HEALTH RELATED QUALITY OF LIFE AMONG CERVICAL CANCER SURVIVORS IN LUSAKA DISTRICT, ZAMBIA.

By

Chisaji Moonde

RM, BSc Nursing.

A Dissertation submitted in partial fulfillment of the requirement for the Degree of Master of Science in Midwifery, Women's and Child Health at the University of Zambia.

THE UNIVERSITY OF ZAMBIA,

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DECLARATION

I Chisaji Moonde declare that this Dissertation entitled **Health Related Quality of Life among Cervical Cancer Survivors in Lusaka District, Lusaka Province** submitted in partial fulfilment for the degree of **Master of Midwifery, Women's and Child Health** represents my own work and that all the sources I have quoted have been indicated and acknowledged by means of complete reference. I, further, declare that this Dissertation has not previously been submitted for a Degree or Diploma or other qualifications at this or other University. It has been prepared in accordance with the guidelines for Master's Degree in Midwifery, Women's and Child health dissertations of the University of Zambia.

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Candidate

Signed…………………………………………. Date………………………….
Supervisor

Signed………………………………………….. Date……………………………
Supervisor

CERTIFICATE OF COMPLETION OF DISSERTATION

I**, Dr. Dorothy Chanda**, having supervised and read this Dissertation is satisfied that this is the original work of the author under whose name it is being presented. I confirm that the work has been completed satisfactorily and approve it for final submission.

Signature…………………………………………… Date……………………

Supervisor

Head of Department

Department of Midwifery, Women's and Child Health, School of Nursing Sciences, University of Zambia.

Name: **Ms. M. M. Makoleka.**

Signature………………………………………….. Date……………………………

CERTIFICATE OF APPROVAL

The University of Zambia approves this dissertation on **Health Related Quality of Life among Cervical Cancer Survivors** in partial fulfillment for the award of Master's Degree in Midwifery, Women's and Child Health.

Examiner I

Name…………………………….......... Signature………………………. Date…………….

Examiner II

Name …………………………… …....Signature…………………………Date……………

Examiner III

Name ……………………………….….Signature…………………………Date……………

ABSTRACT

Health Related Quality of Life is an essential health outcome for improving clinical care and determining targets of intervention for managing cervical cancer survivors. In Zambia the number of cervical cancer survivors is increasing owing to the recent advancement in cancer treatment. However, little is known and documented on HRQoL among CCS. This study determined HRQoL among CCS.

A cross-sectional study involving 83 cervical cancer survivors with histologically-diagnosed cervical cancer was conducted at Cancer Diseases and University Teaching Hospitals in Lusaka, Zambia from October 2019 to December 2019. An interview schedule containing questions from the European Organization for Research and Cancer treatment core 30 and Cervical 24 questionnaires version 4 and self - structured questions were used to collect data. The study was approved by the University of Zambia Biomedical Research Ethics Committee and the National Health Research Authority. Data was analyzed using Statistical Package for Social Sciences Version 25 with confidence level set at 95%. The chi- square test and linear regression were applied in testing for associations. The total score of the questionnaire in the domains of HRQoL range from 0 to 100, with higher scores (≥ 66.7%), indicating a good HRQoL.

The mean score for overall HRQoL was 60.9 (SD=21.4). Better scores were observed in the domains of physical, functional and psychological wellbeing with mean and standard deviations as follows: 71.4 (SD 26.5), 68.2 (SD 26.5), 69.1 (SD 22.8) respectively. Social wellbeing domain presented with the worst score 57.9 (SD 21.4). Time point of treatment and stage of cancer at diagnosis were found to be statistically significant in association with overall Health Related quality of Life after a linear regression test.

Cervical cancer survivors experience good physical, functional and psychological wellbeing, while they perform poorly in the social wellbeing and overall HRQoL due to a large proportion of patients presenting with advanced stages of cervical cancer at diagnosis, financial challenges associated with the disease and treatment and poor family support. The researcher recommends that there is need to include HRQoL assessment in routine management of cervical cancer survivors to enhance their quality of life. In addition, the researcher also recommends that a similar study to be conducted using random sampling to validate the findings of the present study.

DEDICATION

I dedicate this study to my husband and children for being the driving force behind this study.

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LIST OF ACRONYMS

1. EORTC - European Organisation for Research and Treatment of Cancer
2. FACT- CX - Functional Assessment of Cancer Therapy – Cervix
3. FIGO- International Federation of Gynecology and Obstetrics
4. HRQoL - Health Related Quality of Life
5. SPSS- Statistical Package for Social Sciences
6. UNZABREC - University of Zambia Biomedical Research Ethics Committee
7. IARC- International Agency for Research in Cancer
8. EORTC QOQ- European Organisation for Treatment of Cancer Quality of Life Questionnaire.
9. GLOBOCAN- Global Burden of Cancer
10. RH- Radical Hysterectomy
11. TMR- Total Mesometrial Resection
12. SD- Standard deviation
13. WWO- Wertheim- Meigs Operation

CHAPTER ONE

1.0 INTRODUCTION

Globally, Cervical cancer remains the major public health concern with an estimated 570, 000 new cases and 310, 000 deaths in 2018 with the majority of cases occurring in the low and middle income countries and the vast majority in Sub-Saharan Africa (IARC, 2018). However, due to improved and advanced programmes for early detection and prompt treatment, cervical cancer survival rates have increased (World Health Organisation, 2018). Furthermore, even when treatment is generally completed, the cancer burden is still significant due to the short and long term sequelae that impair health related quality of life (HRQoL) (Kimman et al., 2017). HRQoL is an individual's perception of physical and mental wellbeing potentially affected by an illness and its treatment (CDC, 2018).

It encompasses several domains of health that includes physical, psychological, social and functional wellbeing. The increase in the survival rate has caused HRQoL to become an essential health indicator for survivors and the outcome measure is used for analysis and measuring the impact the cancer treatment has on patients (American Cancer Society, 2018). Hence the need for this study to determine the HRQoL among cervical cancer survivors.

1.1 Background Information

Globally, cervical cancer survival rates have been increasing steadily due to improved and advanced programmes for awareness, early detection, and prompt treatment (WHO, 2018). For some women, cancer treatment may destroy all the cancer cells, in others the cancer may not be destroyed completely and these are survivors who regularly receive treatment to prevent the cancer from worsening (ACS, 2018). In this study, a survivor is, therefore, somebody who has been diagnosed and completed at least an initial treatment of cervical cancer.

The advancement of treatment modalities of cancer such as surgery, radiotherapy and chemotherapy has gradually caused an improvement in the HRQOL among cancer survivors (Yin et al., 2017). However, the side effects of cancer treatment leave patients with physical, psychological and social challenges (Owenga, 2018). Patients with stages 1A1 through to Stage 11A1 undergo hysterectomy, as a treatment of choice under the International Federation of Gynecology and Obstetrics (FIGO) treatment criteria because the cancer is in its early stage (Maiti, 2019). Patients with stages 1B2 through to IVB are treated with chemo-radiation as a treatment of choice under FIGO treatment criteria and this combination of chemotherapy and radiotherapy helps control the progression of locally advanced cancer (Maiti et al., 2019).

However, the side effects such as fatigue, pain, vaginal stenosis, premature menopause, body image impairment, urinary, bowel and sexual dysfunctions, usually have an important impact on their QOL (Thapa et al., 2018 and Muliira et al., 2017).

In high resource countries, assessment of HRQOL is routinely practiced in managing survivors with life threatening diseases such as cancer (Medeiros et al, 2015). This has been made possible with the help of several tools that have been developed specifically for HRQOL assessment (Tax et al., 2017). In the United States of America (US), although the incidence of cervical cancer is reducing, it represents a significant public health problem (WHO, 2018). In 2018, there was an estimated 13, 240 women diagnosed and 4, 170 died. In 2019, diagnosis of cervical cancer was estimated at 13, 170 cases and about 4, 250 women died from cervical cancer (ACS, 2019). The decline in incidence and death is attributed to improved early screening and treatment (WHO, 2018). However, the remarkable improvement and advancement in the past few decades in early detection and effective treatment of cancer has caused a steady increase in the number of cancer survivors (ACS, 2019). While many survivors report good HRQOL after cancer, there appears to be a vulnerable subgroup of the survivor population that continues to experience poor HRQOL (ACS, 2019). The poor HRQoL could be attributed to stage of cancer as Medeiros et al., (2015) observed an association between stage of cancer and HRQoL. Similarly, in China there is a reduction of incidence and death of cervical cancer which is attributed to improvement and advancement in immunizations, screening and treatment modalities which has caused an increase in the number of survivors (WHO, 2018). According to Thappa et al., (2018) CCS who stay in urban areas have a good QOL. However, those who live in the rural areas and those of low economic status have poor quality of life as financial challenges prevent them from seeking health services and usually leads to poor follow ups.

In low resource countries such as India, countries in the Sub Saharan region and Zambia inclusive, most women present with advanced disease, often untreatable or suitable only for palliation (WHO, 2018). The late treatment has resulted in increased death rate of cervical cancer as most survivors continue experiencing symptoms of cancer even after completion of treatment due to metastasis (WHO, 2018). Further, inadequate follow up systems after cervical cancer treatment have been reported to negatively influence health in the Sub Saharan region (Opoku et al., 2018). However, Rahman et al., (2017) observed a significant improvement in HRQOL among patients who received early treatment.

At Cancer Diseases Hospital, the survival rate is quite high. In 2018, 328 out of 428 treated patients survived (CDH, 2018). The high survival rate makes assessment of HRQOL among survivors necessary so that individual health needs are identified and managed. This study was set to determine HRQOL among cervical cancer survivors with the aim of using this information to design evidence-based interventions for improving HRQOL of cervical cancer survivors in Zambia.

1.2 Statement of the Study Problem.

Zambia has the third highest CC in Africa (Bruni et al., 2018). CC is a major public health concern and the most frequent cancer among child bearing age group (CDH, 2018). About 2, 994 cases were diagnosed and 1,839 died in 2018 (Bruni et al., 2018). The high morbidity and mortality is due to late presentation of the disease (WHO, 2018). However, there has been an improvement in CCS rate at both CDH and UTH as table1 illustrates (CDH, 2018).

Table 1.1 Prevalence, Mortality and Survival Rate of Cervical Cancer at CDH and UTH

Year	Admissions and treated patients	Mortality	% of Mortality	survivors	Survival rates
2016	258	239	93%	19	7%
2017	378	175	56%	203	54%
2018	428	100	23%	328	77%
Total	1,505	620	41%	885	59%

(CDH, 2018)

Despite the improvement in CCS rates by 70 % between 2016 and 2017 as table 1 illustrates at CDH and UTH, which could be attributed to improvement in the treatment modalities, their HRQoL is uncertain. According to Kimman et al., (2017) even when treatment is completed, the cancer burden is still significant due to the short and long term sequelae that impair HRQoL. Lack of comprehensive assessment of HRQoL among CCS leads to poor HRQoL (Owenga, 2018), as survivors may be living with unmet health needs. In addition, it hinders identification of subgroups with relatively poor health and prevents guidance interventions to improve their situations and avert serious consequences that can lead to poor HRQoL.

Poor HRQoL among CCS affect their individual lives, families and the nation negatively. Some CCS get divorced because their spouses feel uncomfortable with the side effects following surgery or chemo- radiotherapy such as fatigue, urinary and gastro intestinal tract dysfunction, vaginal atrophy, shortness of vagina, loss of libido, vaginal dryness and premature menopause which manifest with symptoms such as hot flushes and infertility which usually result into depression. They literally become socially and physically dependent on others (Muliira et al., 2017). The fact that most of the women depend on their spouses for finances, it becomes difficult for them to provide basic needs for themselves and their families. Their family members are also socially, physically and psychologically affected as they have to do most of the activities of daily living for them such as cooking and cleaning. These survivors experience physical and functional challenges related to the disease and treatment. In addition, most of the women who are not permanently employed lose their jobs because of being absent from work during the period of treatment (Ntinga & Maree, 2015). They generally have little resources to provide basic needs for their families. As a result, they get depressed and isolated from the community, making it difficult for them to adhere to medical advice (Thapa et al., 2018). This makes survivors to contribute less to the development of the country as their physical, psychological, functional and social wellbeing domains are negatively affected.

In promoting good HRQoL, the Ministry of Health (MoH) has trained health workers both locally and abroad, produced health education materials on prevention and treatment and is offering palliative care (MoH, 2018). In addition, the Government has developed a National Cancer Control Strategic Plan for 2016 to 2021 and some of its objectives are to provide quality cancer treatment and develop an effective palliative care service. Despite all these efforts, HRQoL among cervical cancer survivors is not certain. The research will generate evidence that will guide the process of cancer case management

1.3 Theoretical Framework

1.3.1 The Revised Wilson and Cleary Model of Health Related Quality of Life

Utilizing a framework in Health Related quality of life in research is essential as it helps in the selection of appropriate variables and also helps in identification of potential links between variables within the complex construct of Health related quality of life. Therefore the Revised Wilson and Cleary Model (RWC) was adapted to guide this study. In 2005 Ferrans and colleagues developed a revised version of the Wilson and Clearly model (1995). The reason for its development was to explain the relationships of clinical variables that are related to Health Related Quality of life and also to explain the clinical and individual characteristics. The model proposes a classification of different measures of health outcomes that are linked together linearly. These health outcomes are divided into five components: biological functions, symptoms, functional status, general health perception and overall QOL. The determinants of these outcomes are the characteristics of the environment and individual that are nonmedical in nature (Ferrans et al., 2005). The assumption for this model is that, as one moves from left to right in the model, one moves outward from the cell to the individual to the interaction of the individual as a member of society. Among the outcomes of HRQoL, this study adapted the functional status and the overall HRQoL. For the environmental factors, this study included monthly household income and age and level of education were included as the individual characteristics. Stage of cervical cancer at diagnosis and treatment modality were considered to be biological factors and considered to be determinants of both overall and functional status.

Characteristics of individual

Studies have shown that individual characteristics such as age are associated with HRQoL among cervical cancer survivors (Owenga, 2017). Young people are more likely to have poor HRQoL compared to the elderly because they are more sexually active (Thapa, 2018) and the fact that treatment affects also sexual organs, they experience sexual dysfunction (Ntinga & Maree, 2015) that cause depression and isolation. In this study, although it was observed that there were more than half of the study respondents with poor HRQoL who were 45 years old and above, age was not statistically significant with Overall HRQoL. In addition to age, survivors with higher education have a good HRQoL (Javed et al., 2016). This finding may be related to the fact that educated people are more likely to have access to information concerning cervical cancer and they might seek health care services earlier than people with low education. Similarly, this current study found that pa with low education are more likely to have poor HRQoL.

Characteristics of the environment

Monthly household income tend to represent an aspect of the environment in the revised Wilson and Cleary model of HRQOL (Ferrans et al., 2005). Puteh et al., (2019) showed that low household income was associated with poor HRQoL. The reason could be that they might be facing financial challenges related to treatment and the disease. Similarly, the current study observed that survivors with low monthly household income were the majority of those who experienced poor HRQoL.

Biological function

Biological function includes such measurements as laboratory tests, blood pressure and physical examination (Ferrans et al., 2005). Some studies (Rahman et al., 2017 & Thapa et al., 2018) have demonstrated that patients with late stage of cancer have poor HRQoL, as treatment is just palliative. In addition to stage of cervical cancer at diagnosis, treatment modality has also been reported to influence HRQoL among the cervical cancer survivors as some studies have reported physical, social, psychological and functional challenges related to radiotherapy and chemotherapy which dramatically affect HRQoL (Santos et al., 2019 & Owenga 2018). In the current study participants who experienced poor HRQoL were mainly those with late stage and those who received a combination of treatment modalities. However, treatment was found not to be statistically significant associated with overall HRQoL, neither was it statically significant associated with physical or functional wellbeing.

Symptoms: pain and mood

The common treatment side effects experienced by the cervical cancer survivors is pain and fatigue (Endart et al., 2015). The reason could be that they compromise the ability to carry out daily tasks. Sexuality symptoms such as sexual dysfunction and body image were included but not cross tabulated with the outcomes.

Functional status and Overall Health Related Quality of life (general health perception and overall QOL)

In this model, Overall HRQoL and functional status are used interchangeably with functional status. Overall HRQoL is known as a predictor of mortality and survival. However, functional status is defined as the ability of the patient to perform certain tasks and functions and overall HRQoL is a subjective measure used to assess how satisfied an individual is with life and is used as a summary score for functional status (Ferrans et al., 2005). Both outcomes are measured separately. This is the more reason this study adapted this model so that HRQoL is assessed comprehensively. Surprisingly even the EORTC QOL measures HRQoL as a multidimensional measure that also includes assessment of HRQoL on a profile (functional status) and as single entity (overall HRQoL.

