LIFE EXPERIENCES OF MALE SPOUSE CARE-GIVERS OF CERVICAL CANCER PATIENTS AT THE CANCER DISEASES HOSPITAL, LUSAKA, ZAMBIA.

BY

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DEDICATION

To all my family members, friends and the people that participated in this study for their spiritual, moral and financial support. May God bless you all.

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APPROVAL

The dissertation of Emily Walubita has been approved as fulfilling part of the requirements for the award of the Degree of Master of Social Work by The University of Zambia.

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ABSTRACT

Cervical cancer remains the fourth most prevalent cancer among women with an estimated incidence of 570,000 in 2018, representing 6.6 percent of all cancers among women globally. About 90% of deaths are due to cervical cancer occurring in low- and middle-income countries. Men have a critical role to play in reducing cervical cancer burden. However, studies of male partners' life experiences while caring for cancer patients are scarce in Zambia. This study aimed at generating knowledge on the life experiences of male spouse care-givers of cervical cancer patients at the Cancer Diseases Hospital, Lusaka,

The study used qualitative research approach with phenomenological research design. Data was collected from purposively selected twenty (20) male spouse care givers of cervical cancer patients at Cancer Diseases Hospital (CDH), Lusaka, Zambia. An interview guide was used to collect data. Content analysis method, using constant comparison technique of the audio recorded interviews, was used to analyze data.

The study revealed that most male spouse caregiver to cancer patient had limited knowledge of cervical cancer disease, did not know the causes, symptoms and the risk factors. The male partners associated cancer disease with pain and bleeding from the private parts and faced many challenges including reduced financial base, limited time for other family responsibilities and sexual deprivation. The male spouse caregivers, provided emotional support, financial support by paying medical bills and providing transport and food. Emotional support through prayers and, encouragement and spending time with the spouse were also important aspects of male support to their spouses. Their coping strategies where in form of prayers, bible study as well as smoking and drinking alcohol.

The study highlights evidence of life experience of male spouse care-givers of cervical cancer, having not received much attention in the cervical cancer literature. One interesting finding was that most male care givers were not affected by not having sex with their spouses because this is entrenched in the patriarch and masculinity as males construct their genders roles. However, most of them were more affected by the thoughts of where to get financial support and the pain of seeing the spouse lie in bed the whole time. The findings of the study could influence the formulation of deliberate policy strategies that could contribute positively towards much advancement in planning appropriate intervention to support male caregivers of cervical cancer patient.

Key words: Cervical cancer, male spouse, caregiver, life experiences; Zambia.

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ABBREVIATION/ACRONYMS

MOH	Ministry of Health
UNZA	The University of Zambia
UTH	University Teaching Hospital
CDH	Cancer Diseases Hospital
DR	Detection rate
ECC	Endocervical curettage
HPV	Human papillomavirus
RLU	Relative light unit
RR	Relative risk
SCC	Squamous cell carcinoma
SD	Standard deviation
SE	Standard error
STI	Sexually transmitted infection
OPD	Out Patient Department

DECLARATION

I, Emily Walubita, do here by declare that this dissertation is entirely the result of my own personal effort. The various sources to which I am indebted have been clearly indicated and acknowledged by means of complete references. I further declare that this dissertation herein presented for the Degree of Master of Social Work has not been previously submitted either in whole or in part for any other degree at this or any other university nor being currently submitted for any other degree.

Signed: ………………………………………… Date: …………………………..

Walubita Emily (Author)

CHAPTER ONE: INTRODUCTION

1.1 Introduction

This chapter outlines the background of the study, and the statement of the problem upon which research objectives were developed. To answer the research objectives, the research questions were developed. Furthermore, it provides the significance of the study and theoretical frameworks.

1.2 Background of the Study

Cervical cancer remains the fourth most prevalent cancer among women with an estimated incidence of 570,000 in 2018, representing 6.6 percent of all cancers among women globally. About 90% of deaths are due to cervical cancer occurred in low and middle-income countries. It is believed that the high cervical cancer mortality rate could be reduced globally through a comprehensive approach including prevention, early diagnosis, effective screening and treatment programs (WHO, 2019).

In Zambia, the Cancer Diseases Hospital recorded 2, 734 new cancer patients most of them with cervical cancer (CDH, 2018). It has been observed that male partners play a significant role in the healthcare decisions of women and that they can contribute to reducing cervical cancer burden by protecting their partners from Human Papilloma Virus (HPV) infections, motivating their wives to screen and allowing them to protect themselves against the disease (Williams, 2016; Castellsagué, 2017).

According to the Human Papillomavirus and Related Cancers, Fact sheet 2021, Zambia has a population of 5.08 million women ages 15 years and older who are at risk of developing cervical cancer. Current estimates indicate that every year 3161 women are diagnosed with cervical cancer and 1904 die from the disease (HPV Information Centre, 2021). The report further indicates that Cervical cancer ranks as the 1st most frequent cancer among women in Zambia and the 1st most prevelant cancer among women aged 15 and 44 years of age. In Eastern Africa about 4.7% of women in the general population are estimated to harbor cervical cancer HPV – 16/18 infection at a given time, and 67.9% of invasive cervical cancers are estimated to HPVs 16 or 18. (HPV Information Centre, 2021). Zambia may therefore be used as a case study to understand the life experiences of male spouse caregivers to cervical cancer patients.

In the event that the female partner has been diagnosed with cervical cancer, male partner needs adequate knowledge in cervical cancer, how to care for cervical cancer spouse, and support during the treatment so that they are psychologically prepared as they look after cervical cancer patients. Research studies, for example Kayser et al. (2007) has documented that there are negative effects, especially psychological well-being and quality of life of family caregivers of patients with cancer. In addition, it is generally known that cancer and its treatment affect not only the patients, but also their spouse caregivers, leading to relating cancer as a 'we-disease'. This is particularly the case when the primary caregiver is the patient's spouse. This means that primary caregiver (man) needs a lot of time to spend with cervical cancer spouse.

Considering that cancer diagnosis causes psychological disturbance and stress among family members, it is important for both patients and their spouses to begin the learning of cancer disease together, and cope together throughout the disease progression. Demands are placed on caregivers to meet the multidimensional needs of family members with cancer, including treatment monitoring; treatment-related symptom management; provision of emotional, financial, and spiritual support; and assisting with personal and instrumental care (Given et al. 2004). Also, it may require rearrangement and adaptation of the couple including managing household and childcare responsibilities; negotiating changes in family and occupational roles; and changing future life plans (Harden 2005). Similarly, spouses have to cope with other challenges, including worrying about their ability to provide emotional and practical support to the patient, and the potential loss of their life partners (Thomas et al., 2002).

The demands associated with the care of cancer patients have serious effects on the lives of the family caregivers. The extensive review of the literature indicates that there are psychosocial, socioeconomic, and physical health effects associated with caring family members with cancer. A study of experiences of male spouse caregivers of women with cervical cancer found that caregivers experience a disruption of daily routines and transformation of lifestyles, roles, physical intimacy, and plans for the future (Teskereci & kulakas, 2016). Other studies have reported caregivers to have lower levels of physical health than non-caregiver counterparts (Pinquart & Sorenson, 2003b); higher levels of stress hormones and lower levels of antibody responses than non-caregivers (Vitaliano, et. Al. 2003); and are at greater risk of dying prematurely than persons who do not provide care to their spouses (Schulz & Beach, 1999).

Similarly, some studies focusing on economic and psychosocial effects of caring for cancer patients have noted that caregivers tend to experience high levels of burden and psychosocial morbidity, indicative of unmet needs of caregivers associated with lack of financial support, enough time for self, and stress of caring for the loved ones (Yusuf, et al., 2010). Also, studies on coping strategies of male spouse caregivers of breast cancer patients have noted the tendency not to focus on life disruptions, but on tasks of care-giving; and keeping stress to themselves as being congruent with masculinity, meaning being a strong person (Lopez, et al. 2012); and concealing the burden of care-giving roles to minimize their wives' concerns (Wagner, et al., 2011).

From the above, it is evident that to date there is still limited understanding of life experiences of male spouse caregivers in the developing countries. This is partly due to the fact that most research studies have been undertaken in the developed countries. The limited work undertaken has focused mainly on the distress between patients and caregivers more especially in the developed countries. The small body of evidence in the field suggests that male spouses may be inadequately prepared to meet the new, ongoing and variable needs and may be more inclined to use solution-driven strategies in supporting their spouses undergoing treatment for cervical cancer (Fergus and Gay, 2009). Similarly, most of the studies that have examined the burden of care-giving have predominantly used quantitative research designs with less focus on subjective experiences.

