LIVED EXPERIENCES OF CERVICAL CANCER SURVIVORS AT THE MALAWI NATIONAL CANCER CENTER

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LIVED EXPERIENCES OF CERVICAL CANCER SURVIVORS AT THE MALAWI NATIONAL CANCER CENTER

By

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A Dissertation Submitted in (Partial) Fulfilment of the Requirement for the degree of Master of Science in Oncology Nursing of the Muhimbili University of Health and Allied Sciences

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CERTIFICATION

The undersigned certify that they have read and hereby recommend for acceptance by Muhimbili University of Health and Allied Sciences a thesis entitled ***Lived Experiences of Cervical cancer Survivors at the Malawi National Cancer Centre***, in (Partial) fulfilment of the requirements for the degree of Master of Science in Oncology Nursing of Muhimbili University of Health and Allied Sciences.

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Date

DECLARATION AND COPYRIGHT

I, **Chisomo Mtima** declare that this dissertation/thesis is my own original work, and it has not been presented and will not be presented to any other University for a similar or any other degree award.

Signature ……Date ……

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DEDICATION

I dedicate this work to my mother, my husband, my two lovely daughters; Gracielle and Gianelle. You are amazing and mean a lot to me.

ACKNOWLEDGEMENT

My most profound appreciation goes to God; He made the impossible be a possibility for me.

I also thank the Malawi government for sponsoring my studies.

To my supervisors; Dr Stella Mushy and Mr Kibwanda Athumani, I thank you for your time, effort, patience and understanding in helping me achieve my studies. Your vast wisdom and wealth of experience have inspired me throughout my studies.

I'd like to express my gratitude to the patients who agreed to participate in this study, without your voices this study would not be achievable.

To conclude, I would like to thank my mother, my husband, and my children. It would have been impossible to finish my studies without their unwavering support over the past couple of years.

ABSTRACT

Background

Global incidences of cervical cancer are continuously on the rise. Experiences of cervical cancer patients vary based on multiple factors such as physical characteristics, cultural, spiritual, and socio-economic inequalities. Despite variance in the patient experiences, there is little information regarding cervical cancer patient experiences in Malawi.

Aim

The purpose of the study was to explore the lived experiences of cervical cancer survivors at the Malawi National Cancer Center (MNCC).

Methods: A qualitative study with a phenomenological design was conducted from March to April 2024 involving 12 cervical cancer survivors. The survivors were those who had a histologically confirmed diagnosis and had at least three months treatment history up to those on follow-up. Purposive sampling was used to collect a sample of cervical cancer survivors. Data collection was done by using a semi-structured interview guide. Survivors were recruited after reviewing the MNCC's registry and patient records for eligibility. Written consents for participation were obtained from survivors. All of the interviews were recorded and transcribed verbatim afterwards. Data was analyzed using manual thematic analysis as inspired by Braun and Clarke.

Results: Four themes and twelve sub themes on experiences of cervical cancer survivors receiving care at the Malawi National cancer Centre were developed following data analysis. The themes were; Intrapersonal experiences where the survivors experienced varied physical, emotional, and financial burdens, Interpersonal experiences where social support varied with some survivors experiencing strengthened relationships while others faced stigma., community experiences where misconceptions and cultural beliefs cause stigma and discrimination causing delayed seeking of care; and institutional factors where survivors reported having varied interactions within the healthcare system

Conclusion: Living with cervical cancer is cumbersome. Survivors' lives changed after their diagnosis of cervical cancer due to the effects of the disease and its treatment side effects, changed social relationships, community outlook and different treatments from the institutions they seek care from.

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ABBREVIATIONS

FIGO	The International Federation of Gynaecology and Obstetrics
HPV	Human-Papilloma-Virus
KCH	Kamuzu Central Hospital
KUHeS	Kamuzu University of Health Sciences
LMCI's	Low to Middle Income Countries
MNCC	Malawi National Cancer Canter
SSA	Sub Saharan Africa
UNC	University of North Carolina

OPERATIONAL DEFINITIONS

Cervical Cancer: A gynecological cancer that affects the cervix and develops due to infection with human papillomavirus (HPV) in the presence of other risk factors(1).