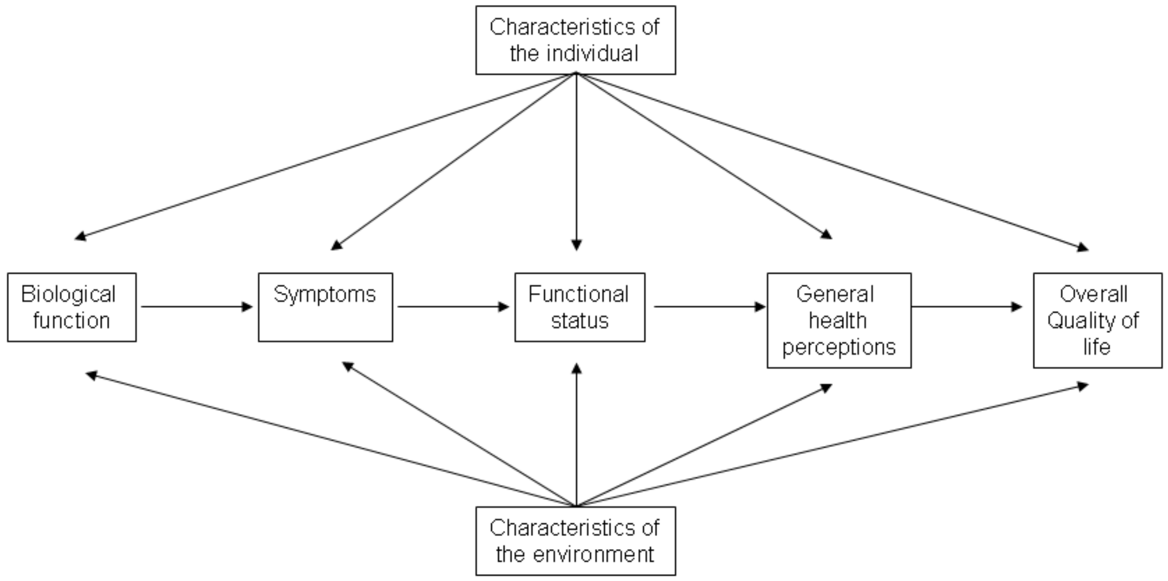


Figure 1.1 Revised Wilson and Clearly Model of Health Related Quality of Life (Ferrans et al., 2005).

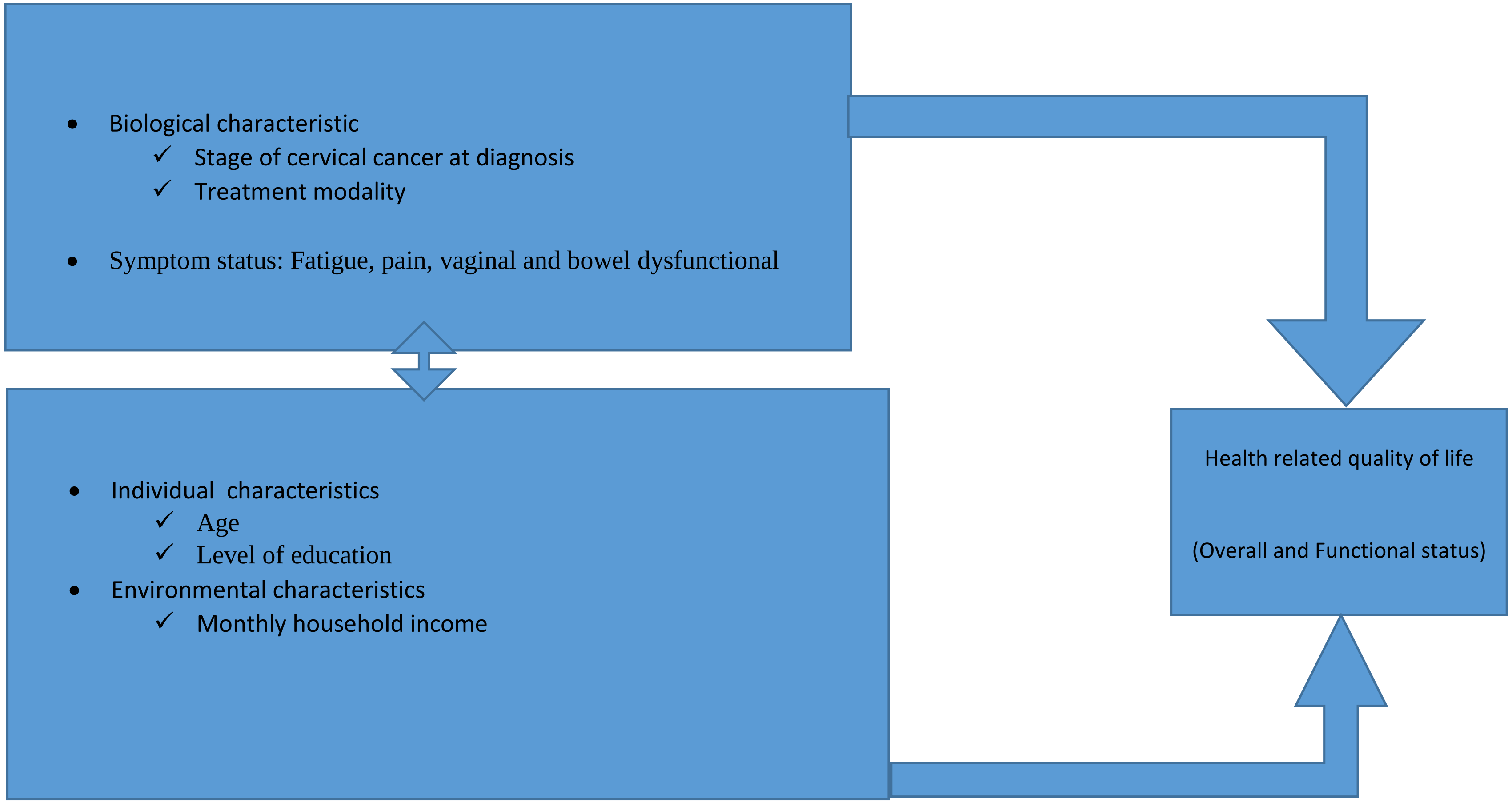


Figure1. 2. Modified Conceptual Framework on HRQoL by Chisaji and Chanda (2020). Adapted from Revised Model of Wilson and Clearly (Ferrans et al., 2005).

1.4 Justification of the Problem

Conducting a study on HRQoL among CCS is essential as it will help determine their HRQoL and identify their unmet health needs and evaluate the control measures that are carried out by MOH and other organisations that uphold their health and wellbeing and determine the best interventions to improve their HRQoL. The researcher did not come across any local information on Health Related Quality of Life among cervical cancer survivors. Therefore the results will assist researchers to begin a larger research trajectory of monitoring HRQoL and determining investigations to maximize it by targeting influencing factors. Further, quantifying of HRQoL may assist stake holders such as the MoH and other organisations in determining the terminal phase of the chronic illness trajectory allowing for early mobilization of palliative services.

Several studies (Muliira et al., 2017, Owenga et al., 2018 & Fadodun et al., 2018) have shown that poor HRQoL is common among CCS and it is mainly due to late presentation of the disease and treatment. In addition, CCS have been neglected as most clinicians concentrate much on treatment. Therefore, assessment of HRQoL among CCS is necessary if we are to understand the true burden of cancer. The number of CCS is increasing and their HRQoL is becoming a major public health concern. Therefore it is important that this study is conducted as the results will be used to design evidence based interventions for improving HRQoL among cervical cancer survivors.

The available knowledge is insufficient as HRQoL among CCS who have undergone surgery or chemo- radiotherapy in Zambia is uncertain.

1.5 Research question

1. What is the Health Related Quality of Life among Cervical Cancer Survivors?

1.6 Null and Alternative hypotheses

The hypotheses used in this study are the Null and the alternative hypotheses.

1.6.1 Null hypothesis

There is no relationship between Health related Quality of Life and factors such as age, level of education, monthly household income, stage of cancer at diagnosis, treatment modalities and time point of treatment.

1.6.2 Alternative hypothesis

There is a relationship between Health related Quality of Life and factors such as age, level of education, monthly household income, stage of cancer at diagnosis, treatment modalities and time point of treatment.

1.7 Research objectives

The research objectives used in this study are the general and specific objectives.

1.7.1 General objective

The general objective is to:

Determine the Health Related Quality of life among cervical cancer survivors at Cancer Diseases and University Teaching Hospitals in Zambia.

1.7.2 Specific objectives

The following are the specific objectives:

1. To identify the relationship between socio - demographic variables (age, level of education and monthly household income) and HRQoL (overall HRQoL) among cervical cancer survivors.
2. To assess the effects of stage of cervical cancer at diagnosis on HRQoL (overall HRQoL, physical, functional, psychological and social wellbeing) among cervical cancer survivors.
3. To evaluate the relationship between time point of treatment (the period that has elapsed from time of initial treatment to the interview day) and HRQoL (overall HRQoL) among cervical cancer survivors.
4. To identify the effects of cervical cancer treatment modalities (surgery, chemotherapy or radiotherapy) on HRQoL (Overall HRQoL, physical, functional, psychological and social wellbeing) among cervical cancer survivors.

1.8 Definition of terms

1.8.1 Operational definitions

- **Cervical cancer** is the abnormal cell growth of the cervix which is the lower portion of the uterus that connects to the vagina (WHO, 2018).

- **Quality of life** is an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationships to salient features of their environment (WHO, 1997).
- **Health** is the complete physical, psychological and social wellbeing and not merely the absence of disease or infirmity (WHO, 1997).
- **Health related quality of life** is a multi- dimensional concept that includes domains related to physical, mental, emotional, and social functioning. It goes beyond direct measures of population health, life expectancy, and causes of death, and focuses on the impact health status has on Quality of life (Pearman, 2003).
- **Overall Health Related Quality of life** is a subjective feeling of an individual of satisfaction in life measured by a summary of the domains of HRQoL (Ferrans et al., 2005).
- **A Cancer survivor** has at least 2 common meaning:
    a) Having no signs of cancer after finishing treatment (ASCO, 2018).
    b) Living with, through, and beyond cancer. This means that cancer survivorship starts at diagnosis. It includes people who receive treatment over a long time. Their treatment can lower the chance of the cancer coming back or help to keep the cancer from spreading (ASCO, 2018).

1.8.2 Operational definitions as used in this study

- **Cervical cancer stage** is the presence of abnormal cell growth on the cervix based on the extent of damage the cancer has caused on the normal cells. In this study it was measured using the FIGO staging.
- **Quality of life** is an individual's sense of satisfaction in all angles of life such as health, having a job, employment, income and neighbourhood.
- **Health** is the ability of carrying out activities of daily living without limitations.
- **Health related quality of life** is a state of living a productive and satisfying life that is subjectively felt by an individual, acquired by maximizing the physical, functional psychological and social wellbeing in the context of a supportive environment.
- **Overall HRQoL** is the overall summary measure for HRQoL. In this study HRQoL was measured using two questions "how would you rate your QOL and how would you

rate your health in the past week"? On a seven likert from one (1) "very poor" to Seven (7) "excellent".

- **A cervical Cancer survivor** is an individual who has been diagnosed with cervical cancer and has at least finished an initial treatment of cervical cancer.

1.9 Variables

The following outlined variables were used in this study:

1.9.1 Dependent variable

Health Related Quality of life.

1.9.2 **Independent variables**

1. Stage of cervical cancer at diagnosis
2. Treatment modalities
3. Time point of treatment (time elapsed since treatment)
4. Age
5. Education
6. Income

Table 1.2 Variables, Cut off points and Indicators of measurements

VARIABLES	INDICATORS	CUT OFF POINT	QUESTION NUMBER
DEPENDANT VARIABLE (HEALTH RELATED QUALITY OF LIFE)			
Physical wellbeing	Good	Scoring ≥ 66.7%	8- 12
	Poor	< 66.7%	
Functional wellbeing	Good	Scoring ≥ 66.7%	13- 14
	Poor	< 66.7%	
Psychological wellbeing	Good	Scoring ≥ 66.7%	15 - 18
	Poor	< 66.7%	
Social wellbeing	Good	Scoring ≥ 66.7%	19 - 21
	Poor	< 66.7%	
Overall Health Related Quality of life	Good	Scoring ≥ 66.7%	22- 23
	Poor	< 66.7%	
INDEPENDENT VARIALES			
Stage of cervical cancer at diagnosis	Early stage	FIGO Stage I	24
	Late stage	FIGO Stage II	
	Very late stage	FIGO Stage III	
	Extremely very late stage	FIGO Stage IV	

Treatment modalities (type of treatment received)	Non aggressive	Surgery only	30
	Aggressive	Radiotherapy	
	Strongly aggressive	Radiotherapy and chemotherapy	
	Very strongly aggressive	Surgery and chemo- radiotherapy	
Time point of treatment (time elapsed between treatment and interview day)	Very early survivors	< 1 year after treatment	29
	Early survivor	1 – 5 years after treatment	
	Outstanding survivors	> 5 years after treatment	
Age	Young	≤ 45 years	1
	Old	≥ 46 years	
Level of education	Low level of education	Never been to school and primary level	5
	High level of education	Attained secondary and tertiary level	
Monthly household income	Low	< K2000,00	7
	Moderate	K2000,00 – K5000,00	
	High	> K5000,00	

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Introduction

Literature review focused on global, regional and local studies conducted on HRQoL among Cancer Survivors. The study variables used to review literature were: HRQoL among Cervical Cancer Survivors; stage of cervical cancer at diagnosis; cervical cancer treatment modalities; age; time point of treatment, level of education and monthly household income. Sources of literature recent documents published between 2015 and 2020 which included books, articles from professional Journals, abstracts, critique reviews mainly from the internet using search engines such as Pub-med, Google scholar, Medline and Hospital records. The purpose of literature review was to acquire foundation knowledge on Health Related Quality of Life among cervical cancer survivors, identify areas of prior scholarship to avoid duplication and identify gaps in existing literature.

2. 2 Health Related Quality of Life among Cervical Cancer Survivors

Globally, cervical cancer is a public health burden (WHO, 2018). However, due to improved screening, early detection and prompt treatment of cervical cancer, there has been a steady increase of CCS (WHO, 2018). CCS are faced with physical, psychological, functional and social (domains of HRQoL) challenges which influence their perception of wellbeing. Depending on the trajectory of their wellbeing, various studies have shown that HRQoL is high in all the domains (Thapa et al., 2018; Huang et al., 2017 & Khalil et al 2017). In contrast, some previous studies have shown poor HRQoL in some domains (Araya et al., 2020; Santos et al., 2019 & Owenga 2018) and the most affected domain was the functional wellbeing. Concerns related to physical wellbeing include fatigue, pain, nausea, bowel and urinary dysfunction. Psychological wellbeing concerns includes worry of recurrence and dying, reduced body image, anxiety, depression, and feelings of uncertainty. Physical and psychological concerns are important determinants of functional status and overall QOL in cervical cancer (CDC, 2018). Social wellbeing concerns include financial challenges related to the disease and illness, sexual dysfunction, disruption of family unit, being dependent on others which was common in most of the articles. Functional concerns include limitation in carrying out activities of daily living and infertility. It is also noted that survivors who report the most challenges of domains of HRQoL are those in the late stage and those who received at least radiotherapy (Owenga, 2018). The inter relationship that exists between domains of

HRQoL and overall HRQoL explains the concerns related to overall HRQoL as it is a summary score for the domains of HRQoL. For instance, in a cross section descriptive study conducted by Santos et al., (2019), in Brazil on HRQoL among women with cervical cancer noted that the overall HRQoL was good and their physical and social wellbeing was good. Similarly Thappa et al (2018) observed a good overall HRQoL and all the domains of HRQoL were good. In contrast, Owenga, (2018) observed a low score in overall HRQoL and in the domains of HRQoL among cervical cancer patients as most of the patients presented with advanced stage of cervical cancer. Basing on these findings, it was established that as some cervical cancer survivors may be having good HRQoL, others might be living with challenges related to the disease and treatment HRQoL. This depends on the trajectory of HRQoL of survivors. While these studies provide some insight into potential differences in HRQoL, Santo et al., (2019) did not find any difference as they did not include stage four cervical cancer survivors, whose treatment is purely palliation and that the sample size was purely on women with low social economic status.

Regionally, in the Sub- Saharan Africa, cervical cancer is a public health problem. There are few studies that have been conducted on HRQoL among cervical cancer survivors. Survivors face physical, psychological, social and functional challenges related to the disease and treatment. A cross section descriptive study conducted by Fadodun et al., (2018), in Nigeria on HRQoL of women with cervical cancer in the University College Hospital, Ibadan showed that only less than 50% of the participants had good Overall HRQoL with less than 50% of women having high level of role functioning and social functioning. The results explain the interrelationship that exists between overall HRQoL and the domains of HRQoL.

Similarly, a cross section descriptive study conducted by Owenga (2018), in Western Kenya on HRQoL among cervical cancer patients observed that more than half of the respondents experienced poor HRQoL and none of the participants had good functional and physical wellbeing. The poor HRQoL is due to a large proportion of patients presenting with stage three and four of cancer at diagnosis. In view of these findings, special attention should be given to specific domains if HRQoL. Further, early detection and treatment of cervical cancer can help improve HRQoL. Despite having similar findings, Fadodan et al., (2018) used the domains of HRQoL as determinants of overall HRQoL while Owenga (2018) used level of education, stage of cervical cancer at diagnosis, age and treatment modalities.

In Zambia, to my knowledge, there is no published article on HRQoL among cervical cancer survivors except on quality of life. Chitashi, (2012) conducted a study on Quality of life in

Zambian on Cervical Cancer women post chemo radiotherapy. The results show that the QOL was high as more than half of the patients had high QOL. The determinant variables used were the socioeconomic and demographic factors as they are closely related with QOL. The researcher suggested a future research to be conducted to include open ended questions. Quality of life and HRQoL are dynamic, they change overtime, therefore the need of future research.

2. 3 Effects of stage of cervical cancer at diagnosis on HRQoL

According to American Cancer Society (2018), survival rates after cervical cancer treatment mainly depends on the stage of cancer at diagnosis. In the USA, when cervical cancer is detected at an early stage, the 5 years survival rate for women with invasive cancer is at 92% (ACS, 2018). Less than half of women are diagnosed early and more than half are diagnosed late. Late diagnosis subjects patients to a combination of treatment modalities (Maiti, 2018), which has been reported to dramatically affect their HRQoL (Prasongvej, 2017).