1.3 Justification of the Study

Male spouses have a major role to play during the treatment process of their partners with cervical cancer. However, the experiences of male spouse caring for cervical cancer patients remains obscure as very little has been reported Additionally, cervical cancer and its impact on male caregivers are less explored than how other cancer diagnoses impact male care givers. In Zambia, the experiences of male spouse caregivers of cervical cancer patients have not been well documented. This is because there have been no studies undertaken to date. This study was designed to explore the knowledge of cervical cancer disease among the male spouse caregivers; support given to cervical cancer patients by male spouse care givers; challenges experienced by male spouse caregivers; and the coping strategies used by the male spouse caregivers during the treatment process. Given the dearth of research in Zambia on the lived experiences of male spouse caregivers, it was anticipated that the findings of the study could provide good understanding of the impact of cervical cancer illness on family members that care for the patients. Similarly, it was anticipated that the findings could be of much use by the health care and social welfare professionals who work with cervical cancer patients, affording them a better understanding of care giving process; and providing a basis for designing effective interventions and support to improve the spousal care giving.

Also, it was anticipated that the findings could form the basis for further research by individuals and organizations interested in the care of patients with cervical cancer illness in Zambia. It was anticipated that the findings of this of this study could lead to enhanced service delivery to cervical cancer patients.

It is against this background that this research assessed life experiences of male spouses, focusing on their knowledge, the support they give, challenges faced and their coping mechanisms.

1.3.1 Research Objectives

The main objective of the study was to explore the experiences of the male spouses in caring for partners with cervical cancer.

The specific objectives were as follows:

1.3.2.1 To understand what male spouse caregivers know about their partners' cervical cancer disease.

1.3.2.2 To explore the support rendered by male spouse caregivers to partners with cervical cancer disease during the treatment process.

1.3.2.3 To explore the challenges faced by male spouses as they take care of their cervical cancer partners.

1.3.2.4 To understand how male spouse care givers to partners with cervical cancer cope with the illness.

1.4 Research Questions

1.4.1 Main Research Question

1.4.1.1 What are the experiences of male spouses in caring for partners with cervical cancer disease in Zambia?

1.4.2 Specific Research Question

1.4.2.1 What is the knowledge of cervical cancer disease among male spouse caregivers?

1.4.2.2 What support do male spouse care givers provide to partners with cervical cancer during the screening and treatment process?

1.4.2.3 What challenges do male spouses face as they care for cervical cancer partners?

1.4.2.4 What are the coping strategies of male spouses caring for partners with cervical cancer?

1.5 Theoretical Framework

1.5.1 Structural Family Theory

Structural family theory (Minuchin, 1974) was one of the conceptual frameworks for the study. It focuses on family interactions to understand the structure or organization of the family. It assumes that a family is a social system made up of four different subsystems: spousal; parental; parent-child; and sibling, composed of interacting roles. If member(s) of a particular subsystem is not playing expected roles, it may have negative effect on other member(s) of a subsystem and of other subsystems, resulting in the family dysfunction.

For instance, if the wife, member of the spousal subsystem, is not able to play expected roles due to illness, the husband may be negatively affected by playing multiple spousal roles and denial of intimacy relationship. Similarly, if the mother, member of the parental subsystem, is unable to play expected roles due to illness, the father would be negatively affected by assuming multiple parental roles. This theoretical perspective was used to understand the possible effects of caring for the family members with cervical cancer illness.
Moreover, the theory focuses on the experiences of families that may have encountered distress which may be a result of dysfunction.

1.5.2 Coping Theory

Coping theory was another conceptual framework for the study. Coping is conceived as constantly changing cognitive and behavioural efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person (Lazarus and Folkman, 1984). In this context, coping is defined as the conscious and unconscious efforts people put in to solve problems and reduce stress. There are so many ways of adapting to a stressful situation. In psychology, coping strategies are a set of adaptive tools that people proactively administer to avoid burnout (Mukwato, 2010). These tools can be thoughts, emotions, and actions are dependent on personality patterns. Based on this definition, it can be argued that:

- Male spouse caring for partners with cervical cancer are expected to spend mental energy in a way that can reduce stress.
- Whether conscious or subconscious, the male spouses need to be strong and firm to provide support and care to the cervical cancer partners;

- Coping is dependent on the personality of a person and the condition or situation being experienced by the individual;

The strategies one chose for adapting to a situation is highly individualized, and it is never the same for two people. However, the coping strategy adopted by a person change over time and in accordance with the situational context in which it occurs (Lazarus & Folkman, 1984). In the context of this study, the coping strategy(s) adopted by the male spouse caregivers of cervical cancer patients would be dependent on the stage and conditions of illness; and their assessment of the support services available to them and their patient.

The coping theory adopted in this dissertation is appropriate to explain how the male caregivers to cervical cancer patients at the CDH in Lusaka will cope with stress of looking after their sick spouses who are terminally ill. The coping theory is instrumental in shaping the stress and coping with the current situation of being caregivers to the spouses something which is not common in the Zambia culture, as men define their gender roles through masculinity in the patriarchal society which is dominated by men. The theory also explains the positive and negative emotions which arises as a result of male partners seeing their spouses spending time lying in bed with pain.

1.6 Definition of Terms

Cervical Cancer: A chronic illness that affects the cervix of a woman and is caused by the Human Papillomavirus (HPV), a sexually transmitted infection.

Caregiver: A male spouse taking care of a wife with cervical cancer illness

Life Experiences*:* The difficulties or hurdles (internal and/or external) a person deals with when faced with a situation. For this study, the situation is the cervical cancer illness.

Coping Strategies: The techniques applied by an individual to change, tolerate or avoid problematic or stressful events and situations in the context of a cervical cancer illness.

Support: The help the male spouse care givers provide to partners with cervical cancer during the screening and treatment process of cervical cancer illness.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter provides a general overview of relevant literature on the care of cervical cancer patients by family members. The information was drawn from research reports, books, and journals articles. According to Bryman (2004) the review of literature involves the systematic identification, location, and analysis of documents containing any information related to the research problem at hand. For any given research topic, it is very cardinal to read and insight about the topic so that the researcher is better informed. In this vein, literature review is very important because it initially acts as a pre-route to problem formulation. It may inspire the researcher to formulate a problem.

2.2.1 Family Care and Cancer

In understanding the demands positioned on spouse caregivers, most literature has focused on women. Women provide most of paid and unpaid acts of care giving. (National Alliance for Care giving). However a cancer diagnosis has direct implication for caregivers, especially spouse caregivers because there are frequently involved in direct care and management of the patient (Stenberg,Ruland,&Miaskowski,2010;Stetz,1987)

A qualitative study of the impact of care giving on the psychological well-being of family care givers and cancer patients, noted that there is a significant reciprocal relationship between patients and caregivers emotional distress (Laurel et al. 2012). According to this study, the sources of distress vary by phase of illness. Evidence- based interventions such as psycho-educational (57.1%); skills training (25.7%); and therapeutic counselling (17.1%) significantly reduced the caregiver's emotional distress and anxiety.

One of the limitations of the study is that it did not specify types of stress experienced by different family members including male spouse caregivers.

This shows that caregivers are affected differently, this also depends on the severity of the disease Also, Lopez, Copp and Molassiotis (2012) conducted a qualitative study on the experiences of male caregivers of patients with breast and gynecologic cancer. However, it was noted that male caregivers experienced varied degrees of cognitive, physical and psychological impacts. In addition, male caregivers dealt with problems that arose congruent with masculinity culture such as minimizing disruptions, focusing on tasks, and keeping their own stress to themselves. Further, it was noted that the experiences of male caregivers have ``not received much attention in the literature on cancer illnesses.

2.2.2 Knowledge of cervical cancer among male caregivers

During the interviews, partners of cervical cancer patients were asked about their knowledge of the disease before their partners were diagnosed with the disease. The male partners reported that they had no knowledge concerning the causes, symptoms and risk factors of the disease prior to the diagnosis of their partners. For example, some

"*I did not know anything about this disease. I did not have any idea about the cause, symptoms or any risk factor of the disease. I only overheard it on the television being debated in Parliament as to whether it should be covered in the national health insurance scheme. That is all I know*".

Another male partner noted that "*In fact, I had no knowledge about the disease and how it is caused, but all I knew was that it could kill. And I do not even know its local name*".

