaptability, Family Stressors Index and data was analysed using Pearson's product-moment coefficient. The results of the study showed that female caregivers with increased family demands, additional dependent relatives experience an increase in caregiver burden. More so, the study highlighted the importance of therapeutic interventions so as to improve sense of unity thus improving the view of burden of caregivers and family functioning.

Another study was done the Increase Ibukun Adeosum (2013), among family members of patients with schizophrenia in Lagos, Nigeria. The research was conducted in an out-patient clinic in Lagos, Nigerian and data was gathered from 181 primary caregivers. A socio-demographic questionnaire was used to gather data regarding age, gender, education level, household composition, occupation and relationship of the caregiver to the patient. The Positive and Negative Syndrome Scale (PANSS) was used to evaluate medical characteristic in the patient with schizophrenia and the ZBI was used to assess the impacts of caregiving.

The study revealed that female caregivers experienced high burden on emotional strain, financial and physical strain. According to the researchers this is due to socio-cultural expectations placed on women to lead the caring role when a family member becomes sick. Caregivers staying in homes with less numbers of people scored greater on financial and physical strain due to the fact that the task is not being shared by a larger number of people. Lower education attainment was predictive of higher burden. This was also highlighted by Inogbo (2017) et al. Caregivers with higher education have some degree of socio-economic advantage and are exposed to wider resources that may lessens the negative effects of caregiving. Caregivers with poor social support, longer caregiver- patient contact time had higher levels of burden and financial obligations especially without a regular source of income. The study also highlighted the need to come up with community based services to provide the necessities of patients with schizophrenia and their caregivers.

## 2.5.2 How these experiences affect caregiver's abilities

According to Lynch (2017) effects of compassion fatigue include psychological, physical, spiritual and social symptoms. Psychological effects being depression, anxiety and feelings of isolation. Showalter (2010), stated that physical symptoms comprise of fatigue, exhaustion, weight loss and gastrointestinal complaints. Showalter (2010), further stated that the costs of caring as one of the consequences and included symptoms such as fatigue, withdrawal and periodic thoughts and images related to the problems. Spiritual symptoms according to Mc Holm (2006), consist of an individual doubting his or her values and beliefs, failure to feel pleasure whereas social symptoms include abuse of chemicals or food, spending less time with friends and feeling others are incompetent.

## 2.5.3 Predictors of caregiver burden

Roick, Heider, Bebbington, Angermeyer, Azorin, Brugha, Killian, Johnson, Toumi, Kornfeld (2007), did a comparison study between Germany and Britain on caregiver burden. The researcher's argued that burden was influenced by differences in mental health service provision. Hence the aim of the study was to analyse whether caregiver burden is affected by differences in the provision of mental health services. Research participants included 333 relatives from Germany and 170 from Britain. The relatives were assessed using the Involvement Evaluation Questionnaire and socio-demographic data such as hours spent per week with patient were measured.

The study revealed that family caregiver burden was connected with patient's symptoms that is gender, employment status and caregiver's coping abilities. The findings of the study also revealed that caregivers in greater contact with the patient experience greater burden. More so, Britain caregivers experienced higher caregiver burden levels as compared to the ones at Germany. According to Roick et al (2007), this was due to the fact that Germany had more psychiatric beds than Britain as Britain main focus on mental health was on the extramural sphere that is taking place outside institutions. This tends to increase contact between patient and relative leading to an increase in caregiver burden.

Yaziel, Karabulut, Yildiz, Baskan Tekes, Inan, Cakir and Turgut (2015), conducted a study aimed at exploring the causes linked with caregiver burden. The study utilized 88 caregivers of patients who were receiving treatment for schizophrenia. The ZBI was used in assessing caregiver burden. The researchers also used socio-demographic data and clinical impression to evaluate the related factors. The factors predicting caregiving burden in this study were the caregiver's years of education, caregiver's frequency of contact with the patient and patient's hospitalization were found to be correlated with caregiver burden.

More so, results of the study identified that as the patient's monthly income decreased, caregiver burden increased. The researchers considered the patient's income to be money received and owned by the patient by working or government support. The recommendation of the study were the importance of setting rehabilitation and support groups for both patients and caregivers and also increasing incentives for caregivers.

Inogbo, Olutu, James, Nna (2017), conducted a study on burden of care amongst caregivers who were relatives of patients with schizophrenia. They used the Zarit Burden Interview (ZBI) for caregivers, to assess burden of care that is levels of burden. Patient's illness severity was assessed using the Brief Psychiatric Rating Scale and Global Assessment of Functioning scales so as to screen probable psychiatric morbidity and levels of functioning. The study was conducted at an outpatient clinic of Nigeria Edo state and 255 patients and caregivers. The gender of family caregiver was not specified, but were first degree relative, 18 years and above.

Key findings of the study identified that caregivers experience caregiver burden, which is related with the presence of psychiatric morbidity in the caregivers themselves, patient's poor functioning status and the educational status of the caregiver. Ingogbo et al (2017), also found out that caregivers with low educational status which is often associated with low income and socioeconomic status were socially and economically disadvantaged which becomes a significant predictor of caregiver burden. Poor psychosocial functioning of the patient poor insight and non-

adherence to medication, frequent hospital admissions and increased cost of care are some of the predictors of caregivers

Hindru, Osman, Lolokote, Li (2016), studied caregiver burden and its related factors among Eritrean families. The study was conducted between October 2015 and February 2016, and its purpose was to assess the levels of family burden among the caregivers and identify the contributing factors that influence the caregiving burden. The exclusion criteria for the participants were patients with any comorbid disorder, less than 18 year and also caregivers who were not living in the same household with the patient.

The Pai and Kapur's FBIS which is a standardized instrument scale used to assess subjective and objective burden scale was used to measure caregiver burden. Hindru et al (2016), found that predictors of caregiving burden included caregiver's age, caregiving duration, income and severity of the symptoms. Hindru et al (2016) also recommended the strengthening of psychological and social support to reduce caregiving burden of the caregivers.

## 2.5.4 Coping strategies used by caregivers

A study was done by in India by Parasar, Nail, Gupta, Patel and Srivatav (2015), which aimed at exploring coping strategies of caregivers of schizophrenia patients that is how they deal with the problems and difficulties likely to be faced in the caregiving relation. According to Parasar et al (2015) there are two types of coping strategies and these are the unconscious and conscious type. The researchers defined the unconscious type as a defense oriented coping strategy were people use Freud's defense mechanisms. Examples of defense mechanisms include repression, rationalization, denial and projection. Parasar et al (2015) highlighted that the defense mechanisms denies, distorts or restricts a person's experiences and reduce emotional and self-involvement. The conscious type according to Parasar et al (2015) are emotional-focused coping and problem-focused coping strategies. Through these coping strategies individuals prevent their negative emotions from overwhelming them.

The study utilized 60 caregivers. A socio-demographic data sheet, GHQ and the Cope scale by Carver 1989 were instruments was used. The findings of the study showed that the caregivers used emotion focused coping strategies in the form of acceptance. The researchers highlighted that this is type most often used to cope with health problems because one's health is an event that must be tolerated.

Hanzawa, Bae, Tanaka, Inadomi, Nakane and Ohta (2010) conducted a comparison study between Japan and Korea to compare caregiver burden and coping strategies between the two Asian countries. The study aimed at examining whether sociocultural factors had an effect on care experience. 99 Japanese and 92 Koreans were sampled for this study. The ZBI was used to assess burden and family coping questionnaire to rate coping strategies. Caregiver burden was paralleled among families with different socio-demographic upbringings. The results of the study revealed that when a patient was younger the more the caregiver burden. No differences in coping strategies were observed between the two countries, resignation, losing social interest were coping strategies caregivers reportedly used.