Thapa et al., (2018) conducted a cross section descriptive study on Impact of Cervical Cancer on QoL of women in Hubei in China. Stage of cancer was found to be associated with HRQoL as those with late stage had poor HRQoL because they were subjected to radiotherapy which has dramatic effects on their HRQoL. These findings are reinforced by several studies conducted by (Mederous et al., 2015; Zhou et al., 2016; Owenga, 2018 and Fadodan et al., 2018) that showed poor HRQoL among those patients who presented with late stage of cervical cancer. Late stage of cervical cancer causes dramatic effects such as fatigue, foul smelling vaginal discharge and abnormal bleeding (WHO, 2018). Even when treatment is completed in stage four, survivors will continue to receive cancer treatment for palliation. In contrast, a follow up descriptive study done by Dahiya et al., (2016) on Quality of Life patients with advanced cervical cancer before and 6 months after chemo- radiotherapy indicated that quality of life of advanced cervical cancer patients improved after chemo radiotherapy treatment. However, their sexual enjoyment and sexual function significantly decreased after treatment. The difference in findings is the use of different methodologies. Thapa et al., (2018); Mederous et al., 2015; Zhou et al., 2016; Owenga, 2018 & Fadodan et al., 2018) used a cross section descriptive study while Dahiya et al., (2016) used a longitudinal study. However, early detection and prompt treatment can help improve HRQoL among cervical cancer survivors.

2. 4 Relationship between time point of treatment and overall HRQoL

A cross section descriptive study conducted by Santos et al., (2019) on Health Related Quality of Life in women with cervical cancer in Brazil showed that those who received treatment more than two (2) years ago had better HRQoL compared to those who received treatment 2 years and below. Similarly, Thapa et al., (2018) showed a better HRQoL among long term cancer survivors than the short term survivors. These findings show that HRQoL improves over time. However, in both studies the sample size was small. Further, Santos et al., (2019) did not include stage four cervical cancer patients and the sample size was purely on women with low social economic status so generalization is limited. In addition, the sample size for stage four for Thapa et al., (2017) was small and the study being a cross section, generalization is limited because HRQoL among CCS changes over time.

A cross section descriptive study conducted by Khalil et al., (2015) in Morocco on Impact of Cervical Cancer on QoL beyond the short term revealed that HRQoL in long term cervical cancer survivors was generally satisfactory as there was minimal statistical differences between the studied cohort and healthy controls apart from the sexual and emotional functioning which had significantly lower scores. The gap for this literature is that the researchers did not complete evaluating the specific cervical core questionnaire. Cervical cancer survivors adapt to the disease and treatment side effects as over time as they learn better adaptive methods.

2.5 Effects of cervical cancer treatment modalities on HRQOL

A retrospective cohort study on Postoperative HRQoL of cervical cancer patients done by Sowa et al., (2014), in New York, noted that patients who underwent surgery had a good HRQoL. The aim of the study was to evaluate the comparison between the Weitheim- Meigs operation (Radical hysterectomy) and the total Mesometrial Resection (TMMR) in relation to HRQoL. The researchers showed that there were no significant differences in the HRQoL domains as both groups of patients had good HRQoL and that it was attributed to early diagnosis of the disease. These findings are similar to Muliira et al., (2017), who noted that survivors who presented with early stage of cancer at diagnosis had good HRQOL as compared to those who presented with late stage of cancer because they were not subjected to radiotherapy side effects such as fatigue, pain, sexual, urinary and bowel dysfunction and distortion of body image and premature menaupose. Early treatment is associated with better health outcomes compared to late treatment where there are effects of radiotherapy which are devastating.

According to Kristaet and colleagues, (2015), in a peer review study on cervical cancer survivorship: Long term quality of life and social support in USA observed that surgery, chemotherapy and radiation had all shown an improvement in the quality of life after treatment, however, the side effects related to treatment had a negative impact on individuals. Women who were treated with radiotherapy had poor HRQoL because of worse symptoms related to the treatment such as menopausal symptoms, bladder and bowel dysfunctions, fatigue, pain, sexual dysfunctional due to dry vagina that prevented them to carryout activities of daily living. However, patients who underwent surgery had a fair HRQoL. These findings are similar to Muliira et al., (2017), who observed that women who were subjected to radiotherapy experienced poor QOL because of the side effects of radiotherapy. A qualitative study done by Ntinga and Maree (2015), in South Africa noted that cancer treatment had adverse side effects that caused women not to carry out activities of daily living effectively. The aim of the study was to describe the late effects of cervical cancer treatment. The researchers observed that physical problems related to treatment such as chronic fatigue, pain, vaginal, bladder and bowel problems, lymphedema, vaginal shortness, stenosis, bleeding and menopausal symptoms affected the patients' ability to enjoy activities they used to before treatment. Further, treatment caused financial hardship as it was difficult for some of them to continue with their full time paid jobs. In addition, some of them were neglected by their spouses because of vaginal problems leaving them with the sole responsibility of taking care of their families. These findings are similar to Muliira et al., (2017) who noted that treatment side effects caused a lot of physical and psychological challenges that hindered individuals from carrying out activities of daily living and some of them got divorced.

2.6 Relationship between Social Demographic variables and overall HRQoL

2.6.1 Relationship between Monthly house hold income and overall HRQoL

A cross section study conducted by Lemos et al., (2015) , in Brazil, entitled Family income is associated with quality of life in patients with chronic disease in the pre dialysis phase; A cross sectional study with a sample size of 170 observed that subjects with a higher income have better QOL in the social, physical emotional domains. They concluded that family income was the most important factor affecting QOL. These findings are in line with Thapa et al., (2017)'s findings that showed an association between family income and QOL as people with a low income status might be unaware of cervical cancer, so they may usually seek health care in the last stage of cancer.

A cohort study by Guhl et al., (2019) on Association of income and Health Related Quality of Life in Atrial fibrillation observed that subjects who had higher household income scored highest means in HRQoL domains. Those with low household income scored low means in the domains of HRQoL. Those with highest income had the highest HRQoL (p value of 0.004).

Low income was also associated with lower HRQoL in mental health score (P value, 0.01). These findings are similar with a study done by Puteh et al., (2019), in Malaysia entitled Health Related Quality of life among low socioeconomic population with a sample size of 551. They defined low socioeconomic status as Low total household income and observed an association between household income and HRQoL.

A prospective cohort study done by Klein et al., (2016) in Hamburg in Germany on socioeconomic status and HRQoL among patients with prostate cancer 6 months after radical prostatectomy showed that SES was significantly associated with HRQoL. Patients with low income, education and low occupational status had poor HRQoL 6 months after treatment particularly in physical, role and emotional domains. The researchers aimed at analyzing the association between SES and HRQoL among patients with prostate cancer 6 months after radical prostatectomy. The researchers concluded that social inequalities in HRQoL among patients affects their health outcomes as shown in the study, patients with low SES also had poor health related quality of life. The findings are similar to Kimman et al., (2017) that showed that people of low socioeconomic status had poor HRQoL. On the contrally, Medeiros et al., (2015) observed that HRQoL was not associated with individual's economic status as they all had similar side effects of cancer treatment regardless of their SES.

2.6.2 Relationship between level of education and overall HRQoL

A cross section descriptive study conducted by Javed et al., (2016), in India on a sample of 100 women which aimed at assessing and comparing QOL of educated and uneducated Muslim housewives and also on assessing and comparing wellbeing of uneducated and educated Muslims, observed no significant association between education and QOL. However, there was a significant association observed between education and wellbeing of the women. Educated people were more social, less emotional and more mentally strong as compared to uneducated women and this difference was significant. This finding is similar to Thapa et al., (2017), who observed a significant association between Education and QOL. Literate patients had good QOL (p value, 0.000), good social functioning (P value, 0.001) and good physical functioning (P value, 0.042.). Less educated people are less likely to have follow up care with health providers leading to a poor health outcome.

Hajria and Alajbegovic (2015), conducted a study on Impact of education level and employment status on HRQoL in Multiple Sclerosis with a sample size of 100. Results show that patients with college degree had higher median scores compared to others. However, there was no significant relationship observed between education and HRQoL. Similarly, a study done by Santos et al., (2019), in Brazil on Health related Quality of life in women with cervical cancer also found no significant correlation between HRQoL and education. These findings do not concur with the findings of Owenga, (2018), that showed a statically significant relationship between education and HRQoL. Improvement in HRQoL was seen with an increasing level of education.

3.6.3 Relationship between age and overall HRQoL

An analytic observation with a cross section descriptive study by Fadhilla et al., (2017) in Indonesia on Effects of Age and Economic Status on the Quality of life of patients with Cervical Cancer with a sample of 100 women aimed at examining effects of age and socioeconomic status on QOL with cervical cancer. The results showed that there was a statistically significant relationship between age and QOL. Age of more than or equal to 45 years, decreased QOL (P value, 0.001) .Higher income increased QOL (p value, 0.009) and higher education increased QOL (P value, 0.001). Most of the patients had poor QOL because they were ≥ 45 years and were affected by the effects of chemotherapy. This finding is consistent with Owenga (2018), in the study on Assessment of Health Related Quality of Life of Cervical Cancer patients who also reported that age, marital status and education influenced overall QOL of patients. However, Tadele (2015), in Ethiopia, differs with this finding in his study on evaluation of QOL of adult cancer patients which showed no significant association between QOL and socio demographic variables such as sex, age patient's level of education and marital status.

Another study conducted by Leinert et al., (2017), on the impact of Age on Quality of Life in breast cancer patients Adjuvant Chemotherapy: A comparative Analysis from the prospective Multicenter Randomized ADEBAR trial with a sample size of 1362 with the aim of comparing QOL in patients aged < 65 years and 65 to 70 years receiving adjuvant chemotherapy as a secondary outcome in the prospective randomized multicenter ADEBAR trial observed that Global health status and physical functioning were lower in patients between 65 and 70 years. Physical functioning decreased by 13.4 points in patients aged < 65 and 15.9 points in patients aged between 65 and 70 years. In both groups, global health status/ QOL exceeded baseline by 6 points under. Physical functioning was 1.3 points under baseline in patients who were between 65 and 70 years. A trend of an increase in fatigue in the elderly patients was observed while more nausea and vomiting in the younger patient. Further there was a higher dropout rate in patients aged between 65 and 70 years (25.7%) than in patients aged < 65 years (16.2). A similar study done by Thapa et al., (2017), on Impact of cervical cancer on quality of life of women in Hubei, China showed that the global health status of the older people was lower than the younger patients and that fatigue was more in the elderly than the young patients.

2.7 Conclusion

Literature review revealed that cervical cancer survivors generally have poor HRQoL, even after completion of treatment due to the short and long term sequelae that impair HRQoL. It also demonstrated that a good number of women present late for treatment mainly in the low income countries which subjects them to a combination of treatment modalities which dramatically have an influence over their HRQoL. Literature also revealed that HRQoL among survivors varies from region to region because other regions are well developed such that they have a comprehensive management of cervical cancer starting from primary level to tertiary level. In addition, they also have good social support due to their high economic status. HRQoL among cancer survivors differs basing on the survivor period and the age of the patient. Most of the researchers either used validated EORTC or FACT CX questionnaires for data collections which have both been used in both high and low income countries. Assessment of HRQoL among survivors is not routinely done in most countries. This causes some survivors to live with unmet health needs as assessment of HRQoL is subjective data from the patient that would help health workers render quality care to this group.

In Zambia, no study has been conducted on Health Related Quality of Life among Cervical Cancer Survivors. There is an increase in the number of cervical cancer survivors and their HRQoL is not certain as there is no recent documented data. Basing on this fact, it is imperative that studies like Health Related Quality of Life among Cervical Cancer Survivors be conducted in order to address patients unmet health needs.

CHAPTER THREE

3.0 METHODOLOGY

3.1 INTRODUCTION

This chapter presents the methodology used in this study and is organized under the following headings: the study design, the study sites, study population, sampling method, inclusion and exclusion criteria, data collection tool, validity and reliability, data collection technique, pilot study, data management and storage and ethical consideration.

3.2 The study design

This was a cross- section descriptive study. This design was chosen because it provides a snapshot of the frequency of health-related characteristics in a population at a given point in time and can be used to assess the burden of disease or health needs of a population.

3.3 The study sites

This study was conducted at CDH and UTH in Lusaka District. CDH and UTH were purposively selected because they are level three referral hospitals that offer cancer services. CDH is the only hospital in Zambia that offers radiotherapy and oncology surgical procedures are mainly conducted at UTH. These study sites also enabled the researcher to get a more generalized picture as the hospitals render health services to all the population of Zambia including neighbouring countries.

3.4 Study population

The study population included cervical cancer survivors with histologically diagnosed cervical cancer, who were visiting CDH and UTH for their follow up. A cancer survivor is either one who has no signs of cancer after finishing treatment or one who is living with, through, and beyond cancer. This means that cancer survivorship starts at diagnosis. It includes people who receive treatment over a longer time. Their treatment can lower the chance of the cancer coming back or help to keep the cancer from spreading (ASCO, 2018).

3. 4. 1 Target population

The target population comprised of cervical cancer survivors visiting CDH and UTH for follow ups regardless of their location of residence during the period of study.

3.4. 2 Accessible population

The accessible population consisted of all cervical cancer survivors, with histologically diagnosed cervical cancer, who had at least received an initial cervical cancer treatment, visiting CDH or UTH for their follow up during the period of study and were willing to participate in the study.

3.5 Sampling method

A sampling selection of respondents involved a purposive sequential enrolment of survivors. Purposive sequential enrolment of study participants is a nonprobability sampling technique where the researcher deliberately selects sample units that conform to some predetermined criteria (Basavanthappa, 2014)). Since the process did not involve a predetermined sampling frame, selection of sample units depended on the researcher's judgment. Those who did not meet the inclusion criteria were rejected. This process was employed in view of a limited number of respondents. Therefore respondents who were selected were survivors with histologically diagnosed cervical cancer and who had at least received an initial cervical cancer treatment as they became available at the facility till the required sample size reached. The healthcare providers in charge of the survivors helped in identifying survivors based on information in the patients' files then referred them to the researcher who confirmed their eligibility and then consent was obtained from each of them. This was done until the desired sample size (83) was achieved.

3.5.1 Inclusion criteria

Survivors with histologically diagnosed cervical cancer and with history of being treated of cervical cancer, such as surgery, chemotherapy and radiation UTH or CDH who agreed to participate in the study by signing an informed consent or consent by proxy were included.

3.5.3 Exclusion criteria

Participants with major systemic illnesses such as: severe cardiac failure, renal failure and severe pulmonary oedema.

3.6 Sample size: Sample size was 83

3.7 Data collection tool

A pretested interviewer administered instrument included open and closed ended questions. The tool consisted of 4 sections. The first section included the socio- demographic data, the second section included questions on the dependent variable, the third section included questions on stage of cervical cancer at diagnosis and treatment and the fourth section included questions on symptoms of the disease and treatment, which was obtained by reviewing the medical records and interviewing the participants respectively. The interview schedule consisted of self and adapted questions from a validated Questionnaire for European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core-30 item (EORTC QLQ-C30) version four and EORTC QLQ-CX24 (Cervical cancer module) respectively. The EORTC questionnaires have been widely employed both in high and low resource countries and tested in different studies among the various cultural groups and demonstrated acceptable validity (Thapa et al., 2018; Tax et al., 2017, & Rahman et al., 2017) with a high tests / retest reliability measured by Pearson's correlation coefficient for all functional scales, with a range of 0.82 for cognitive and role function to 0.91 for physical function and 0.85 for overall HRQoL. The closed ended questions helped capture certain specific and guided responses. The open ended questions permitted the participants to provide responses in their own words and express themselves. The information on the interview schedule was communicated in the language best understood by a particular participant

3.8 Validity

Internal and external validity were observed in this study.

3.8.1 External validity

External validity in this study was ensured by appropriately complying with the planned study design, study population, the inclusion and exclusion criteria for selection of study participants and use of purposive selection of participants. The researcher also made sure that participants experienced the real events of the study by explaining the aims of the study to them. Further, the researcher recommended conducting of the study again with different samples by use of random sampling or in different settings to see if the same results can be obtained.

3.8.2 Internal validity

To ensure internal validity, questions in the questionnaire were clearly constructed with simple language to avoid ambiguity. A cancer specific validated questionnaire for EORTC was used and was simple, concise and brief and has been used both in developing and developed countries. The interviewer administered schedule was subjected to academic scrutiny by the research supervisors. The instrument was pre-tested before the main study commenced to ensure that it captured the required information. Further, since a test should measure the construct it purports to measure (Burns and Glove, 2007), the used EORTC questionnaire is a cancer questionnaire which has been validated and used both in developed and low income countries and evaluates HRQoL as a profile or a single score (Anderson et al., 1993), as the result of HRQoL measure can be reported either as a single composite score (Overall HRQoL) or as a profile that includes physical, social, psychological and functional wellbeing (Gill et al., 1994). In ensuring internal validity, I also evaluated HRQoL on a profile and also on a single score.

3.9 Reliability

To ensure reliability, the research assistants were trained on data collection and the research tool was tested before the main study was undertaken through a pilot study which was done in the similar environment with similar characteristics. Questions that were not well phrased were rephrased before administering the main study.

