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THE PSYCHO-ONCOLOGICAL BURDEN OF CARE: EXPERIENCES OF FAMILIAL CAREGIVERS FOR PEOPLE WITH CANCER.

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EXPERIENCES OF FAMILIAL CAREGIVERS FOR
PEOPLE WITH CANCER**

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DEDICATION:

**THIS PROJECT IS A SPECIAL DEDICATION TO MY LATE FATHER GEORGE
CHIKANYA WHO GAVE ME THE COURAGE AND DECISION TO PERSUE
EDUCATION IN A DIRECTION OF MY CHOICE AND TO MY PRECIOUS MOM
FOR THE UNCONDITIONAL LOVE AND SUPPORT**

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May God bless you all

ABSTRACT

There has been a lot of ignorance on the issue of cancer and cancer caregiving in Zimbabwe. The purpose of the study is to identify the burden of care of familial caregivers for people with cancer that is; psychological or emotional, social, physical and financial problems experienced by familial caregivers of cancer patients with research findings and make recommendations for appropriate intervention. There is need to research on the experiences of familial caregivers of people with cancer since cancer care has shifted from the hospital to homes; familial caregivers are faced with a burden to care without any training and knowledge of the disease. The research made use of qualitative research approach and will also be conducted as an interpretive phenomenological study. The sample of the study will consist of six familial caregivers with different ages, different types of cancer and different locations. The research data collected through unstructured interviews. Data was analysed in an interpretive phenomenological way which is; first by coming up with main themes then break them down into subthemes that were then discussed in line with the responses of the caregivers. Findings indicate that caregivers are sometimes not aware of the burden they carry when caregiving, they have also had reported to have experienced physical , social, psychological and financial problems and finally they reported to have come up with coping strategies that have helped them to cope with the burden. Conclusively, familial caregivers of people with cancer are having a hard time to adjust to changes that occur from the diagnosis of a family member through the time he/ she will be getting treatment.

ACRONYMS

WHO:	World Health Organisation
HIV:	Human Immunodeficiency Virus
AIDS:	Acquired Immune Deficiency Syndrome
IARC:	International Agency for Research on Cancer
ACA:	American Cancer Association
CT:	Computerized tomography
CAZ:	Cancer Association in Zimbabwe
NCPCS:	National Cancer Prevention and Control Strategy

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CHAPTER ONE

INTRODUCTION AND BACKGROUND

1. INTRODUCTION

The academic study is about the psycho-oncological burden of care: experiences of familial caregivers for people with cancer. This chapter will focus on the introduction of the whole study with its main focus on the background of the study, problem statement, the research questions of the study, also the significance of the study, defining key terms used in the study, the delimitations of the study, its limitations, assumptions of the study and finally the ethical considerations of the study.

1.1 BACKGROUND

People have been mostly focusing on the cancer patient; there is need to also equally focus on the caregivers as much as is done with the patient. The family caregiver is expected to provide for all that is required by the cancer patients from caregiving, moral support, spiritual and financial support. Meanwhile, there is no cure for cancer, it can only be reduced and suppressed by chemotherapy, radiotherapy and other medical procedures and it has been noted that the disease is leading to the death of many people leaving the family caregivers with nothing but psychologically conditions, heavy financial burden and in other cases physical illness. The way family members and caregivers respond to the illness can determine the patient's outcome in adopting the disease Kurtz, Kurtz , Given and Given (1995). Therefore, in a way to help the patient to cope with the disease from the instant time he/she diagnosed through to the treatment phase and coping to attain best quality of life, it is important to address at the same time the problems and needs of the whole family Morse and Fife (1998).

Cancer has over the year progressed to become more prominent in Zimbabwe affecting and killing many people annually with the number of deaths increasing annually, the latest statistics from the Cancer Registry in Zimbabwe indicates that a total of 17 018 new cases were recorded in 2014 comprising of 2981 males and 4037 females compared to those in 2009 which recorded

3 519 new cases with 1 427 males and 2 092 females respectively. According to News day on an article by the national cancer prevention and control strategy in Zimbabwe over five thousand new cases of all types of cancer are diagnosed yearly. According to the latest report by the World Health Organisation (WHO) in 2012 on the world cancer report, cancer was recorded as the leading cause of death claiming an estimated 8.2 million. In addition, the World Cancer Report 2014 submitted by WHO's International Agency for Research on Cancer (IARC) the estimated the rise of the disease from fourteen million new cases in 2012 to twenty two million in next 20years. These high rates of cancer cases have affected many families with some families having to deal with more than one cancer patient at a time who are at different stages of the cancer development. This has left family caregivers with a burden of care. Family caregivers are mandated to provide care to patients without adequate preparation and support Van Ryan ,Sanders and Kahn(2011) The American Cancer Association's statistics of 2017 reports that in the year 2017 a total of 1 688 780 new cancer cases were expected to occur in the United States Nature (2012). The discovery and treatment of cancer has led to a prolonged life of the patient, this is through different therapies on an out- patient basis, and decrease in the length of hospitalization as according to Raveis, Karus and Siegel (1998).This means caregivers are becoming increasingly assigned to provide for physical, financial and emotional care than other form of illnesses where patients are treated in hospitals Payne, Smith and Dean (1999).

Lederberg (1999) is of the view that, considering that most cancer patients prefer out patient care, most of the caregivers are reported to be taking caregiving responsibility as a full time role and for others caregiving can take fewer years and pushing them to even quit their jobs to put all the focus on caregiving, most people prefer fellow family members as caregivers unlike employing nurse aids and other medical home based helpers to handle them when they are diagnosed. According to Halley, Allen, Reynolds, Chen, Burton and Thompson (2002) the caregivers have a stressful challenge they face from the time one is diagnosed they have to embark on stressful decision making of whether to hospitalize the patient during treatment or consider home based care, most patients prefer to have their treatment from home in some cases the patient's choice may be different from that of the family caregivers which may result in the negation of choices. It is difficult to pin point the specific requirements of a cancer caregiver since the extent of the disease may differ from one patient to another and the requirements for caregiving differ too.

The psycho-oncological burden of care experienced by familial caregivers during cancer treatment is heavier during the time of treatment of the patient more than the other stages of the disease. According to World Health Organisation (WHO)(2013) cancer treatment is a chain of strategies that in involve psychological and social support, surgery, chemotherapy, radiotherapy and hormonal therapy that is directed towards curing the patient and or prolonging the quality of life. Caregivers play an important role as they act more as advocates of the patient. In an Australian caregivers research found out that during treatment cancer caregivers experience physical problems such as loss of physical strength, sleep disturbances, loss of appetite, fatigue, weight loss and pain Glajchen (2012). According to Fisher and Briggs (2000) the research showed that more than two thirds of caregivers of cancer that is advanced reported to have fatigue which increased as the patient deteriorated, fatigue then resulted in the caregiver to having decreased motivation and inability to concentrate.

The familial caregiving of cancer weighs a psychological or emotional burden on the caregiver. When a patient is diagnosed with cancer according to Northouse (2005) the disease is considered to provoke the physical, social, spiritual and emotional state of the person diagnosed and those giving care this may lead to depression, anxiety and fear. According to Shell and Kirsch (2001) from one's diagnosis with cancer the patient and caregiver's response is initially the same on the diagnosis as they both face the challenge of severe distress, shock ,anxiety and disruption, the feeling of failing to protect each other can lead to helplessness also blaming each other and denial may occur during diagnosis on both the patient and the family. During the time of treatment the caregiver may feel helplessness in seeing their family member in pain and agony and frustrated that they can do nothing about it. During this treatment phase familial caregivers may feel resented, having to deal with the patients without enough training, they tend to have more emotional distress Kurtz, Kurtz and Given (2004).

The burden of familial caregiving people with cancer results in social problems on the caregivers. The burden of caregiving gives destruction on the caregiver's way of life, socialization and their choices, their main focus will divert to be on the patient neglecting themselves. In an Australian study on social effects on cancer caregivers as according to Mor, Allen and Malin (1994) it reported more than half of the caregivers' life choices are affected, Caregiving also reported to have an effect of holidays and time away, travelling, hobbies and

socialization and this resulted in loneliness, lack of interest in intimacy and affection and isolation by the caregiver. The caregiver also encounters financial problems during caregiving a family member with cancer. The treatment of cancer requires a lot of money and the need for financial support even a financially stable individual may experience a financial challenge when it comes to cancer. Hagedoom(2008) asserts that during the time of cancer caregiving most caregivers loss their jobs either willingly as a choice to take full responsibility of the patient or some are forced to retire some may leave without pay , others opt to work fewer hours per week resulting in low incomes. Long term financial impacts may result in the use of insurance money, retirement's benefits and accumulation of heavy financial debts.

1.2 STATEMENT OF THE PROBLEM

According to, Blum and Sherman (2010), familial caregivers are partners, close relatives and close relatives who has a distinct personal relationship with the patient. They are supposed to assist the patient in all areas of life. In spite of the suddenly rise in the attention given to familial caregivers, some health institutions and professionals are still unaware of problems that are faced by familial caregivers of people with cancer and result in failure to address their needs Eames, Hoffmann ,Worrall and Read (2011).Little is known about the burden of care on cancer familial caregivers yet they are the ones who know the patient more than anyone, they are most affected by the disease since they can separate the change on the patient before and after diagnosis. Familial caregivers' lives are jeopardized by the disease, they have to adapt and adjust in all areas of their lives from their social life, emotional well-being and work balance. A report by Hayman et al (2001) indicates that cancer patients diagnosed and treated had ten hours of caregiving per week depending on the stage of the disease.

There is need to research on the burden of familial care for people with cancer since the disease has been the most life threatening of late and many people are still not as aware on the effects of the disease on others and how to handle them. The caregivers take care of the out patients. In almost all instance cancer patients are treated from home. There is need to research on the burden of care on these caregivers since they are untrained but they have to provide home based care on patients like professionals. The fact that they do not have formal training and adequate preparation, it is not easy for them and they end up developing depression, anxiety, emotional

instability and feeling of helplessness. According to Haley (2013) since little is known about the effects of cancer on family caregivers, some of the caregivers may fail to live the normal quality of life due to the effect of the disease on them.

1.3PURPOSE OF THE STUDY

The purpose of this study is to explain the burden of care of familial caregivers for people with cancer looking at the problems they experience from the psychological problems, social, financial and physical. With research findings will make recommendations for appropriate intervention.

1.4 RESEARCH OBJECTIVES

This research's objectives are:

1. To identify psychological or emotional, social, physical and financial problems experienced by familial caregivers for people with cancer.
2. To describe the psychological or emotional, social, physical and financial problems experienced by familial caregivers for people with cancer.
3. To recommend the appropriate coping strategies in dealing with the psychological /emotional, social, physical and financial problems experienced by familial caregivers of people with cancer.

1.5 RESEARCH QUESTIONS

1. How do caregivers describe the impact of cancer on their own lives over the course of their caregiving experiences?
2. What are the psychological and physical problems experienced by familial caregivers of people with cancer?
3. What are the social and financial problems experienced by familial caregivers of people with cancer?
4. What are the coping strategies in dealing with psychological or emotional, social, physical and financial problems experienced by familial caregivers of people with cancer?