Similarly, another male partner indicated that "*I have never heard of cervical cancer disease. Is it also a disease that affects women*? *Then women are really suffering.*"

The male partners who became aware of the disease after the diagnosis, noted that they had no knowledge of the causes, symptoms and risk factors of the disease. Some of the respondents only got general information about the disease from the doctors. This is also documented in a qualitative study on male support for cervical cancer screening and treatment in rural Ghana which generated interesting findings (Binka, 2019).

2.2.3 Support male partners provide to partners with cervical cancer disease.

Binka (2019) undertook a qualitative study on male support for cervical cancer screening and treatment in Ghana among 41 participants including cervical cancer patients, their partners, and other married men (Binka., 2019).

Male spouse care givers of cervical cancer patient experience poor quality of life

The research findings revealed that some male partners provide various forms of support–financial, social, material and emotional to their partners with cervical cancer during the screening and treatment stages of the disease. Some men, however, abandoned their partners during the screening and treatment process of the disease.

2.2.4 Challenges of caring for patients with Cervical Cancer Disease

Karianne Oldertrøen Solli, Marjolein de Boer (2018) carried out a study entitled *Male partners' experiences of caregiving for women with cervical cancer -a qualitative study* at University of Oslo in Norway. The study employed a qualitative design with semi-structured interviews with six men/partners recruited through the gynaecological section at a hospital.

Findings of the study indicated that men's experiences of being caregivers and partners of women treated for cervical cancer are multifaceted, comprising emotional and practical aspects. However, three main findings stand out as particularly significant for men in the context of cervical cancer: loneliness, an altered sexual relationship (sex as "a difficult issue", throughout the treatment period) and shared feelings of vulnerability. The men had different situations when it came to friends and family to lean on. If the men had family nearby, they got practical help and emotional support. If that was not the case, or if they did not have many friends, the men experienced more feelings of being by themselves in a difficult situation. The study concluded that there is an interdependence of women with cervical cancer and their male spouse care givers. Furthermore, it shows how relationships have been seriously altered, particularly when it comes to sexuality.
However, this study was conducted in Norway which is in Europe, but a study of a similar nature needs to be conducted in Africa to ascertain the life experience of caregivers caring for their spouse suffering from cancer knowing quite well the cultural variability of the two continents in terms male spouse care giving.

2.2.5 Male Spouse Caregivers Copying Strategies of Cervical Cancer Patients.

Mukwato, Mweemba, Makukula and Makoleka (2010) undertook literature review on stress and coping mechanisms among breast cancer patients and family caregivers in Zambia. Results of the review indicated that of the 22 research reports reviewed, 13 focused on coping with breast cancer, 5 on stress and adaptation to cancer and the last 4 on experiences of family members on care of the terminally ill. Most of the studies used qualitative research design. Content analysis of the research reports revealed four predominant types of copying mechanisms for both patients and family members. It includes (a) seeking social support, (b) reliance on God, (c) positive suggestion/attitude or re-affirmation and (d) acquisition of information and education. The study concluded that a diagnosis of breast cancer is a stressor to both the patient and the family caregivers, and strategies are therefore required to adapt.

However, this study focused on stress and coping mechanisms among breast cancer patients and family care givers. The current study focused on the life experiences of male spouse caregivers of cervical cancer patients in Zambia.

Fatima and O'Neill (2018) conducted a study entitled: *The experiences of caregivers providing home care for terminally ill family members at the end of life: A phenomenological study* in Bahrain. Results of the study indicated three main themes emerging from the data: (1) the burden of care, (2) comforts, and (3) coping. The findings showed that the lived experience of home caregiving includes physical, emotional and financial burdens, combined with a lack of professional support. The collective experience was infused with intense emotions because of a lack of structured support, resulting in negative emotions that frequently affected the caregivers' well-being and their ability to care for the ill person. Nevertheless, it was noted that caregivers tried to maintain care and comforts for their terminally ill relative in the home.

They adopted the home environment, arranged resources to ease caring and provided psychological care. Caregivers utilized three coping mechanisms, faith, personal strategies and distribution of the care responsibilities among family members. It was concluded that caregivers were not prepared for the commitment and burdens of home care when a family member is terminally ill. A recommendation from the study findings is that training be offered on nursing care before patients discharge. In addition, a reactivation of the palliative care clinic hotline service would support family caregivers. It was further recommended that home nursing care and hospice services be established to improve homecare services for family caregivers in Bahrain.

Margaret, Bevans and Sternberg (2012) conducted a study entitled *Caregiving Burden, Stress, and Health Effects among Family Caregivers of Adult Cancer Patients.* When the condition of the patient is perceived as a chronic stressor, caregivers often experience negative psychological, behavioral, and physiological effects on their daily lives and health. In this report, we describe the experience of a 53-yearold woman who is the sole caregiver for her husband, who has acute myelogenous leukemia and was undergoing allogeneic hematopoietic stem cell transplantation. During his intense and unpredictable course, the caregiver's burden is complex and complicated by multiple competing priorities. Because caregivers are often faced with multiple concurrent stressful events and extended, unrelenting stress, they may experience negative health effects, mediated in part by immune and autonomic dysregulation.

The literature review was guided by the question on what is the live experiences of male spouse caregivers of cervical cancer patients at the cancer diseases hospital in Lusaka. To synthesis the literature review meta-analysis was done to see what specific findings came from the articles which were studied in this review.

Summary of Literature review

AUTHOR	SUMMARY TITTLE	SUMMARY OF FINDINGS
Laurel etal (2012)	Impact of caregiving	Significant reciprocal relationship between patients and care givers emotional stress. The source of distress varies by illness.
Lopez etal	Experiences of male caregivers	Male caregivers' experiences varied degree of cognitive psychological impacts.
Binka (2019)	Knowledge of male caregivers on cervical cancer	Male partners had no knowledge concerning the causes, symptoms and risk factors of cervical cancer.
Mukwato etal (2010)	Male spouses copying strategies	Seeking social support, reliance on prayer and God, positive suggestion/attitudes or reaffirmation of acquisition of information and education.
Karianne etal (2018)	Challenges of male caregivers	Men's experiences of being caregivers and partners women cervical cancer are multifaceted, comprising emotional and practical aspects. Loneliness, shared feelings of vulnerability and altered sexual relationships.
Fatima (2018)	Experiences of care givers	Major emerging themes; burden of care, comforts and coping, physical, emotional and financial burden.

Margaret etal (2012)	Male Caregivers burden	Negative psychological behaviors and psychological effects on daily lives and healthy.

2.2.6 Conclusion

The selected reviewed literature on caring for patients with cancer illnesses, indicate that the male caregivers as a separate group with their own needs have not received much attention in the cervical cancer literature and their concerns and challenges may differ from those of female caregivers.

CHAPTER THREE: RESEARCH METHODS

3.1 Introduction

This chapter presents the research methods used including research design; data collection methods; data processing and analysis; and ethical consideration.

3.2 Research Design

According to Kombo and Tromp (2009: 70), "a research design is used to structure the research, to show how all of the major parts of the research project work together to address the central research questions." Additionally, Kothari (2004) submits that research design is a blueprint for the collection, measurement and analysis of data. It is a master plan specifying the methods and procedures for collecting and analyzing the needed information, and it ensures that the study is relevant to the problem and that it uses right procedures in collection and analysis of data.

For this research study, phenomenological qualitative research design was used. Phenomenology is essentially the study of lived experience and the emphasis is on the world as lived by a person. This research design was used as the study aimed at exploring the experiences of male spouses in caring for partners with cervical cancer. Phenomenology focuses on the meaning of things that people do. The lived experience simply means the everyday encounters that people go through. Phenomenology also helps in describing phenomena from the respondent's lay accounts (Van Manen, 1997, Valle et al., 1989 and Creswell, 2007).

3.3 Data Collection

3.3.1 Research Site

The study was conducted at the University Teaching Hospital, Cancer Diseases Hospital, Lusaka, Zambia. The Cancer Diseases Hospital has been selected because it is the largest cancer disease referral hospital in Zambia. According to the Cancer statistics from 2017-2018 out of the top 10 Out Patient Department (OPD) cases; cervical cancer, breast cancer, and prostate cancer were most common; with cervical cancer most predominant. Furthermore, the hospital was selected because the researcher works from the hospital hence accessibility of participants will be easy and less costly because of its proximity.

3.3.2 Study population

According to Kombo and Tromp (2009: 76), "a population is a group of individuals, objects, or items from which samples are taken for measurement." Population can also refer to an entire group of persons or elements that have at least one thing in common (Kothari, 2004). The participants for this study included the male spouse caregivers of cervical cancer patients at the Cancer Diseases Hospital in Lusaka, Zambia.