3. 10 Data collection Technique

Before gathering information from respondents, the researcher and research assistants started by introducing themselves and getting permission from the staff in charge of the Department. The researcher and research assistants then introduced themselves to the respondents and the purpose of the study was explained to the eligible participants. The eligible respondents were allowed to read the information sheet where confidentiality was assured. They were also told that all the filled in interview schedules were to be secured by the interviewer in sealed envelopes. To those who consented, written consents were obtained from them to allow the research team to administer the questionnaires. Each respondent was interviewed for approximately 15 – 20 minutes using appropriate time for the participants during their follow up visits at the Hospitals to avoid stressing the participants. Each research assistant was asked to interview only up to a maximum of five (5) people per follow up day. This allowed them to concentrate and avoid mistakes due to exhaustion. The researcher filled in the questionnaire. After filling in the interview schedule, the respondents were given chance to ask questions which were answered appropriately. Some responses from the interview schedule were confirmed with their file records such as stage of cancer at diagnosis, treatment received and time point of treatment (time elapsed between treatment and interview date). This was done with permission from the respondents and the person in charge of the out - patient department and records were reviewed in a private room.

Questionnaires were administered by the researcher and research assistants who were nurses by profession in the two hospitals. All the respondents responded to the interviewer administered questionnaire to promote consistency in data collection. Data was collected from the Outpatient Department between October, 2019 and December, 2019 on every Thursday of the week as this was the only day for follow up and never collected on public holidays because the department was closed.

3.11 Pilot study

A pilot study was conducted at Cancer Diseases Hospital (CDH) in the out - patient department. Nine (9) cervical cancer survivors with histologically proven cervical cancer, who were visiting CDH for their follow up were interviewed after giving consent. The sample was based on 10% calculation of the target population as the sampling method was purposive sampling. The center was chosen for conducting the pilot study because it is the only Hospital in Zambia that offers radiotherapy as cancer treatment. Thereafter, adjustments were made to the data collection tool. Questions that were not well phrased were rephrased such as “How old are you?” was rephrased to “Date and year of birth”, as it was difficult for some survivors to calculate their age. Some questions such on blood transfusion and hormonal therapy were removed as blood transfusion was not a specific treatment for cancer and hormonal therapy was not often given.

3. 12 Data management and storage

The principal researcher was responsible in ensuring that the data collected was well managed and stored. The interview schedules were checked at the end of each interview for completeness and consistency of information and also before storage. For interview schedules that had gaps, the researcher relocated the respondents to ensure all necessary data was obtained. The data collected were stored under lock and key and also by using technological resources such as the computer protected with a password, flush discs, hard drives and as well as online storage for back up. Data was stored in a different name for protection. Confidentiality was maintained by keeping personal data in confidence and only the principal researcher and trained research assistants had access to it.

3.13 Ethical consideration

Ethical clearance was obtained from University of Zambia biomedical Research Ethics Committee (approval number: REF. 230-2019) and from National Health Research Authority. The nature and purpose of the study were explained to the potential participants verbally and in writing to enable them make informed decisions. Participation was voluntary and confidentiality and anonymity were guaranteed. Individual written consent was obtained from each participant before being enrolled into the study. Survivors who were unable to write were asked to sign through thumb stamping. Permission to conduct a study was granted from both UTH and CDH.

Before the interview, the researcher and trained research assistants screened out those at high risk of psychological trauma based on the exclusion criteria. The researcher and research assistants also took into consideration the psychological trauma the participants faced when asking sensitive questions. Minimizing psychological trauma during the interview was considered as follows: the researcher and research assistants anticipated that some distressed participants could experience some stress as a consequence of conducting the study and were prepared to offer solutions. Some of the interventions were as follows: the researchers were individuals who were trained to handle psychological distress, consistently monitored participants' reactions during the interviews such as behaviour or statements that suggested that the interview was too stressful, such participants were screened out to prevent psychological trauma. They were also equipped with referrals for supportive care or counselling in case participants became significantly distressed. The researchers also provided frequent breaks during stressful data collection procedures as well as information on available psychological or social services. The Participants' information sheets were kept in confidence to promote privacy and the collected data was kept under lock and key.

CHAPTER FOUR

4.0 DATA ANALYSIS AND PRESENTATION OF FINDINGS

4.1 INTRODUCTION

This chapter presents the study findings. The current study answered the following question: what is the health related quality of life among cervical cancer survivors. The study findings presented were obtained from 83 cervical cancer survivors who came for follow up at Cancer Diseases and University Teaching Hospitals. Data was collected over a three months period (October, November and December, 2019). The response rate of the questionnaires was 100%.

4.2 Data processing and analysis

The raw data that was collected was grouped in categories. The data collecting instrument was checked for completeness, consistency after each data collection day, after which data was coded. Data was analyzed using SPSS version 25.0. Chi square test and linear regression were used to test for associations between the dependent and independent variables. Significant level was set was set at 0.05 with 95% confidence interval.

4.3 Presentation of findings

The findings of the study are presented according to the sequence of the interview schedule using frequency tables, graphs and cross tabulation tables. The frequency tables summarized the study results in such a way that helps readers to be able to understand the findings of the research study. Cross tabulations of the variables helped to show clearly the relationship between variables and hence it enabled the researcher to draw meaningful inferences.

4.3.1 **Section A: Demographic data**

Section A presents the respondents' demographic data. The variables considered were age, marital status, number of children, level of education and monthly income. The data is presented in table 4.1.

Table 4.1 Demographic Characteristics (n = 83)

Demographic characteristics	frequency	Percentages
Age		
≤ 45	28	33.7
≥ 46	55	66.3
Marital status		
Single	9	10.8
Married	36	43.4
Divorced	9	10.8
Widow	29	34.9
Number of children		
> 2	74	89.2
1	6	7.2
None	3	3.6
Level of education		
Never been to school	11	13.3
Primary level	37	44.6
Secondary level	26	31.3
Tertiary level	9	10.8
Employment		
Not employed	47	56.6
On Contract	3	3.6
Permanent	4	4.8
Self employed	29	34.9
Monthly household income		
< k2000	71	85.5
K2000- k5000	9	10.8
> k 5000	3	3.6

Table 4.1 shows that more than half (66.3%, n = 55) of respondents were ≥ 46 years. The average mean age was 52.55 with standard deviation of 12.4 and a range of 24 to 81 years. Slightly below half (43.4 %, n = 36) of the participants were married and more than three quarters (89.2 %, n= 74) had two or more children. Slightly above one tenth (11%, n = 9) of the participants had attained tertiary education while the rest had not and only below (4.8%, n = 4) were employed on permanent basis and (3.6%, n = 3). Further, less than one tenth (3.6%, n = 3) of the participants had monthly house hold income of more than K5, 000.00 while the rest had less.

4.3.2 **Section B: Health Related Quality of Life among Cervical Cancer Survivors**

In this section, information on responses on Health Related Quality of Life is presented. Health related quality of life was evaluated both as an overall health related quality of life (summary measure of HRQoL) and as a profile/ functioning scale involving: physical, functional, psychological and social wellbeing which is in accordance with the European Organization for Research and Treatment of cancer questionnaire (EORTC) (Fayer et al., 2001; Aaron et al., 1993 & Gill et al., 1994) and also the conceptual framework (Ferrans et al., 2005).

Table 4.2 Health Related Quality of Life status of respondents (n =83)

Domains of well being	Good (Frequency)	Good (Percentage)	(Frequency)	Poor (Percentage)	Mean (SD)	Total
Physical wellbeing	57	68.7	26	31.3	71.4 (26.5)	83
Functioning wellbeing	53	63.9	30	36.1	68.2 (26.5)	83
Psychological wellbeing	50	60.2	33	39.8	69.1 (22.8)	83
Social wellbeing	47	56.6	36	43.4	57.9 (28.1)	83
Overall Quality of Life	53	63.9	30	36.1	60.9 (21.4)	83

Table 4.2 shows that in the domains of HRQoL, slightly below three quarters (68.7%, n= 57) of the study participants had good physical wellbeing. The overall mean for physical wellbeing was 71.4 with standard deviation above the average mean of 66.7.Therefore, the physical wellbeing was good. Above half (63.9%, n = 53) of respondents had good functional wellbeing. The overall mean for functional wellbeing was 68.2, therefore it was good. More than half (60.2%, n = 50) of the participants had good psychological wellbeing. The overall mean for psychological wellbeing was 69.1 above the average mean of 66.7. Therefore, the psychological wellbeing was good. On the other hand, slightly above half (56.6%, n = 47) of the participants experienced good social wellbeing, while less than half (43.4%, n = 36) experienced poor social wellbeing. However, the overall mean for social wellbeing was 57.9 which was below the average mean of 66.7 with SD of 28.1. Therefore, the psychological wellbeing was good.

The highest means of the domains of HRQoL were observed in physical and psychological wellbeing. The lowest mean was observed in the social wellbeing.

More than half of the respondents 53 (63.9%) had good overall HRQoL. However, the overall mean for HRQoL was 60.9 below the average mean/ baseline of 66.7. This means that the overall HRQoL among cervical cancer survivors was poor as the score was below the average score of 66.7.

4.3.5 Section C: Clinical Characteristics

This section includes responses on stage of cervical cancer at diagnosis and treatment modality and time point of treatment.

Table 4.3 clinical characteristics (n= 83)

Clinical characteristics	**Frequency**	**Percentages**
Stage of cervical cancer at diagnosis		
Stage I	13	15.6
Stage II	40	48.2
Stage III	28	33.7
Stage IV	2	2.4
Treatment modality		
Surgery only	7	8.4
Chemo radiotherapy	53	63.9
Surgery and chemo radiotherapy	18	21.7
Radiotherapy only	5	6.0
Admitted during treatment		
Yes	47	56.6
No	36	43.4
Feeling after treatment		
Fine	8	9.6
Much better	73	88.0
No improvement	2	2.4
Time point of treatment		
< 1 year	37	44.6
1 – 5 years	40	48.2
> 5 years	6	7.2

Table 4.3 shows that the majority (n= 40, 48.2%) of the study participants were in cervical cancer stage II at diagnosis and the least (n= 2, 2.4%) was observed in stage IV and those who received Chemo radiotherapy were the majority (n= 53, 63.9%) and the least (n= 5, 6%)

number of participants received radiotherapy only. Slightly above half (n= 47, 56.6%) of the study participants were admitted during the period of treatment and above three quarters reported to be feeling much better after treatment. This mains that treatment improves the quality of life among cervical cancer survivors. Further majority of the participants (n= 40, 48.2%) were those who received treatment 1 to 5 years ago.

4.3.6 Section D: Side effects of the disease and treatment

This section includes responses on diseases symptoms, general side effects, side effects related to sexual dysfunction and body image.

Figure 4.1 Responses on whether they still experience disease symptoms after treatment (n= 83).

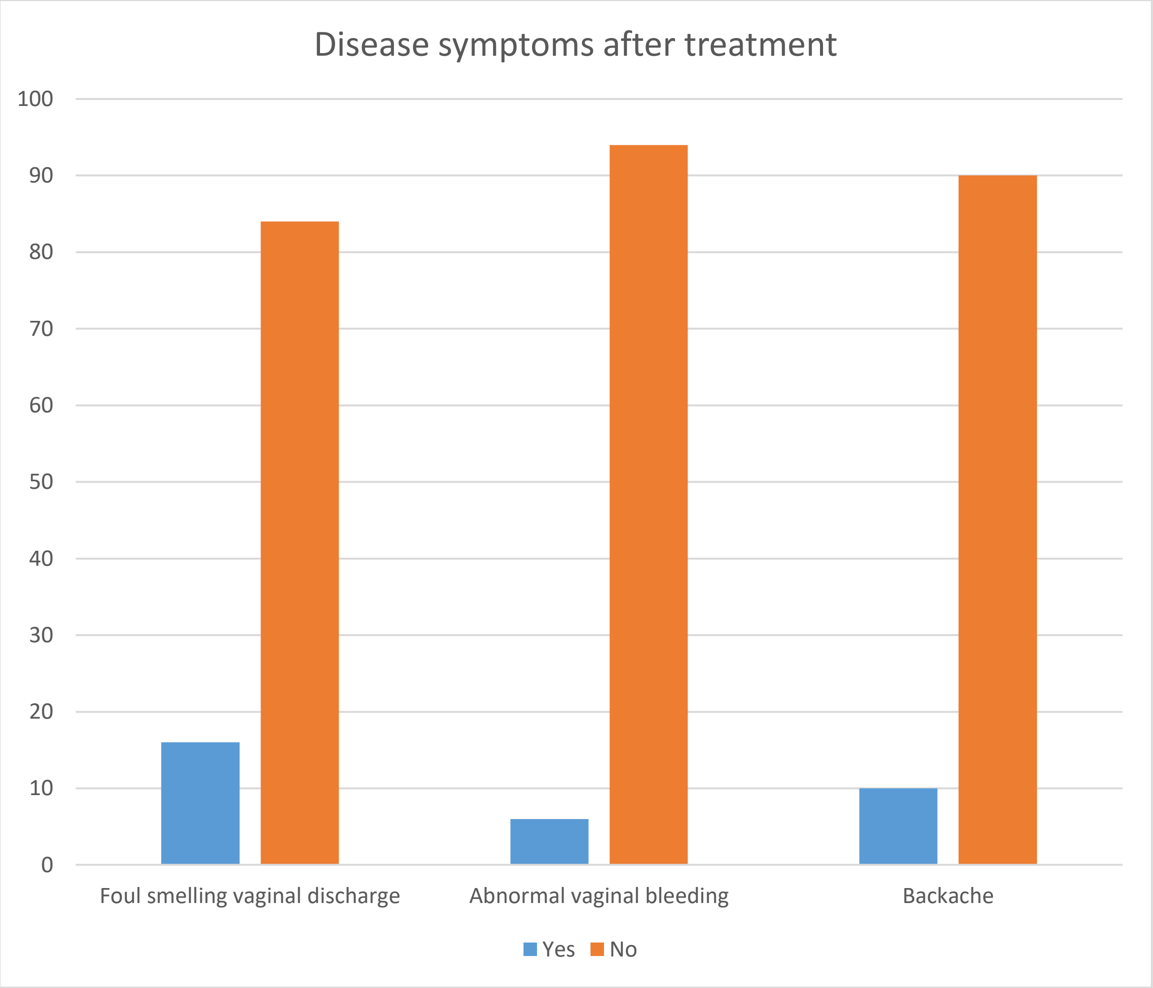


Figure 4.1 shows responses on whether they still experienced disease related symptoms. Above three quarters (84%, n = 70) of the study respondents did not experience foul smelling vaginal discharge. On whether respondents still had abnormal vaginal bleeding, above three quarters (94%, n = 78) of the study respondents did not experience abnormal vaginal bleeding. On

whether respondents had backache, more than three (3) quarters, (90% n = 75) of respondents did not have backache. This shows that a good number of participants did not have the disease symptoms after treatment**.**

Figure 4.2 Responses on experiencing general side effects of treatment (n= 83)

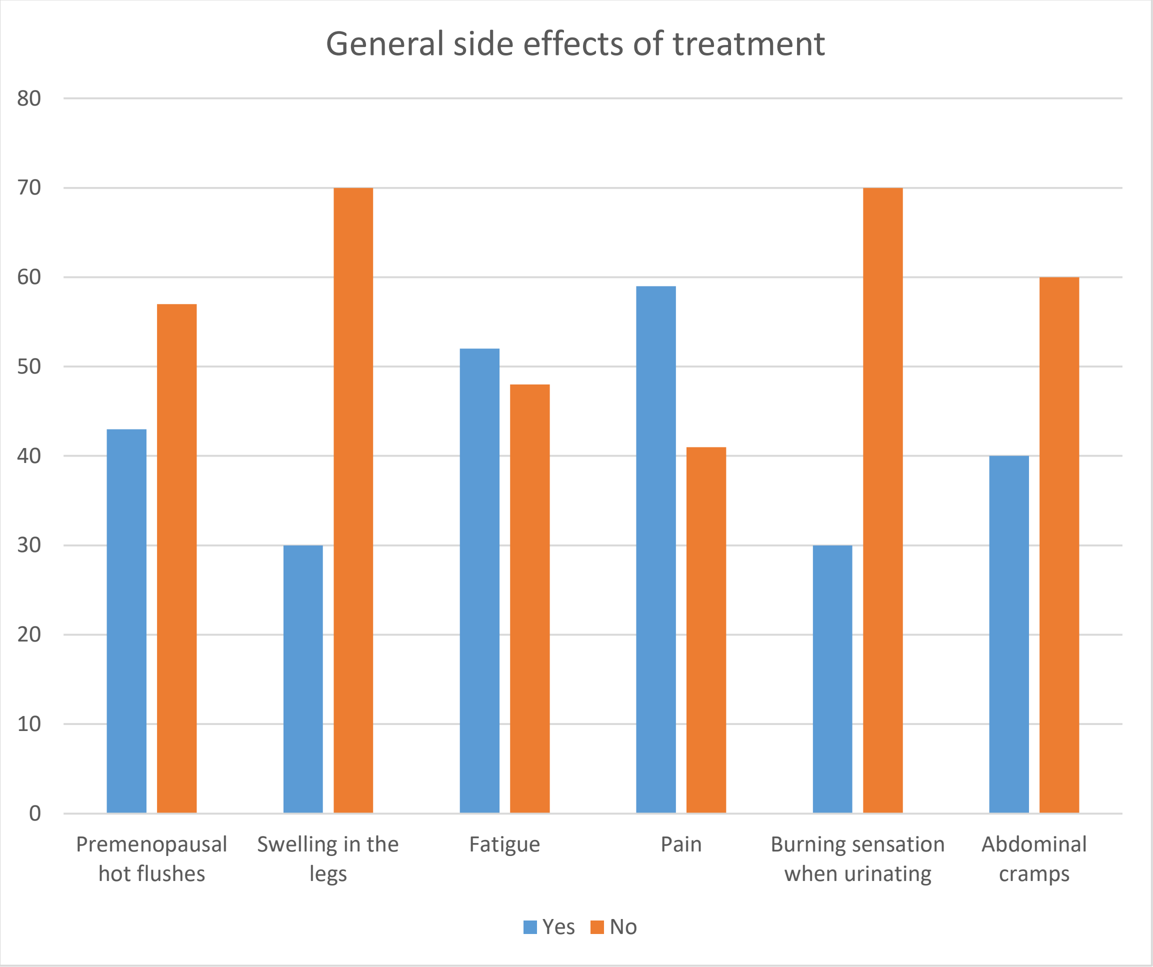


Figure 4.2 shows that above half (57%, n = 47) of the study respondents did not have pre-menopausal hot flushes. On whether they had swelling in one leg or both, slightly below three (3) quarters (70%, n = 58) did not experience the swelling, while slightly below half (48%, n = 40) had no fatigue. On whether the respondents had pain, above half (59%, n = 49) had pain while slightly below three (3) quarters (70%, N = 58) reported having not felt burning sensation when passing urine and above half (60%, n = 50) of the study participants did not experience abdominal cramps.