1.6 SIGNIFICANCE OF THE STUDY

The significance of this study is that it may assist different people through organisations such as such as the Cancer association of Zimbabwe as the researcher will give feedback on the findings after completion and the association will in turn use the information to help its members who are the caregivers and the cancer patients. The people who are going to benefit from the study are also anyone who has once been a cancer family caregiver, those who are currently caregivers and those who in future will become cancer caregivers. Also support groups for cancer caregivers and cancer patients will benefit from this study, since it focuses much on the family and anyone can have their family members involved in the situation. If the effect of cancer on caregivers is not researched many caregivers are ending up changing their personalities due to the situations they face during caregiving and some may develop conditions that lead to death. Lastly the research will assist the researcher to have a better understanding of the problems experienced by familial caregivers of people with cancer and also become an advocate of cancer caregivers.

1.7 ASSUMPTIONS

It is assumed that there are psychological or emotional, social, physical and financial factors that affect familial caregivers of people with cancer; there is also little knowledge about the care and monitoring of cancer patients who are treated from home. Familial caregivers are willing to discuss about the challenges that affect them in taking care of cancer patients. Lastly it is assumed that the research will provide accurate information

1.8 DELIMITATIONS OF THE STUDY

This study is focuses at psycho-oncological burden of care, basing on the experiences of familial caregivers. The study is not going to focus on caregivers who are not familial it only involves those that are related to the cancer patient. Also cancer is the disease of focus in this research not HIV and AIDS or Dementia because cancer care has been a segregated topic of research. Caregiver experience will be an issue of much focus. Caregiver experience will be an issue of much focus.

1.9 LIMITATIONS OF THE STUDY

This study also have limitations, firstly its sample size is small hence there will be a generalizability of findings. The study's testing sample size of familial cancer caregivers willing to share their experiences is limited with some not even finding time for the researcher and hence the results of the study will end up being generalised.

There can encounter a bias since some of the information to be discussed the caregivers may take it as their privacy and fail to disclose some information. The researcher will discuss with the participants issue of confidentiality and the ethics governing the research. Also there is little of local research content.

1.10 DEFINITION OF KEY TERMS.

- **Burden of care-** this is a term that is used to refer to the physical, psychological or emotional, social and financial problems that can be experienced by family members caring for people with cancer (in this case). According to Hooyman and Kiyak (2002 p.279) burden of care is “the personal energy, time restrictions, financial strains, and/or psychological frustrations associated with assisting persons with long-term care needs”.
- **Familial caregivers-** Familial caregivers refer to a member of the family taking care of a fellow family member. Family can be blood relatives, guardians, next of keen and friends. According to Girgis and Lambert (2009) the activities done by familial caregivers for cancer patients include household duties and tasks, emotional and physical support and managing finances.
- **Experiences** – Experiences in this context are the new adjustments brought into the life of a caregiver that occurs during the course of their caregiving. The experiences are believed to be subjective that is they give an understanding of the perceptions which the caregiver has about taking care of a cancer patient and how they consciously react to it Giorgi (1997). Experiences differ from one individual from another and it makes it impossible to measure personal experiences

1.11 CHAPTER SUMMARY

Conclusively, this chapter was a foundation of what the research is going to focus on. The ideas of what led the researcher to follow the path of this research were laid out as well the research questions off the study. The significance of the study was outlined giving also the boundaries that guide this research. What the study assumes was laid out. The delimitations of the study were fully highlighted as well as the limitations of the study. The key concepts in the study were also described clearly. The chapter gives an overview on what to expect on the study and prepares the researcher on the following chapter of the theoretical framework.

CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

According to Kombo and Tromp (2009) literature review is the analysis of previous work that has been discussed by the researcher in order to investigate and have an understanding of the research problem. This chapter involves the review of literature such as journals, press articles, books, legislation and other people's dissertations that have the same or similar topics. In this chapter, the researcher will focus on the insights of the researches that other researchers have already conducted on the psych-oncological burden of care focusing on the experiences of familial caregivers of people with cancer. Also highlight will be on the literature gap, strength and weaknesses of previous researches conducted by other researchers. Firstly, the review will look at how the burden of caregiving experiences. Secondly, the review will look at the psychological/ emotional and social problems experienced by familial caregivers of people with cancer. Thirdly the review will look at the physical and financial problems experienced by familial caregivers of people with cancer. Fourthly the review will look into the coping strategies in dealing with the psychological/emotional, social, physical, and financial problems experienced by familial caregivers of people with cancer and lastly the review will examine the conceptual framework used in the study.

2.2 BURDEN OF CARE

The term burden of care is generally described as the emotional, physical, financial and social problems that are faced by familial caregivers. The cancer caregivers are mostly not considered important or talked about when people are talking about cancer yet they are the ones who suffer the burden of the disease. The most recent development by most medical facilities for patients with cancer to be treated and taken care of home has given the familial caregivers the burden of care without any knowledge and support. According to Hsu, Loscalzo, Ramani et al (2014), cancer and its treatment affects not only the person suffering from it but the familial caregivers too are affected, emotionally watching a family member in pain and agony affects the caregiver, also financially the expense encountered during treatment is expensive and the patient's funds may be exhausted and may end up calling for family members' financial contributions, also the caregiver because of the attention needed by a cancer patient they may start to absent themselves

from social activities and gatherings such as weddings and church activities, lastly Hsu et al (2014) is also of the view that the burden of care refers to the physical challenges faced by the familial caregivers as they encounter too much mobility. The term burden of care can be used and applied to other medical conditions other than cancer.

Cancer care has some challenges that go along with it. These challenges are the ones termed burden of care. In a 1993 journal with the title Cancer and the family: a strategy to assist spouses by Northouse and Golden they suggested that caring for a family member with cancer becomes a burden when three major concerns affects the caregiver. The first and greatest concern is the fear of cancer as a deadly disease and its spread. Generally just like HIV and AIDS most people have a fear of cancer as a disease and death, the way cancer affects a patient scares the familial caregivers and they start to fear that their family member is dying. The familial caregivers worry about the spread of the disease from time of diagnosis depending on which stage it would have been diagnosed at. In addition, the spread of the disease also is a major concern by caregivers especially when the tumour is small during the time of diagnosis, there is fear of spreading for example if it is breast cancer, familial caregivers and the patient have fear that it may spread to the other breast or other body parts surrounding the breast.

The second concern by caregivers that leads to cancer being a burden to them relates to helping the patient in dealing with his or her emotional distress caused by cancer. Family members are often caught off guard when it comes to caring for patients and they are often unprepared with no idea on how to help. Northouse further asserts that, this is when caregivers neglect their own feelings and needs and starts to focus more on how the patient is feeling. In some instances familial caregivers will even go to an extent of entertaining and tolerating things that they don't like for the sake of impressing the patients. This results in increased anxiety and depression on the familial caregivers. Lastly, the third category of concern is to manage the disturbances and changes in family relationships and daily routines caused by cancer. After a family member is diagnosed with cancer, every member of the family assumes extra duties and responsibilities. 24 hour monitoring of the patient is required and they take turns to do so, transportation for the patient from home to the hospital is done more often and entertaining the patient. The familial caregivers are expected to perform their normal duties inside and outside home which gives them

pressure to balance both ends. Disturbances are mostly reported at work, in school, extra-curricular activities, domestic routines and duties and social activities.

2.3 CANCER: TYPES AND EFFECTS

2.3.1 Types

According to the American Cancer Society (2010) Cancer was first described in ancient Egypt with the recording of history, as time went by Greek Physician Hippocrates started to describe cancer as finger-like tumours using the Greek words “carcinoma” and “carcinoma” which later translated to cancer. Cancer is a genetic disease in which a cell grows out of control or divides abnormally and ends up destroying body tissue. According to the American Cancer Association (ACA)(2012) most types of cancers are rooted in the genetic damage that result from both internal and external factors, internally from hormones or the metabolism of nutrients within cells and externally from tobacco, chemicals and radiation. Cancer can be treated depending with the type of cancer and stage it is. The type of treatment also depends on the stage and type of cancer. There are more than 150 types of cancer .In Zimbabwe the most commonly diagnosed types of cancer in an article of the Daily News by Chokunonga and Kadzata (2016) on a research of the Cancer Association of Zimbabwe are: Cervical cancer at a rate of 18%, Kaposi sarcoma 10%, Breast cancer 7% and prostate cancer at 7%. Cervical cancer is a type of cancer that occurs on the lower part of the uterus, it is mainly caused by the Human papillomavirus (HPV), and this virus can be caused by sexual contact with a person who has it. Kaposi Sarcoma, this is an opportunistic type of cancer for people with HIV and AIDS, it is a cancer that leads to formation of red or purple patches and lesions in the lining of the mouth, nose and throat or on other organs of the body. Breast cancer is a type of cancer that is characterised by a growth of a lump, hardening of the breast and or nipple colour change, mostly it affects women but some man can be diagnosed with it .Lastly the other most common type of cancer in Zimbabwe is Prostrate cancer, this is a most common type of cancer in men some prostate cancers grow slowly and may not harm the individual but some are aggressive and spread easily.

2.3.2 Diagnosis

According to the recent report by the National Cancer Prevention and Control Strategy for Zimbabwe (2014-2018), there diagnostic infrastructure for detection of cancer is limited in Zimbabwe maybe because there is little attention given to the pandemic. In Zimbabwe cancer can be diagnosed through computerised tomography (CT) scanning that is available in Harare and Bulawayo, Biopsy which is done at provincial and central hospitals and a few mission hospitals, plain x-rays are also done at district, provincial and central hospitals and cytology is limited in Zimbabwe but some private laboratories offers this expensive method

2.3.3 Treatment

The recent updated online information by the Cancer Association in Zimbabwe (CAZ), cancer can be treated in Zimbabwe and the forms of treatment are through surgery, radiotherapy, chemotherapy, hormonal therapy and palliative care. Patients vary and treatment also varies from person to person, it is determined by the location of the cancer, the size of the tumour and the stage of the cancer. Some people have one type of treatment but most people use a combination of treatment. After diagnosis there is need to make decisions on which type of treatment to use, the doctors gives the family and the patient information about the types of treatment available and they choose which one they would feel best for their patient.

2.3.3.1 Surgery

This is the oldest type of cancer treatment. It is a type of treatment whereby surgeons removes the cancer tumour from the body through a procedure of cutting it off. This procedure has been greatly accepted by most people since people always have surgery procedures for other illnesses and the results have always proved to be better. Surgery is also done when cutting off the body part affected by cancer to stop it from spreading to other parts for example in the case of breast cancer the whole breast is removed and in the case of cervical cancer, the whole uterus is cut off from the body. However according to Jacobsen, Roth and Holland (1998), some surgeries give changes to the appearance and function of the body such as breast , head , genital and neck cancer surgeries and seeing these changes increases distress on both the familial caregiver and the patient. Surgery as a procedure is done after considering the stage of cancer and whether it has already stretched out to other body parts. If surgery is appropriate for the patient, it is done

before other forms of treatment although the order of treatment has no effect on the outcome CAZ (2017).