Lived Experience: Intimately relating to situations gained through direct, first-hand involvement with the occurrence of a terminal illness(2)**.**

Cancer Treatment: Therapeutic use of surgery, chemotherapy and radiotherapy to control the progression of cancer(3).

Quality of Life: Multidimensional perspective of an individual's well-being with regard to the positive and negative elements in their existence(4).

Cancer Survivor: An individual who has been diagnosed with cancer and continues to live with it throughout the remainder of their life(5).

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background of the study

Cancer is a global health concern. Globally, nearly 10.0 million cancer-related deaths and 19.3 million new cancer cases occurred in 2020(6). Low to middle-income countries (LMICs) including those in Sub-Saharan Africa (SSA) are significantly burdened by the disease(6). In 2020 cancer incidence and mortality in SSA were approximately 801, 392 and 520, 158 respectively(7). Worldwide cancer burden is projected to rise in 2040 by approximately 47% increase from 2020(6).

Cervical cancer is the fourth most diagnosed cancer globally among women(8). Cervical cancer is a gynecological cancer that affects the cervix and develops due to infection with human papillomavirus (HPV) in the presence of other risk factors(1). HPV infection is mostly common in sexually active women aged 15-49 years. Persistent HPV infection coupled with low immunity initiates the conversion of normal cervical cells to pre-cancerous lesions which if left untreated progress to high-grade cancerous lesions on the cervix(1,9).

Globally, close to 604, 000 women were diagnosed with cervical cancer in 2020 while an approximate 342,000 deaths occurred due to cervical cancer in 2020 (8). The incidence and mortality of cervical cancer are highest in LMICs, the vast majority are in SSA(10). Cervical cancer incidence in SSA approximated 110,300 in 2020 and the region contributed to 24.55% of the global deaths from cervical cancer(11,12). In Malawi, current estimates indicate that nearly 4,124 women are diagnosed with cervical cancer every year and, an estimated 2,905 women die every year from this illness(13). Malawi also experiences the highest age-standardized incidence rate globally(10).

If left uncontrolled, cervical cancer cases are estimated to surpass 700,000 by 2030 with women in LMICs still experiencing significant disease burden(14,15). Malawi, a country in the LMICs still faces challenges with the rising incidence and mortality related to cervical cancer(16). This is largely due to inadequate cervical cancer prevention initiatives,

inadequate screening and diagnostic resources, a lack of readily available and easy access to efficient cancer treatments, severe lack of skilled, experienced medical personnel and long distances that patients need to cover to access cancer treatments(16,17).

Cervical cancer mortality and morbidity are attributed to factors such as behavioral (smoking, early initiation of sexual intercourse, multiple sexual partners, prolonged use of oral contraceptives), low socio-economic status, and infections like human papillomavirus(9,18–20).

Cervical cancer is a preventable condition mostly resulting from Human papillomavirus (HPV) infection(8). Interventions to reduce cervical cancer incidence and mortality are a crucial tool in the battle against the disease and prevention is available before disease initiation and across all stages of the disease(21,22). Global interventions for cervical cancer prevention are in primary, secondary and tertiary levels(23). Interventions include community sensitization to reduce exposure to carcinogens, adoption of risk reduction behaviors like smoking cessation, immunizations against infectious diseases known to cause cancer, screening and detecting cancer early, treating cervical cancers, palliation, establishing national cancer strategic plans and cancer registries(23–25). Over the years, interventions for eliminating cervical cancer like targeted cervical risk education, routine screening for cervical cancer, early treatment for cervical cancer and vaccination against HPV in women aged 9-15 years have led to a decline in cervical cancer burden(1,15). High income countries have faced increased reduction in cervical cancer incidences due to increased social and economic development(26). On the other hand the LMICs face a significant burden due to low socio economic status, inadequate health financing, low levels of HPV vaccination, reduced uptake of cervical cancer screening and early treatment, and limited access to comprehensive cancer treatment(26–30).