Table 4.4 Responses on whether they were sexually active (n= 83)

Sexually active	Frequency	Percentage
Yes	29	35
No	54	65
Total	83	100

Table 4.4 shows that above half (65%, n = 54) of the study respondents were not sexually active while below half (35%, n = 29) were sexually active.

Figure 4.3 Responses on sexuality after treatment (n= 29)

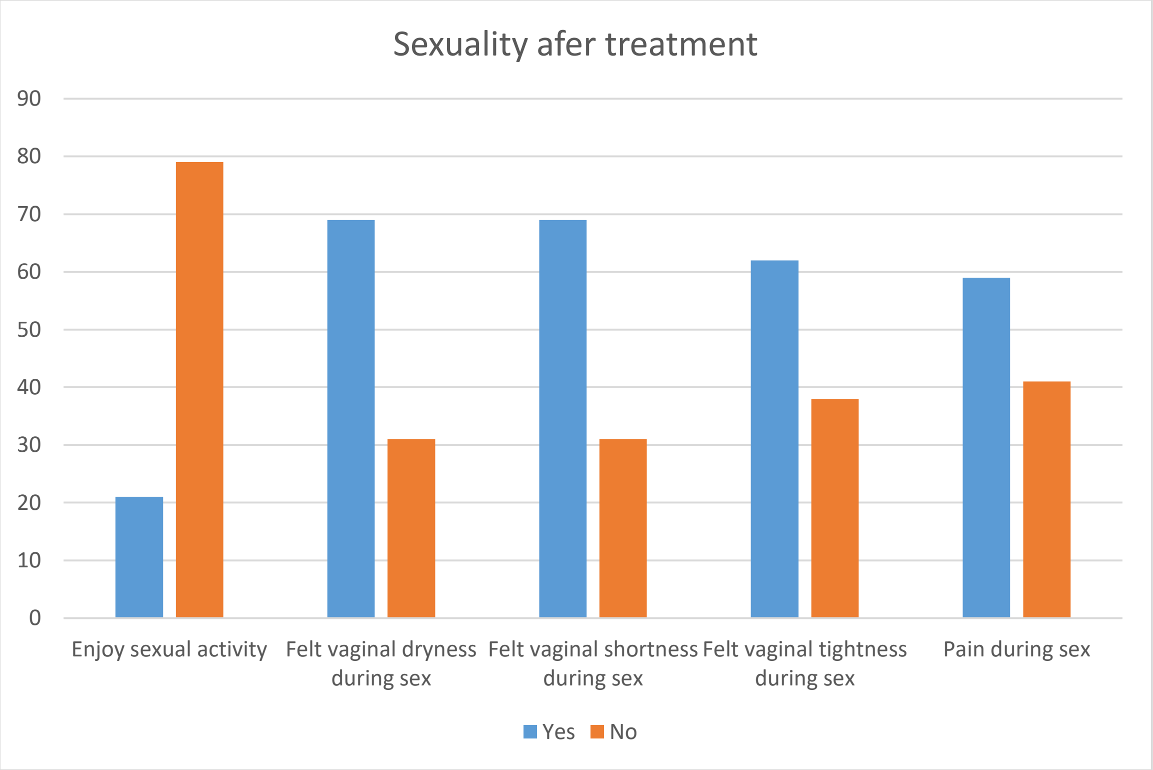


Figure 4.3 shows that slightly above three (3) quarters (79%, n = 23) did not enjoy sexual activity and less than half (31%, n = 9) did not feel vaginal dryness during sex. Below half (31%, n = 9) of the respondents did not feel vaginal shortness during sex and below half (38%, n = 11) did not feel vaginal tightness, while above half (62%, n = 18) did. Concerning, whether they had pain during sexual intercourse, below half (41%, n = 12) of the respondents did not. Further, above half (62%, n = 18) of the respondents were worried about sex that it will be painful, while less than half (38%, n = 11) were not.

Table 4.5 Responses on whether they worry about the disease or illness (n= 83)

Do you worry about your disease	Frequency	Percentage
Yes	35	42.2
No	48	57
Total	83	100

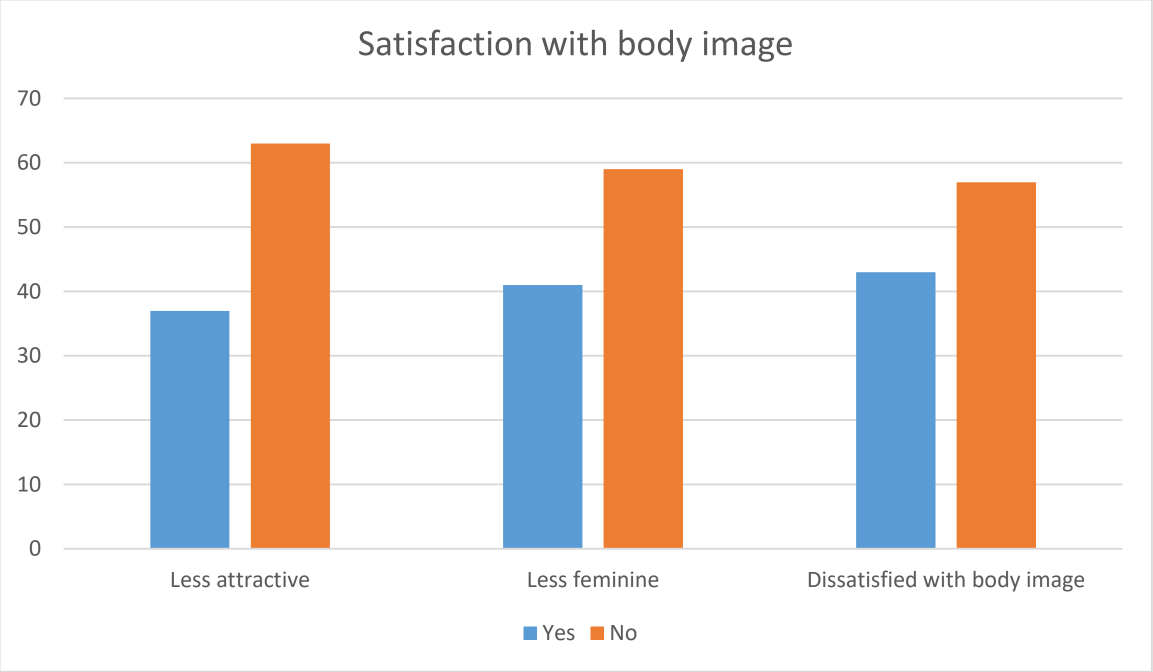
Table 4.5 above shows that slightly above half (57.8%, n = 48) of the study respondents were not worried about the disease while below half (42.2%, 35) were worried.

Table: 4.6 Responses on what made them not to worry (n= 48)

Why the did not worry	Frequency	Percentage
Believed in God	36	75
Were used to the disease and treatment effects	12	25
Total	48	100

Three quarters (75%, n = 36) of the respondents said they did not worry because they believed in God, while a quarter (25%, n = 12) said they were used to the disease.

Figure 4.4 responses on satisfaction with body image after treatment (n= 83)



The figure 4.4 shows that above (63%, n = 52), did not feel less attractive, while below half (37%, n = 31) felt less attractive. On the other hand, (59%, n = 49) did not feel less feminine as a result of treatment, while (41%, n= 34) felt less feminine. On whether the respondents were dissatisfied with their body image as a result of treatment, slightly above half (57%, n = 47) did not feel dissatisfied while (43%, n = 36) felt.

4.4 Section E: Cross Tabulation

4.4.1 Introduction

This section presents cross tabulations of study variables according to sections in the interview schedule. Overall Health Related Quality of Life was cross tabulated against Age, Education, Income time point of treatment, stage of cancer and the treatment modalities. Physical, psychological, functional and social wellbeing were cross tabulated against stage of cervical cancer at diagnosis and treatment modalities. Table 4.7 gives a summary of findings.

Table 4.7 Association of Demographic, Clinical variables and HRQoL (n= 83). Chi square

Variables	Physical wellbeing		Functional wellbeing		Psychological wellbeing		Social wellbeing		Overall HRQoL	
	Mean (SD)	P value	Mean (SD)	P value	Mean (SD)	P value	Mean (SD)	P value	Mean (SD)	P value
Age									66.6 (19.3)	0.132
≤ 45 years										
≥ 46 years									58.1 (22.0)	
Level of education									67.1 (21.6)	**0.031**
Low education										
High educated									56.5 (20.3)	
Income									59.3 (20.1)	0.399
<K2000										
K2000-K5000									64.8 (27.1)	
> K5000									88.9 (19.3)	
Time point of treatment										**0.005**
< 1 year									58.8 (22.0)	
1-5years									60.8 (22.2)	
> 5 years									69.4 (6.7)	
Stage of cancer at diagnosis										
Stage i	96.4 (5.1)	**0.004**	92.2 (11.1)	**0.044**	83.3 (16.0)	0.082	78.7 (16.6)	**0.005**	74.4 (16.1)	**0.034**
Stage ii	69.0 (21.3)		69.5 (27.0)		67.9 (19.4)		59.2 (30.2)		60.75 (20.1)	
Stage iii	64.2 (17.9)		57.7 (23.3)		67.0 (19.8)		48.4 (24.7)		57.0 (23.0)	
Stage iv	56.5 (4.9)		33.0 (0.0)		33.0 (0.0)		33.0 (0.0)		33.0 (0.0)	
Treatment										
Surgery only	94.2 (12.4)	0.118	97.6 (6.4)	0.677	85.7 (17.2)	0.106	82.5 (14.1)	**0.000**	76.2 (16.2)	**0.010**
Radiotherapy	75.9 (13.8)		66.5 (20.4)		71.5 (15.3)		46.6 (32.8)		69.9 (24.8)	
Chemo radiotherapy	66.6 (21.4)		62.8 (27.9)		64.9 (21.9)		50.3 (27.2)		50.3 (27.2)	
Surgery & chemo radiotherapy	75.2 (19.2)		73.0 (20.7)		74.4 (12.7)		74.1 (21.5)		74.1 (21.6)	

Table 4.8 Overall Health Related Quality of Life in relation to age, level of education and monthly household income (n= 83)

Age of the patient	**Overall Health Related Quality of life**			
	Good	Poor	Chi square	P value
≤ 45 years	21 (40%)	7 (23%)	2.274	0.132
> 45 years	32 (60%)	23 (77%)		
Total	53	30	83 (100%)	
Level of education	**Overall Health Related Quality of Life**			
High	27 (51%)	8 (27%)	4.630	0.031
Low	26 (49%)	22 (73%)		
Linear Regression test				0.239
Total	53	30	83 (100%)	
Monthly household Income	**Overall Health Related Quality of Life**			
< K2000,00	44 (83%)	27 (90%)	1.838	0.399
K2000,00- K5000,00	6 (11%)	3 (10%)		
> K5000,00	3 (6%)	0 (0%)		
Total	53	30	83 (100%)	

Table 4.8 shows that slightly above three quarters (77%, n = 23)of the study respondents with poor overall HRQoL were more than 45 years old, while slightly below a quarter (23%, n = 7) were aged 45 years and below. Poor HRQoL was therefore more common in older women than in young women. The P value was more than 0.05, hence the finding was not statistically significant indicating that this observation could have occurred by chance.

Further, it also shows that slightly below three quarters (73%, n = 22) of the study participants with poor overall HRQoL were those with low education. Good overall HRQoL was therefore more common in women with high education level than those with low education level with a chi square test result indicating a P value of 0.031. However, after a regression test was, it was found that level education was not statistically significant with a P value 0.239. Therefore this observation could have occurred by chance. The table also shows that above three quarters (90%, n = 27) of participants with poor overall HRQoL had monthly household income of less than K2000, 00. None (0%, n = 0) of the participants with monthly income of more than K5000 00 had poor overall HRQoL. Therefore poor HRQoL was more common in women with low monthly income than those with high monthly income. However, there was no significant association between income and overall HRQoL as the Chi- square test result indicated a P value of 0.399.

Table 4.9 Overall Health Related Quality of Life in relation to stage of cervical cancer at diagnosis, treatment received and time point of treatment (n= 83)

Stage of cervical cancer at diagnosis of the patient	**Overall Health Related Quality of life**			
	Good	Poor	Chi square	P value
Stage I	12 (23%)	01(3%)	8.672	0.034
Stage II	25 (47%)	15(50%)		
Stage III	16 (30%)	12 (40%)		
Stage IV	0 (0%)	2 (7%)		
Linear Regression test				0.005
Total	53	30	83 (100%)	
Treatment received	**Overall Health Related Quality of life**			
Surgery only	7 (13%)	0 (0%)	11.314	0.010
Chemo radiotherapy	27 (51%)	26 (87%)		
Surgery and chemo radiotherapy	15 (28%)	3 (10%)		
Radiotherapy	4 (8%)	1 (3%)		
Linear Regression test				0.055
Total	53	30	83 (100%)	
Time point of treatment	**Overall Health Related Quality of Life**			
< 1 year	17 (32%)	20(67%)	10.691	0.005
1-5 years	30(57%)	10 (33%)		
> 5years	6 (11%)	0(%)		
Linear Regression test				0.01
Total	53	30	83 (100%)	

Table 4. 9 shows that a high proportion consisting half (50% N = 15) of the study respondents with poor HRQoL had stage II CC at diagnosis. Only less than one tenth (3%, n = 1) of those patients with poor overall HRQoL had stage I cervical cancer at diagnosis. None (0%, n = 0) of the patients with stage IV cervical cancer at diagnosis had good overall HRQoL. A chi square test and a regression test showed a statistically significant relationship between stage of CC at diagnosis and overall HRQoL.

In addition, three quarters (87%, n = 26) of the study respondents with poor HRQoL were those who received chemo radiotherapy. None (0%, n = 0) of the participants who received surgery only had poor overall HRQoL. Poor overall HRQoL was therefore common in participants who received chemo radiotherapy and less likely among cervical cancer survivors who received surgery only. The Chi square test result indicated a P value of 0.010. However, after a linear regression test (p value. 0.055), it was observed that treatment modality was not statistically significant with overall HRQoL.

Further, the table also shows that above half (67%, n = 20) of the study participants with poor Overall HRQoL were those who received treatment less than one (1). None (0%, n = 0) of the respondents who were treated more than 5 years ago had poor overall HRQoL. This trend shows that long term survivors experience better HRQoL compared with the new survivors. Therefore, good HRQoL was more common in women who received treatment more than 5 years ago than those who received treatment 5years and below. The Chi- square test indicated a statistically significant (P value = 0.005) relationship between time point of treatment and overall HRQoL and a regression test showed a statistical significance. Hence the observation could not have occurred by chance.

Table 4.10 Physical Wellbeing in Relation to stage of cervical cancer at diagnosis and treatment received

Treatment received	**Physical wellbeing**			
	Good	Poor	Chi square	P value
Stage I	13 (23%)	0 (0%)	13.556	0.004
Stage II	29 (51%)	11(42%)		
Stage III	15 (26%)	13 (50%)		
Stage IV	0 (0%)	2 (8%)		
Regression test				0.000
Total	57	26	83 (100%)	
Treatment received	**Physical wellbeing**			
Surgery only	7 (12%)	0 (0%)	5.881	0.118
Chemo radiotherapy	32 (56%)	21 (81%)		
Radiotherapy only	4 (7%)	1 (4%)		
Surgery and chemo radiotherapy	14 (25%)	4 (15%)		
Total	57	26	83 (100%)	

Regarding physical wellbeing, table 4.10 shows that half (50%, n = 13) of those study respondents who experienced poor physical wellbeing were in stage III, while no respondent in stage I experienced poor physical wellbeing. A trend of increase in poor physical wellbeing was observed with advancing stage of cervical cancer. This means poor physical wellbeing was not common in stage 1 as compared to the advancing stages. A chi square test showed statistically significant relationship between physical wellbeing with stage of cancer at diagnosis with p value of 0.004 and it was also statistically significant after a regression test. The p value was less than 0.05, therefore stage of cervical cancer at diagnosis was significantly associated with physical wellbeing.