2.3.3.2 Radiotherapy

This is a form of treatment that uses very high doses of radiation to kill cancerous cell and shrink the tumours .Most cancer patients and caregivers fear radiation therapy and it is usually one of the last options which the caregivers suggests after all have failed or have been deemed unnecessary. The patient is faced with fear and isolation during radiation therapy when he meets new physician and treatment team, lying alone on the table with big machines over his head gives great fear for the caregiver too. The myths about radiation therapy also gives the familial caregivers fear as most people describe radiation as actual burning alive of a patient to supress cancer cells Walker, Nail, Larsen, Magill and Schwartz (1996). The main goal of radiotherapy is suppress cancer cells on a targeted area by destroying them and making it extremely impossible for them to multiply. However, radiotherapy has reported to destroy both normal and abnormal cells and some normal effects heal and recover from radiation and function properly.

2.3.3.3Chemotherapy

This is a type of cancer treatment that uses drugs to cure cancer these drugs are anticancer drugs and cytotoxic drugs; it is usually done with the help of another cancer treatment method. According to Knobf (1998), National Cancer Prevention and Control Strategy (NCPCS) 2014-2018 chemotherapy is viewed negatively by most people and it is because of irrational fears , misperceptions by the caregivers and patients as well as inaccurate, researched and out-dated information that is at times even published in local papers or the internet. In the report by NCPCS it asserts that, chemotherapy leads to changes in family roles and routines as they change in order to meet the schedules of the doctor’s appointments for chemotherapy to be administered to the patient. The side effects of chemotherapy have an effect on the familial caregivers as they have to watch their loved ones in pain and suffering. The fatigue and irritability caused by chemotherapy experienced by the patient also can lead to an increase on the impact of cancer on the family system. Just like radiotherapy, chemotherapy has the ability to harm healthy tissues and cells. Chemotherapy drugs work better with a combination of two or more drugs at a time.

2.3.3.4Hormonal therapy

Hormonal therapy is a form of cancer treatment that uses hormones to cure cancer. Hormonal therapy is usually done in breast and cancer patients; it slows or stops the growth of breast and prostate cancer cells. The hormonal therapy works in a way that in cases of breast and prostate cancer estrogen and testosterone is removed or blocked from the body and this treatment is not guaranteed to cure cancer but what it does is that it only relieves symptoms.

2.3.3.5Palliative care

Palliative care is according to WHO (2012) is “an approach is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems-physical, psychosocial and spiritual.” It is not a form of treatment method but palliative care very important determinant of the caregiver and patient’s quality of life; it plays a role in deciding treatment options. CAZ views palliative care as a specialized medical care for people with life threatening illnesses. Palliative care is administered by a team of medical doctors, nurses and other specialists who work together with patient and his family with the goal of relieving symptoms, pain, and stress of the disease as well as improve the quality of life of both the patient and familial caregivers. Palliative care should be introduced early into the patient’s life such that in works along treatment methods such as chemotherapy and radiotherapy.

2.3.4 Effects

Cancer is a deadly disease that has a major effect also on the patient. The side effects of cancer are caused when the treatment start affecting already healthy tissue cells. The effects include amnesia, constipation, bleeding and bruising, diarrhea, delirium, fatigue, memory or concentration loss, hair loss, nausea and vomiting, sleep problems, pain, sexual health issues and urinary and bladder problems. Pain is typically a common effect of advanced stage cancer treatment, chronic conditions affect cancer survivors even after advanced stage treatment and these are obstruction, plexopathy, neuropathy and proctitis Dow (2003). Dow (2003) further asserts in his findings that, cancer treatment has a cognitive defect in adults which is caused by chemotherapy. This after effect of chemotherapy is sometimes called chemo brain. Cognitive

defects have been reported in most patients with different types of cancers, the defects have a potential to be permanent and are related to the dosage and duration of chemotherapy Meyers (2000), Ahles and Saykin (2002). Physical defaults and challenges have been a major effect of cancer treatment on cancer survivors after the end of treatment. A study by Ness, wall, Oakes, Robison and Gurney (2006), they studied 279 recent survivors and 434 long term survivors and compared them with 9370 people with no history of cancer. Ness et al's findings were that cancer survivors had restrictions in participation and their performance was limited compared to their cancer free control.

2.3.5 Prevention

The external causes of cancer that is tobacco, chemicals and radiation can be prevented. According to ACA (2012) there are measures that are taken as precaution against cancer. The most effective precaution measure against cancer is behavior change. Behavior change works for those cancers such as cervical cancer that are caused by infections such as the human papillomavirus (HPV) and human immunodeficiency virus (HIV) and also reduction in tobacco intake is a prevention of lung cancer. Another prevention measure is protecting oneself from direct exposure to intense sunlight as prevention against skin cancer which is diagnosed in more than two million people each year. Vaccines and antibodies are other measures that nations are taking as a way of prevention against cancer.

2.4 IMPACT OF CAREGIVING EXPERIENCES

The caregivers have a way of describing the way cancer impact them on their lives which is different from an observer point of view. Most of them view caregiving experience as less of a burden but more of a mandatory. Familial caregivers consist of spouse, siblings, relatives, next of kins and friends. The familial caregivers are different with other types of caregivers such as professionally trained caregivers; familial ones are not paid and have no specific training so when taking care of cancer patients they do it with a helping and caring mindset not for remuneration or rewards. Some familial caregivers when asked to describe their caregiving experiences the as not stressful but according to a research by Kurtz, Kurtz, Given and Given (2004) on depression and physical health among family caregivers of patients with cancer they described caregiving as labor intensive with roughly a quarter of caregivers spending in excess

40 hours a week or more giving services to a family member or a friend .Previous studies have managed to acquire the true thoughts and views of caregiver experiences by means of interviews but observations have not been doing justice to what the caregiver feels and thinks about their experiences. Some studies ended up giving assumptions and instead of taking cancer care as a burden of care most familial caregivers overlook it for love and sacrifice and end up content with the challenge.

There are certain roles that are expected to be played by the familial caregiver. According to Glajchen (2009) these tasks can be grouped into four as administrative tasks that is payment of medical and other bills and managing cases, instrumental tasks that is running personal errands for the cancer patient, accompanying them to their medical appointments, cooking, cleaning and all housekeeping, thirdly navigation tasks which means seeking information that may be hard to find, looking for medication that is out of the patient's reach and finding a doctor and last task is social support activities that is providing support, companion and socialization.

2.5 THE PSYCHOLOGICAL AND PHYSICAL PROBLEMS EXPERIENCED BY FAMILIAL CAREGIVERS

The familial caregivers when they are faced with a demand that exceeds their resources they tend to be stressed and that stress has a higher negative impact on the psychological wellbeing of the caregiver and if the stress continues it will end up impacting physically on the caregiver too. According to Gouin, Hantsoo and Kiecolt-Glaser (2008) familial caregivers do experience psychological and physical effects in some cases result in the disturbance of the function of the immune system, heart disease and early death. From diagnosis of cancer the familial caregivers are disturbed psychologically with news since cancer is a pandemic in Zimbabwe which doctors are failing to fully cure. During the course of treatment the family is faced with stressful decisions to make such as pursuing their own careers over caregiving, the type of treatment they will use, the concern of financial burden and if the family member who is suffering from cancer was the bread winner it becomes stressful for the spouse and children on how to make ends meet. Other researchers have reported that the effects of stress on the caregiver manifests psychologically in form of increased emotional distress, anxiety and or depression, feeling helplessness, loss of control and difficulty in coping with caregiving roles Ferrell, Ferrell, Hassey

Dow and Grant (1995). Emotional distress affects any member of the family who is caregiving but it has been reported to be higher among spouses.

Physically familial caregivers are faced with the challenge to move around with the cancer patient, if the patient has cervical or prostate cancer it is difficult for them to walk and whatever they need should be brought to them such as food water, medication and for other things like using the bathroom and moving from one room to another they will be carried or assisted in walking. Continuously doing everything for the cancer patient will result in sore legs for the caregiver, they may end up having lack of sleep which would result in headaches, loss of appetite, weight loss and eye problems. The way caregivers respond to cancer differs with people, some people respond to stress in a way that they want to eat more often than before, other caregivers report to be overweight and have too much appetite during the course of their caregiving. In a study published by the National Institute of Health (2012) about the caregiving burden, stress and health effects among family caregivers of adult cancer patients the research showed the relationship between psychological effects of cancer on the caregiver that end up causing physical effects, however most studies have been neglecting the conclusive impact of cancer on all the different familial caregivers doing different roles to the patient. Also some researchers have been separating the physical from the psychological impact of cancer on the familial caregivers yet each one has an effect on another

2.6 THE SOCIAL AND FINANCIAL PROBLEMS EXPERIENCED BY FAMILIAL CAREGIVERS OF PATIENTS WITH CANCER

There are several studies that has reported that social connections and activities of the familial caregiver of a patient with cancer are disturbed as all the focus will be on the patient's recovery Stenberg, Ruland and Miaskowski (2010). In an Australian study by Briggs and Fisher in association with the Carers Association of Australia in an article called Caring is a health hazard it reported "more than half that is 58% of the familial caregivers reported a dramatic effect of caregiving on their lives and choices. 45.4% was affected negatively holidays and time away, 30.2% were affected on travel time, 25.6 were affected on their time for hobbies and lastly 15.6% were affected on their time for socialization". The effect of social burden of caring for a family member who has cancer leads to loneliness, social isolation, a change in the family set up

and other relationships, a sense of grief and loss and no or less time for other personal relationships such as courtship.

Lack of social support has also been a burden for familial cancer caregivers. In most cases familial caregivers have the desire and would want to participate in social activities as weddings, parties and sports but they end up withdrawing due to lack of time to fully participate and concern on the patient. The younger caregivers have the tendency to neglect even their needs and some may end up changing career choices. Cancer creates a financial burden for the family. The disease's treatment is very expensive and the regular hospital visitations and checkups financially drain the family of all their savings. According to Grunfeld, Coyle, Whelan et al (2004) cancer familial caregivers tend to be unemployed since they cannot work for many hours away from their patients and this leads to social isolation and accumulation of debts. These researchers have managed to highlight the social issues and financial issues affecting cancer caregivers, however they failed to use international standard currencies like the American dollar for their figures in financial budgets of cancer patients, also the prices of cancer care vary from one country to another where some have the government paying for people with such diseases.

2.7 COPING STRATEGIES OF FAMILIAL CAREGIVERS OF PEOPLE WITH CANCER

There are many ways in which familial cancer caregivers of patients with cancer can be helped out to cope with the disease. Northouse, Katapodi, Zhang, Song and Mood (2010) offered a solution to cope with effects of familial caregiving a cancer patient. They discovered three types of interventions that can be offered to caregivers that are; psychoeducational, skills training and therapeutic counseling. They asserts that it is important for health practitioners to offer both the patient and caregiver information on how to maintain family and marital relationships, information about cancer patient care and one's self care when caring for a cancer patient. Northouse et al found out that this knowledge helps caregivers to prepare for their caregiving experience and reduces distress even though they are not very effective. Given, Given and Kozachik (2001) asserts that, medical practitioners generally agree on the value of providing adequate information to the caregivers. They view information and cancer education as a guideline to implement care and reduce caregiving stress and feelings of helplessness. Familial caregivers of cancer patients do need true and valid information about the cancer, its treatment,

its effects, related symptoms and side effects. It is important that they get enough specific details for them to know what to do and know how a particular type of cancer is more likely to behave like. There are some time periods during the patient's disease trajectory which are very crucial for the familial caregivers to receive information concerning the patient and cancer, the periods are at diagnosis, during the time of hospitalization, at the beginning of new treatments, at recurrence and during the palliative phase McCorkle and Pasacreta (2001).