The review of the studies above shows that most researchers used a quantitative approach to reach their conclusions. The researcher will use a qualitative approach in this study so as to get an in-depth and detailed account of caregiver's experiences of compassion fatigue and caregiver burden

## 2.6 THEORETICAL FRAMEWORK

The theoretical framework for this research study was provided by Lazarus and Folkman's (1984) Transactional Model of Stress and Coping provided

The model is built on the notion that stress is a person- situation interaction, thus it emphases on the precise relationship between external demands (stressors) and bodily processes (stress). According to the theory as the individual and environment interact in a mutual and shared relationship, stress would most likely to occur when the interaction between the person and the environment burdens an individual coping resources and threatens his or her physical and psychological wellbeing. For example caregiving for an individual with schizophrenia can be financial burdensome to the family caregiver. As a result when the demands of the environment exceed the individual resources, creating an imbalance between demands and resources, compassion fatigue and caregiver burden is most likely to occur. Hence there is a need to a balance between resources and demands so that an individual does not exceed their ability to cope and mediate stress.

More so, according to the theory psychological stress happens when an individual comes across situations that tend to be challenging beyond the individual's capitals. As a result posing a risk to the person's physical, mental and emotional wellbeing.

Furthermore, according to the theory in the presence of threats an individual engages in both primary and secondary appraisals. In primary appraisals a stressing situation is appraised as harm, threat and challenges. Whereas in secondary appraisals an individual looks for best possible ways they can use to deal with the situation and change the undesirable conditions Lazarus and Folkman (1984). For example a caregiver can decide to sell wares such as tomatoes so as to ease the financial burden. The individual evaluate internal or external coping strategies so as to create a more positive environment. The more menacing the individual perceives the stressful situation the more unfavourable the stress reaction. More so the Transactional Model of Stress and Coping theory also states that stress may be aggravated by inadequate caregiving skills and inadequate coping strategies to manage the caregiving stresses. Hence there is need for caregivers to be equipped with adequate skills and coping strategies.

According to Pearlin (1990), Lazarus and Folkman's 1984 Transactional Stress Theory has resulted in researchers expanding the theory to clearly explain the occurrence of stress among caregivers. For example, the Zarit Caregiver Burden Interview was developed.

#### 2.7 KNOWLEDGE GAP

An analysis of literature that was reviewed by the researcher identified these major themes. Thematic analysis of caregiver's experiences of providing care to their schizophrenia family member identified stigma, financial problems and disruption of daily life routines as being some of the major experiences caregivers reported. For predictors of caregiver burden patients identified cost of care, caregiving duration, lack of support, severity of symptoms and socioeconomic status as being the triggers of burden. On coping strategies used by caregivers they reported using defence mechanisms such as denial and projection, acceptance and resignation as being their way of coping with the burdensome responsibility of caregiving.

Despite some research having been done on experiences of compassion fatigue and caregiver burden among familial caregivers of schizophrenia relatives, the studies cannot be generalized to the Zimbabwean context. Most of these studies were done in developed countries such as Japan, Korea. Although some studies did focus on African countries such as Nigeria and Eritrea to note is that none of these two countries can be compared with Zimbabwe in terms of resources and health care services provisions, hence the researcher saw a need to carry out a study in a Zimbabwean setting.

## 2.8 CHAPTER SUMMARY

This chapter has reviewed the available literature related to this study. The researcher reviewed literature on schizophrenia, compassion fatigue and caregiver burden. A theory that explains the concept of stress and how it results in caregiver burden and compassion fatigue was also brought up as this enhances one's understanding of stress functions. Research studies were also outlined

to identify the knowledge gap and rationale of carrying out this study. In the following chapter, the researcher will explain on the research methodology that was adopted for this study.

## **CHAPTER THREE**

#### RESEARCH METHODOLODY

#### 3.1 INTRODUCTION

In this chapter the methodology adopted to provide an understanding of the experiences of compassion fatigue and caregiver burden among familial caregivers of relatives with schizophrenia is described. Therefore this section covered the following areas, research approach, research design, target population, sampling size and procedures, research instrument, data collection and analysis as well ethical considerations which guided the researcher will be discussed.

#### 3.2 RESEARCH APPROACH

A qualitative approach to the research was adopted. According to Polit and Beck (2004) a qualitative approach goal is to develop a clear understanding of a phenomena as it exists in the world. According to Kelly (1999) qualitative research approach aimed at understanding human behavior from the participant's perspective. Denzin and Lincoln (1994) further on highlighted that a qualitative research approach seeks to understand or interpret phenomena in terms of the meanings brought by people. Through a qualitative approach, the researcher was able to explore further and get a clear understanding of the experiences of the caregivers. The researcher also used the approach to identify the demographic characteristics of the participants. These included age, gender, occupation, duration of illness as well as the number of years that the caregiver had looked after their relative who is schizophrenic as this might be a predictor of compassion fatigue and burnout.

#### 3.3 RESEARCH DESIGN

A phenomenological research design was adopted by the researcher. According to Waters (2017), one of the aims of qualitative phenomenological research design is to allow participants to describe a lived experience. One of the advantages highlighted by Armstrong (2010), is that there is a better understanding of meanings attached by people. A descriptive phenomenological design was used so as to get a 'pure' description of caregiver's experiences of compassion fatigue and caregiver burden and also to increase an understanding of caregiver's experiences of caring for a relative with schizophrenia.

According to Langdridge (2007), descriptive phenomenology is the most traditional approach to phenomenological psychology and it emerged in the 1970 through the work of Amedeo Giorgi and colleges. When distinguished from descriptive phenomenology, in interpretative phenomenological analysis there is less emphasis on description and greater interpretation Langdridge (2007). Goble (2014) differentiated hermeneutic phenomenology from descriptive phenomenology by stating that it attempts to explain as it naturally occurs appear in everyday life before been theorized, interpreted or explained.

## 3.4 TARGET POPULATION

According to Searle (2002) the target population refers to all members of the group in which the researcher is interested in. The entire target population for this research was caregivers who had relatives suffering from schizophrenia and being reviewed at the Out Patients Department (OPD) of Ingutsheni Central Hospital a sample was then drawn from the targeted population. Hence caregivers who met the following inclusion criteria were nominated to be research participants:

- a. 18 years of age and older
- b. Caregiver living with the patient or spending most of the time with the patient
- c. Patient should have been diagnosed with schizophrenia for more than a year and should not be comorbid with alcohol or substance abuse.
- d. Patient should have been admitted at Ingustheni Central Hospital

The study focused on out-patients only because their caregivers were the ones most likely to be affected by caregiver burden and compassion fatigue as compared to inpatients who are looked after by professionals such as nurses, social workers and doctors.

The exclusion criteria for the present study were patients who had been diagnosed with schizophrenia for less than a year. More so, the study included both male and female caregivers so as to see how gender norms and societal expectations affect the caregiving role and to see which gender is particularly vulnerable to compassion fatigue and caregiver burden.

### 3.5 SAMPLE SIZE

According to MacDonald and Heldman (1986) a sample is a section of the wider population that will be engaged in the study. Kothari (2004) further defines a sample size to the number of people to be selected from the universe to constitute a sample. Kothari (2004), also highlights that the selected sample should be characteristic of the total population so as to affect the reliability of the study findings. Bearing this on mind the sample was drawn from the OPD of Ingutsheni Central Hospital. The researcher sampled seven (7) participants 3 males and 4 females who were primary caregivers of their relatives with schizophrenia so as to create an appropriate sampling frame. According to Langridge (2007), sample sizes should be small due to the time consuming nature of the analytical process.