In addition, it also shows that above three quarters (81%, n = 21) of the study respondents with poor physical wellbeing were those who received chemo radiotherapy. None (0%, N = 0) of

the participants who received surgery only as treatment had poor physical wellbeing. Below one tenth (4%, n = 1) of those with poor HRQoL received radiotherapy only while slightly above one tenth (15%, n = 4) received surgery and chemo radiotherapy. This means that poor physical wellbeing is mainly associated with a combination of treatment modalities.
However, a Chi- square test indicated a p value of 0.118. Hence, functional wellbeing was not statistically significant associated with treatment received.

Table 4.11 Functional wellbeing in relation to stage of cervical cancer at diagnosis and treatment received.

Stage of cervical cancer at diagnosis	**Functional wellbeing**			
	Good	Poor	Chi square	P value
Stage I	10 (19%)	03 (10%)	8.119	0.044
Stage II	29 (55%)	11 (36.7%)		
Stage III	14 (26%)	14 (46.7%)		
Stage IV	0 (0%)	2 (6.6%)		
Regression Test				0.000
Total	53	30	83 (100%)	
Treatment received	**Functional wellbeing**			
Surgery only	4 (7.5%)	3 (10%)	1.525	0.677
Chemo radiotherapy	32 (60%)	21 (70%)		
Radiotherapy only	4 (7.5%)	1 (3%)		
Surgery and chemo radiotherapy	13 (25%)	5 (17%)		
Total	53	30	83 (100%)	

Table 4.11 shows that a high proportion which is slightly below half (46.7%, n = 14) of those study respondents who experienced poor functional wellbeing were in stage III. None (0%, n = 0) of the patients with stage IV cervical cancer at diagnosis had good functional wellbeing. This means that those with stage VI cervical cancer at diagnosis were not likely to have good functional wellbeing. A chi square test showed statistically significant relationship between functional wellbeing and stage of cancer at diagnosis with p value of 0.044. A regression test showed a statistical significant relationship as well. Stage of CC was found to be statistically associated with functional wellbeing as the p value was less than 0.05.

The table further shows that slightly below three quarters (70%, n = 21) of the study respondents with poor functional wellbeing had history of receiving chemo radiotherapy. The least with poor functional wellbeing was observed among those with history of receiving surgery only and radiotherapy only at one tenth (10 %, n = 3) and less than one tenth (3 % , n = 1) respectively. However, there was no significant association observed between treatment received and function wellbeing as the p value was 0.677.

Table 4. 12 Psychological Wellbeing in relation to Stage of Cervical Cancer at diagnosis treatment received

Stage of cervical cancer at diagnosis	**Psychological wellbeing**			
	Good	Poor	Chi square	P value
Stage I	11 (12%)	02 (6%)	6.716	0.082
Stage II	22 (54%)	18 (55%)		
Stage III	17 (34%)	11 (33%)		
Stage IV	0 (0%)	2 (6%)		
Total	50	33	83 (100%)	
Treatment received	**Psychological wellbeing**			
Surgery only	6 (12%)	1 (3%)	6.121	0.106
Chemo radiotherapy	27 (54%)	26 (79%)		
Radiotherapy only	3 (6%)	2 (6%)		
Surgery and chemo radiotherapy	14 (28%)	4 (12%)		
Total	50	33	83 (100%)	

Table 4.12 shows that a high proportion of slightly above half (55%, n = 18) of study respondents with poor psychological wellbeing were those with stage II cervical cancer at diagnosis. None (0%, n = 0) of survivors with stage IV cervical cancer at diagnosis had good psychological wellbeing. This means that survivors with stage IV cervical cancer at diagnosis were less likely to have good psychological wellbeing. However, stage of cervical cancer at diagnosis was found not to be statistically associated with psychological wellbeing with a Chi-square test, as the p value (0.082) was greater than 0.05.

The table also shows that slightly above three quarters (79%, n = 26) of the study respondents with poor psychological wellbeing were those with history of receiving chemo radiotherapy. The least, below one tenth, (3%, n = 1) with poor HRQoL in the psychological domain were those with history of receiving surgery only followed by less than one tenth (6%, n = 2) those with history of receiving radiotherapy only. This meant that patients who received a single type of treatment had better HRQoL as compared to those with a combination of treatment modalities. However, there was no significant association observed between treatment received and psychological wellbeing as the p value was 0.106. Therefore, treatment received among cervical cancer survivors is not significantly associated with psychological wellbeing.

Table 4.13 Social Wellbeing in relation to Stage of Cervical Cancer at diagnosis and treatment received

Stage of cervical cancer at diagnosis	**Social wellbeing**			
	Good	Poor	Chi square	P value
Stage I	11 (23.4%)	02 (6%)	12.885	0.005
Stage II	26 (55.3%)	14 (55%)		
Stage III	10 (21.3%)	18 (33%)		
Stage IV	0 (0%)	2 (6%)		
Regression test				0.000
Total	47	36	83 (100%)	
Treatment received	**Social wellbeing**			
Surgery only	7 (15%)	0 (0%)	18.484	0.000
Chemo radiotherapy	22 (47%)	31 (86%)		
Radiotherapy only	2 (4%)	3 (8%)		
Surgery and chemo radiotherapy	16 (34%)	2 (6%)		
Regression test				0.01
Total	47	36	83 (100%)	

Table 4.13 shows that a high proportion of slightly above half (55%, n = 14) of those who experienced poor social wellbeing were survivors with stage 11 cervical cancer at diagnosis. None (0%, n = 0) of the patients with CC stage IV at diagnosis had good social wellbeing. This meant that cervical cancer stage IV survivors were less likely to have good social wellbeing. A chi square test showed statistically significant relationship between social wellbeing and stage of cancer at diagnosis with p value of 0.004. A regression test also showed the significant association.

The table also shows that above three quarters (86%, n = 31) of the study respondents who experienced poor social wellbeing had history of receiving chemo radiotherapy and none (0%, n= 0) of them those who received surgery only had poor social wellbeing. Participants with history of receiving surgery only were less likely to have poor social wellbeing. A chi square test showed a P value of 0.000. This means that treatment received is statistically associated with social wellbeing as the p value was less than 0.05 and also a regression test showed a significant association.

Table 4.14 linear regression of overall health related quality of life

	Overall Health Related Quality of Life			
Variables	Unstandardized coefficients B	Coefficients (Beta)	t- statistics	P value
Constant	1.573		5.240	.000
Stage of cancer	-.186	-.291	-2.900	**.005**
Treatment modality	.104	.200	1.944	.055
Level of education	-.117	-.121	-1.186	.239
Time point of treatment	.261	.336	3.331	**.001**
Adjusted R square = 0.20				

Table 4.15 linear Regression of domains of health related quality of life

	Physical wellbeing			
Variables	Unstandardized coefficients B	Coefficients (Beta)	t- statistics	P value
Constant	2.175		12.033	0.000
Stage of cancer	-.253	-.419	-3.905	**0.000**
Adjusted R square = 0.139				
Variables	**Functional wellbeing**			
Constant	2.127	.192	11.149	0.000
Stage of cancer	-.278	.068	- 4.064	**0.000**
Adjusted R square= 0.15				
Variables	**Social wellbeing**			
Constant	1.924		10.547	0.000
Stage of cancer	-.303	-460	-4.645	**0.000**
Treatment modality	0.141	.263	2.654	**0.01**
Adjusted R square = 0.22				

CHAPTER FIVE

5.0 DISCUSSION OF FINDINGS

5.1 Introduction

A cross-sectional study was conducted to determine the HRQoL among cervical cancer survivors at Cancer Diseases and University Teaching Hospitals in Lusaka. The study consisted of 83 women who had at least finished their initial treatment who were visiting the hospitals for their follow up and the response rate was 100%. The discussion is according to research objectives. The researcher was prompted to conduct this study due to an increase in the number of cervical cancer survivors whose HRQoL was not certain.

5.2 Health Related Quality of Life

The HRQoL among cervical cancer survivors was poor as the mean score (60.9) was below the set average score (66.7). The poor HRQoL could be attributed to financial challenges they faced as three quarters (81.9%, n = 68) of the respondents had financial challenges and the majority (96%, n = 80) of the respondents were of low family house household income. These findings are similar to published data by Fadodun et al., (2018) in Nigeria and Owenga, (2018) in Kenya that showed poor HRQoL among cervical cancer patients. People with a low household income status might be unaware of cervical cancer, such that they seek health services in the late stage of cancer (Lemos et al., 2015). In contrast, Thapa et al., (2018) and Huang, et al, (2017) in China observed good HRQoL among the patients. This could be attributed to the good economic status of the participants and having less participants with stage four as stage four cancer patients continue to receive treatment for palliation (Dahiya et al., 2016).

The best HRQoL domains were physical, functional and psychological wellbeing and the least was observed in the social wellbeing. These results are in line with a study done in china that observed the best mean in the physical wellbeing and the least in the social wellbeing (Thapa et al., 2018). Better means in the physical and functioning wellbeing could have been attributed to the stage of cervical cancer at diagnosis as a little less than half (48.2%, n = 40) of the study participants were in stage II. Stage I, II, and III are localized cancers that are treatable (Maiti et al., 2019). Similarly, Huang et al., (2017) also observed good physical and functional score among the participants. The good scores in their study could be due to the fact that the researchers omitted stage IV cervical cancer patients whose treatment is purely t for palliative. In contrast, Owenga (2018), in Kenya observed poor physical and poor functional wellbeing among the respondents. This could be attributed to late presentation of the disease as little more than half (54%) of the respondents were in stage IV.

The good psychological wellbeing in this study could be attributed to their belief in religion. Furthermore, it may have cushioned them from worry and depression. Above half (57.8%, n = 48) of the respondents in this study said they did not worry about the disease and three quarters (75%, n = 36) said the reason was because they believed in God. Belief in religion might help individuals not to focus much on the outcome of the disease and this also can help divert their minds from the negative effects of the disease and give them hope to live again. The good psychological wellbeing could also be due to good counselling services rendered to the survivors at both UTH and CDH.

Social wellbeing of the patients was poor. This could be attributed to poor family unity which is mainly seen in chronic illnesses and the fact that the disease and treatment caused financial challenges on a little more than three quarters (81.9%, n 68) of the survivors. The poor social wellbeing could also be attributed to low monthly household income as a little more than three quarters (85.5%, n = 71) of the respondents had low household income. People with a low income status might be unaware of cervical cancer, so they may usually seek health care in the last stage of cancer (Lemos et al., 2015). Further, pain and fatigue which were the commonest side effects of treatment observed, could have also prevented them from mingling with their friends, family members, and from seeking health care. In contrast to these findings, Huang et al., (2017) observed that cervical cancer survivors scored well in all the physical, social, psychological and functional wellbeing. This difference might be that Huang et al (2017) excluded stage IV cervical cancer patients and also those who had low monthly household income were slightly above a quarter (36%, n = 27) while in this study they were above three quarters (85.5%, n = 71).

5.3 Relationship between Demographic Characteristics and Overall Health Related Quality of life.

Relationship between Age and Overall Health Related Quality of Life

Majority (77%) of participants with poor HRQoL were aged > 45 years old. This meant that older survivors were more likely to experience poor overall HRQoL as their mean score was even lower than those who were 45 years and below. However, the findings were not statistically significant. Similarly, a study conducted by Thapa et al., (2018) in China observed that those who were 45 years and younger scored better means than those who were more than 45 years old in HRQoL .However, there was no statistical significance between age and overall QOL. The physical functioning of elderly patients decrease and they get fatigued more than the young ones leading to a more poorer QOL compared to the young ones (Leinet et al., (2017). In contrast to these findings, Owenga, (2018) in Kenya found that the young had higher odds of poor HRQoL as compared to the elderly and observed an association between age and overall QOL. This could be attributed to depression and fear over their childbirth as majority of the participants in the previous study were in stage four cancer. The difference in findings could be the sample size and stage of cancer. Owenga, (2018) had a bigger sample size and majority of the participants were in stage four compared to the sample size and stage of cancer for this study and the study conducted by Thapa et al., (2018).

Relationship between level of education and Overall Health Related Quality of Life

In this study, majority (73%) of the study participants with poor HRQoL were those with low education level. In addition, participants who had high level of education scored better means than those with low education. However, the relationship was not statistically significant after a regression test. Similarly, a study conducted by Tadele (2015), showed no correlation between QOL and education. In contrast, Owenga, (2018) observed an improvement in HRQoL with increasing levels of education and observed an association between education and HRQoL. Illiterate people might be unaware of cervical cancer and this might cause them to seek health care services in their late stage of cancer, which might lead to poor HRQoL as treatment might just be palliative. Educated people are more social, less emotional and mentally strong as compared to uneducated women and this finding was significant (Javed et al., (2016). The difference in findings could be that, Tadele (2015), also evaluated other cancers such as breast cancer as well and the sample size included men as well and in the current study there were only 2 participants with stage IV cervical cancer.

Relationship between monthly household income and overall Health Related Quality of Life.

In relation to monthly household income, majority (73%) of the study participants with poor HRQoL in this study were those with low monthly household income. However, monthly household income was not significantly associated with HRQoL. In contrast to this finding, Huang et al., (2017) and Thapa et al, (2018) in China, observed that monthly household income was statistically associated with QOL as those with high income had scored better means in overall QOL. The discrepancy could be due to the small sample size of respondents with high monthly household income of below one tenth (3.6%, n= 3) in this study as compared to Huang et al., (2017), who's findings showed slightly above one third (34.7%, n = 26) of participants with high monthly household income. People with high monthly household income are more likely to be compliant with the therapeutic regime because they have little problems with financial difficulties and feel more secure (Tadele, 2015).

5.4 Effects of stage of cervical cancer at diagnosis on Health Related Quality of Life

Effects of stage of cervical cancer at diagnosis on overall HRQoL

In the current study, none of the patients with stage IV cervical cancer at diagnosis had good overall HRQoL. In addition, study participants with stage I cervical cancer at diagnosis scored a better mean than stage II, III and IV. This means that survivors with stage I cervical cancer at diagnosis are more likely to have a good overall HRQoL than the advancing stages. A chi square test showed statistically significant relationship between stage of CC at diagnosis and overall HRQoL with p value of 0.034. In addition, a regression test also showed an association. This means that patients with stage IV cervical cancer were less likely to have good HRQoL.

Several studies have reported an association between stage of cancer and QOL. Advanced stage of CC patients are usually treated with radiotherapy which has been seen to have aggressive effects such as fatigue, pre menopause symptoms, urinary and bowel dysfunction which affect their QOL (Kristaet and colleagues, 2015). A study conducted by Thapa et al., (2019) in China, also reported similar findings that patients with early stages of cervical cancer have a good overall QOL compared with patients with advanced cancer with P value 0.000. Further, in a study of Assessment of QOL in treated patients in India also observed similar findings with P value of less than 0.05 (Rahman et al., 2017). Similarly, in a study of Assessment of HRQoL in cervical cancer patients in Western Kenya observed that stage of cervical cancer was significantly associated with overall HRQoL as those with early stage had low chances of poor quality of life with P value of 0.0001, (Owenga, 2018). In contrast to these findings, a study by Santos et al., (2019), on Health Related quality of life in women with cervical cancer and in a study of Quality of Life of breast and cervical cancer in China (Huang et al., 2017) found no association between stage of CC and overall QOL. The discrepancy observed could be attributed to differences in stages of cervical cancer as Santos et al., (2019) and Huang et al., (2017) did not include stage IV cervical cancer participants.

Effects of stage of cervical cancer at diagnosis on Physical wellbeing

A high proportion (50%, n = 13) of study participants who experienced poor physical wellbeing were in stage III, while no respondent in stage I experienced poor physical wellbeing. A trend of increase in poor physical wellbeing was observed with advancing stages of cervical cancer .This meant poor physical wellbeing was not common in stage 1 as compared to the advancing stages. A chi square test showed statistically significant relationship between physical wellbeing with stage of cancer at diagnosis with p value of 0.004. In addition a regression test also showed an association. The p value was less than 0.05, therefore stage of cervical cancer at diagnosis is statistically significantly associated with physical wellbeing.

HRQoL in the physical domain is poor in late stage of cancer when compared with early stage. These results are concordant with earlier findings (Owenga, 2018 [P value, 0.0001]; Thapa et al., 2018 [P value, 0.003]) in Kenya and China respectively. In contrast to these findings, a study on Health Related Quality of Life in Brazil found no association between stage of cervical cancer and physical wellbeing (Santos et al., 2019). The discrepancy could be that Santos et al (2019) did not include patients with stage IV cervical cancer in their study as stage IV is more associated with poor health as treatment is just palliation.

Effects of stage of cervical cancer at diagnosis on functional wellbeing

A high proportion of study participants who experienced poor functional wellbeing were in stage III. None of the participants with stage IV cervical cancer at diagnosis had good functional wellbeing. This means that those with stage VI cervical cancer at diagnosis were not likely to have good functional wellbeing. A chi square test showed statistically significant relationship between functional wellbeing and stage of cancer at diagnosis with p value of 0.044. In addition, a regression test also showed an association.

These results are concordant with earlier findings (Thapa et al., 2018). Patients with advanced stage of CC are subjected to a combination of treatment modalities (Maiti, 2018), which have dramatic effects on an individual’s QOL such as fatigue, pain urinary dysfunction and bowel dysfunction. (Muliira et al., 2018). In contrast to these findings, Santos et al., (2019) in a study of Health Related Quality of Life in Brazil found no association between stage of CC and physical wellbeing. The discrepancy could be that Santos did not include stage IV cervical cancer patients as late stage of cancer is associated with functional challenges such as inability to perform daily activities of living because of fatigue and pain. Late stage of cancer is often untreatable only suitable for palliation (WHO, 2018).