Clinical presentation of cervical cancer is dependent on the stage of the disease(31). Early cervical cancer presents with abnormal vaginal bleeding (post-coital, inter menstrual or post-menopausal bleeding), abnormal foul smelling vaginal discharge and lower abdominal pain(32–34). Late presentation of cervical cancer is associated with lower limb edema, lower

back pain and fecal or urinary incontinence(32,35). Diagnosis of cervical cancer combines a complete medical history, physical examination and diagnostic tests such as Papanicolaou smear test and cone biopsy examination(1,32,36). The International Federation of Gynecology and Obstetrics (FIGO) considers cervical cancer stages 1a, 1bi and 1bii as early stages and these are treatable by conization and hysterectomy(34,37). Conization is a surgical procedure that removes a portion of the cervix for diagnosis and treatment of early cervical cancer while hysterectomy is the surgical removal of the uterus and cervix for cancer treatment(38,39). Late-stage cervical cancer, defined as FIGO stage II or greater, is generally considered inoperable and recommended treatment is chemotherapy and radiation(34,40). Chemotherapy is the therapeutic use of cytotoxic chemical agents that work to suppress cancerous tumour growth and multiplication(41). Radiation therapy is the therapeutic use of radioactive substances directed at body tissues to destroy cancer cells by retarding their growth(42). Despite these significant advancements in the knowledge of cervical cancer as a disease that may be prevented, the disease burden continues to be high(43).

Cancer treatment can have both short and long term implications on quality of life thus making survivorship difficult(43). Cervical cancer survivors have reported discomfort, exhaustion, urinary complications, sexual dysfunction and other treatment related side effects(44). This is due to the fact that cervical cancer affects the body's vital organs for recreation and reproduction(43). Complications include treatment side effects (nausea, vomiting, anaemia, proctitis, cystitis, secondary malignancy and infertility), altered social interactions (1). Advanced disease may complicate to renal failure, hydronephrosis, pain, lymphedema, bleeding disorders, sexual dysfunction and fistulas (1,45,46) The complications of cervical cancer and its treatment leave women with low self-esteem, poor self-image, self-despise, and trauma (44,47). Women also experience psycho-social disturbances which can present with anxiety, sadness, fear of disease recurrence and affected relationships (48). Othe studies have also documented that women face lack of support, stigma and limited access to care(49).

Despite the varying experiences of patients with cervical cancer revealed through studies on experiences of cervical cancer survivors, there is a dearth of information on experiences of

cervical cancer survivors in Malawi. Several studies conducted in Malawi have focused on improving cervical cancer screening, increasing uptake of cervical cancer screening services among women and the prevalence of cervical cancer in Malawi (50–53). Therefore, this study aims to explore the lived experiences of cervical cancer survivors at the Malawi National Cancer Center.

1.2 Problem Statement

Cervical cancer is a major health concern in Malawi (13,54). It is the most frequently diagnosed cancer and ranks as the first cause of cancer deaths among women in Malawi (13,54). Cervical cancer is also the number one diagnosed cancer among all cancers in Malawi (13).

Malawi is faced with a high prevalence of Human Immuno-deficiency Virus and HPV infection among females aged between 15-49 years and this increases the risk of developing cervical cancer (55). Malawi is a low to middle-income country that is faced with low utilization of cervical screening services, poor health financing, lack of human resources, and long distances to health centers (50,51,53,56). Malawian women also lack knowledge on the signs and symptoms of cervical cancer and seek health care late (57). These factors contribute to the increased burden of cervical cancer among Malawian women.

Cervical cancer diagnosis alters an individual's quality of life and women experience changes in their physical, psychological, social and cultural aspects which are measures of good health in an individual (58). The Government of Malawi through the Ministry of Health and Population Services developed the National Cancer Control Strategic Plan and National Cervical Cancer Strategy in an attempt to attain a state of health for all Malawians, reduce cancer burden and increase their quality of life and productivity. Interventions in the strategy to reduce cervical cancer include vaccination against human papillomaviruses (HPV), reducing exposure to probable cancer risk factors through sensitization campaigns, screening and early detection of cervical cancer, chemotherapy treatment and palliation (6).Despite these efforts by the government, Malawi continues to face a high disease burden of cervical cancer with an estimated 4,124 morbidity and 2,905 mortality cases in 2020**.**

Several studies conducted in Malawi have focused on improving screening for cervical cancer, increasing uptake of cervical cancer screening services, and prevalence of cervical cancer in Malawi (50–52). To the best of our review, there are limited publications on the lived experiences of cervical cancer survivors in Malawi. These untold stories of resilience and survival, highlight the necessity of conducting a study that explores the lived experiences of cervical cancer survivors at the National Cancer Center in Malawi. By shedding light on their experiences, this study aims to better understand the unique needs of cervical cancer survivors in Malawi and facilitate the initiation of targeted interventions to improve their quality of life.