## 3.6 SAMPLING PROCEDURE

The sample technique that was adopted is heterogeneous sampling. According to Walliman (2011), heterogeneous sampling is a technique used to capture a wide range of perspectives relating to the thing that one is interested in studying in. Hence this technique searches for variations in perspectives. Batlagia (2008) asserts that the basic principle behind heterogeneous sampling is to gain greater insights into a phenomenon by looking at it from all angles, which in turn helps a researcher identify common themes that are evident across the sample. According to Polkinghorne (1989) as cited in Langridge (2007), in this technique the researcher seeks out participants who have a common experience but who vary on demographic characteristics. In

this present study participants had a common experience that is of providing care to their schizophrenic relatives but differed in demographics such as age, gender and occupation.

## 3.7 RESEARCH INSTRUMENTS

According to MacDonald and Headlam (1986) research instruments are measurement tools used to collect information from participants on a topic of interest from research participants. These include questionnaires, scales, surveys and interviews. The researcher used interviews to obtain the interviewees experiences of compassion fatigue and caregiver burden. The researcher used semi structured interviews as the interview style to collect information from participants. According to MacDonald et al (1986) semi structured interviews follow a framework to address key themes and also allows the researcher to respond to answers of the interviewee and as a result developing themes and issues as they arise. More so, the semi-structured interviews were experiential in type. According to Mac Donald (1986), experiential interviews aim at drawing out people's feelings, experiences or perceptions over a specific period of time. The interviews were audio taped.

#### 3.8 RIGOR IN RESEARCH

Rigor in research is a systematic way of handling the research process. According to Speziale and Carpenter (2003) the aim of rigor in research is to accurately represent each participant's experience. It includes the careful and thorough collection, analysis and interpretation of data in such a way that an independent researcher should be able to re-analyses the data using the same processes and come up with the same results Bowling (2009). Rigor was observed by undertaking measures that ensured the trustworthiness of the research results in the qualitative study.

The researcher attempted to simplify questions by bringing them to level of the participant's understanding. For example some participants did not understand English, for example the researcher had to translate the interview questions to Ndebele for some of the participants.

## 3.9 TRUSTWORTHINESS

Trustworthiness in qualitative research deals with establishing validity and reliability. It is the value of study finding on how accurate the investigator interpreted the participants experiences (Silverman, 2010). Four constructs were used mentioned by Polit and Beck (2014). These were credibility, transferability, dependability and conformability.

# 3.9.1 Credibility

Holloway and Wheeler (2002) defined credibility as the sureness that can be placed in truth of the research findings. Polit and Beck (2012) asserted that this was similar to internal validity in qualitative research. Credibility was determined when the research findings correctly interpreted the experiences of caregivers providing care to their schizophrenia family members. The researcher carried out lengthy interviews of 30-45 minutes in a quiet room, using a semi – structured interview guide and allowed participants time to fully express their experiences as a caregiver without being judgmental. Hence the findings presented the original views of the caregivers.

# 3.9.2Transferability

This construct describes the degree to which the results of a study can be generalized to other setting or groups Polit and Beck (2014). The researcher facilitated transferability through thick descriptions and purposeful sampling. The researcher provided thick descriptions about methodology used and research participants were selected purposively. The researcher decided which participants to use for the study through the inclusion criteria that was highlighted earlier.

However in this study, since it is a qualitative study, transferability may be impossible in which generalisability is not always possible. The generalisation often sought in qualitative studies is that of ideas that they can be applied in many contexts. In this study, the ideas that were generated may have a powerful influence in health care providers taking care of caregivers.

## 3.9.3 Dependability

According to Bitsch (2005) dependability refers to the stability of data over time. If the study is repeated it would yield the same results if done to the same participants in the same context and credibility cannot be attained in the absence of dependability Polit and Beck (2014). The

researcher established dependability by doing a peer examination. This involved discussing research findings with colleges who were also doing qualitative research. This helped the researcher to identify categories not covered by the research questions.

# 3.9.4 Confirmability

According to Holloway and Wheeler (2010) conformability are the results of the research and not the researcher's assumptions and preconceptions. The researcher observed confirmability by writing and audio taping raw data for later use. Notes written and tapes were reserved and data units were coded in numerical order for easy location. The participants identities were safeguarded and they were identified using coded names. The researcher was sensitive not to intimidate participants to talk.

#### 3.10 DATA COLLECTION

Data collection is a process of gathering and preparing information from the research participants. Prior to collecting data at Ingutsheni Central Hospital a draft interview guide was analyzed by the supervisor and corrections made. An approval and confirmation letter to prove that the researcher was a student at Midlands State University was obtained from the University's Psychology Department. The researcher then went to seek permission to conduct the study from the hospital's Clinical Director. When permission was granted the researcher set up interview schedules with selected participants.

## 3.11 DATA ANALYSIS

According to Flick (2013) data analysis is an effort by a researcher to summarise gathered data and find meaning. In this present study data was thematically analysed, the researcher identified and listed themes that kept repeating. According to Ibrahim (2012), thematic analysis is adopted so as to analyse classification and present themes (patterns) that are related to the data.

The researcher adopted Giorgi's (1985) four stages to descriptive phenomenological analysis as cited in Langdrigde (2007). The first stage involved the researcher reading and listening the collected data for overall meaning and this was done individually for all seven participants. The second stage involved the researcher breaking down the data into smaller units of meaning and

adopting a psychological attitude towards the text. The next stage involved evaluating the meaning to find psychological meaning. The last stage was a production of individual structural descriptions for each participant .This was done through the identification of a main theme and sub themes that fall under the main theme. Participant's responses about their experiences were presented using verbatim quotations. This was done and presented in the next chapter that is Chapter 4.

#### 3.12 ETHICAL CONSIDERATIONS

According to Resnik (2005), ethical considerations can be defined as methods, procedures or perspective for deciding how to act when conducting a research study. Resnik (2005) highlights that it is important to observe ethical guidelines in research as they promote the aims of research and these are avoidance of error, build public support and promoting public health and safety.

The researcher adopted the following ethical principles in accordance with the Medical Research Council of Zimbabwe MRCZ (2004) guidelines for researchers since the study was done in a health institution and involved patient representatives.

## 3.12.1 Debriefing

According to McLeod (2007) debriefing refers to giving research participants a general idea of what the research is all about. Therefore research participants were given the opportunity to ask questions if they had any. This was done so as to eradicate any misunderstandings and worries they had about the research Harris (1998).

#### 3.12.2 Confidentiality

Confidentiality refers to handling participant's information in a private manner. The researcher emphasized to the participants that everything they said will be kept between the agreed parties. Identities of all participants remained confidential so as to allow participants to discuss openly their experiences without fear of victimization. The voice recorded interviews were stored on a protected phone which only the researcher had access to.

#### 3.12.3 Informed consent

According to McLeod (2007), refers to simply getting the participants to say "Yes" to participate in the study. Participants were given a detailed outline of what the research is all about and asked their permission to take part. Participants consent was sought verbally before the interview began.