Effects of stage of cervical cancer at diagnosis on psychological wellbeing

In the domain of psychological wellbeing, a high proportion (55%) of study participants with poor psychological wellbeing were those with stage II cervical cancer at diagnosis. None of the survivors with stage IV cervical cancer at diagnosis had good psychological wellbeing. This meant that survivors with stage IV cervical cancer at diagnosis were less likely to have good psychological wellbeing. However, stage of cervical cancer at diagnosis was found not to be statistically associated with psychological wellbeing as the Chi- square test showed a p value of greater than 0.05 (0.08)

These findings are in line with Thapa et al., (2018) in China. Similarly, Santos et al., (2019), in Brazil found no association between stage of cervical cancer at diagnosis and psychological wellbeing. This could be that clients are not given enough information on the differences of the stages of cancer that could affect their reporting of their psychological wellbeing. Further, in the current study, slightly above half (57.8%, n = 48) of the participants said they did not worry about the disease and three quarters (75%, n = 36) said the reason was because they believed in God. Belief in religion might have cushioned their worry and helped them not to focus much on the outcome of the disease. Further, it could have helped divert their minds from the negative effects of the disease and given them hope to live again.

Effects of stage of cervical cancer at diagnosis on social wellbeing

A high proportion (55%) of study participants who experienced poor social wellbeing were survivors with stage 11 cervical cancer at diagnosis. None of the patients with CC stage IV at diagnosis had good social wellbeing. This meant that cervical cancer stage IV survivors were less likely to have good social wellbeing.

A chi square test showed statistically significant relationship between social wellbeing and stage of cancer at diagnosis with p value of 0.004. Similarly a regression test showed an association.

These findings are in line with the findings for Thapa et al., (2017) in China that found an association between social wellbeing and cervical cancer stage at diagnosis (P value, 0.034). In contrast to these findings, Santos et al., (2019) in Brazil in a study of Health Related Quality of Life in women with cervical cancer found no association between stage of cervical cancer and social wellbeing. The discrepancy could be that Santos et al., (2019) did not include cervical cancer stage IV which is associated with social challenges such as social isolation mainly due to fatigue and pain which hinders patients to seek health care when they need it thus affecting their QOL. The difference in tools used also could have caused a discrepancy as Santos et al., (2017) used FACT- Cx while the current study and Thappa et al., and (2017) used EORTC tools.

5.5 The Relationship between Time Point of Treatment and overall HRQoL

In this current study, majority of the study participants who received treatment less than 1 year ago, had poor Overall HRQoL. None of the respondents who were treated more than 5 years ago had poor overall QOL. This trend shows that long term survivors are less likely to have poor overall HRQoL. The Chi- square test indicated a statistically significant (P value = 0.005) relationship between overall HRQoL and time point of treatment. Similarly a regression test showed an association.

In terms of mean calculation, survivors who received treatment more than 5 years ago scored better means in the overall of HRQoL as compared to those who received cancer treatment less than 5 years ago. On the contrally, Thapa et al., (2018), did not observe an association between QOL and time point of treatment. This could probably be due to a difference in sample size as Thapa et al., (2018) had a bigger sample size. Longer term survivors might have developed good copying mechanisms thus the good HRQoL. Further, according to Zhang et al., (2018), the study revealed that pain, reduced over time, perception of own body image improved over time and concerns about future state of health increased over time.

5.6 Effects of cervical cancer treatment modalities on Health Related Quality of Life

Effects of treatment modalities on overall Health Related Quality of life.

Majority (87%) of the study participants with poor HRQoL were those who received chemo radiotherapy. None of the participants who received surgery only had poor overall HRQoL. Poor overall HRQoL was therefore common in participants who received chemo radiotherapy. The research could therefore deduce that cervical cancer survivors who receive surgery only are less likely to experience poor overall HRQoL.

The Chi square test result indicated a P value of 0.010. However a regression test showed no association. Hence the finding was not statistically significant. Therefore, there was no statistical significant relationship between overall HRQoL and treatment received. In contrast, a study conducted in USA reviewed a relationship and that participants who undergo surgery only have a fair HRQoL as compared to those who receive radiotherapy and chemotherapy or radiotherapy only or a combination of surgery (Krista et al., 2015). Further, a study conducted in China also observed that patients who undergo radiotherapy and chemotherapy experience more symptoms like fatigue, nausea and vomiting, pain, appetite loss, constipation, diarrhoea and financial difficulty than those who underwent surgery only (Thappa et al.,2018).

The adverse treatment effects experienced in this study were mostly pain, tingling and numbness in the legs, fatigue, hot flashes, abdominal cramps and burning sensation when passing urine. Pain (59%) and fatigue (52%) were the highest scores of symptoms among the symptoms experienced by survivors. The study findings were in line with those of other countries using different HRQoL instruments. For example a similar study in Indonesia that used Ero QOL 5 Dimension questionnaire (EQ- 5D), observed that pain (67.8%) was the highest score among the symptoms experienced by the patients (Endart et al., 2015).

Sexuality, an essential determinant of HRQoL in this study decreased significantly in terms of sexual enjoyment and vaginal functioning. The current study findings were in line with a study conducted in China that revealed a reduction in sexual enjoyment and functioning among the patients (Thapa et al., 2018). This could be attributed to treatment like surgery and radiotherapy as they affect the same parts of the body that are involved in sexual responses by causing vaginal stenosis and decreased lubrication which result in dyspareunia which results in poor quality of life (Kumar et al., 2014).

Effects of treatment modalities on physical wellbeing

The majority of participants with poor physical wellbeing were those who received chemo radiotherapy. None of the participants who received surgery only as treatment had poor physical wellbeing. This meant that poor physical wellbeing was mainly associated with a combination of treatment modalities.

However, a Chi- square test indicated a p value of 0.118. Hence, physical wellbeing was not statistically significant associated with treatment received.

This study’s findings are in line with a study conducted in Brazil by Santos et al., (2019), that also observed no association. In contrast to these findings, a study done in China by Thapa et al., (2018) found that there was an association between stage of cervical cancer at diagnosis and physical wellbeing (P value, 0.000). Those who received surgery only had a better HRQoL in the physical wellbeing domain as compared to those who received radiotherapy with or without chemotherapy. Patients who undergo radiotherapy and chemotherapy experience more symptoms like fatigue, nausea and vomiting, pain, appetite loss, constipation, diarrhoea and financial difficulties than those who undergo surgery only which have been observed to affect the physical wellbeing of patients negatively (Thapa et al., 2018). Radiotherapy also cause sexual dysfunction such as vaginal stenosis, dryness and bleeding and also premature menaupose that affect their physical wellbeing (Ntinga, 2015). The discrepancy observed may have been attributed to differences in the samples as in the current stage there were just 2 (2.4%) respondents with stage IV cervical cancer and Santos et al (2019), did not include patients with stage IV while stage IV patients in Thapa et el., (2018) were 14 (5.4%).

Effects of treatment modalities on functional wellbeing

The majority of respondents with poor functional wellbeing had history of receiving chemo radiotherapy followed by those with history of receiving surgery and chemo radiotherapy. The least with poor functional wellbeing was observed among participants with history of receiving surgery only and radiotherapy only. This meant that poor functional wellbeing was common among survivors who received chemo radiotherapy. However, there was no significant association observed between treatment received and function wellbeing as the p value was 0.677.

In line with these findings, Santos et al., (2019) also observed that there was no association observed between treatment received with functional wellbeing. In contrast to these findings, a study done in China by Thappa et al., (2018) observed that there was an association (P value, 0.003) between treatment received and functional wellbeing and patients who received surgery only had better HRQoL as compared with those who received radiotherapy with or without chemotherapy. The discrepancy could be due to a difference in sample size as Thapa et al., (2018)'s sample size was bigger and also due to difference in study population. Radiotherapy and chemotherapy cause physical problems such as fatigue and pain that prevent individuals from carrying out activities of daily living (Ntinga, 2015). Further it causes sexual dysfunction due to vaginal stenosis, shortness and dryness.

Effects of treatment modalities on psychological wellbeing

Above three quarters of the survivors patients with poor psychological wellbeing were those with history of receiving chemo radiotherapy. The least, number of participants with poor HRQoL in the psychological domain were those with history of receiving surgery. This meant that patients who received a single type of treatment had better HRQoL as compared to those with a combination of treatment modalities. However, there was no significant association observed between treatment received and psychological wellbeing as the p value was 0.106. Therefore, treatment received in cervical cancer is not significantly associated with psychological wellbeing. However, participants who received surgery only, had better scores and therefore had better HRQoL as compared with those who received radiotherapy with or without chemotherapy.

A similar study done by Santos et al., (2019) in Brazil observed that there was no significant association between treatment modalities and psychological wellbeing. Further, Thapa et al., (2018) also found similar results. The discrepancy in findings could be attributed to cultural differences in study populations. Physical effects such as pain and fatigue cause patients to think about who would look after their children should they die (Ntinga, 2015)

Effects of treatment modalities on social wellbeing

In the domain of social wellbeing, above three quarters of the study participants who experienced poor social wellbeing had history of receiving chemo radiotherapy and none of the participants who received surgery only had poor social wellbeing. Patients with history of receiving surgery only were less likely to have poor social wellbeing. A chi square test showed a P value of 0.000. This meant that treatment received was statistically associated with social wellbeing as the p value was less than 0.05.

Similarly, Thapa et al., (2018) in China also observed an association between social wellbeing and treatment received. They stated that patients who received surgery only as treatment mostly had better HRQoL as compared to those who received radiotherapy with or without chemotherapy. In contrast to these findings, Santos et al., (2019) observed that there was no association between treatment received and social wellbeing. The discrepancy in findings could be that Santos et al., (2019), did not include stage IV patients in their study as stage IV is untreatable and treatment is just palliative. Poor social wellbeing can cause social isolation of patients and inability to seek health services (Muliira et al., 2018). Sexual dysfunction due to vaginal dryness, stenosis and bleeding cause their spouses uncomfortable such that most of them are neglected leaving them with a sole responsibility of providing basic needs of their children (Ntinga, 2015). The study findings on pain in this study found that about 59% of respondents experienced pain and about 52% experienced fatigue. Social activities tend to be limited due to pain and fatigue associated with chemotherapy and radiotherapy. Pain and fatigue could probably have contributed to a lower score in the social wellbeing domain.

5.7 Implications of the study to the Health Care System

Nursing education

The study findings showed that slightly above three quarters (79%, n = 23) of the study participants who were sexually active did not enjoy sex. Further, above half (69%, n = 20) of the study participants had vaginal shortness, similarly above half (69%, n = 20) had vaginal dryness, slightly above half (62%, n = 18) had vaginal tightness slightly above half (59%, n = 17) had pain during sexual intercourse. There is need to put more emphasis on importance of sexuality and how to improve sexuality after treatment during training of nurses in order to improve the HRQoL among cancer survivors. On the other hand, CDH is doing everything possible to improve sexuality by educating the survivors on how to use vaginal dilators to improve sexuality. There is also need to strengthen giving of health education to survivors before and after treatment so that they are aware of sexual challenges related to treatment. Identification of sexual challenges can be done easily if nurses were trained on assessment of HRQoL. Therefore, there is need to include assessment of HRQoL in the nursing process so that it is comprehensively done. This can help bridge the gap between research and clinical practice. Training nurses also can help in identification of other unmet health needs of cervical cancer patients as they can be knowledgeable on how and when to assess HRQoL of patients. These problems highlight the need for inclusion of HRQoL in the Nursing education.

The study findings also reveal that cancer treatment has improved the lives of survivors as above three quarters (88%, n = 73) of the study participants reported feeling of much better, below one tenth (9.6%, n = 8) stated they were fine and only below one tenth (2.4%, n = 2) experienced no improvement. Those who experienced no improvement could be that they reported late for treatment. Considering that the majority felt much better and fine and that slightly below half (48. 2%, n = 40) were interviewed between one (1) and five (5) years after treatment, there is likely to be an increase in the number of survivors. This calls for educating and training more nurses in Oncology nursing to cater for the increase.

Nursing practice

The study findings revealed that the social wellbeing was poor with mean score (57.9) of less than the average mean (66.7). This calls for nurses to appreciate the fact that measurement of HRQoL is a multidimensional concept that involves a full spectrum of behaviours that include physical, social, psychological and functional wellbeing. The study findings also revealed that above three quarters (92%, n = 76) of the study participants received at least radiotherapy which caused distress such as hormonal changes such as hot flushes (43%, n = 36), body image concerns (43%, n = 36), fatigue (52%, n = 43), sexual dysfunction (79%, n = 23) and pain(59%,n = 49) which affected their physical, social, psychological and functional wellbeing. Therefore, Nurses need to be responsive to these long-term consequences. Failure to identify and deal with this distress may reduce cervical cancer survivors' HRQoL and can result in low adherence to follow ups, thus leading to low self-esteem and negative feelings. This calls for Nurses to routinely assess HRQoL among cervical cancer patients to identify whether a person has developed or is at risk of developing further distress or whether she is managing psychologically to adjust to her illness.

The results further reviewed that only slightly above one tenth (15.6%, n = 13) had their disease diagnosed in the first stage and rest presented with advancing stages. This means that cervical cancer patients still report late for treatment. There is need for nurses to integrate cervical cancer programs into existing health care services as this can help in the early diagnosis of the disease and treatment. Further, there is need for nurses to support the need for their patient's overall satisfaction by providing information about stage of cancer and treatment and facilitating a therapeutic interpersonal relationship that can encourage cancer survivors to both participate in their care and achieve optimal quality of life.

Nursing research

The overall health related quality of life among cervical cancer survivors was poor with mean score of 60.9 and social wellbeing was poor with mean score of 57.9 which were less than average score of 66.7was poor. Stage of cancer were found to be statistically significant with HRQoL.

These may be topics of further nursing research to establish reasons for poor overall health related quality of life and poor social wellbeing.

Nursing administration

The study results showed that the social wellbeing (57.9) and the overall HRQoL (60.9) were poor with mean scores of less than 66.7 and above three quarters (81.9%, n = 68) of the study participants faced financial challenges as a result of the disease. There is need to strengthen linkages of such survivors to social welfare and organisations that render social support to cervical cancer patients to lessen the problem. There is also need for nurse managers to use the study findings in order to evaluate community interventions and identify better ways of managing cervical cancer survivors. Further, the study results showed that only slightly above one tenth (15.6%, n= 13) were diagnosed with stage one (I) cervical cancer. This means that there is a good number of patients who are diagnosed late.

Nurse Managers need to reinforce integration of cervical cancer programs such as cervical cancer screening into existing health care services in primary health-care facilities that are accessible to most women as incorporation of such services might help in the early identification of the disease and treatment. Further, management of symptoms should be integrated with prevention, diagnosis, treatment, and palliation of cervical cancer patients.

5.8 Conclusion

The overall mean for overall Health Related Quality of Life was poor with a mean score (60.9) of less than the average score of 66.7. The social wellbeing, physical wellbeing, functional wellbeing were significantly associated with the stage of cancer. Regarding treatment modalities, treatment received was statistically associated with social wellbeing. Assessment of HRQoL helps in identification of unmet health needs of cervical cancer survivors which can help in identification of specific ways on how to manage the survivors. A comprehensive assessment that includes domains of HRQoL (physical, social, psychological and functional wellbeing) is recommended for specific care in order to improve HRQoL among survivors.

5.9 Recommendations

Basing on the research findings, the researcher would therefore recommend the following to relevant authorities and institutions:

Ministry of Health,

1. Slightly above one tenth (15.6%) of the total number of patients presented with stage one at diagnosis. This means that the majority (84.4%) of the total respondents presented with advancing stages (II, III and I). Ministry of Health should strengthen

and increase funding for cervical screening programme and strengthen the programme for vaccinating of girls against human papilloma to reduce late presentation of cervical cancer at diagnosis.

2. Since overall HRQoL was poor (60.9) there is need to incorporate assessment of HRQoL in the Nursing curriculum to enhance knowledge among nurses on how to carry out the assessment. Further, to enhance assessment of HRQoL among cervical cancer survivors, MOH should develop a tool that can help in the assessment of HRQoL of patients.
3. Slightly below half (48.2%) of the total participants received treatment one (1) to five (5) years ago. This means that the number of survivors is increasing therefore there is need for the Ministry of Health to deploy more oncology health workers to cater for the increased number of survivors. And also to expand the services for radiotherapy in other provincial hospitals because at the moment only Cancer Diseases Hospital offers radiotherapy services.
4. Absence of a tool to access HRQoL. There is need to develop a tool that can be used in assessing the HRQoL in cervical cancer survivors as assessment of HRQoL among cervical cancer patients can help in identification of unmet health needs of the survivors and manage accordingly.
5. Knowledge deficit on how to conduct assessment of HRQoL among cervical cancer survivors. Since HRQoL is not comprehensively taught and is not in the curriculum, very few nurses might be aware on how to assess it. It is there imperative for MOH to train all nurses on HRQoL in order to identify unmet needs of patients which will help render quality care to patients.
6. A similar study to be conducted using random sampling to validate the findings of the present study.

University Teaching Hospital Management

1. Slightly above one tenth (11%) of the total participants, had surgery for treatment at University teaching Hospital. The rest of the patients received their treatment at Cancer Diseases Hospital. This means that majority of the patients received at least radiotherapy which possess a lot of distress to patients. UTH should incorporate cervical cancer screening programmes into existing health care services.
2. Since the number of cervical cancer survivors is increasing as majority of the cervical cancer survivors received treatment one (1) to five (5) years ago, there is need for UTH to start offering radiotherapy services to cater for the increased number of survivors as some of the survivors receive radiotherapy as palliation.
3. Increasing number of cervical cancer survivors also calls for more counselling services to be given to the survivors and also link women who seem to be in need of social support to appropriate organisations to promote social wellbeing.