Counseling and psychotherapy is another coping strategy skill for familial caregiver for people with cancer. Counseling and psychotherapy are designed in a way of reducing distress on the familial caregiver by helping them to adjust psychologically to the demands of caregiving. According to Harding and Higginson (2003) psychotherapy and counseling is designed to enhance morale, self-esteem, coping and sense of control and in the process reducing anxiety and depression. The skills training that can be adopted by the familial caregivers include having to host family meetings where every member of the family is involved in decision making and supporting each other, some families that are religious do have daily or weekly family prayer time together with the patient. However, some of the coping strategies are administered by professionally trained individuals and that makes it impossible for poor people and those in remote areas. Although many studies have been conducted about helping cancer patients to cope with the disease, little has been said or researched about coping strategies for familial caregivers' burden of cancer.

2.8 THEORITICAL FRAMEWORK

2.8.1 The transition theory (Schlossberg 1981)

The theory which is focused by this research is the transition theory by Nancy K Schlossberg. She propounded her theory through her collaborations with other authors as well as documenting her findings. Schlossberg's first publication and idea of her transition theory started in 1981 when she published an article about analyzing human adaption to transition in a periodical called *The Counseling Psychology* Evans et al (1995 p110). She made another publication in 1984 about counseling adults in transition and many other publications. Schlossberg always makes sure her books are up to date; in 2001 she collaborated with Chickering and came up with the 2nd

Edition of the book getting the most out of College. In 2006 she applied her Schlossberg transition theory in an updated version of counseling adults in transition.

Schlossberg defines transition as an event or non-event which results in a drift and twist in relationships, routines, assumptions and roles. She notes that perception is a key role in transitions as an event or non –event and is best defined by the person experiencing it, in this case the familial cancer caregiver. Schlossberg came up with four sets of factors that are influential in a person’s ability to cope with a transition (cancer) these are what she called four S that is situation , self, support and strategies. In addition, in order for the researcher to understand the meaning that a transition has to someone there are certain things to be considered such as the type, context and impact of the transition must be considered. According to Meleis (2010) transition is not as general as simple change but it is a process and an outcome. The transition theory by Schlossberg takes into account the dynamic and changing nature of cancer caregiving experiences along the journey from the patient’s diagnosis, treatment, survival and or death. The theory also takes into account the concepts of physical and psychosocial contexts of the caregiver during the patient’s sickness period, it allows for simultaneous various transitions, both expected and unexpected Meleis , Sawyer , Messias and Schumacher (2000), Meleis (2010).

The transition theory can has been widely used in other researchers including Cynthia Marie (2013) on her thesis entitled *The Impact of Cancer Caregiving on Cancer Caregivers: Stories of lives in Transition*, the theory has been useful in a number of research and different areas including relocating to different living situations Rossen and Knafl(2007) and Davies (2005),Immigration Samarasinghe ,Arvidsson and Fridlund (2006), developmental transitions such as parenthood Shin and White-Traut (2007) and understanding patient discharge Rossen (2007).

2.9 KNOWLEDGE GAP

The research on the burden of care of familial caregivers of patients with cancer is not a new subject of study; a few researchers have been interested in the topic for different reasons. Miguel Moreira and Freire (2017) of Portugal published their study on burden, quality of life and distress of the main caregiver in head and neck, cervix and rectal cancer patients. Miguel et al’s research was based on specific types of cancers and a specific person who is the main caregiver. Wipanee

(2014) of Thailand came up with his research entitled Resilience and coping : The perspectives of cancer patients , family caregivers and medical volunteers at Khampramong Monastery, Thailand, his research looked at more than one group of people at a time and in cases like those much focus will end up on cancer patients with little research on the familial caregivers. Other people have researched on this area and have highlighted their ideas but the researcher of this paper is still interested in the topic because most of the cancer researches that are used to guide the response to cancer in Zimbabwe are foreign studies. Most of the statistics about cancer caregiving is Euro-American yet the challenges which caregivers in an African setup is different from what may be recorded in an American setup and adaptation and coping strategies differ for people in different continents. It is therefore, crucial for the nation to have local researches which in the opinion of the Cancer Association of Zimbabwe are likely to be more applicable to the local scenario. The research will be focusing on Zimbabwe thus most likely to change the outcome of the results of the same research in a foreign country.

2.10 CHAPTER SUMMARY

This chapter made an exploration of work previously done on the psycho-oncological burden of care mainly focusing on the experiences of familial caregivers of patients with cancer. The literature review also focused on the coping strategies which can be implimated by familial caregivers and another focus was on the types, diagnosis, prevention, treatment and effects of cancer. This allowed the researcher to get a deeper understanding of the research topic and permitted the researcher to be familiar with the type of supplementary data necessary in the study.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 INTRODUCTION

In order to fully understand this research and valid it is important to outline the research paradigm, research design, target population , the sample, sampling technique , research instruments, data collection procedures , data presentation , data analysis and lastly ethical considerations used in the study. This chapter will give an overview of the procedures mentioned.

3.2 RESEARCH APPROACH

The current study is analysing, gathering and capturing data using the qualitative approach. This is a data capturing approach that makes use of structured and semi structured techniques. The characteristics of qualitative research approach include individual interviews, participation, observations and case studies. Qualitative research approach is focused mainly on finding out the meanings that is how people make sense of the world, how people experience certain events and what meaning they get from events, In short qualitative research approach is more concerned with the quality of experience rather than casual relationships. Qualitative research approach best suits this study because there is need for semi-structured interviews that enable in-depth verbal discussions with participants as they explain their experiences in taking care of their family members with cancer. Kothari (1999) is of the view that, qualitative research is the plan of conditions for gathering and analysis of information in a way that anticipates joining relevance to the research purpose. He was supported by Hunt (2011) who states that qualitative research approach picks up a deeper understanding of experiences of a group and in the case of this study it is the experiences of familial caregivers of people with cancer. According to Wiling (2008) data collection in qualitative research is frequently done in natural set ups thus at home, school and hospital and both the researcher and participant's interpretation of the topic under study is being accounted in the analysis process. Since the topic on research is about the experiences of familial

caregivers of cancer, qualitative research is the best approach to tackle it through the use of individual close up interviews with the caregivers. It gives the researcher a detailed knowledge of the experiences of familial caregivers. Also the researcher chose this research approach because she is also a participant when it comes to familial caregiving of cancer, she has a sister who survived cervical cancer and still under recurrence monitoring and six months ago she lost her father of prostate cancer.

3.3 RESEARCH DESIGN

This study is making use of the interpretive phenomenological analysis (IPA) method in data collection. Phenomenological research design was developed by Edmund Husserl as an eidetic method and he was concerned with the way things appear to individuals in their experiences. Martin Heidegger (1962) who was Husserl's follower later developed this method into existential philosophy and hermeneutics. According to Freeman (2008) hermeneutics is derived from a Greek word which means to interpret or to make clear. Freeman asserts that the researcher needs to understand the mindset of a person and their language which mediates one's experiences of the world in order to then translate his or her message. He believed that IPA method seeks for the researcher to understand what it feels like to be in someone's (their subject's) shoes and it is done through interpretative activity making meaning understandable by translating it. Smith and Osborn (2008) describes the analytical process in interpretive phenomenological analytical process in terms of double hermeneutic or dual interpretation process because at first participants make meaning of their world and experiences then secondly, the researcher strives to decode the meaning to make sense of the participants' meaning.

Phenomenological research design analyses human experiences through the descriptions provided by the people involved and in this study it is the experiences of the familial caregivers of cancer. The goal of this research design is to describe the meaning caregiving experience hold for each person. Phenomenological research design is used to research areas that little knowledge is known and areas that differ meaning and experience from one individual to another Donalek (2004). Taylor (1985) assumed that people are self –interpreting beings which means that they are actively engaged in interpreting the events, objects, experiences and people in their lives. According to Smith (2009), interpretive phenomenological analysis' aim is to explore in detail how participants are making sense of their personal and social world. It examines human

experiences through the descriptions provided by the people involved. These experiences are called lived experiences. The study will describe the experiences that family caregivers encountered during the care of cancer patients. This descriptive research uses direct observation, questionnaires, interviews and document analysis.

3.4 TARGERT POPULATION

According to Lucan (1986) target population is the universe from which the subjects of research are drawn. In context of research, sampling refers to the process of choosing people or organisations from a population of interest in order to reasonably generalise the findings back to the population from which they were chosen by studying the sample Trochim (2006). In this study, the target population is people living with their family members who have cancer and those that recently took care of family members who had cancer. The target population will include parents, children, siblings, close family members and friends whether male or female of different age groups.

3.5 SAMPLE AND SAMPLING TECHNIQUE

3.5.1 Sample size

Battaglia (2010) asserts that, sampling involves the selection of a portion of the finite population being studied. The research design of this research is interpretive phenomenological analysis and its main concern is to give maximum appreciation to each participant. For maximum focus on each and every participant IPA sample sizes are smaller. According to Creswell (1998) an Interpretive phenomenological analysis research interviews should have ten or less participants and Morse (1994) supports him with a suggestion of 6 or more participants. The sample size of this research is 6 participants.

3.5.2 Sampling procedure

The sampling technique to be used in this study is homogenous sampling technique. The purpose of homogeneous sampling is to describe a particular subgroup in detail. In this study the researcher chose only those that met the criteria of being family caregivers of cancer patients present or before. The targeted population for this study is going to be found from the

community where the researcher will find other people including her (the researcher's) family members who were once cancer caregivers and those that are currently caregiving.

3.6 RESEARCH INSTRUMENTS

There is need to address the type of research instruments that the researcher is using, this research will make use of semi structured interviews. Best and Kahn (1995) cite that, the interview is in a sense an oral questionnaire. Instead of writing the response, the subject or interviewee gives the needed information orally and face to face .One on one interview are important and useful for getting personal experiences or participant's life situations. Hogle and Sweat (1996) contend that, capturing what research participants say in their own particular words is the most crucial contribution of qualitative research in the quest for understanding human behavior. The interviewees are going to be chosen from people who qualify to be familial caregivers. The interviewer is going to write simple word answers during the interview session and expand them into sentences immediately after the interview in order to avoid interruption or stoppages. . This research used in-depth interviews as a method of gathering data from the sampled population so as to get knowledge about the burden of care which cancer has on familial caregivers. The interview questions were drafted in line with the research questions.

3.7 DATA COLLECTION PROCEDURE

The researcher was guided by the need to satisfy the demands of the validity and reliability of the data collected when collecting data so she followed a few steps in ensuring so.

1) Seek approval by the institution that is Midlands State University.

The researcher consulted the University senior authorities for an approval letter to collect data from people outside the University. The letter serves to inform all the organisations and people which the researcher consulted that she was a student at Midlands State University who is working on her dissertation.

2) Ask around the community for people living with cancer and those that recently lost their family members to cancer.

3) Get informed consent with the participants.