# 3.12.4 Voluntary participation

The researcher emphasized on the voluntary nature of the study. The research participants were not coerced in any form to take part in the study, but took part willingly. No form of remuneration will be given to participants

#### 3.12.5 Withdrawal

Withdrawal refers to participants being able to leave the study at time if they feel uncomfortable or if they feel that the issues being discussed are too sensitive. The researcher did explain to the participants that they are allowed to withdraw from the study at any given time.

## 3.12.6 Respect for participants

The researcher did ensure that the research participants were treated with utmost respect they deserved. The MRCZ (2004) states that respect for autonomy and protection of impaired and diminished autonomy as being fundamental. The researcher also ensured that no harm was inflicted on research participants, and therapeutic debriefing was done so as to make sure that participants do not get disturbed during the research.

### 3.13 CHAPTER SUMMARY

This chapter focused on the research methodology for this study. The research approach, design, target population, sampling techniques and data analysis and data collection methods were also highlighted. Ethical considerations which guided the researcher were also emphasized. The following chapter, the researcher will focus on data presentation and analysis.

# **CHAPTER FOUR**

# DATA PRESENTATION, ANALYSIS AND INTERPRETATION

## 4.1 INTRODUCTION

This chapter presents, analyses and interprets data collected from seven caregivers through semistructured interviews on their experiences of compassion fatigue and caregiver burden. The research findings are presented in light of the research questions which guided the study. Emerging themes and sub themes were drawn from the data acquired and these were illustrated by participant's responses which were presented verbatim.

#### 4.2 CHARACTERISTICS OF PARTICIPANTS

A total number of 7 caregivers participated in the study, 4 females and 3 males. Data was collected at Ingutsheni Central Hospital OPD. The youngest participant was 24 years old and the oldest was 58 years. True identities of participants were not revealed but were named using pseudonym names.

Table 4.2.1 Summary of participants' demographic information

Participant	Gender	Age	Occupation	Duration of	Relationship
		(years)		caregiving	to patient
				(years)	
1	Female	30	Beauty therapist	3	Cousin sister
2	Female	58	Self- employed	2	Sister

3	Female	36	Domestic	8	Niece
			worker		
4	Male	24	Student	2	Son
5	Female	55	Lecturer	4	Niece
6	Male	41	Miner	5	Brother
7	Male	33	Kombi	7	Brother
			Driver		

The research was guided by the following research questions:

- 1. What is the nature of familial caregivers lived experiences with compassion fatigue?
- 2. How do familial caregivers experiences caregiver burden?
- 3. How does this experience affect caregiver's ability to care for their relatives?
- 4. What are the perceived predictors of burden on familial caregivers of relatives with schizophrenia?
- 5. What interventions can be made to reduce family burdens?

## 4.3 MAIN THEMES AND SUBTHEMES

Four themes with subthemes emerged from the interpretative analysis of the interview transcripts as indicated in table 4.3.1

**Table 4.3.1 Main themes and subthemes** 

Main themes	Sub themes
Experiences of caregiving	Conflict
	Stigma
	Fear
	Satisfaction
Predictors of caregiver burden	Financial problems
	Lack of support

	Lack of adequate skills
	Duration of caregiving
Coping strategies used by caregivers	Alcohol use
	Seeking spiritual assistance
Caregiver needs/ interventions to be made	Financial assistance
	Training of caregivers
	Support groups
	Awareness campaigns

## 4.4 THEME ONE: EXPERIENCES OF CAREGIVING

Participants stated that by being the primary caregivers of their relatives with schizophrenia they encountered various experiences and reported it to be a challenging task. The thematic issues that arose in regard to caregivers experiences included conflicts, stigma, fear and satisfaction.

### 4.4.1 Sub theme 1: Conflicts

Participants reported that on several occasion arguments arose leading to conflict between them and their relatives. Participants conveyed that conflict in the care process arose due to the patient's failure and stubbornness to take basic instructions.

Participant 6 (male) reported that:

"...even when I am off duty I always ask the mine supervisor to give me something to do, so that as to avoid quarrels with my quarrels with my brother..."

Participant 7 (male) reported that:

"... by simple asking him to take a bath or take his medication leads to quarrels to the extent that at times I lose my temper and end up shouting

back at him..."

Participant 2 (female) reported that:

"... It's not easy, he is a problem at times I wish he was not staying with

me. He drinks a lot and smokes mbanje and when he comes back drunk he

becomes a problem and hard to control..."

The conflict that the participants experienced mainly emanated from the patient's failure to take

directives from their caregivers. Therefore this highlights that the care process involves a lot of

conflict between patients and their familial caregivers.

4.4.2 Sub theme 2: Stigma

Participants also reported experiencing discriminatory attitudes from the communities they live

in including their own relatives. Data collected from participants revealed that patients as well as

caregivers faced social isolation from the communities they live in. People avoid hanging around

mentally ill people and go to the extent of even calling them names. Basically mentally ill people

are seen as renegades in the society and are treated differently.

Participant 1 (female) reported that:

"... we no longer attend family gatherings like weddings like we used to.

Reason being that some relatives see us as a cursed family since my

cousin is not the first family member to be admitted at Ingutsheni..."

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Participant 7 (male) reported that:

"... whenever I ask him to go to errands in town or anywhere in the neighborhood he comes back complaining saying people are saying he is mad, people do not understand mental health conditions so in turn he is isolated and self- isolates himself by avoiding going outside the yard..."

Participant 3 (female) reported that:

"... I remember at one time I asked her to go collect my share of United Nations donation from the community leaders on my behalf. She came back crying saying people were insulting her calling her all sort of names..."

People have not fully embraced mental health conditions. African traditional beliefs such as witchcraft being the cause of mental conditions still hold substance in people's minds. The failure of people to accept mentally ill people and feel comfortable around them emphasizes on the lack of insight that people have into mental illnesses. Consequently therefore due to stigmatization of mentally ill people, a patient's emotional wellbeing is affected as revealed by participants who reported that their relatives were crying and had to deal with insults. A stable mentally ill individual adhering to medication is just like any other normal person. Participant's reports show how the society perceives and treat mentally ill people.

## 4.4.3 Sub theme 3: Fear

As a result of the unpredictable nature of people suffering from schizophrenia, participants conveyed that most of the times they were in constant fear. An overall evaluation of symptoms and behavior of people suffering from schizophrenia is that the condition causes unpredictable and inappropriate behavior. Participants reported that they always feared that their relatives might inflict self-injury or harm someone else hence they were always watchful.

Participant 4 (male) recounted his experience and reported that:

"... at one time I had accompanied him to the doctor's review, and all of a sudden he started to be irritated and agitated shouting at everyone including me..."

## Participant 3 (female) reported that:

"... she has attempted to take her life twice because she felt the illness was to hard a burden to bear. So we are always on the lookout because who knows there might be a third attempt and a successful one this time..."

# Participant 5 (female) reported that:

"...when he does not get what he wants he becomes aggressive and it becomes difficult to calm him down..."

One participant reported that he feared that his relative might end up locked up because of his unpredictable violent behavior.

# Participant 7 (male) reported that:

"... he is always involved in violent brawls but lucky enough he is not charged because of his mental condition..."

Caregiver's experiences of taking care of their family members with schizophrenia are frightening. Participant's reports provide evidence that caregivers also suffer from witnessing their relatives struggle with behavioral symptoms of schizophrenia, it disturbs their psychological wellbeing.

#### 4.4.4 Sub theme 4: Satisfaction

Although caregivers recounted that the caregiving process was filled with conflicts, fear and stigma, they reported that they were positive aspects of caregiving that gave them satisfaction.

Participant 1 (female) reported that:

"... seeing her happy, being able to do something that she wants makes me feel good. Just being able to put that smile on her face is just amazing..."