3.3.3 Sample Size

According to Kombo and Tromp (2009: 77), a sample is “a set of people selected from a larger population for the purpose of survey. The sample size for this study was twenty (20 male spouse care givers to the partners with cervical cancer at Cancer Diseases Hospital). This sample size was adequate for the study, given the huge volume of interviews to be conducted to collect data. Kothari, (2004) suggests that phenomenological studies usually focus on a group of between 8 and 12 people.

For phenomenological studies, Creswell (1998) recommends a sample of 5 – 25 research participants; and Morse (1994) suggests at least six. For this study, a sample size of 20 research participants was used. The sample size was adequate to allow for data saturation. It has been noted that for qualitative research design, data saturation could be obtained with sample size of 5-8 respondents (Braun, 2026).

3.3.4 Sampling Technique

Sampling is the procedure a researcher uses to select participants, place, or things for the research study. Polkinghorne (1983), defined sampling as a process of selecting individuals or objects from a population such as that the selected group contains elements representative of the characteristic of the entire group.

For this research study, non-probability purposive sampling method was used to select the twenty research participants with cervical cancer partners receiving treatment at Cancer Diseases Hospital. This process started with a thorough review of the register to identify patients who had been diagnosed with cervical cancer. The sample was selected among male spouses who escorted their cervical cancer partners as they attended the cervical cancer clinic every Thursdays. This method was used because it allowed the researcher to choose a homogenous sample with characteristics of interest.

3.3.5 Data Collection Instruments

Saunders (2007) defines research instruments as tools that are used in collecting necessary data. This research study used an interview schedule containing semi-structured questions to collect data from research participants under each research objective.

To ensure that the research instruments and questions were appropriate for study, the researcher pre-tested the research instruments before the actual data collection. During the pre-test, the research instruments was administered on 4 male spouse care givers to partners with cervical cancer at Cancer Diseases Hospital. After the pre-test, the questions in the research instruments were edited taking into account issues that emerged during the pretesting such as the need to paraphrase some questions for clarity.

3.3.6 Data collection procedure

Primary data was required for this research. The data was obtained from male spouse caregivers of cervical cancer spouses using in-depth interviews. Interviews are form of a conversation to collect specific information (Morse, 1994). The in-depth interviews helped to know divergent experiences among male spouses caring for cervical cancer partners (Creswell, 2007).

Each interview was audiotaped and lasted between 30 minutes and 1 hour. Interviews were conducted at the hospital but separately from the patient precisely when the patient was receiving treatment. Demographic characteristics of research participants were collected including age, education, and employment status.

3.4 Data Processing and Analysis

Data analysis is the systemic organisation and synthesis of research data (Polit and Beck, 2012). Content analysis was used to process and analyse primary data. Content analysis is the process of organising and integrating material from documents often narrative information from qualitative study according to key concepts and themes (Glaser and Strauss, 1967). Content analysis method, using constant comparison technique of the audio recorded interviews was employed to process and analyze the data thematically in relation to research objectives (Miles and Huberman, 1994). Data collection and analysis were done concurrently using a thematic analysis approach. The process involved transcription of recordings on the digital recorder verbatim to ensure that there is no change in the meanings and that the actual text represent actual statement from the participants and this was followed by coding, and theme generation by looking at the frequency of the data in terms of occurrence. The researcher performed data familiarization, coding, theme generation, defining, and writing up as key steps in content analysis. Generation of descriptive categories; construct categories and themes for research objectives were done.

3.5 Ethical Considerations

Ethical considerations are acceptable behavior during a given research process that involve human beings (Polit and Beck, 2016). The ethical guidelines described by Polit and Beck (2016) from the *Belmont Report* was applied in the study. The *Belmont Report* described three broad principles on which to base standards of conducting research in an ethical manner which are: beneficence (minimise harm and maximise benefits), respect for human dignity (right to self-determination and full disclosure), and justice (right to fair treatment and privacy).

3.5.1 Ethical Approval:

Before the study was undertaken, ethical approval was obtained from the UNZA, School of Humanities & Social Science Research Ethics Committee. Also, informed consent agreement was obtained from research participants by requesting them to sign the informed consent form, as well as provision of verbal information about the aims, objectives, and research process. An informed consent form is a document that shows and outlines the aim and purpose of the study to the participants. The research participants were also informed that their involvement was voluntary and they could withdraw from the study at any time.

3.5.2 Confidentiality and Privacy

Confidentiality was taken to mean that identifiable information about individuals collected during the process of research was not disclosed without permission. The notion of confidentiality was founded on the principle of respect for autonomy (Miles et al,1994). In research it also means presenting findings in ways that ensure individuals cannot be identified. Protecting research participants' right to privacy requires respect for their autonomy, their right to self-determination, as well as their general welfare. The descriptions of their experiences will not be stored with any identifying labels, and codes will be used to replace names.

3.5.3 Informed Consent and Voluntary Participation

Informed Consent was a voluntary agreement to participate in research as participants were not forced to take part in the study (Polit and Beck, 2016). It is not merely a form that is signed but is a process, in which the subjects are made to understand the research and its risks. Obtaining consent involved informing the subject about his or her rights, purpose of the study, procedures to be undergone, and potential risks and benefits of participation.

3.5.4 Security/Safety of Data

Effort was made to ensure that data was used appropriately for the intended purpose only; and in the best interests of the research participants. Data was kept under lock and key to ensure that unauthorized people did not access the same.

To ensure that the above principles were adhered to so that the study was conducted in an ethical manner, the following were practically applied: -

- Presentation of the proposal at the Department of Social work for peer review.

- Formal written ethical clearance was sought from the University of Zambia, Ethics Committee to conduct the study.
- Permission was sought from the Senior Medical Superintendent, Cancer Diseases Hospital.
- Information document was first given to the participants (appendix A) and then informed consent obtained (appendix B) from participants who was invited to participate willingly and this was on going, even before audio taping the face to face interviews (appendix C). Interviews were conducted in a quiet and private place.
- Human dignity was respected including their right to self-determination as participants will also be made aware of their right to freely withdraw from the study if they wished with no effect on their care. Codes were used instead of participant's names. Confidentiality was ensured by not divulging the information obtained and using it for the intended purpose.
- Once the interviews were transcribed, there were transferred to a flask drive and deleted from the computer. All data sheets and the flash disk were sealed in an envelope and placed in a safe in the Department of Social work for a period of three years after the report has been published, thereafter destroyed.
- Participants could withdraw at any point except when the interviews have been transcribed because at this point names have been removed and so would not know which one to withdraw.

CHAPTER FOUR: RESESARCH FINDINGS

4.1 Introduction

This chapter is divided into two sections. The first section presents the demographic characteristics of research participants while the second section presents the research findings in relation to the three research objectives of the study. The findings have been presented in accordance with the headings derived from the research objectives and questions. These findings have been deduced from the verbatim excerpts from audio-recorded interviews with research participants and analyzed and presented here.

4.2 Demographic characteristics of respondents

This section presents demographic characteristics of 20 male spouse caregivers that were interviewed. All the care givers in this study were Christians by religion and looking after patients with cervical cancer at the Cancer Diseases Hospital in Lusaka Zambia. All the interviewed care givers were male with an average and median age of 45.6 and 46 years respectively. These care givers were all married to the patient they were looking after except one was divorced. Of these care givers six had 1 to 3 children, eight had 4 to 6 children, four had more than 7 children and one did not disclose the number of children he had.

The educational status of the participants showed that 8 had junior secondary level education, 7 had tertiary education, 3 had primary level education, whilst one had higher secondary education and the only one without ever gone to school. In terms of employment status 4 were unemployed while 9 worked for private companies, 5 were self-employed and 2 worked in the government. Of these care givers 11 admitted to taking alcohol and 9 did not drink alcohol.

4.3 Research Findings

4.3.1 Male spouse's knowledge of Cervical Cancer

The study assessed the knowledge the male spouses had about cervical cancer, including the causes and symptoms as well as the source of information. The findings indicated that the caregivers had some information about cervical cancer and that it was a disease affecting only women but were not able to relate this information to the illness of the wife. They did not understand the causes of cervical cancer and they had vague information on the symptoms. These respondents got most of the information about cervical cancer from mainly peers until recently when they interacted health care providers explained to them.

Some of the common responses recorded to the question "what do you know about your wife's condition?" are below:

"*We were told she has cancer for the women. We used to see discharge even without sex, so we went to the hospital to find out what it was and we were told it was cancer……*".

"I got surprised when it started, she said she was bleeding and felt pain in morning. Then we went to the hospital where we were told that she had cancer. So for now what I know is that she has cancer….."