After approaching the qualifying candidates for her research, the researcher had time to introduce herself to the participants. She informed them on how she intended to interview them, allowing room for volunteers and informing them of the ethical considerations of the interview and privacy and confidentiality.

4) Conducting the interviews with the familial caregivers.

The researcher conducted closed in depth interviews of the familial caregivers. The researcher took notes during the interview session also she made use of current technology where she tape recorded the interview for use in her data presentation and for further evaluation after the interview.

3.8 DATA ANALYSIS

Data analysis will be done in the interpretive phenomenological way that is by following the stages used that is; a detailed reading of data is done so as to obtain a holistic perspective so that future interpretations stays grounded within the participant's account, initial themes are identified and organized into clusters and checked against the data, themes are then refined and condensed and examined for connections between them and lastly a narrative account of the interplay between the interpretive activity of the researcher and participant's account of her experience in her own words is produced, Breakwell, Hammond, Fife-Schaw and Smith(2006). In presenting the findings, The researcher will create an interview summary after every interview. The interview summary will give fully and in detail, the venue where the interview took place, the time and the duration of each interview and the results of each interview. The researcher will analyze, interpret and organize it through the use of graphs as well as making comparisons with literature.

3.9 ETHICAL CONSIDERATIONS

i) The participants were treated with dignity and respect- most of the participants were older than the researcher and she treated them with respect. Also even those younger than her and illiterate she treated them with the respect they deserve for their time and commitment.

ii) Informed consent of participants was maintained- the researcher informed the participants on what the interview was all about. She even allowed room for questions and clarifications where necessary by the participants.

iii) Participants were given the right to withdraw when they felt threatened or provoked- the researcher allowed the participants to withdraw from the interview when they felt threatened , some felt their cultures were being threatened and some felt the questions were too personal. In such cases the researcher allowed participants to withdraw from some questions and let them pass.

iv) The researcher made sure that the findings are kept confidential and used for purposes of Educational research only- the researcher made sure the interviews' findings were kept private and confidential and could only be used for educational research purposes only. The conversation also was made sure to be private and other participants preferred to have the interviews in a private manner for example at an open space under a tree that also was granted

3.10 CHAPTER SUMMARY

This chapter presented the research methodology and covered the research design used, identified the target population, outlined the sample, detailed the research instruments. The chapter also discussed data collection, examined issues to do with interviews the questionnaire used, explained how data was presented and analysed and finally summarised how ethical matters were dealt with.

CHAPTER FOUR

DATA PRESENTATION, ANALYSIS AND INTEPRETATION

4.1 INTRODUCTION

This chapter involves the presentation of the researched data, its analysis and presentation. In this chapter a detailed presentation of findings produced from participants during the data collected through semi structured interviews. The semi structured interviews brought out the lived experiences of familial caregivers of people with cancer. This chapter also represents and analyses the data gathered from the participants while giving answers to the research questions of this research.

4.2 CHARACTERISTICS OF PARTICIPANTS

The participants in this study were six people ranges from 22-55years of age. They were three males and three females. The participants were from different backgrounds but they had one thing in common which was taking care of a family member with cancer. All participants wanted full privacy and confidentiality and the researcher made sure of that by separating the participants during the time she interviewed them. The participants' data and information is presented in table form (below) and each participant is identified numerically from 1-6 for the sake of their confidentiality.

TABLE 1: Characteristics of participants

Participant Number	Age	Gender	Type of cancer	Relation to the cancer patient
1	37	Male	Prostate cancer	Uncle
2	22	Male	Cervical cancer	Brother
3	55	Male	Breast cancer	Husband
4	35	Female	Prostate cancer	Daughter
5	22	Female	Breast cancer	Daughter
6	27	Female	Prostate cancer	Daughter

This research was guided by these research questions

1. How do caregivers describe the impact of cancer on their own lives over the course of their caregiving experiences?
2. What are the psychological and physical problems experienced by familial caregivers of people with cancer?
3. What are the social and financial problems experienced by familial caregivers of people with cancer?
4. What are the coping strategies in dealing with psychological or emotional, social, physical and financial problems experienced by familial caregivers of people with cancer?

These research questions guided the research through data collection and in this chapter they are going to be used in acquiring the major themes of the research. Also each major theme is supported by sub-themes.

TABLE 2

MAIN THEMES	SUB-THEMES
Impact of caregiving experiences	Transition period
	Value of family
Psychological and physical problems	Fear of cancer
	Stress and depression
	Pain
Social and economic problems	Social disengagements
	Family interactions
	Change of life style and plans
	High expenditure
Coping strategies	Acceptance
	Devine interventions
	Counseling
	Social support

4.3 THEME 1:IMPACT OF CAREGIVING EXPERIENCES

The caregivers have their own way of describing their experiences, when asked to describe their caregiving experiences most caregivers started with a long sigh and they would explain how they have been helping out from the time of diagnosis to present. Caregivers explained their experiences as an act of love and sacrifice for their relatives.

4.3.1 Subtheme 1: Transitional Period

A transitional period simply means a period of change and in this study the participants' lives transformed in one way or the other after their relatives were diagnosed with cancer. The care of a cancer patient has reported to be a transitional period for all of the caregivers. It was reported to be the first time for most cancer caregivers to take care of someone with the disease. The

caregivers have been mainly affected by the change they noticed after diagnosis on the physical appearance of their relatives. The familial caregivers report that watching their family members' health and appearance change and not being able to do what they used to do as a great change in their lives as well. Other participants report having to start visiting traditional healers and white garment churches for the first time seeking to end the disease

"We have been living together well and he was in very good health and now it has changed a bit, it has become tough for me...."

(Participant 1)

"A year into the disease thinking it was just a lump that is when we discovered it was cancer, I didn't believe in traditional healers but when my wife got sick it changed I panicked and believed anything could make her" (Participant 3)

"When my mom was diagnosed of breast cancer she was still breastfeeding my little brother and I had to watch her after she got the breast removed, I literally became more like the mother to my little brother it was a tough experience" (Participant 5).

Participant 1's description of the impact of cancer on his life over the course of his caregiving experience is explained by the way he talks about the how well his nephew used to be and how it all suddenly changed after he was diagnosed. Beliefs also change which is great transition, as it was explained by participant 3 cancer made him to stop believing in clinical medication, he also stopped believing in his church and was ready to try out any new spiritual beliefs and healing methods. The participant 5 described her experience as a tough one, the transition from being just a normal nineteen year old girl to being her brother's babysitter and her mother's keeper was too much for her considering her age and being in school.

4.3.2 Subtheme 2: Value of family

The familial caregivers reported how valuable their families were to them. Some of the caregivers were not even the immediate family members but still they chose to take care of each other. This great value of family made the participants to overlook the burden they were carrying

for taking care of a cancer patient. For some of the participants it was reported that it was not their first time to take care of family members with cancer and they knew what to expect in terms of cancer caregiving.

“My nephew lived alone and worked for himself before he got diagnosed, when he started getting worse his neighbors called me and I had to go and take him to put him under my care...his parents died a long time ago and I am his guardian” (Participant 1)

“It is my second time taking care of a cancer patient, the first time was my sister who survived cervical cancer” (Participant 4)

“My relationship with my father has drifted since he was diagnosed with cancer...maybe because we can no longer do the things we used to do together” (Participant 6)

The first participant took care of his nephew since he was orphaned, he was his guardian and he valued him as his own family. The feelings participant 1 has for his nephews are that of a parent, the disease has in a way reunited him with his nephew who was staying on his own. The way participant 6 talks about her relationship with his father is that of a person losing the one she loves and her love for his father can make her do anything for him to get better even if what has a negative impact on her own life. Participant 4 was once a cancer caregiver to her sister who once had cervical cancer, it can be a good thing that she has a little knowledge about cancer but in the case of this study having to take care of a parent is different from taking care of a sibling of the same sex.

4.4 THEME 2: PSYCHOLOGICAL AND PHYSICAL PROBLEMS

The participants of this study research had psychological and physical problems that they encounter on a daily basis as they take care of their family members who have cancer. Some of the physical problems manifest as effects of the psychological problems

4.4.1 Subtheme 1: Fear of cancer

The participants had a general fear of cancer. The number of deaths being recorded for cancer are scaring cancer caregivers and daily increasing fear on familial caregivers. The fear was mainly fear of death, the fear of losing a family member. Some participants who were caregiving cancer patients whose cancer was recurring feared most and feared the spread to other body organs. Other participants who once gave caregiving to family members who had cancer before were optimistic of the disease's outcome.

“The first time we learned that my sister has cancer, I panicked... you know when people hear that someone has cancer they would be thinking that the person is already dying and that was the fear I had on my sister considering the fact that she is HIV positive, I ended up going for counseling to understand better about the disease”
(participant 2)

“She had breast cancer the first time and she got her breast removed , then for a year she had recovered and then it recurred this time the doctors said the cancer had spread all over her body and nothing could be done and every day I feared she could die” (Participant 5)

“I once took care of my sister who survived cervical cancer, so I was optimistic that my father was going to recover from cancer the same way my sister had pulled through.” (Participant 6)

Participant 2 felt death as inevitable for her sister just because she was diagnosed with cancer while already HIV positive. He must have doubted the many years her sister had survived with HIV and to him the combination on it with cancer was nothing but death. Participant 5's fear was still on what life was going to be like for her and her little brother after the death of her mother. She feared recurring of the cancer was going to spread all over her other body parts and there would be very slim chances of survival. However not all the participants had a great fear of the disease, participant 6 was very optimistic cancer could be cured after her previous experience with her sister who survived cervical cancer.

4.4.2 Subtheme 2: Stress and Depression

The participants reported high levels of stress and depression. Some of the participants reported not eating well when the patient is not eating. Some because of exhaustion from running errands for the patient they end up stressed. Some patients reported high blood pressure which is a disease that is stress related. Other participants report being depressed by the procedures which the doctors commend for example having breasts cut off and having the uterus cut off too.

“The way I eat was greatly affected, you know when you make food expecting the patient to eat and they fail to eat because of the pain they are feeling. Nomatter how hungry you will be you end up unable to eat as well, even if you try to eat later the thought that another member of the family has not eaten will make you lose your appetite for food.”(Participant 4)

“I haven’t been feeling any pain but I was diagnosed with high blood pressure” (Participant 3)

“The decision to remove her womb was the doctors’ suggestion and she has never had children, I was worried about the fact that she was never going to bore any children but I said to myself her life was more important.”(Participant 2)

The participants showed stress and distress all of them. Stress is a psychological problem that affects the mind and if not handled it can cause physical problems to a human being. For participant 4 stress manifested in the way she used to eat, she lost appetite because of perhaps the guilty conscience of having to eat when the patient is not eating. She reports that the first days after diagnosis she was unable to eat probably stressed about her father’s future with cancer. Participant 2 was depressed by the doctors’ decision to remove her sister’s womb. His main worry was her sister was going to be barren all of her life and having no offspring not by choice is also stressful for the cancer patient. Participant 3 got diagnosed with high blood pressure, a disease that is in his case, is a result of stressful thoughts about his wife’s conditions.

4.4.3 Subtheme 3: Pain

Some of the participants recorded physical pain due to increased mobility. Some participants the pain was stress related most of them recorded headaches and tiredness. Lack of sleep also was a reason for tiredness and headaches. Pain and hurt was also as a result of seeing their relatives in pain. Some participants couldn't handle the sight and it pained the too. Some of the participants reported to have experienced back pains as a result of having to carry their relatives around frequently.