Participant 3 (female) reported that:

"... the fact that she is my sister's child and seeing her happy and seeing her mental state stable brings me pleasure..."

Participant 5 (female) reported that:

"... just the satisfaction that I am taking care of my uncle makes me pleased.

Basically being able to provide all most all his daily needs..."

Data collected shows that caregivers find satisfaction in caring for their schizophrenic family members. Data analysis from what the participants reported shows that satisfaction is a positive aspect of caregiving they experience and that uplifts and motivates them to keep doing more. The participants felt obliged to care for their relatives because of the love they had for them and sense of responsibility by being able to provide for them. When one is satisfied they are bound to perform their duties well.

## 4.5 THEME TWO: PREDICTORS OF CAREGIVER BURDEN

Despite the various aspects of caregiving that the participants experienced, participants reported that caregiving was a burdensome task. They identified factors such as financial problems, lack

of support, lack of adequate skills, duration of caregiving and other life demands as being the reasons why they experience burden.

## 4.5.1 Sub theme 1: Financial problems.

Financial problems was reported by participants as one of the reasons as to why they feel burdened by the care process. Notable was that there was no support in the caregiving role hence all the responsibility of caring for their schizophrenic family member lay within them.

# Participant 2 (female) reported that:

"... I've to spend hours in the bank queuing for my late husband's pension even when I get the money it's not enough to pay rentals, feed and clothe him, buy medication since most of the times it's not available at the hospital. It is just too much for me..."

# Participant 3 (female) had this to say:

"... it's taxing, over burdening I have other things to do with the little salary I earn. So her financial needs become an extra burden for me..."

# Participant 6 (male) reported that:

"... despite him knowingly very well that I do not earn much, he demands money to buy cigarettes and alcohol..."

Some participants reported that their financial problems were heightened by the fact that their relatives could not get decent well-paying jobs because of their mental conditions.

Participant 1 (female) reported that:

"... the minute they discover that she is schizophrenic she losses her job,

she has a mental condition but she can be productive like any other

employee..."

Participant 5 (female) reported that:

" he has a diploma in mining but every time a medical report is requested

and they discover that he has a mental condition they tell him that he is

unemployable..."

Participants reported facing financial problems in the care process. This poses a lot of strain in

caregivers as they have to work extra hard to meet financial demands.

4.5.2 Sub theme 2: Lack of support

Participants reported that lack of support in their caregiving role made it difficult for them to

cope and at the same time balance other responsibilities. Participants highlighted that lacking the

physical presence of a support system meant that they had to shoulder the entire burden of their

relatives care. Although some participants did highlight that there were other people in the

household of note was that they were either young or old to help. As a result they are faced with

stress and some reported being fatigued, having sleeping problems and feeling too tired and not

having the energy to maintain focus in the care process.

Participant 5 (female) reported that:

"... his not my core business and juggling between work and him is too

much for me..."

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Participant 3 (female) reported that:

"...if I had money I would look for a helper to assist me, I also have two young children to look after..."

Participant 4 (male) reported that:

"... at times I find myself too tired to even concentrate in my studies, If my mother was still alive or my siblings were supportive as they ought to be, the burden will ease and I will be able to fully concentrate on my studies..."

From participants responses caregiving is a labor intensive task, and it becomes more stressful when there is no support system.

# 4.5.3 Sub theme 3: Lack of adequate skills

Participants reported that lack of adequate caregiver skills hindered them from fully performing their caregiving responsibilities well and in turn leading to the caregiving process being burdensome.

Participant 3 (female) had this to say:

"... I am not a health worker so some of the things I do not know how to handle..."

Participant 1 (female) reported that:

"... for someone like me who does not know anything, even the basics of taking care of mentally ill people, I need to be taught about symptoms and signs to be always in the lookout for..."

Participant 7 (male) reported that:

"... as a male I need to be equipped with skills, by so doing I thinkl the burden of taking care of my brother will decline.

Familial caregivers reported and emphasized on the need to be properly equipped with skills and training in order to deal with caregiving responsibilities.

## 4.5.4 Sub theme 4: Duration of illness

Participants reported that being the sole and primary caregiver's of their relatives combined with the number of years they have been caregiving is a cause for them to experience heavy load which in turn leads to caregiver burden. Some participants felt that the responsibilities of caregiving were primarily focused on them because of gender and societal norms.

Participant 3 (female) reported that:

"... I've been taking care of my niece ever since my sister passed away 8 years ago. Everyone in the family expects me to take care of her mainly because I'm the only surviving female left in the family..."

Participant 6 (male) reported that:

"...I've been doing this for way to long almost all the time I feel drained..."

However notable also was that one participant reported that, Participant 7 (male)

"... I wish that the hospital could admit him for some time so that I can also rest and regain my energy..."

From what was reported by the participants it is evident that participants who have been taking

care of their relatives for a long time experienced higher levels of burden as compared to those

who have been caregiving for a shorter period. Consequently therefore duration of caregiving is

a cause of caregiver burden.

4.6 THEME THREE: COPING STRATEGIES USED BY CAREGIVERS

Caregiving is not an easy task as evidenced by what participants were reporting. Caregivers

reported using various strategies order to cope with care demands. Participants reported that they

engage in these coping strategies so as to deal with their relative's ever stressful mental condition

and stigmatizing attitudes they receive in the society. The coping strategies that the participants

reported using were alcohol use and seeking spiritual assistance. These thematic issues that

represented caregivers coping strategies will be presented below.

4.6.1 Sub theme 1: Alcohol use

Some participants reported using alcohol as a way of coping with emotional demands of

caregiving.

Participant 7 (male) reported that:

"...I always end up drinking alcohol because this caregiving situation is

very stressful..."

Participant 6 (male) reported that

"... the main reason why drink alcohol and making sure that I get drunk is

so that I temporarily forget my worries..."

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Participant 4 (male) reported that:

"... whenever I knock off from my lecturers on Friday's, I binge on alcohol It makes me feel less stress..."

Although participants knew the hazardous health effects of taking alcohol in excess, they reported that using it as a coping strategy was beneficial for them and their psychological well-being as it made them worry less. Also notable was that participated who reported using alcohol as a coping strategy were males only.

# **4.6.2** Sub theme 2: Spiritual assistance

Participants reported visiting different spiritual places so as to cope with care demands. Some participants reported visiting church and others consulting traditional healers such as *nyanga*'s.

Participant 2 (female) reported that:

"... I've been made to believe that my brother's condition is linked to witchcraft so I frequent a lot of traditional healers with the hope that maybe his condition will be cured..."

Participant 1(female) reported that

"... I am a devote Seventh Day Adventist member so attending church every Saturday and putting everything in God's hand is my way of coping..."

Participant 5 (female) reported that:

"... praying to God acts as a source of comfort for me..."

Although some participants sought assistance from traditional healing methods some resorted to

attending church as a way of coping. To note was that this coping strategy was motivated by

what the caregiver believed in, some felt it was indeed witchcraft and some accepted that it was

God's will.

4.7 THEME FOUR: CAREGIVER NEEDS

In light of the vast positive and negative experiences of caregiving that participants reported, the

factors they felt led to them experiencing caregiver burden, respondents felt that certain measures

should be adopted by healthcare providers so that they can be able to manage their tasks and the

emotional demands of caregiving. Thematic issues related to the caregiver needs included

financial assistance, training of caregivers, support groups and awareness campaigns.