Cancer Diseases Hospital Management

1. Enhance education on prevention, diagnosis, treatment, the side effects of cancer treatment and sexual functioning to improve the patients’ understanding and effective copying strategies. This needs to be mandatory for all healthcare providers involved in the care of female cancer survivors. Involvement of Nongovernmental organization can also help in the dissemination of information of health education to the public and also strengthen community partnership can also enhance health education because when communities are involved the easier the dissemination of information on prevention and early treatment of cervical cancer.
2. Financial challenges among cervical cancer respondents. Social support is very important as the majority of survivors reported having experienced financial challenges caused by the disease and treatment. Cancer Diseases Hospital should reinforce linking survivors to organisations that are offering social support to improve on their social wellbeing. Also educating care givers on the disease and involving them in the care of the patient can help promote social wellbeing.
3. Due to the increase of cervical cancer survivors, CDH should consider training more health workers in oncology in order to cater for the increasing number of survivors.

Lusaka District Health Office

1. Late presentation of cervical cancer patients at diagnosis. Majority of the participants (84.4%) presented with advancing stages (stage II, III and IV) of

cervical cancer. Lusaka District Health Office should enhance integration of cervical cancer programs into existing health care services in primary health-care facilities where most women can access them. This can help identify women who are not screened, and link them to facilities offering screening services to enhance screening and prevention of cervical cancer. It can also help increase access to treatment as some women have to travel long distances from other provinces for treatment and review. Therefore, there is need to extend radiotherapy services to other provinces other than Cancer Diseases Hospital only.

2. Further, Lusaka district should expand cervical cancer screening services to all the health centers in promoting early detection and treatment of cervical cancer. Early detection and early treatment of cervical cancer promotes good HRQoL.

5.10 Dissemination of study findings

The results of the study will be presented to the postgraduate in the nearest seminar week.

The results will also be communicated to Cancer Diseases Hospital, University Teaching Hospital, Lusaka District Medical Office, Lusaka Provincial Medical Office, and Ministry of Health, Lusaka.

In addition, bound copies will be submitted to the UNZA Medical Library, the main library at UNZA Great East Road Campus and School of Nursing Sciences UNZA.

The researcher hopes to publish the findings in one of the Medical Journals such as UNZA journal.

5.10.1 Utilization of findings

Evidence based practice is the utilization of research results in order to provide effective health care based on current research results. Therefore I will publish my research findings to the public through a medical journal to make the findings known and the results will also be made available to UTH, CDH, UNZA and MOH so that the findings are utilized. I will also write recommendations based on the research findings to UTH, CDH and the MOH since they are the major shareholders in order for them to develop policies that will promote quality care through development of programmes, advocacy and resource allocation using information generated from research. I will also provide technical assistance to policy makers and programmme implementers. In this way, my research results will be utilized and the cervical cancer survivors will receive quality care as their individual health needs will be identified and addressed respectively.

At the current moment HRQoL information is not routinely collected. My research findings will be an advocacy to ensure that HRQoL information is routinely collected in order to identify individual health needs that will ensure that appropriate care is given to the patient.

5.11 limitations

1. Random selection of participants was not used instead a purposive sampling was used due to a limited number of survivors, therefore the generalizability of the study results to all survivors is limited. However, our study results may provide reference for other countries.
2. The study being a cross section design which does not allow for causal inferences, but only describes the factors associated with self- reported QOL outcomes.

5.12 Strengths of the study

1. The study was carried out at UTH and CDH which are the biggest level three referral hospitals that offer cancer services and CDH is the only public Hospital in Zambia that offers Radiotherapy. These study sites also enable also enabled the researcher to get a more generalized picture as the Hospitals render health services to all the population of Zambia.
2. The study used multiple data sources such as self- structured questions and the EORTC tool to collect data.

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APPENDIX 1: CONSENT FORM

THE UNIVERSITY OF ZAMBIA

SCHOOL OF NURSING SCINECES

I____have read and understood the information contained in the participant information sheet on the research topic, '**Health Related Quality of Life among cervical cancer survivors at University Teaching Hospital and Cancer Diseases Hospital in Lusaka**' and with full knowledge of the research to be undertaken, I do hereby agree to participate in the research.

Name of participant ____

Signature ____

Date ____

Name of interviewer ____

Signature ____

Date ____

Name of witness____

Signature____

Date____

This consent form will be kept by the researcher for at least three years beyond the end of the study

APPENDIX II: SEMI- STRUCTURED INTERVIEW SCHEDULE

TOPIC: HEALTH RELATED QUALITY OF LIFE AMONG CERVICAL CANCER SURVIVORS

DATE OF INTERVIEW: ____

PLACE OF INTERVIEW: ____

NAME OF INTERVIEWER: ____

SERIAL NUMBER (of respondent):___________________________________

INSTRUCTIONS TO THE INTERVIEWER

Introduce yourself to the respondent.

Explain the reason for the interview.

Assure the respondent of confidentiality and voluntary participation.

Write only the serial number and not the name of the respondent on the questionnaire.

Clearly Tick or Circle the response to the question or fill in the blank spaces provided.

Thank each respondent at the end of the interview.

Provide time to the respondent to ask questions at the end of the interview

SEMI – STRUCTURED INTERVIEW SCHEDULE

We are interested in some things about you and your health. Please respond to all the questions. There are no “right “or “wrong” answers. The information that you provide will remain strictly confidential.

Today’s date (Day, Month, Year) ______________________________

SECTION A

Socio Demographic Data

1. Date and year of birth______________________________________

2. Marital status
    1) Single ☐
    2) Married ☐
    3) Divorced/ Separation ☐
    4) Widow ☐

Answer question 3 only if divorced/ separation

3. Was your divorce/ separation related to the disease or treatment
    1) Yes ☐
    2) No ☐

4. Number of children
    1) None ☐
    1) I ☐
    2) ≥ 2 ☐

5. Level of education
    1) Never been to school ☐
    2) Primary level ☐
    3) Secondary level ☐
    4) Tertiary level ☐

6. Employment
    1) Not employed ☐
    2) On contract ☐
    3) Self employed ☐
    4) Permanently employed ☐

7. Monthly household income
    1) Less than K2,000 ☐
    2) Between K2, 000 and K 5, 000 ☐
    3) More than K 5, 000 ☐

SECTION B
HEALTH RELATED QUALITY OF LIFE

Physical wellbeing	**Not at all**	**A little**	**Quite a bit**	**Very much**
8. Do you have any trouble doing Strenuous activities like carrying a heavy shopping bag or a bucket of water?	1	2	3	4
9. Do you have any trouble taking a **Long** walk?	1	2	3	4
10. Do you have trouble taking a **short** walk outside the house?	1	2	3	4
11. Do you need to stay in bed or sit Down during the day?	1	2	3	4
12. Do you need help with eating, dressing, bathing or using the toilet?	1	2	3	4

Functioning wellbeing

During the past week	**Not at all**	**A little**	**Quite a bit**	**Very much**
13. Were you limited in doing either your work or other daily activities such as cleaning, cooking and washing?	1	2	3	4

14. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4

Psychological Functioning wellbeing

During the past 4 weeks	**Not at all**	**A little**	**Quite a bit**	**Very much**
15. Did you feel tense as a result of your disease and treatment?	1	2	3	4
16. Did you worry?	1	2	3	4
17. Did you feel irritable?	1	2	3	4
18. Did you feel depressed?	1	2	3	4

Social functioning

During the past 4 weeks	**Not at all**	**A little**	**Quite a bit**	**Very much**
19. Has your physical condition or medical treatment interfered with your family life such as family break up, divorce or separation or lack of family support?	1	2	3	4
20. Has your physical condition or medical treatment interfered with your social activities like going for work, checkup care , church and interacting with others?	1	2	3	4
21. Has your physical condition				

or medical treatment caused
financial challenges for you? 1 2 3 4

For the following questions please circle the number between 1 and 7 that best applies to you

OVERALL HEALTH RELATED QUALITY OF LIFE

22. How would you rate your overall health during the past week?

1 2 3 4 5 6 7 ☐

Very poor Excellent

23. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7 ☐

Very poor Excellent

SECTION C

Effects of stage of cervical cancer at diagnosis on HRQL

24. Cancer stage at diagnosis: ☐

1) Stage I ☐
2) Stage ii ☐
3) Stage iii ☐
4) Stage iv ☐

Time point of treatment

25. Time point of therapy (time elapsed between therapy and interview) ☐

1) < 1 year ☐
2) 1- 5 years ☐
3) > 5 years ☐

26. Treatment received: ☐

1) Surgery only ☐
2) Surgery and chemo- radiation ☐
3) Chemo- radiation ☐
4) Radiotherapy only ☐

27. How long were you admitted during the period of your treatment?

____

____ ☐

28. State how you feel after the treatment you received.___________________ ☐

____

____

____

SECTION D

29. Has your disease caused you financial challenges such that you are unable to provide basic needs for your family?

1) Yes ☐

2) No ☐ ☐

30. Do you worry about your disease

1) Yes ☐ ☐

2) No ☐

Answer question 27 only if your answer for question 26 is NO

31. What makes you not to worry?____ ☐

____

32. Side effects/ symptoms related to treatment (general symptoms) (Cycle your answer)

During the past week:

☐

a) Have you had abdominal cramps? Yes ☐ No ☐

b) Have you had burning feeling when passing urine? Yes ☐ No ☐ ☐

c) Have you felt pain Yes ☐ No ☐ ☐

d) Have you had hot flushes and/ or sweats? Yes ☐ No ☐ ☐

e) Have you had swelling in one or both Legs? Yes ☐ No ☐ ☐

f) Have you easily felt fatigue Yes ☐ No ☐ ☐

Effects of treatment modalities on HRQoL

33. Disease related symptoms experienced after treatment (Cycle appropriately)

During the past week

a) Have you had foul smelling vaginal discharge Yes ☐ No ☐

b) Have you had abnormal vaginal bleeding Yes ☐ No ☐ ☐

c) Have you had backache Yes ☐ No ☐

34. Sexuality

During the last four weeks

a) Have you been sexually active? Yes ☐ No ☐ ☐

b) Has sexual activity been enjoyable for you? Yes ☐ No ☐ ☐

c) Has your vagina felt dry during sexual activity? Yes ☐ No ☐ ☐

d) Has your vagina felt short? Yes ☐ No ☐ ☐

e) Has your vagina felt tight? Yes ☐ No ☐ ☐

f) Have you had pain during
sexual intercourse or other
sexual activity? Yes ☐ No ☐ ☐

g) Have you worried that sex
would be painful? Yes ☐ No ☐ ☐

35. Body image

During the past week

a) Have you felt physically less
attractive as a result of your
treatment? Yes ☐ No ☐ ☐

b) Do you feel less feminine as a result
of your treatment? Yes ☐ No ☐ ☐

c) Have you felt dissatisfied with your
body as a result of your
treatment? Yes ☐ No ☐ ☐

UNIVERSITY OF ZAMBIA
BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
Federal Assurance No. FWA00000338

Ridgeway Campu
P.O. Box 5011
Lusaka, Zamb
E-mail: unzarec@unza.z
IRB00001131 of IORG000077

9th September, 2019.

REF. No. 230-2019

Ms. Monde Chisaji,
University of Zambia,
School of Nursing Sciences,
P.O Box 50110,
Lusaka.

Dear Ms. Chisaji

RE: "HEALTH RELATED QUALITY OF LIFE AMONG CERVICAL CANCER PATIENTS SURVIVORS AT CANCER DISEASES AND UNIVERSITY TEACHING HOSPITALS" (Ref. No. 230-2019)

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee o 9th September, 2019. The proposal is **approved**. The approval is based on the following documents tha were submitted for review:

a) **Study proposal**
b) **Questionnaires**
c) **Participant Consent Form**

APPROVAL NUMBER : REF. 230-2019

This number should be used on all correspondence, consent forms and documents as appropriate.

- APPROVAL DATE : **9th September 2019**
- TYPE OF APPROVAL : **Standard**
- EXPIRATION DATE OF APPROVAL : **8th September 2020**
  After this date, this project may only continue upon renewal. For purposes of renewal, a progres report on a standard form obtainable from the UNZABREC Offices should be submitted one mont before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING**: All SAEs and any other serious challenges/problem having to do with participant welfare, participant safety and study integrity must be reported t UNZABREC within 3 working days using standard forms obtainable from UNZABREC.
- **MODIFICATIONS**: Prior UNZABREC approval using standard forms obtainable from th UNZABREC Offices is required before implementing any changes in the Protocol (including changes i the consent documents).
- **TERMINATION OF STUDY**: On termination of a study, a report must be submitted to th UNZABREC using standard forms obtainable from the UNZABREC Offices.

REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH
University Teaching Hospitals
ADULT AND EMERGENCY HOSPITAL

P/Bag
Lusaka -
Fax: +260 211 250305
e-mail: mduth@yahoo.com
Tel: +260 211 253947 (Switch
+260 211 251451

OFFICE OF THE SENIOR MEDICAL SUPERINTENDENT

Our Ref:

26th June, 2019

Your Ref:

The Dean
The University of Zambia
School of Nursing
<u>LUSAKA</u>

Dear Sir/Madam,

<u>RE: RESEARCH PROJECT: CHISANJI MOONDE (COMPUTER NO. 2017013603)</u>

Reference is made to your letter dated 4th July, 2019.

I wish to inform you that permission has been granted to Chisanji Monde to conduct research entitled **"Health Related Quality of Life among Cervical Cancer Survivors at University Teaching Hospitals** UTH. She is advised to liaise with the Head of Department.

Yours faithfully,

Dr. Charles Mutemba
Head Clinical Care
for **/Director Clinical Care and Diagnostic services**
<u>UNIVERSITY TEACHING HOSPITALS-ADULT</u>

Cc: Head of Department
Cc: Chisanji Moonde

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

In reply p

No.......

REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH
CANCER DISEASES HOSPITAL

P.O. Box R
L

MH/CDH/101/18/1

July 11, 2019

Ms. Chisaji Moonde
C/O Solwezi School of Nursing
SOLWEZI.

Dear Ms. Moonde,

RE: APPROVAL TO CONDUCT RESEARCH – YOURSELF

Reference is made to the above.

I wish to inform you that CDH has no objection to your request to conduct research a
our institution entitled: **'HEALTH RELATED QUALITY OF LIFE AMONG CERVICA
CANCER SURVIVORS AT CANCER DISEASES HOSPITAL.'** Further, the Hospita
would appreciate being availed a copy of the research report for the library for use b
other students and staff.

Kindly come with a copy of this letter during the research.

Yours sincerely,

Dr. Lewis Banda
SENIOR MEDICAL SUPERINTENDENT

UNIVERSITY OF ZAMBIA
SCHOOL OF NURSING SCIENCES
JOURNAL OF RESEARCH IN NURSING, MIDWIFERY AND HEALTH SCIENCES

30th September, 2020

Ms Chisaji Moonde
University of Zambia
School of Nursing Sciences
LUSAKA

Dear Ms Moonde,

RE: ACCEPTANCE OF MANUSCRIPT TO THE JOURNAL OF RESEARCH IN NURSING, MIDWIFERY AND HEALTH SCIENCES (JRNMHS)

This to inform you that your manuscript entitled **HEALTH RELATED QUALITY OF LIFE AMONG CERVICAL *CANCER SURVIVORS AT CANCER DISEASES AND UNIVERSITY TEACHING HOSPITALS, LUSAKA, ZAMBIA*** has been accepted for publication. You are hereby advised that publication will be done after payment of the stated fees that will be communicated to you. Congratulations!

Best regards,

CKwaleyela

Dr Concepta N. Kwaleyela (PhD)
CHIEF EDITOR (JRNMHS)

cc: A/Dean – Postgraduate

NATIONAL HEALTH RESEARCH AUTHORITY
Paediatric Centre of Excellence, University Teaching Hospital, P.O. Box 30075, LU
Tell: +260211 250309 | Email: znhrasec@gmail.com | www.nhra.org.zm

Date: 20th July, 2020

The Principal Investigator
Ms. Moonde Chisaji
University of Zambia
School of Nursing Sciences
PO Box 50110
LUSAKA.

Dear Ms. Chisaji,

Re: Request for Authority to Conduct Research

The National Health Research Authority is in receipt of your request for authority to conduct research titled **"Health Related Quality of Life Among Cervical Cancer Survivors."** I wish to inform you that following submission of your request to the Authority, our review of the same and in view of the ethical clearance, this study has been **approved** on condition that:

1. The relevant Provincial and District Medical Officers where the study is being conducted are fully appraised;
2. Progress updates are provided to NHRA quarterly from the date of commencement of the study;
3. The final study report is cleared by the NHRA before any publication or dissemination within or outside the country;
4. After clearance for publication or dissemination by the NHRA, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted, University leadership, and all key respondents.

Yours sincerely,

Prof. Godfrey Biemba
Director/CEO
National Health Research Authority

- **NHRA:** Where appropriate, apply in writing to the National Heath Research Authority for permissio before you embark on the study.
- **QUESTIONS**: Please contact the UNZABREC on Telephone No.256067 or by e-mail o unzarec@unza.zm.
- **OTHER**: Please be reminded to send in copies of your research findings/results for our records. You'r also required to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study. Use the online portal: unza.rhinno.net for further submissions.

Yours sincerely,

Munsaka.

Sody Mweetwa Munsaka, BSc., MSc., PhD
CHAIRPERSON
Tel: +260977925304
E-mail: s.munsaka@unza.zm