"*My wife has a condition called cancer and what I know at the moment is that she experiences a lot of pain and I know it is painful because I imagine being on me* …."

4.3.2 Support Male Spouses Provide to Cervical Cancer Partners.

The study explored the kind of care and support rendered by male spouses to partners with cervical cancer. These male care givers provided significant support to their spouses both financial and psychological support. The financial support included payment for medical bills, food and transport. Emotional support was in form of prayers and encouragement.

Common responses included;

"*For the past three years, I have been spending a lot of money on medical bills and transport for my wife. I am always with her for emotional support through prayers and encouragements".*

"I support her through raising money for her treatment, I also support her emotion through encouraging her and reading the word of God to her".

"I do a lot of things for my wife; I provide financial help as well as spiritual support through prayer and reading the word of God to her".

As a care giver except for one who did not want to discuss the wife's condition the others had understood and were able to take responsibility of looking after the spouses. However more than 50% of them admitted taking alcohol and had good self-control and none of them expressed dissatisfaction in looking after or removing themselves from the situation.

4.3.3 Problems experienced by Male Spouses

The study examined the problems or challenges experienced by the male spouses during the course of partners' cervical cancer illness.

Major findings including;

1. All the respondents were negatively affected financially as the wife's condition required more resources than usual and also a loss of family income because the wife who had an

informal business was no longer active and care givers income became insufficient to support all the family activities.

2. The caregivers experience social isolation, others became attention seekers (always wanting to be around people), and had a lot of stress with distorted sleep patterns.
3. Results obtained revealed that the major psychological problem experienced include sexual deprivation and loss of self-esteem although they said it matter much.

Some responses recorded were;

"Am not affected by not having sex and I rarely think about it, I get affected mostly by thoughts of where to get financial support and when I see her lie in bed all day".

"I have started having a challenge since the condition developed. My wife used to sell at the market but now I have to divide the little I make. I really don't have time to meet with my friends and stopped having sex when she was found with the condition and it is not her faulty……"

The majority expressed being faithful to their wives and that they had stayed for long without sex.

"We have not met for a long time now and all I need is to make a sacrifice,"

The participants revealed that taking care of spouses with cervical cancer was a challenge.

"It has been expensive to divide resources between home and the patient and I cannot even mingle with my friends because of spending a lot time in the hospital……".

Care givers are aware that caring for cervical cancer patients is a long journey and a difficult one.

4.3.4 Male Spouse Coping Strategies

The study explored how the male spouses cope with the challenges of caring for partners with cervical cancer illness and how they have adjusted to condition of the spouse. The study found that among the 20 men interviewed the widely used coping strategies included drinking alcohol, smoking, consolation from family members and attending church services as well as listening to gospel music, as shown in the common responses below;

"*Mostly, I read the bible and encourage myself and I go to church sometimes and I just to endure to make sure the family is okay*……"

"Family members help me to cope with the condition of my wife and sometimes I drink alcohol just to cope with the situation…….".

The study revealed that the most of the participants used prayers and bible studies; smoking and drinking alcohol; and support from family members and friends as major coping mechanisms.

CHAPTER FIVE: DISCUSSION

5.1 Introduction

This chapter discusses the findings in relation to the research questions on the experiences of the male spouse caregivers of partners with cervical cancer illness. In order to interpret the findings, relevant literature and theoretical frameworks will be used. The family plays a crucial role in care and support for a person with cervical cancer, family and friends typically play a crucial role. This is what it means to be a caregiver. Even if they reside far away, caregivers provide physical, practical, and emotional support to the patient. Caregivers may be responsible for a variety of tasks on a daily basis, including providing encouragement and support, having a conversation with the medical staff, medication administration, assisting in the management of symptoms and side effects, keeping track of medical appointments, assisting with transportation to and from appointments, assisting with meal preparation, assisting with household tasks and taking care of insurance and billing issues.

5.1.1 Male Spouse Knowledge of Cervical Cancer.

The study explored the knowledge male spouses had about cervical cancer. The study established that participants knew cervical cancer as a disease for women, but did not know the causes and symptoms of the disease. This finding was similar to those of the studies by William and Amoateng (2012) and Binka et al., (2019), which noted that men had little knowledge of cervical cancer including the causes, symptoms, and risk factors of the disease.

The effect of inadequate knowledge among male spouses is that they hardly identify in good time what exactly is wrong with their wives and take the necessary steps to save their lives. On the other hand, it has been noted that good knowledge of cervical cancer could result in the increase partner financial support (Adewumi et al., 2019). This is because the family will have adequate time to mobilize financial resources for treatment before the disease reach an advanced stage.

5.1.2 Male Spouse Support to Cervical Cancer Patients.

According to the men, they would provide any form of support including financial, spiritual and emotional support for their wives to be treated. A supporting study by Edelman, Kudzman, and Mandle 2014, states, the stability of the family functioning, Family Structural theory is concerned about the family life with the vital interest in the sources of social support and the sources of the stress of the family members, to drive therapeutic change that would be necessary for the family. The above, attest to how the male spouse caregivers adjusted to the changes in family roles.

Men provide financial support which was needed for medical bills, food and transport during the course of the treatment. They also gave spiritual support through prayers and bible studies for the purpose of a positive psychological aspect. Additionally, male provided emotional support such as hugs, listening and encouragements. These findings were in line with the report by Binka et al. (2019) who found that male partners to cervical cancer patients provided financial, spiritual, social and emotional support.

This study provides evidence that male partners had little or no knowledge about cervical cancer. Nevertheless, some of them supported their partners financially, socially, emotionally and materially during the illness. They, however, asked for more education on the causes and treatment options. Admittedly, in this socio-cultural context where there is no specific local name for cervical cancer, the conceptions of disease and illness may be potentially confounded by many unknown factors, particularly among respondents who had little or no knowledge about the disease. Despite this, male partners of cervical cancer patients have shown in this study that they were educated on the disease by doctors after the diagnosis of their female partners and that they had some knowledge about the disease at the time of the study.

5.1.3 Problems Experienced by Male spouses.

The economic, social, and psychological problems experienced by the male spouse care-givers in this study included loss of family income, social isolation, sex deprivation, loss of self-esteem and stress. These study findings are in line with Karianne etal 2018 who found that men's experiences of being caregivers and partners' women treatment for cervical cancer are multifaceted, comprising emotional and practical aspects. The study also pointed out loneliness, shared feelings of vulnerability and altered sexual relationship as some of the challenges faced by male spouse caregivers of the cancer patients. These findings are also compatible with that of the study by Teskereci et. al., (2016) which noted that male spouse care-givers experienced disruption of daily routines and transformation of lifestyles, roles, physical intimacy, and plans for the future. It was observed that lack of finance stability among participants was the major challenge faced in taking care of cervical cancer patients. Cervical cancer was known among participants to be the cause for inability to pay school fees and buy food as more monies were being spent to buy drugs. Those who were employed had a challenge in time management and social interactions.

These experiences could best be contextualized from the perspective of the Structural Family Theory (Minuchin, 1974). The basic assumption of the theory is that the family, as a social system, consists of sub-systems that are functional interrelated. Therefore, the problem(s) of a particular family sub-system may have direct or indirect negative effect on the functions of the other sub-systems. In this context, the problems experienced by the male spouses are closely associated with the malfunctioning of the spousal and parental family sub-systems. For instance, the economic or financial problems experienced by male spouses is partly accounted for by the fact that family income is reduced as the mother is unable to actively participate in the family income generation activities during the course of medical treatment.

Also, the inability of the male spouses to socialize or participate actively in the community activities is partly due to the malfunctioning of the parental family sub-system. The male spouses tend to assume more parental responsibilities during the course of medical treatment for their partners. This is particularly the case with the caring for children and performing other household activities. Similarly, the psychological or emotional problems relating to the sexual deprivation of the male spouses could be associated with the malfunctioning of the spousal family sub-system. During the course of cervical cancer illness and medical treatment, the female spouse is usually unable to engage in sexual activities to the disadvantage of the male spouse.

The findings indicate that taking care of a partner with cervical cancer has negative effect on the financial, social, and psychological conditions of the male spouse care-givers. The financial problems are reflected in reduced family income and high cost of medical treatment beyond affordable levels. The social problems relate to the inadequate time to socialize with relatives and friends. The psychological problems relate to the lack of sexual activities during the course of illness.

5.1.4 Male Spouse Copying Strategy

The study revealed that the most of the participants used prayer and bible studies; smoking and drinking alcohol; and support from family members and friends as major coping mechanisms.