**4.7.1** Sub theme 1: Financial assistance

Participants reported facing financial problems in taking care of their schizophrenic family

members. Participants felt that the Zimbabwean government in partnership with Non-

Governmental- Organizations (NGO) should come up with measures to assist mentally ill people

financial.

Participant 2 (female) felt that:

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"... NGO's that always donate food stuff in rural areas should assist

caregivers with money so that we can do our own projects and take care

of our relatives..."

Participant 1 (female) reported that:

"... the government should set aside a budget for people living with

mental health conditions, so as to ease financial strain in families..."

Participant 5 (female) echoed her sentiments and reported that:

"... people living with chronic mental conditions such as schizophrenia

should be put on the government payroll since most of them cannot get

decent well-paying jobs..."

By being assisted financially caregivers felt that other caregivers from economically

disadvantaged backgrounds would be able to take care of their relatives. Participants felt that

intervening and assisting caregivers or patients with money would go a long way in making the

care process to be less burdensome.

4.7.2 Sub theme 2: Training of caregivers

Participants emphasized on the need to be trained to deal with mental conditions. Notable was

that some participants were not able to handle the unpredictable behavioral symptoms of their

relatives.

Participant 4 (male) reported that:

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"... caregivers need to be trained about handling psychological problems, we need to be equipped with knowledge and experience..."

Another participant, participant 5 (female) reported that:

"caregivers just like registered mental health nurses should go for mental health training courses..."

Participant 7 (male) had this to say:

"... what people have to notice is that caregivers are affected more than those who they provide care to, so we should be taught about mental illness and how to manage our family member's condition..."

Training caregivers not only about dealing with their relative's mental condition but also teaching them about psychiatric problems and symptoms to anticipate would go a long way in helping caregivers. This may help caregivers feel less overwhelmed by their relatives condition and in turn they would not neglect their own health also.

# **4.7.3** Sub theme **3:** Support groups

Participants felt that support groups for people with schizophrenia and caregivers should be established so as to help them cope with the condition.

Participant 4 (male) reported that

"...by belonging to a support group one can develop coping skills as well as well as receive emotional support as we will be sharing a common problem..."

Participant 6 (male) reported that

"... by being around people that I know will be facing the same problem with me, will give me hope that I am not alone and can fight through..."

Participants highlighted that support groups are part of the needs that have to be looked into by responsible authorities. Respondents felt that having people around you who share the same goal and experiences is vital. Participants felt that by belonging to a support group and having people facing the same struggle as them, will assure and give them hope that there are not alone.

# 4.7.4 Sub theme 4: Awareness campaigns

Participants highlighted that as a way of eradicating stigma that they and their schizophrenic relatives were subjected to, awareness campaigns should be done in communities.

Participant 6 (male) had this to say:

"... people need to be taught about mental health conditions the same way they are educated about HIV/AIDS related issues..."

Participant 1 (female) weighed her opinion by saying that:

"... just like all the other holidays World Mental Health Day should be publicly and widely commemorated so that even those with mental illnesses do not feel Indifferent from the community at large..."

Participant 2 (female) felt that:

"... psycho-educational teachings should be done so that people gain insight about mental health issues..."

Participants felt that community perceptions of schizophrenia and mental illnesses as a whole can be changed through awareness campaigns, that will be aimed at educating the community. Stigma attached to schizophrenia, myths and misconceptions that people hold should change so that mentally ill people who have been discharged into the community can recover better.

#### 4.8 CHAPTER SUMMARY

Familial caregivers of relatives with schizophrenia play a vital role in taking care of their relatives. An analysis of data collected brought into greater detail the experiences of caregivers, the predictors of caregiver burden, coping strategies that have been adopted by caregivers in order to deal with the demands of caregiving. The chapter also presented caregiver needs which they reported need to be met by health-care professionals. The analysis of data did reveal that caregivers experienced stigma, fear and satisfaction during the care process. Findings also revealed that predictors of caregiver burden are financial problems, lack of adequate skills and training. Participants also reported that they use alcohol and seek spiritual assistance so as to cope with care responsibilities. To deal with these issues participants highlighted the need for financial assistance, establishment of support groups and awareness campaigns to educate the community.

### **CHAPTER FIVE**

# DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS

#### 5.1 INTRODUCTION

This chapter presents a discussion of research findings. The chapter will also draw conclusions from the research and recommendations to healthcare providers will also be outlined based on the findings of the study.

#### 5.2 DISCUSSION OF RESULTS

The research was aimed at bringing out familial caregiver experiences of compassion fatigue and caregiver burden. The researcher focused on various research questions. The results of the study revealed caregivers experiences of providing care to a schizophrenic family member, predictors of caregiver burden, coping strategies caregivers reportedly used and interventions or measures caregivers felt needed to be implemented by health care providers.

## 5.2.1 Familial caregivers lived experiences.

Findings of the research showed that family caregivers experienced conflict, stigma, fear and satisfaction.

In the research findings there were occurrences of conflict as reported by the participants experiences. Conflict was evident in participants recounts during the interview were they reported that they would argue with their relatives during the care process. Participants reported that on frequent occasions they would argue with their relatives as they failed to listen to basic instructions such as taking their medication or bathing. These findings are in line with the findings of a study that was done by Cabral, Almeida, Ferreira, Goncalves & Duarte (2016). The outcomes of the study revealed that family caregivers experienced several difficulties as they went about the daily process of taking care of their relative with schizophrenia as a result the situation leads to conflict between the care-receiver and the caregiver. A study that was done by

Yazici et al (2016) also identified conflict as one of the experiences caregivers reported encountering in the care process.

The research findings revealed that caregivers together with their relatives experienced stigma. In the present study participants reported experiencing discerning attitudes from the communities they lived in and from their relatives. Participants reported that people segregated them due to beliefs they had about mental illnesses. A study conducted by Koschorke, Padmavati & Thornicroft (2017) also revealed that in India caregivers reported being avoided or excluded from social interactions due to stigma. A previous study that was done by Koschorke et al (2014) also identified that caregivers experiences of stigma were closely linked to those of their mentally ill family member.

The researcher also found out that family caregivers of people with schizophrenia experienced fear. This was in line with the results of a study that was conducted in Ghana by Yusuf, Nuhu & Akinbiyi (2009). In the study participants reported facing subjective burdens with emotions such as fear. Another study that was done by Shankar & Muthuswamy (2007) also identified that participants reported experiencing fear. The participants reported fearing for their own and their relatives safety during times of intensifying mental health crisis due the fact that schizophrenics are unpredictable.

The findings of the study also revealed that familial caregivers experienced compassion satisfaction during the care process. These findings are in agreement with Lynch et al (2012) study were participants reported that although caring for a family member with schizophrenia was complicated and difficult they developed a sense of satisfaction by being able to assist their relative. These findings were also supported by a study that was done by Hsia (2014) which identified that participants were able to finding satisfaction in their caregiving role despite caring for a family member with schizophrenia being burdensome. Fidley's (2001) model of compassion fatigue also supports these findings as it highlights that caregivers develop a sense of satisfaction by being able to assist their relative, without a satisfaction a caregivers is at risk of developing compassion fatigue.

# 5.2.2 Predictors of caregiver burden

The research findings managed to identify predictors of caregiver burden among familial caregivers of relatives with schizophrenia.

Research findings identified financial problems as being one of the predictors of caregiver burden. Due to current economic challenges in Zimbabwe participants reported that they had finances not enough to manage the care process. Participants also attributed this to the fact that they had no support in the caregiving role, hence all the burden of caring for their relative lay with them. These findings were also supported by a study by Ibukun Adeosum (2013) were participants reported experiencing financial strain due to caregiving. Participants also attributed financial strain to being a predictor of caregiver burden as they highlighted that they had no social support hence all financial obligations were directed at them.