“No I haven't been sleeping well at night because it is hard to sleep when you have a patient to take care of and sometimes he works up in pain in the middle of the night and at times he will be hungry and makes demands for food and you will be mandated to start cooking the middle of the night and if it goes on for days, I would have headaches.” (Participant 6)

“I have been experiencing back pains due to carrying my mom around when she couldn't walk on her own.... ” (Participant 5)

“Having to watch my wife in pain I felt hurt, it pained me too just the sight of the woman I love mourning in pain.” (Participant3)

The physical problems of the participants are mostly caused by the psychological issues surrounding their caregiving. Thinking and worrying a lot is another reason why familial caregivers end up experiencing physical problems especially headaches. Participant 6 expressed discomfort in having to woke up in the middle of the night to cook, having to be up all day and all up all night perhaps made her a bit more frustrated towards the patient. The participant 5 was carrying her mother on her back which led to her developing back pains. The participant's weight and age did not match that of her mother who she carried and may lead to serious damage to her back. Physical pain is also felt when a person is hurt as experienced by participant 3 who felt pain when he saw his wife struggling in pain.

4.5 THEME 3: SOCIAL AND ECONOMIC PROBLEMS

The participants of this study reported to have experienced social and economic problems when caring for their family members with cancer. Caring for a cancer patient requires maximum cooperation and commitment and that would mean that the participants lost their social way of living to focus more on caregiving. Also cancer care and treatment is expensive, not many of the participants could afford it.

4.5.1 Subtheme 1: Social disengagement

The participants reported to have disengaged themselves in social activities. Other participants willingly disengaged themselves while others were forced by the situation. Some participants did not have time for social activities and gatherings; some reported that it was uneasy to be at a gathering with other people when you are thinking about the patient you left at home. Some participants have reported to be rude to their neighbors and workmates.

“My interaction with others is different now, I am a soccer fan and since I started taking care of my nephew i have been limiting my attendance to soccer matches. When I decide to attend i end up leaving earlier before the match is over rushing to my patient.”
(Participant1)

“Our neighbors have been complaining about my absenteeism in community gatherings , they do not understand that I have to take care of my father. Some even think I am being rude and avoiding them when I am not....” (Participant 6)

“I have had challenges with the people at work and neighbors. Sometimes I get made when asked how my sister is doing because at times I would have been asked by a lot of people and they may think I am rough or rude but no I will just be frustrated”(Participant2)

The participants have been disengaging themselves from social activities; they are actually pulling themselves away from the crowd. For instance, participant 2 shows that he has a rude character and wants to take out his frustrations on just anyone that tries to talk to him so instead

of people sympathising and comforting him they end up leaving him alone. Participant 6 had challenges with neighbors who think that she is still in a position for social meetings and gathering, they do not understand the change that has happened to her. The mind of participant 1 is not at ease when he is out with his friends enjoying soccer when his nephew is at home in pain. Perhaps he will tell himself that he can pull through in the absence of his nephew but he ends up withdrawing in the middle of the game.

4.5.2 Subtheme 2: Family interactions

Family is a very important institution for all of the participants. The disturbances in the family affect the wellbeing of all the caregivers. Some participants reported divisions in the family as to what caused the cancer and which form of treatment the family should go for. Most participants have reported that siblings are more supportive to them compared to the support they got from external family members.

“ My siblings were there for me and they helped in any way possible, the problem was with my mother’s relatives who thought that the illness was because of witchcraft and they wanted her to get treatment from white garment churches and traditional healers” (Participant 5)

“I am the only family that he has, his mother died and he never knew his father... so i have to take care of him with the help of my other little brother who comes by to help sometimes.” (Participant 1)

Participant 5 was disappointed in the way her mother’s relatives behaved. She had a challenge dealing with them. Disagreements and fighting over which treatment to use on her mom is a hard thing for the participant 5 whose main duty was to take care of her mother and she is young to raise the issue against older family members. Participant 1 also had a challenge of being the only responsible relative of his nephew who was orphaned. He had less of family support and comfort.

4.5.3 Subtheme 3: Change of life style and plans

The plans and lifestyle of participants change due to caregiving. Some participants reported a change in their way of life, their daily routines changed. Others reported changes in their dreams

and aspirations in life while others reported great changes in the plans they would have set up in life. Participants had to make harsh decisions to suite the care of their family members at the cost of their own happiness and lives.

“I stopped working when i started taking care of my father; I used to be a cross border trader and it’s no longer possible to travel for days leaving him at home alone.” (Participant 6)

“I was supposed to get married a year ago but I decided to hold the marriage until my sister gets better plus i ended up using the lobola money for my sister’s care.” (Participant 2)

“My daily routines have changed , I still go to work but I stopped working during the weekends, I have to be home watching over my nephew and that comes with a consequence where my pay was reduced..” (Participant 1)

The participants experienced changes that affected the plans they had for their lives and that of their individual families. Participant 6 stopped pursuing her business of buying and selling to care for her father. It is good that she did it for her father but they also need money to take care of him too. Her lifestyle as an independent woman changes as she now has to depend on other people financially. Participant 2 may perhaps end up losing the girl she wants to marry because he is failing to fulfill his promise of marriage. Participant 1 reduced his working days that mean less income for him and his family. The change in life plans of the participants is a great problem to their lives.

4.5.4 Subtheme 4: High Expenditure

The cost of life for the participants changed due to cancer caregiving. The diets for the patients change and the type of food they are expected to eat is more expensive than other ordinary foods. The other participants also reported to have encountered debts and loans to carter for medical bills as well as the welfare of the patient. The cost of cancer treatment is expensive for just once chemotherapy session participants were expected to pay US \$150 or more depending with which cancer type it is.

“When my mom’s cancer recurred we were still paying for the previous debts that we had encountered. We had no choice but to take another loan from the bank in order for her to get treatment the second time.”

(Participant 5)

“I was unable to pay my sister’s medical bills even after putting together all my savings. I borrowed money from most of the people I know and still it was not enough I had to get a loan from the bank” (Participant 2)

“My father had a valid and working medical aid but there was a time when the doctors wanted the bills to be paid in cash and in other instances they ended up saying cancer treatment is not catered by your medical aid fund, we had to make contributions as a family to raise the money.”

(Participant 6)

The recurrence of cancer has led to participant 5 and her family to end up with a pile of debts. They had to start paying for the second treatment before they were done paying for the previous diagnosis. The participant 6 explains the decision to encounter a debt as the only option they had, she says “we had no choice...” meaning they had no other source of income except for the debts. Participant 2 revealed that all his savings including the money he had borrowed from people wasn’t enough to take care of his sister’s hospital bills, he still had to take a loan from the bank. The cost of caring for a cancer patient can be felt even after the patient dies or gets better because they still have to pay for the debts encountered during the time they were paying for medication and upkeep.

4.6 THEME 4: COPING STRATEGIES

There are certain strategies that the participants employed to cope with the problems of caregiving. Some of these strategies were suggested by professionals while the others are just activities and things that the participants adopted to reduce the pressure and stress caused by caring for a family member with cancer.

4.6.1 Subtheme 1: Acceptance

Acceptance has recorded to be the main coping strategy for all the participants. Most Participants have taken acceptance as the first step to dealing and handling cancer care. The participants have recorded accepting the outcome of the disease which also has helped in the patients accepting the disease. Other participants went to the extreme of helping out patients of the opposite sex in any way possible after accepting the situation.

“I just accepted that my sister now has cervical cancer and I didn’t care that I was male I could help her even when she was bleeding.. I no longer saw the disgust when she spoiled blankets. I became more like her sister even though I am his brother...” (Participant 2)

“To cope with caregiving problems, I accepted my father’s condition first, the fact that he has been diagnosed and he was still alive ...”
(Participant 6)

“When I learned that my wife has cancer I accepted her condition, I was going to be by her side all the way” (Participant 3)

The participants handled their problems by firstly accepting that a member of their family now has cancer. Acceptance have been a way they use to move forward and think of the next step as to handle the disease and reduce pressure on themselves. Participant 3 after accepting his wife’s condition he pledged to be supportive throughout the wife’s condition. He made the decision to stick with her after accepting the condition. Participant 2 also overlooked the fact that he was male after accepting his sister’s condition; he was helpful in all her sisters needed though having to see the spoiled blankets may be disgusting even after they are cleaned up ,this may be another reason why the participant had troubles eating. Participate 6 when she learned her father was cancer, she was thankful for his life overlooking the fact that has cancer, she accepted his condition by being more thankful he was alive.

4.6.2 Subtheme 2: Devine interventions

Devine interventions refers to the use of religion to cope. Most participants reported that prayer and religious activities helped them to accept and cope with caregiving. Some participants reports attending religious functions such as church meetings helped them cope and reduce stress on their wellbeing. Other participants reported that prayer and leaving the situation in God’s

hands was more helpful in coping with cancer. The other participants reported that a visitation by fellow church members and pastors was more helpful in their coping with caring for their relatives with cancer.

“We used to pray for my father. I used to call my other sisters and we pray together as a family, I t was really helpful and you can be relieved after praying.” (Participant 4)

“I am into church so i spent most of my time at church, whenever I felt down I could go to church and visit my pastor.”(Participant 5)

“My sister went to church before she got sick so she had people from her church coming to visit, that also made me cope with the situation knowing that I have other people who want to help.”
(Participant 2)

The participants were helped a lot by divine interventions to cope with their caregiving experiences. Some of the participants believed in the power of prayer. Participant 4 made the time of prayer a family bonding time because she did not do it by herself she involved her sisters and the rest of the family. Perhaps they had to come up with dates to meet when everyone is would be free like during the weekends. The participant 2 was not a church attender but he felt thankful and was helped to cope by the people from the church which her sister attended. It can be noted that the participants that are more inclined to divine interventions are females, males do not usually confide in prayer.

4.6.3 Subtheme 3:Counseling

Participants have made use of counseling as a way of coping with caregiving problems. The type of counseling they used involved that conducted by professionals as well as those done by those with caregiving experience and the elderly. Some participants reported going for counseling sessions with their spouses to get ideas on how to care for each other in a situation like theirs. Other participants reported turning to their friends for advice on how to cope with their situation a well. Also some reported attending counseling sessions that are meant for the patients to get more knowledge about the illness.

“Sometimes I go with my father to attend counseling sessions that are meant for the cancer patients only...it helps me get more insight on the disease” (Participant 6)

“I and my wife have decided to go for counseling as a couple where we are able to discuss our condition together and getting the help we need to overcome the illness.” (Participant 3)

“My workmates and friends have been really helpful in my situation, they give me advice when I need it even when they feel like I need it” (Participant 1)

The participants got counseling one way or the other, some would call it advice and others would call it support yet it is all counseling which they got from different people professionals or not. Participant 1 gets counseling from his work colleagues and friends, he views it helpful since he has no much family to get counseling from. Due to lack of finances people like participant 1 can only afford free counseling which is that from friends and not professionals. Participant 3 is more dedicated to making his relationship with his wife work; he goes for counseling with her such that they cope together. People like participant 3 are more focused in the knowledge of the disease she uses knowledge about the disease as a coping strategy and the counseling that is meant for the patient she uses it for her own good too.