The research findings on the copying strategies of the male spouse care-givers can generally be referred to as the male spouses' social capital. It is conceived as the networks of relationships developed by individuals or families that are used as the source of support in time of need. Such network of relationship includes extended family members; friends; church organizations; cultural associations, etc. It is an important dimension of the traditional or informal system of social welfare in Zambia based on the principals of mutual-Aid (reciprocal support and cooperation among individuals and social groups). In the context of this study, social capital has been a major copying strategy, including seeking emotional support from family and church members. In the study by

Binka, it was established that family members helped male spouse care givers to cope with cervical cancer in their homes. Family members prayed with them, encouraged and gave financial support. These finding were in agreement with results of Binka et al. (2019) and these social interactions reflected the coping theory as explained by Blum et al. (2012). The findings are further in line with the study done on male spouse copying strategy by Mukwato. In this study the results indicated that seeing social support reliance, reliance on prayers and God, positive suggestion or reaffirmation acquisition of information and education were some of the copying strategies employed by male spouse care givers to the cervical cancer patients.

Similarly, the research findings are in accordance with the basic assumptions of the Copying Theory (Lazarus & Folkman, 1984). One basic assumption is that the coping strategy adopted by a person to a stressful situation change over time and in accordance with the situational context in which it occurs. In the context of this study the stress or emotional problems experienced by the male spouse caregivers are more intense during the process of medical treatment of spouses. This is particularly the case when the outcomes of the medical treatment are uncertain. Under such circumstances, seeking emotional support from family members; friends, and church members is an important adaptive strategy.

According to Lazarus and Folkman, copying mechanism can be emotional- focus based or problem -focused based. This resonates with the copying strategies of the spouse male caregivers who, prayed, read the bible, which is emotion focused based. Problem –focused based can be seen in the male spouse time management and asking for help from family and friends. These copying strategies can be positive or negative vices, Some negative copying strategies where drinking beer and smolking.

The findings indicate that prayers and bible studies; smoking cigarettes; drinking alcohol beverages; and support from family members and friends are the major copying mechanisms with the problems associated with taking care of spouse with cervical cancer.

It was believed among participants that God was their source of hope. Hence, they read the bible and went to church as a coping mechanism. It was felt that reading the bible helped them to cope with cancer related stress. Others resorted to drinking alcohol beverages to reduce the stress associated with the poor health conditions of partners with cervical cancer.

CHAPTER SIX: CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

6.1 Conclusion

This study found that the male care givers lacked knowledge and understanding of cervical cancer that affected their spouses in Zambian. The study confirmed the interwoven display of many psychosocial factors that affect the support mechanisms of these care givers as they care for their spouses. Changes in loss of financial stability, loss of self-esteem, self-isolation, sexual deprivation and family and friends support affected the responses of these men to the way they provided support to their spouses with cervical cancer. The study has shown that male care givers in Zambia experience physical and emotional challenges as they care for their spouses with cervical cancer. Further the study has shown that even among Zambian male care givers the coping responses to stressful events are different depending on the level of education, financial capability, family support and friends. This requires further research and understanding.

These findings underscore the critical role men can play in considerably reducing the cervical cancer incidence and mortality. This could be done through education that would equip the men with the needed knowledge of the disease. This can contribute to the removal of the barriers to screening and treatment in, particularly, rural areas of Zambia. Men have not been adequately targeted in cervical cancer campaigns simply because it is not men's disease. However, the findings of this study highlight the need for cervical cancer education among men, particularly those in marital union. Cervical cancer education interventions for Zambian men need to focus on providing information about the disease and contribute to increasing spousal support during cervical cancer screening and treatment.

6.2 Study Limitations

This study was designed to provide insights on the life experiences of the male spouse care-givers of cervical cancer patients at the Cancer Diseases Hospital, Lusaka, Zambia. The lack of external validity is one major limitation of the study. This is because of the use of a small non-randomized sample size. However, much of the findings of the study are consistent with that of the previous studies and relevant theoretical frameworks. Therefore, the findings could serve as preliminary perspectives; as the basis for further research on the life experiences of male spouse care-givers of cervical cancer patients in Zambia.

6.3 Recommendations

Based on the findings of the study, the recommendations are as follows;

a. The Ministry of Health and stakeholders should increase awareness on educating the men on Cervical cancer and involving them in them in cervical cancer prevention campaign.
b. Strengthening counselling services in Health Care facilities and encourage patients and their caregivers to seek services.
c. Care givers should be encouraged to seek professional help when faced with psychosocial and emotional challenges

6.4 Suggestion for Future Research

Based on the findings of this study, there is need to undertake further research on the knowledge of cervical cancer prevention and treatment among men in Zambia. It is the researcher's considered view that the findings of such a study could inform the formulation of policy strategies that could contribute positively towards achieving much advancement in taking care of cervical cancer patients in Zambia.

REFERENCES

1. Boer, M. De, & Thoresen, L. (2018). *Male partners' experiences of caregiving for women with cervical cancer - a qualitative study. October*. https://doi.org/10.1111/jocn.14688
2. Carlson, L. E., Bultz, B. D., Speca, M., & Pierre, M. S. (2000). Partners of cancer patients: Part I. Impact, adjustment, and coping across the illness trajectory. *Journal of Psychosocial Oncology*, *18*(2), 39–63. https://doi.org/10.1300/J077v18n02_03
3. Coughlin, S. S., Ayyala, D. N., Tingen, M. S., Cortes, J. E., & Health, P. (2020). *Financial distress among breast cancer survivors*. *2*(1), 48–53. https://doi.org/10.25082/CCR.2020.01.004.Financial *Association of Social Support and Education With Breast and Cervical Cancer Screening*. https://doi.org/10.1177/1090198114557124
4. Hesari, P. M., & Montazeri, A. (2020). Health - related quality of life in breast cancer patients : review of reviews from 2008 to 2018. *Health and Quality of Life Outcomes*, 1–25. https://doi.org/10.1186/s12955-020-01591-x
5. Huang, Y. P., Wang, S. Y., Chen, S. H., Hsu, W. Y., & Chang, M. Y. (2019). The experience of spousal caregivers of patients recently diagnosed with cancer in Taiwan. *Collegian*, *26*(4), 477–484. https://doi.org/10.1016/j.colegn.2018.12.005
6. Kapambwe, S. K. (2008). *Review of cervical cancer screening program in Zambia 44 th International Course in Health Development (ICHD) KIT (Royal Tropical Institute)*

Development Policy & Practice / Vrije Universiteit Amsterdam Table of contents.

7. Lopez, V., Copp, G., & Molassiotis, A. (2012). Male caregivers of patients with breast and gynecologic cancer: Experiences from caring for their spouses and partners. *Cancer Nursing*, *35*(6), 402–410. https://doi.org/10.1097/NCC.0b013e318231daf0
8. Mbozi, P., Ratcliff, C., & Roberts, D. (2020). *Challenges Facing Women Caring for a Spouse Having Cancer Treatment : A Critical Literature Review*. 34–68. https://doi.org/10.4236/ojn.2020.101003
9. Oldertrøen Solli, K., de Boer, M., Nyheim Solbrække, K., & Thoresen, L. (2019). Male partners' experiences of caregiving for women with cervical cancer—a qualitative study. *Journal of Clinical Nursing*, *28*(5–6), 987–996. https://doi.org/10.1111/jocn.14688
10. Sales, E., Schulz, R., & Biegel, D. (1992). Predictors of strain in families of cancer patients: A review of the literature. *Journal of Psychosocial Oncology*, *10*(2), 1–26. https://doi.org/10.1300/J077v10n02_01 *Social and emotional issues related to cancer*. (n.d.). 44–51. https://www.cancerinstitute.org.au/how-we-help/reports-and publications/cancer-treatment-side-effects-a-guide-for-aborigi/the-effects-of-cancer-on social-and-emotional-well#
11. World Health Organization. (2019). Globocan: Zambia Fact Sheet. *The Global Cancer Observatory*, 1–2. https://gco.iarc.fr/today/data/factsheets/populations/894-zambia-fact-sheets.pdf *คู่มือผู้ช่วยเหลือดูแลผู้สูงอายุ (Care giver)*. (n.d.).
12. Given, B., Wyatt, G., Given, C., Gift, A. (2004). Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum*, 31(6), 1105-1117.
13. Harden, J. (2005) Developmental life stage and couples' experiences with prostate cancer– a review of the literature. Cancer Nursing, 28 (2), 85–98.
14. Kayser, K., Watson, L.E. & Andrade, J.T. (2007) Cancer as a'we-disease': Examining the process of coping from a relational perspective. Families, Systems, & Health, 25 (4), 4

15. Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. Journal of the American Medical Association, 282(23), 2215-2219.