Lazarus and Folkman (1984) Transactional Model of Stress and Coping which provided the theoretical framework for this study is congruent with financial burden and lack of support being predictors of caregiver burden. The theory asserts that psychological stress or burden results when a person encounters situations that tend to be demanding beyond the individuals resources. This was evident in research findings as participants recounted that caring for a family member with schizophrenia was financial burdening as they had to cover all the expenses alone. As a result the caregiver develops caregiver burden as there is an imbalance between demands (of the care recipient) and resources (what the caregiver has on offer).

The research findings also identified lack of adequate skills as being a predictor of caregiver burden. Participants reported that they had no basic knowledge about providing care to a schizophrenic individual. This was supported by a study by Cobral et al (2016) who argued that caregiving duties were affected by lack of skills that can be used to solve possible problems. This finding is also supported by the Transactional Model of Stress and Coping theory which emphasizes that stress which may later on result in caregiver burden is aggravated by inadequate caregiving skills.

The study also found that duration of illness which goes hand in hand with duration of caregiving is a predictor of caregiver burden. Another study that was done by Yazici et al (2016) also

identified duration of illness and duration of providing care to the relative as being positive predictors of caregiver burden. This was also identified and supported by a study that was done by Shamsae et al (2015). The study identified duration of illness as a factor affecting caregiver burden. A study that was done by Hindru et al (2016) also identified and supported the findings as participants reported that caregiving duration was a predictor for caregiving burden. This is also supported by Fidley (2001) compassion fatigue process. The model argues that an individual's prolonged exposure to suffering is a risk factor for compassion fatigue.

## **5.2.3** Coping strategies used by caregivers

The researcher identified coping strategies that caregivers reportedly used in dealing with the demands of caregiving.

Alcohol use was one of the coping strategies participants admitted to use. Participants revealed that they drank alcohol as a way of relieving stress. This tallied with a study by Veague (2009) whose participants reported using alcohol so as to ease the overwhelming duties of caregiving. This was also supported by a study that was done by Geriani, Savithy, Shivakumar, Kanchan (2015) participants also reported using alcohol as a coping strategy.

More so, findings of the study also identified seeking spiritual assistance from churches and traditional healers as a coping strategy. This was supported by a study that was done Marimbe-Dube (2013) in Annexe Hospital, Harare. Participants reported using spiritual methods as a coping strategy and this was influenced by the desire to get more details about the patient condition. The study by Marimbe-Dube (2013) also did highlight that some participants sought spiritual assistance as they were seeking more information about their relative's condition.

## **5.2.4** Caregiver needs

The study managed to identify needs that caregivers reportedly required. Participants also reported that certain measures should be adopted by the government so as to be able to handle the demands of caregiving.

The researcher identified that caregivers required financial assistance to go about with their daily care duties. Findings of the study identified that financial assistance was a measure that needed to be adopted by healthcare providers in order to assist caregivers and their mentally ill relatives. This was similar to study that was done by Lasekiban & Ayinde (2013) which revealed that caregivers need financial assistance as caregiving becomes an extra expenditure to familial caregivers hence putting them at risk of caregiver burden.

Results of the study also revealed that caregivers needed to be trained to deal with mental health conditions. These findings were also corroborated by a study that was done by Shamsaei et al (2015), participants in the study expressed interest in receiving training. Caregivers voiced the need for their skills to be improved through training. The findings were also supported by a study by Jagannathan, Hamza & Nagendra (2010), participants expressed their willingness to partake in trainings that would help them take care of their relatives.

In the present study, findings also called for the establishment of support groups. Participants felt that by having support groups there will be able to cope better with the demands of caregiving through sharing experiences. Chou, Liu, Chu (2002) study also showed that caregivers echoed similar sentiments about being part of support group. They felt that support groups would make them to be more effective and levels of burden may decrease. A study by Lynch et al (2012) also supported these findings as caregivers expressed the need to belong to a support group so that they can share their struggles with people facing the same problem.

Results of the study also identified use of awareness campaigns as measures to be adopted by the government in a bid to eradicate stigma. Participants felt that communities views of schizophrenia and mental conditions in general can be changed through awareness campaigns aimed at educating people. These findings were also supported by Yaziel (2015) study were participants advocated for educational campaigns in communities aimed at increasing awareness about mental illnesses. Findings were also consistent with findings by Gonzalez (2007), study participants felt that stigma in societies can reduce if communities are taught about mental illnesses and experiences that caregivers endure in providing care for their schizophrenic relative.

#### **5.3 CONCLUSIONS**

Caring for a relative with schizophrenia is one of the most burdensome tasks that family caregivers go through. Caregivers lived experiences of compassion fatigue and caregiver burden showed that that they are stigmatized because of their relative's condition. Caregivers also experienced psychological emotions such as fear because of the unpredictable nature of their relative's condition. Conflicts also emanated from during the care process. Despite caregiving being a challenging task caregivers did feel a sense of satisfaction by providing care for their relative. Notable was that these experiences caregivers experienced were universal as caregiving is a burdening task to everyone.

There was also variety in coping strategies that caregivers reportedly used. Although the study findings were aimed at equipping caregivers with positive coping strategies that promote self, participants used coping strategies such as alcohol use that were hazardous to their health. The researcher felt that this was not a good coping strategy as it will make caregivers more vulnerable to depression and other conditions and end up neglecting their care duties.

In predictors of caregiver burden financial problems seemed to be largely contributing factor to caregiver burden. Economic challenges are making it difficult for people to procure finances, unemployment rate is high, and economy is poor. With finances not being a problem, caregivers would be able to find support in the caregiving role (through looking for a helper), gain skills (through attending training programs or workshops) and duration of caregiving would not be an issue as all the challenges in the caregiving role would have been dealt with.

In reducing family burden, financial assistance would be of great help for caregivers. With enough finances caregivers can be able to handle the caregiving role. Eradicating stigma in communities would also be a good strategy that health care providers should adopt. Without the community understanding mental health issues it would be very difficult for discharged patients to make a full recovery and not relapse in a place with negative attitudes towards mental health conditions. Hence awareness campaigns would be off great help.

## **5.4 RECOMMENDATIONS**

Based on research findings from the study, the following recommendations are suggested:

- Psychoeducational programs. There is need for healthcare service providers to educate family members about mental health conditions and how to manage them.
- Decentralization of services. Mental health services should also be offered in communities. By so doing costs would be cut as they will be easy access to clinics, stigma levels would decrease and patient's adherence to medication can be boasted.
- Support groups. Families of people with schizophrenia should be encouraged to form or join support groups so as to offer guidance and support to each other.
- Awareness campaigns should be done at a regular basis so that the public is educated
  about mental conditions and effects that stigma and discrimination has on mentally ill
  people. By so doing people would feel comfortable in engaging in conversations about
  mental health and assisting where there is need.
- Training of caregivers. There is need for caregivers to be equipped with skills before their relatives are discharged or given a Leave Of Absence (LOA) by the hospital. This can be done through caregivers volunteering in half-way homes whilst relative is awaiting LOA.
- Government should collaborate with NGO's or mental health stakeholders and come with initiatives such as projects to assist caregivers financially.
- Psychosocial support for caregivers and patients. Caregivers should be counselled frequently so that their mental and emotional wellbeing is not disturbed during the care process. An individual prolonged exposure to their relatives suffering can trigger psychological problems such as depression.
- Further research should be done to using a larger sample and at different geographical locations so that findings can be generalized.