4.6.4 Subtheme 4: Social support

The participants reported to have had social support from their friends, families, workmates and neighbors. The other participants reported to have received support at places like the beer hall where they find their friends and socialize drinking beer. Other participants have supporting neighbors who help out and confide with them. Supportive friends have been reported by most participants though the places of socialization differed but they all reported social support to be a coping strategy.

“Sometimes after i am done washing my nephew, i go out to the beer hall for one or two drinks just to relieve the stress and have time to catch up with my friends. We chat for a short while and it’s good that

I get to talk about other things that does not concern my nephew's sickness” (Participant 1)

“I usually would go to church for social support and also I have very supportive friends who are there for me, they always check on me and how I am doing with my mother” (Participant 5)

“I received support and encouragement from my pastor and our neighbors. The neighbors also helped take care of my dad for example when he needed company while I do other things they came along to help” (Participant 4)

The participants took certain measures to cope with the burden of caring for their family members with cancer. The participant 1 used the beer hall as a place for socialization where he can forget his troubles in the company of his friends. Participant 5 relied on her friends from church and from home for support, she trust them for being loyal and being there for her at her time of need. The participant is still a teenager and that is the age where friends can either build her or break her and in this case they are there for her. Neighbors of participant 4 were there for her, helping her adjust and cope to the situation and overcome the problems.

4.7 CHAPTER SUMMARY

The participants were open enough to disclose all the information that made up this chapter. Most participants experienced psychological problems such as stress, fear and depression. These problems end up causing other physical problems such as headaches which was also experienced by other participants. There was a time in the life of the participants when they chose the patient over themselves and they ended up losing social ties. Another thing that was highlighted in this chapter was the financial burden carried by the participants in caring for people with cancer. Most of them are sinking in debts. Finally the participants had different measures that work best for each and every one of them to cope with the burden of caring for a family member with cancer.

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CHAPTER FIVE

DISCUSSIONS, RECOMMENDATIONS AND CONCLUSIONS

5.1 INTRODUCTION

This is the final chapter of the research. It shall discuss the findings of the study as per each research questions mentioned in chapter one and giving an overview of the findings discussed in chapter four. It also shall discuss the possible recommendations applicable to the study and finally draw possible conclusions.

5.2 DISCUSSION OF RESULTS

This study was about the psycho-oncological burden of care: experiences of familial caregivers of people with cancer. Its focus was to come up with the different problems experienced by familial caregivers of people with cancer. The study was a qualitative narrative with its research coming from semi-structured interviews that were done on six participants, three of them being male and the other three female from different age groups and marital statuses. The familial caregivers opened up on the different challenges they faced while caring for their relatives from diagnosis, through to treatment and the possible outcomes after treatment.

5.3 IMPACT OF CAREGIVING EXPERIENCES

The first research objective of this study was to determine the impact of caregiving experiences on the familial caregivers of people with cancer. The impact of these experiences were recorded as the caregivers experienced a transition period and experience of the value of their families.

5.3.1 Transition period

The cancer care period was recorded to affect both sexes of familial caregivers. One third caregivers reported to be caregiving for the first time. It was a new experience for them and most of them were not ready, being a first time thing these participants experienced great changes and shifts on their daily routines and way of life. Schlossberg (1981) propounded the transition theory which describes transition as an event or non-event which results in a drift and twist in

relationships, routines, assumptions and roles. The caregivers reported changes in many aspects of their lives thus making their caregiving experiences a transitional period in their lives. Spouses and children have reported to dedicate most of their time to caregiving .According to Montgomery and Koskloski (1994) the average number of hours per week that is spent by spouses and children caregiving is greater than that of a distant relative. The more time a familial caregiver spends of a patient , the less time he still have for other duties including having to care for themselves. Some familial caregivers may fail to realize that their life is changing and may have to be reminded of the changes going on in their lives by other people.

5.3.2 Value of family

The value of family has been used to explain the impact of the burden of caregiving on the caregivers. According to Seyegh and Knight (2010) who used the term familism to describe the individual's multisided identity with the family and may include the strength of dedication, loyalty and obligation the individual has towards their family. The loyalty familial caregivers have towards their families makes them overlook the burden of caring for people with cancer. Schlossberg (1981) also asserts that perceptions play a major role in transitions; she believed that events are best defined by the person experiencing them. The way the familial caregivers described their experiences was out of their love and care for their families other than what other people or the researcher thought about their experiences. They did not want to view their relatives as a burden.

5.4 PSYCHOLOGICAL AND PHYSICAL PROBLEMS

The psychological and physical problems experienced by familial caregivers of people with cancer included fear of cancer, stress and depression and pain. The psychological problems in most cases resulted in the physical problems.

5.4.1 Fear of cancer

The familial caregivers reported fear of cancer. Just as similar to panic, fear destroys the caregivers' ability to concentrate and process information Harden, Schafenacker, Northouse, Mood, Smith, Pienta, Hussain and Baranowski (2002). The fear on caregivers was reported as fear of losing a loved one and fear of the loved one's survival of cancer. According to findings

by Roing, Hirsch and Holmstrom (2008) learning about the diagnosis of cancer resulted in fear. Some caregivers perceived a diagnosis of cancer as a death penalty. The other participants reported to have expected the death of their loved ones after diagnosis only. Fergus and Gray (2009) on their research on relationship vulnerabilities during breast cancer reported that after diagnosis the fear of death made the caregivers not to live their lives as they did before the diagnosis.

5.4.2 Stress, depression and pain

High levels of stress and depression were reported among three quarters of the participants. The care of people with cancer was more burdensome to some of the participants. Stress was caused by the feeling of helplessness when the caregivers did not know how to take care of the patient Shaw, Harrison, Young, Bustow, Sandroussi, Martin and Solomon (2005). The side effects of cancer and its treatment caused pain on the patient and caregivers expressed being helpless and in turn become stressed because they is nothing they could do to help them than to just watch them deteriorate Senden ,Vendecastele, Vandenberghe, Versluys, Piers, Grypdonck and Van Den Nooetgate (2015). The participants' stress manifested in different forms, almost all of them reported to have changed the way they eat, from the amount of food they used to eat to the number of times a day they eat. The stress that comes with watching a family member with cancer unable to feed themselves reported a lack of interest with food by the familial caregivers.

In a study conducted by Keller, Heinrich, Sellschop and Beutel (1996) , they reported ion their findings that 67% of their sample of spousal caregivers of people with cancer recorded high to very high illness related levels of distress. This research reported high levels of distress two thirds of the caregivers. The male familial caregivers reported more depression than females and the single caregivers expressed more than married ones. In another study by Hodges and Humphris (2009) they found out that recurrence of cancer was another manifestation of depression and distress found in a sample of 101 caregivers of head and neck cancer patients.

The caregivers stress has also shown not to end as just stress, if not handled well it develops to depression and depression end up have a physical effect on the wellbeing of the caregiver. According to Vitalio (1997) the stress of caregiving has been shown to have negative biological consequences for familial caregivers. In a caregivers study by Haley, La Monde, Han, Burton

and Schonwetter (2003) they reported 62% of a sample of 465 caregivers reported declines in health resulting from caregiving experiences. Approximately half of the participants of this research reported headaches due to sleepless nights and stress, a quarter experienced back pains associated with moving around carrying the cancer patient and helping them with mobility. The last quarter developed conditions such as High blood pressure due to the burden of caregiving.

5.5 SOCIAL AND ECONOMIC PROBLEMS

The participants experienced social and economic problems. The familial caregivers reported to have socially disengaged themselves, others because of the decisions associated with cancer treatment experienced family disagreements and the high expenses of cancer care led to change of life plans.

5.5.1 Social disengagements, family interactions and change of life plans

The familial caregivers that participated in this research experienced social disengagements. Some of the participants dedicated all of their time to caregiving with little or no time to spare. In a study by Mor, Allen and Malin (1994) that focused on the social consequences of caregiving found out that more than half of cancer caregivers report disturbances of their daily routines, with over half of the caregivers also reporting reduced socialization with neighbors, friends, workmates and church colleagues. The results of this study show that caregivers have a tendency to pull themselves away from the crowd whenever they try to be a part of a social gathering like a soccer match; they reported to prefer caregiving to any other social activities. They reported to have discomfort when “having fun” knowing that they have left a sick cancer relative at home.

Family interactions reported to be malfunctioning on two thirds of the participants. They reported disagreements as to what course of treatment to use for the caregiver. These disagreements usually occur when the treatment suggested is surgery for example surgery to remove the breast or uterus affected with cancer. The other participants had family disagreements when other family members suggested the disease was not cancer but which craft which needed spiritual cleansing and not hospitalization. According to Rivera (2009) familial caregivers are laypersons who usually have no professional training and the demands for caregiving can lead to distress. Distress then lead to familial caregivers giving up their life goals they would have set to meet at a certain age of their lives. A caregiver reported to have cancelled

the marriage he was supposed to have because by the time he had planned to marry he was already caregiving his sister and lost track of time for courtship. Changes in the life plans also lead to caregivers to experience stress as they will have to figure out if they would be able to compensate for the lost time.

5.5.2 High expenditure

Cancer care and treatment has reported to be more expensive than any other diseases. Hayman et al (2001) used United State of America's data to come up with a reported detailed study of the economic impact of familial caregiving for older persons. The estimate for caregiving was US\$ 1200 per patient per year, totaling over US\$ 1 billion annually in the USA. However that is not the same case in Zimbabwe the cost of carrying for someone with cancer can amount for US\$ 1200 per month which is N mount that is used by a cancer patient in the US annually. This research recorded that the caregivers could use up to \$150 for medication on every visitation they do the hospital for chemotherapy and radiotherapy. This amount does not include transport for the patient and caregiver; it does not include food and other expenses. It becomes a burden for the familial caregivers to manage their finances in an economic situation like the one in Zimbabwe.

5.6 COPING WITH CANCER CARE

The familial caregivers employed strategies to cope with the various caregiving problems. The first strategy was acceptance of the disease, then divine interventions, counseling and social support.

5.6.1 Acceptance and divine interventions

The familial caregivers have reported acceptance and divine interventions to have worked for them in helping them cope. Acceptance that their family member now has cancer and having to accept the caregiving responsibilities reported to have worked for most of the familial caregivers. They reported that after acceptance everything seemed to have fallen in place and having to figure out the next step towards getting the patient treated. Duggleby, Bally, Cooper and Doell and Thomas (2002) reported that some caregivers found the foundation of psychological and spiritual strength in their religious beliefs. Some familial caregivers explained that they got

strength and support from their church meetings and fellow church members. They found their support in the sentiments offered by fellow members Harden et al (2002).

5.6.2 Counseling and social support

Counseling is designed to reduce distress by helping the familial caregivers to adjust, cope and have a sense of control at the same time reducing anxiety and depression. Individual counseling is designed to provide caregivers with support, education and coping skills Harding and Higginson (2003). Counseling that is individual and couples counseling have reported to be useful in helping caregivers to cope with caregiving. Social support is another coping strategy that the caregivers used to cope with the problems encountered when caregiving. Caregivers reported to have different ways of socialization others drink beer; others attend social functions while others hang out with family and friends. The familial caregivers had one thing in common which are the people they describe as important who are friends and family Esbensen and Thome (2010).