16. Sharpe, L., Butow, P., (2005). Relationship between available support, unmet needs & caregiver burden in patients with advanced cancer and their carers. Psycho-Oncology, 14, 102-114.

17. Teskereci, G., & Kulakac, O. (2016). Life experiences of caregivers of women with gynaecological cancer: a mixed –methods systematic review. European Journal of Cancer care, n/a-n/a.doi:10.1111/ecc.12456

18. Valle, R., King, M., & Halling, S. (1989). An introduction to existential-phenomenological thought in psychology. In R. Valle & S. Halling (Eds.), Existential-phenomenological perspective in psychology (pp. 3-16). New York: Plenum Press.

19. Vitaliano, P. P., Zhang, J. & Scanlan, J. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. Psychological Bulletin, 129(6), 946-72.

20. Wagner, C. D., Tanmoy Das, L., (2011) Characterizing burden, caregiving benefits, and psychological distress of husbands of breast cancer patients during treatment and beyond. Cancer Nursing, 34(4), E21-30. doi: 10.1097/NCC.0b013e31820251f5.

21. World Health Organisation. (WHO). (2019). Cervical cancer. https://www.who.int/cancer/prevention/diagnosis-screening/cervical-cancer/en/. Accessed 19 May 2020.

22. Williams MS, Amoateng P (2016) Knowledge and beliefs about cervical cancer screening among men in Kumasi, Ghana. Gh Med J. 2016; 46(3): 147–151.

APPENDIX A: INTERVIEW SCHEDULE

THE UNIVERSITY OF ZAMBIA
DEPARTMENT OF SOCIAL WORK AND SOCIOLOGY
MASTER OF SOCIAL WORK

Introduction

Dear participant,

My name is Emily Walubita. I am a student at the University of Zambia pursuing a Master of Social Work. As a partial fulfillment of the requirements for the program, students are required to research on topics of their choice. As a topic of choice, to explore male spouses/partners experience of caring for wives/partners with cervical cancer at the Cancer Diseases Hospital in Lusaka, Zambia.

You have been purposively selected to participate in this interview. The information you will give is purely for academic purposes and will be treated with complete confidentiality. Furthermore, you are free to choose to participate in this research and you can also choose to pull out any time. I would appreciate if you could spare sometime to answer some questions because your participation will be highly valued.

Section 1: Background characteristics of the Respondents

1.What was your age…………………………………………………………………………………

2.Sex………………………………………………………………………………………

3.Marital status

1. Married [ ] 2. Divorced [ ] 3. Separation [ ]

4.**What is your level of education**

1. No formal education [ ] 2. Primary [ ] 3. Junior High school [ ]
4. . Junior High school [ ] 5. Tertiary [ ]

5. What is your employment Status

1. Government employee [ ] 2. Private employee [ ] 3. Self-employed [ ]

4. Unemployed [ ]

6. How many children?

1. 0 [ ] 2. 1-3 children [ ] 3. 4-6 children [ ] 4. 7 & above children [ ]

7. Religious Affiliation

1. Christian [ ] 2. Muslim [ ] 3. Traditional [ ]

8. Do you smoke?

1. Yes [ ] 2. No [ ]

9. Do you drink alcohol?

1. Yes [ ] 2. No [ ]

Section 2: Family Care and Cancer Support

- How has been your experience living/ taking caring for a cervical cancer patient?
- What does it take for you to take care of cervical cancer patient?
  - Financially
  - Time
  - Emotional support

- Sacrifices

- Based on your experience, how can the Cancer Diseases Hospital help in process of caring for cervical cancer patients?

  Probe

-Health services

-Psychosocial support

-Community centered

Section 3: Knowledge on cervical cancer among male partners

May you please share with me about your wife's condition?

Section 4: Support male partners provide to partners with cancer

Noting the condition your wife is in, please describe your support.

[Probe on types of support] If the following is not mention spontaneously.

- Disclaiming.
- Escape-avoidance.
- Accepting responsibility or blame.
- Exercising self-control.
- Positive reappraisal.

Section 5: Male partners' experiences of caregiving for women with cervical cancer

- How has the cervical cancer condition of your partner affected you economically at your household level from the time your partner was diagnosed with it till now?
- How has the cervical cancer condition of your partner affected you socially and healthy wise from the time your partner was diagnosed with it till now? [Probe more on emotions, psychologically, stress, burden, healthy]
- How has been sexuality in your marriage from the time your partner was diagnosed with till now?
- You told me that your wife has been in this condition for years. Please describe?
  (Probe personal, social and economic affects.)

Section 6: Coping strategies with caregiving for cervical cancer partner

- What strategies do you use to copy up with cervical cancer condition of your partner at personal level?
- With all that you have told me, please describe for me how you have managed to cope. To what extent have the strategies worked for you?

APPENDIX B: INFORMED CONSENT AGREEMENT

THE UNIVERSITY OF ZAMBIA

DEPARTMENT OF SOCIAL WORK AND SOCIOLOGY

MASTER OF SOCIAL WORK

Study Title: **Life Experiences of Male Spouse Care-givers of Cervical Cancer Patients at the Cancer Diseases Hospital, Lusaka, Zambia**

Dear Sir,

My name is Emily Walubita, a graduate student at the University of Zambia, Department of Social Work and Sociology. You are invited to participate in my research.

The purpose of the study is to find out the challenges faced by spouses who care for their wives with cervical cancer during the course of receiving treatment at the Cancer Diseases Hospital in Lusaka, Zambia. The findings of the study will help the health care workers to provide good support services to families caring for cervical cancer patients. The research has been approved by UNZA, School of Humanities & Social Science Research Ethics Committee, responsible for the protection of human subjects involved in research.

Participation in the study is by answering questions, through face-to-face interview, on the challenges faced when caring for a spouse with cervical cancer. The interview will last about 30 minutes. The interview will be audio-recorded to facilitate data analysis. You are free to decline answering any question, and withdraw from the interview at any time. Your decisions will not be held against you. Participation in the study is completely voluntary; and there are no financial benefits for participating.

There are no foreseeable risks for participating in the research. The responses to the questions will be kept highly confidential. Your responses will be combined with that of other participants so that no individual respondent is identifiable. The research findings will not be disaggregated or broken down by participants, but will be combined so that no particular participant is identifiable.

If you need further information about the study, please contact me, Emily Walubita. My cell phone number is 0977200133. If you would like more information about the ethical permission of the study or would like to report or complain about how the study was conducted, you can contact the UNZA, School of Humanities & Social Science Research Ethics Committee; P. O. Box 32379, Lusaka, Zambia.

I have read the above information, understand it fully and have had any questions regarding the study answered to my satisfaction. I consent to participate in the research.

______________________________ __________________________________

Signature of Participant Date

APPENDIX C: RESEARCH TIME-FRAME

ACTIVITY	TIME									
	May 2020	June 2020	July 2021	Aug 2021	Sept 2021	Oct 2021	Nov 2021	Dec 2021	January 2021	Feb 2021
Proposal writing	XX	XX								
Data Collection			XX	XX						
Data Processing/ Analysis					XX	XX				
Report Writing							XX	XX		
Report Submission / Defense									XX	
Report Publication										XX

APPENDIX D: ETHICAL APPROVAL

THE UNIVERSITY OF ZAMBIA

DIRECTORATE OF RESEARCH AND GRADUATE STUDIES

RESEARCH DEPARTMENT

APPROVAL OF STUDY:

17th June, 2020.

REF NO.HSSREC-2019-OCT-026

Emily Walubita

LUSAKA

Dear Ms. Walubita,

RE: "LIFE EXPERIENCES OF MALE SPOUSE CARE-GIVERS OF CERVICAL CANCER PATIENTS AT THE CANCER DISEASES HOSPITAL, LUSAKA, ZAMBIA"

Reference is made to your protocol dated 1st September, 2019. HSSREC resolved to approve this study and your participation as Principal Investigator for a period of one year.

Review Type	**Ordinary Review**	**Approval No.** **HSSREC-2019-OCT-026**
Approval and Expiry Date	Approval Date: 25th March, 2020	Expiry Date: 24th March, 2021
Protocol Version and Date	Version - Nil.	24th March, 2021
Information Sheet, Consent Forms and Dates	• English.	To be provided
Consent form ID and Date	Version - Nil	To be provided
Recruitment Materials	Nil	Nil
Other Study Documents	Questionnaire.	
Number of Participants Approved for Study		

Specific conditions will apply to this approval. As Principal Investigator it is your responsibility to ensure that the contents of this letter are adhered to. If these are not adhered to, the approval may be suspended. Should the study be suspended, study sponsors and other regulatory authorities will be informed.