## **5.5 CHAPTER SUMMARY**

The discussion of research findings, conclusions drawn from the study and recommendations aimed at helping familial caregivers and their schizophrenic relative were presented in this chapter. The findings of the study identified similarities with other research studies that were done. The study generally identified and emphasized on the need for health care providers such

to also pay attention to caregivers psychological, emotional, physical wellbeing as they are also affected by providing care.

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#### APPENDIX 1: RESEARCH INSTRUMENT

My name is Sithandekile Moyo, a Psychology student at the Midlands State University (Gweru Campus). I am conducting a study on the "Experiences of compassion fatigue and caregiver burden among familial caregivers of relatives with schizophrenia". The information obtained from this research will be included in my dissertation. I would like you to share your experiences so that we can help other caregivers and create mental health awareness among the community. Your participation is requested because you are a caregiver of a relative diagnosed with schizophrenia.

Everything that we talk about will remain confidentially. No information I include in my dissertation will have your name or any other identifying personal details. Our interview will be audio taped so that I do not miss anything. Participation in this interview is voluntary and please feel free to end the interview at any given time. If you have any questions please ask. Your participation will be highly appreciated.

### Thank you

Do you agre	ee to participate in the study described above?
YES	NO NO
Signature:	Participant:
	Researcher:
	Witness:

## Demographics for caregivers

- 1. Age
- 2. Gender
- 3. Occupation
- 4. Relationship to patient
- 5. Marital status
- 6. Income
- 7. Education status
- 8. Living situation ( number of people in the household)

### Demographics for patient

- 1. Age
- 2. Gender
- 3. Occupation
- 4. Educational status

# **INTERVIEW QUESTIONS**

- 1) When was the patient first diagnosed with schizophrenia?
- 2) What was it like when your relative first started experiencing symptoms of schizophrenia?
- 3) How many times has your relative been hospitalized for schizophrenia?
- 4) How are you involved in your relatives treatment?
- 5) How long have you been taking care of your relative?
- 6) What are you caregiving responsibilities and how much time a day do you spend caregiving
- 7) Are there areas in your life that have been impacted by caregiving? If so how?
- 8) Do you have support in your caregiving role? If you do please describe?
- 9) How would you describe your life at the present moment judging from the fact you are taking care of your schizophrenic relative.
- 10) What sort of things or activities do you do to take care of yourself?
- 11) What advice would you give to another caregiver of a relative with a recent diagnosis of schizophrenia?

- 12) Are there aspects of caregiving that are satisfying to you?
- 13) What encourages you to take care of your relative?
- 14) Have you ever felt too tired or drained or not having the energy to take care of your relative?
- 15) Have you ever experienced feelings of guilt?
- 16) How has caregiving changed your relationships?

### APPENDIX 2: SUPERVISOR- STUDENT AUDIT SHEET

DATE	TOPIC DISCUSSED	COMMENT	STUDENT'S SIGNATURE	SUPERVISOR'S SIGNATURE	
10/10/17	Research topic	Revork on topic and proceed to research propesal	Mogo	Mosos	
17/10/17		Rework	Moyo	Jullser	
14110117	Research	Proceed to chapter 1	May:	Masch	
28/10/17	Chapter 1	Rido add more on background of the study	Moy o	MARA	
11/11/17	Chapter 1	Proceed	May o	Participation	
31/01/18	(hopter 2	Restructure some	May 6	March	
13/02/18	Chapter 2	Proceed	play o	THY	
13 /03/18	Chopter 3	you need to attend to	Noy:	March	
13 104118	Chapter 3	Proceed to instrument development	Neyo	TXXXX	
17/03/18	Research	Proceed to data collection	Mey o	(Al Esta	
05/04/18	Chapter 4	verbation quotations	Moy c	1000802	
07 10418	Chapter 4	Proceed	Noyo	ASTO T	
12/04/18	Chapter 5	first draft	Mayo	allosof	
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22/04/18	first draft	Proceed to final	May o	Willoger	

STUDENT'S SIGNATURE

SUPERVISOR'S SIGNATURE

### **APPENDIX 3: PERMISSION LETTER**

Telephone: +263-9-466896 + 263-09-466463- 5 472420/463411-3

Fax: +263-9-473966



INGUTSHENI CENTRAL HOSPITAL P.O. Box 8363 Belmont BULAWAYO Zimbabwe

Ref:

20 March 2018

Ms S Moyo 12A Founders Road Richmond BULAWAYO

RE: REQUEST TO CARRY OUT A STUDY ON EXPERIENCES OF COMPASSION FATIGUE AND CAREGIVER BURDEN AMONG FAMILIAL CAREGIVERS OF RELATIVES WITH SCHIZOPHRENIA: MS S MOYO REG NO: R144128-N

Permission has been granted to Ms S Moyo to carry out a study at Ingutsheni Central Hospital. Permission is valid as from 20 March 2018 to 19 March 2019.

I wish you the best in your studies.

INGUTSHENI CENTRAL HOSPITAL

20 MAR 2018

P.O. BOX 8363, BELMONT BULAWAYO, ZIMBABWE

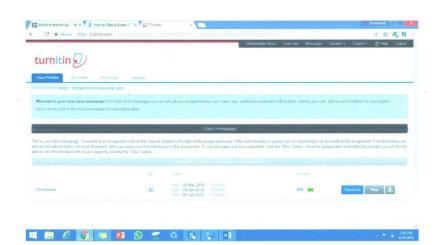
S.I Sibanda (Mrs)

**Ethics Committee Member** 

For: CHIEF EXECUTIVE OFFICER

Board members: Mrs S.V. Mhemba-Gumbo (Chairperson); Dr C.M.Z. Chasokela (Vice-Chairperson); Justice L. Kamocha; Mr E.M. Shora; Mr C.P. Mweyamweya; Dr R. Ndlovu; Mr E.T. Manyawu

### APPENDIX 4: TURNITIN REPORT



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# **APPENDIX 5: MARKING GUIDE**

Name of student: Sithandekile Moyo REG NO: R144128N

	ITEM	POSSIBLE SCORE	ACTUAL	COMMENT
A	RESEARCH TOPIC	5		
	Clear and concise			
В	PRELIMINARY PAGES	5		
	Title page, approval form, release form, dedication, acknowledgments, appendices, table of comments			
С	AUDIT SHEET PROGRESSION	5		
D	CHAPTER 1	10		
	Background, statement of the problem, significance of the study, research questions, objectives, hypothesis, assumptions, purpose of the study, delimitations, limitations, definition of terms			
Е	CHAPTER 2	15		
	Addresses major issues and major concepts of the study. Findings from previous work, relevancy of literature to the study, identifies knowledge gap, subtopics			
F	CHAPTER 3	15		
	Appropriateness of design, target population, population sample, research tools, data collection procedure, presentation and analysis			
G	CHAPTER 4	15		
	Findings presented in a logical manner, tabular data properly summarised and not repeated in the text			
Н	CHAPTER 5	20		
	Discussion (10) Must be a presentation of generalizations shown by the results: how results and interpretations agree with the existing and published literature, relates theory to practical, implications, conclusions(5) Ability to use findings to draw conclusions Recommendations (5)			
I	Overall presentation of dissertation	5		
J	References	5		
K	TOTAL	100		

Marker	Signature	Date
	<u>C</u>	
Madaratar	Cianatura	Data