5.7 CONCLUSIONS

The purpose of the study was to have a descriptive view of the impact of cancer on the lives of the familial caregivers. The familial caregivers gave an account of their caregiving experiences as a duty which they are mandated to do. The caregivers showed love for their relatives and the eager for their loved ones to get better which is could make them strain themselves to do anything for them to get better.

The study also concluded that psychological and physical problems are experienced by familial caregivers of people with cancer. The caregivers reported fear from the time of diagnosis. There is an increased fear and stress as the disease progresses and treatment commences. Physical problems are also experienced as a result of the psychological problems distress led to headaches and tiredness. Younger caregivers who had to carry people who weighed more than them experienced back pains. The cost of cancer caregiving can leave a caregivers affected with lifetime illnesses such as high blood pressure and back pains.

Another purpose of this study was to address the social and financial problems experienced by familial caregivers of people with cancer. The familial caregivers experienced social problems,

they voluntarily disengaged themselves from social activities and some of them dedicated all their time to caregiving to an extent that they forget about their own wellbeing. The research has also concluded that the familial caregivers end up in debts because of the drain on finances that is caused by cancer. Treatment of cancer has proved to be very expensive and it is a burden to balance the money for treatment and upkeep of the whole family.

The familial caregivers have managed to come up with ways to cope with the burden of care. Different strategies have proved to work for different people and not everyone adjust to them in the same way the other does. Others have employed associating with others while others have employed divine interventions.

The general conclusion of the study is that familial caregivers of people with cancer do experience psychological, physical, social and financial problems during the course of their caregiving.

5.8 LIMITATIONS OF THE STUDY

- The sample size was small hence there will be a generalizability of findings.
- Cancer related organizations keep protect the confidentiality of the patients to an extreme extent where it is difficult to even get information from them.
- The caregivers are still afraid of the stigma associated with cancer and it took them a lot of time for the researcher to convince them to have interview.

5.9RECOMMENDATIONS

- The researcher recommends for cancer to be treated the same way as other deadly diseases are being treated, that is having frequent numerous awareness to teach the general public about the disease such that when the time for one to be a caregiver comes everyone will have a little knowledge on how to give care.
- The researcher also recommends government assistance with paying for cancer treatment. Most households are watching their family members die because of lack of finances.

- The researcher thinks cancer survivors should be given a national platform to share their experiences with their caregivers.
- The researcher thinks that focus groups for cancer caregivers should be made a compulsory in all communities
- The researcher recommends access to information from organisations pertaining to cancer caregiving for future research to be more reliable..
- The researcher also recommends that the future researchers should include a combination of cancer patients who are also HIV positive.

5.10CHAPTER SUMMARY

The final chapter of the research looked at the discussion of the findings from the interviews, and gave the necessary recommendations as well as the conclusions drawn from the findings. The last chapter also managed to highlight the limitations of the study.

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APPENDIX A-RESEARCH INSTRUMENT INTERVIEW QUESTIONS

My name is Chipo Chikanya. I am a student at midlands state university studying Bachelor of Science Honors Degree in Psychology. I am carrying out a study on The psycho-oncological burden of care: Experiences of familial caregivers of people with cancer. I am kindly asking for your assistance in conducting my research by participating in an interview that I am going to conduct with you. Your responses will be treated with confidentiality and will be used for academic purposes.

SECTION A – Demographic data

What is your name?

What is your age?

Which sex are you?

What is your occupation?

What is your marital status?

Which type of cancer was diagnosed with the family member you take care of have?

What is the relationship between you and the cancer patient?

SECTION B

Can you describe your caregiving experience?

Can you describe for me how the disease impacted on your relationship with the patient?

Is he/she the first cancer patient you have ever given care, if no when was the previous time?

How did you feel after learning that your relative has cancer?

Watching your family member in pain, how do you feel?

I understand sometimes your relative is unable to move around because of the pain how have you been taking them to hospital and what type of errands have you been doing for them?

Have you been eating well, how many times a day?

Have you been experiencing any pain on your body?

Have you been sleeping well at night if not what is the reason?

How has daily routines changed since the time you started caregiving?

How has these changes made you feel?

What has been your relationship with others that is neighbors, church mates, and workmates?

Have you been working since you started caregiving?

Do you still have the same dreams and aspirations as you had before you started caregiving?

Are you managing the hospital bills?

Have you encountered debts or loans to carter for the medical bills?

SECTION C

What are your coping strategies that you employed to accept your condition?

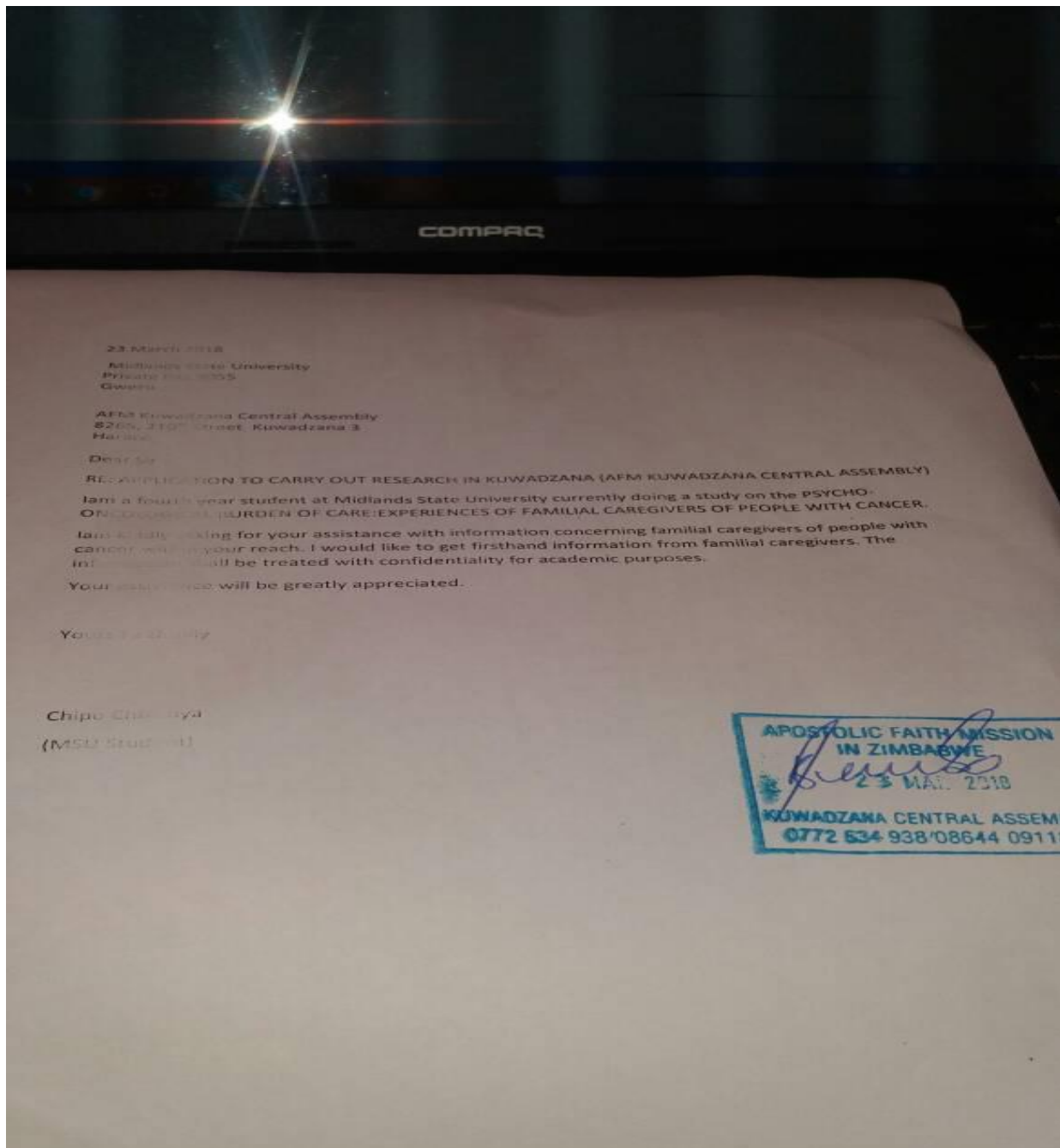
What measures did you take to reduce stress on your well-being?

What lessons did you learned from your caregiving experience?

What advice would you give to other people who are taking care of their family members who have cancer?

APPENDIX B – PERMISSION LETTER

APPENDIX C- GATEKEEPER'S LETTER



**APPENDIX D-AUDIT SHEET
MIDLANDS STATE UNIVERSITY**

SUPERVISOR – STUDENT AUDIT SHEET

DATE	TOPIC DISCUSSED	COMMENT	STUDENT'S SIGNATURE	SUPERVISOR'S SIGNATURE
15/09/17	Proposal	Rework		
10/10/17	Proposal	Proceed		
01/12/17	Chapter 1	Rework		
18/12/17	Chapter 1	Proceed		
11/01/18	Chapter 2	Rework		
31/01/18	Chapter 2	Proceed		
15/02/18	Chapter 3	Rework		
21/02/18	Chapter 3	Proceed		
01/03/18	Chapter 4	Rework		
08/03/18	Chapter 4	Proceed		
15/03/18	Chapter 5	Rework		
12/04/18	Chapter 5	Proceed		
16/04/18	First draft	Rework		
	Final draft	Submit		

STUDENT'S SIGNATURE:

SUPERVISOR'S SIGNATURE:

APPENDIX E- TURNITIN RESULTS

**APPENDIX F – WEIGHTING SHEET
A GUIDE FOR WEIGHTING A DISSERTATION**

NAME OF STUDENT: CHIPO CHIKANYA REGISTRATION No: R 1 45711G

	ITEM	POSSIBLE SCORE	ACTUAL SCORE	COMMENTS
A	RESEARCH TOPIC AND ABSTRACT Clear and concise	5		
B	PRELIMINARY PAGES Title page, approval form, release form, dedications, acknowledgement, appendices, table of contents	5		
C	AUDIT SHEET/PROGRESSION Clearly shown on the audit sheet	5		
D	CHAPTER 1 Background, statement of the problem, significance of the study, research questions, objectives, hypothesis, assumptions, purpose of the study, delimitations, limitations, definition of terms	10		
E	CHAPTER 2 Addresses major issues and concepts of the study, findings from previous work, relevance of literature to the study, identifies knowledge gap and subtopics	15		
F	CHAPTER 3 Appropriateness of design, target population, population sample, research tools, data collection procedures, presentation and analysis	15		
G	CHAPTER 4 Findings presented in a logical manner, tabular data properly summarised and not repeated in the text	15		
H	CHAPTER 5 Discussion (10) Must be a presentation of generalizations shown by results; how results and interpretations agree with existing and published literature, relates theory to practical implications. Conclusions (5) Ability to use findings to draw conclusions Recommendations (5)	20		
F	Overall presentation of dissertation	5		
G	References	5		
	Total	100		

MARKER:SIGNATURE:DATE:.....
 MODERATOR:SIGNATURE:DATE:.....