Conditions of Approval

- No participant may be involved in any study procedure prior to the study approval or after the expiration date.

- All unanticipated or Serious Adverse Events (SAEs) must be reported to HSSREC within 5 days.

- All protocol modifications must be approved by HSSRECprior to implementation unless they are intended to reduce risk (but must still be reported for approval). Modifications will include any change of investigator/s or site address.

- All protocol deviations must be reported to HSSRECwithin 5 working days.

- All recruitment materials must be approved by HSSRECprior to being used.

- Principal investigators are responsible for initiating Continuing Review proceedings. HSSRECwill only approve a study for a period of 12 months.

- It is the responsibility of the PI to renew his/her ethics approval through a renewal application to HSSREC.

- Where the PI desires to extend the study after expiry of the study period, documents for study extension must be received by HSSRECat least 30 days before the expiry date. This is for the purpose of facilitating the review process. Documents received within 30 days after expiry will be labelled "late submissions" and will incur a penaltyfee of K500.00. No study shall be renewed whose documents are submitted for renewal 30 days after expiry of the certificate.

- Every 6 (six) months a progress report form supplied by The University of Zambia Humanities and Social Sciences Research Ethics Committee as an IRB must be filled in and submitted to us. There is a penalty of K500.00 for failure to submit the report.

- When closing a project, the PI is responsible for notifying, in writing or using the Research Ethics and Management Online (REMO),both HSSRECand the National Health Research Authority (NHRA) when ethics certification is no longer required for a project.

- In order to close an approved study, a Closing Report must be submitted in writing or through the REMO system. A Closing Report should be filed when data collection has ended and the study team will no longer be using human participants or animals or secondary data or have any direct or indirect contact with the research participants or animals for the study.

- Filing a closing report (rather than just letting your approval lapse) is important as it assists HSSRECin efficiently tracking and reporting on projects. Note that some funding agencies and sponsors require a notice of closure from the IRB which had approved the study and can only be generated after the Closing Report has been filed.

- A reprint of this letter shall be done at a fee.

- All protocol modifications must be approved by HSSREC by way of an application for an amendment prior to implementation unless they are intended to reduce risk (but must still be reported for approval). Modifications will include any change of investigator/s or site address or methodology and methods. Many modifications entail minimal risk adjustments to a protocol and/or consent form and can be made on an Expedited basis (via the IRB Chair). Some examples are: format changes, correcting spelling errors, adding key personnel, minor changes to questionnaires, recruiting and changes, and so forth. Other, more substantive changes, especially those that may alter the risk-benefit ratio, may require Full Board review. In all cases, except where noted above regarding subject safety, any changes to any protocol document or procedure must first be approved by HSSREC before they can be implemented.

Should you have any questions regarding anything indicated in this letter, please do not hesitate to get in touch with us at the above indicated address.

On behalf of HSSREC, we would like to wish you all the success as you carry out your study.

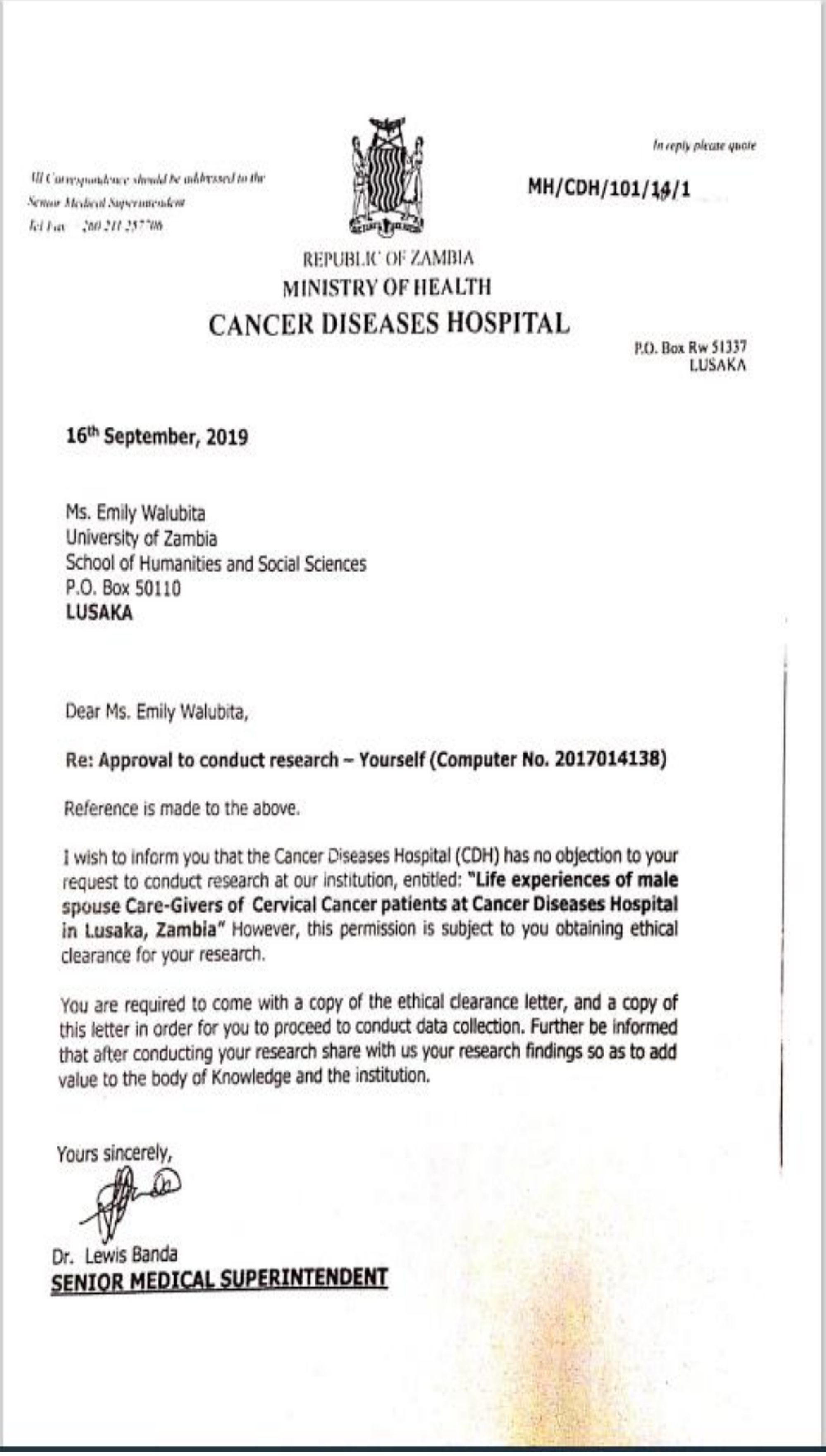
Yours faithfully,

Dr. J. Mwanza

DR. JASON MWANZA
Dip. Clin. Med. Sc., BA.M.Soc., PhD

CHAIRPERSON
THE UNIVERSITY OF ZAMBIA HUMANITIES AND
SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE - IRB

cc: Director, Directorate of Research and Graduate Studies
Assistant Director (Research), Directorate of Research and Graduate Studies
Assistant Registrar (Research), Directorate of Research and Graduate Studies



All Correspondence should be addressed to the
Senior Medical Superintendent
Tel Fax: 260 211 257706

In reply please quote

MH/CDH/101/14/1

REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH
CANCER DISEASES HOSPITAL

P.O. Box Rw 51337
LUSAKA

16th September, 2019

Ms. Emily Walubita
University of Zambia
School of Humanities and Social Sciences
P.O. Box 50110
LUSAKA

Dear Ms. Emily Walubita,

Re: Approval to conduct research – Yourself (Computer No. 2017014138)

Reference is made to the above.

I wish to inform you that the Cancer Diseases Hospital (CDH) has no objection to your request to conduct research at our institution, entitled: **"Life experiences of male spouse Care-Givers of Cervical Cancer patients at Cancer Diseases Hospital in Lusaka, Zambia"** However, this permission is subject to you obtaining ethical clearance for your research.

You are required to come with a copy of the ethical clearance letter, and a copy of this letter in order for you to proceed to conduct data collection. Further be informed that after conducting your research share with us your research findings so as to add value to the body of Knowledge and the institution.

Yours sincerely,

Dr. Lewis Banda
SENIOR MEDICAL SUPERINTENDENT

APPENDIX E: PERMISSION TO CONDUCT RESEARCH