1.3 Rationale for the study

Notably, efforts have primarily focused on reducing cervical cancer incidence and death in Malawi sidelining the lived experiences of cervical cancer survivors. The study will provide a comprehensive understanding of the experiences by cervical cancer survivors at the intrapersonal, interpersonal, community and institutional levels in Malawi. This knowledge can guide the development of policies targeted to intervene and support specific needs of cervical cancer survivors and improve their quality of life.

Furthermore, by highlighting the stories of resilience and survival, this study will contribute to raising awareness about the experiences of cervical cancer survivors in Malawi. It will provide a platform for their voices to be heard, fostering a greater understanding and empathy within practices in the healthcare system and society at large. This increased awareness can lead to a more compassionate and supportive environment for cervical cancer survivors, thus improving their overall well-being. The knowledge gained can also enhance understanding of unique challenges at the center.

1.4 Research Questions

1.4.1 Main Research Question

What are the lived experiences of cervical cancer survivors ?

1.4.2 Specific Research Questions

i. What are the intrapersonal experiences of cervical cancer survivors at the Malawi National Cancer Center

ii. What are the interpersonal related experiences encountered by cervical cancer survivors at the Malawi National Cancer Center?

iii. What experiences do cervical cancer patients at the Malawi National Cancer Center encounter at the community level?

iv. What are the institutional related experiences of cervical cancer survivors at the Malawi National Cancer Center?

1.5 Research objectives

1.5.1 Broad Objective

I. To explore the lived experiences of cervical cancer survivors at the National Cancer Center in Malawi.

1.5.2 Specific Objectives

i. To gain insight into the intrapersonal related experiences of cervical cancer survivors at the Malawi National Cancer Center**.**

ii. To uncover the interpersonal related experiences of cervical cancer survivors at the Malawi National Cancer Center.

iii. To describe the community related experiences of cervical cancer survivors at the Malawi National Cancer Center.

iv. To describe the institution related experiences of cervical cancer survivors at the Malawi National Cancer Center.

1.6 Theoretical Framework

The study was guided by McLeroy's Social Ecological Model (SEM) which was proposed in 1988. The socio-ecological model provides a framework to understand numerous factors

that influence an individual to change their health behavior. The theory asserts the importance of human-environment interactions in understanding and changing behavior. The theory also acknowledges that there is interdependence of the levels in the theory which shape an individual's health behavior. The SEM identifies two key concepts that are crucial intervention points for promoting health. The first key concept is that behavior has multiple levels of influence and the second is that there is a reciprocal causation between the individual and social environment.

McLeroy et al (59) identified five levels of influence for health-related behaviors and conditions as sub-concepts that make up multiple levels of influence. These levels include; the intrapersonal level, interpersonal level, and community level, institutional level and policy level. Each level of influence has an affect an individual's health behavior.

Intrapersonal Level

This level recognizes individual characteristics that shape an individual's behavior, such as knowledge, attitudes, beliefs, and personality traits (60).

Interpersonal Level

Comprises of interpersonal processes and primary groups. These include interactions with family and friends that provide social identity, support, and role definition (60).

Community Level

These are structures in the individual's community which recommend an individual's accepted behavior. These structures comprise of rules, regulations, policies, and informal structures within the community (60)

Institutional Level

These are social networks, services, norms, or standards, which exist as formal or informal among individuals, groups, and organizations

Public Policy Level

Local, state, and federal policies and laws that regulate or support healthy actions and practices for disease prevention, early detection, control, and management

Reciprocal causation identifies that there is a two -way interaction between people and the environment which influence their behaviors.

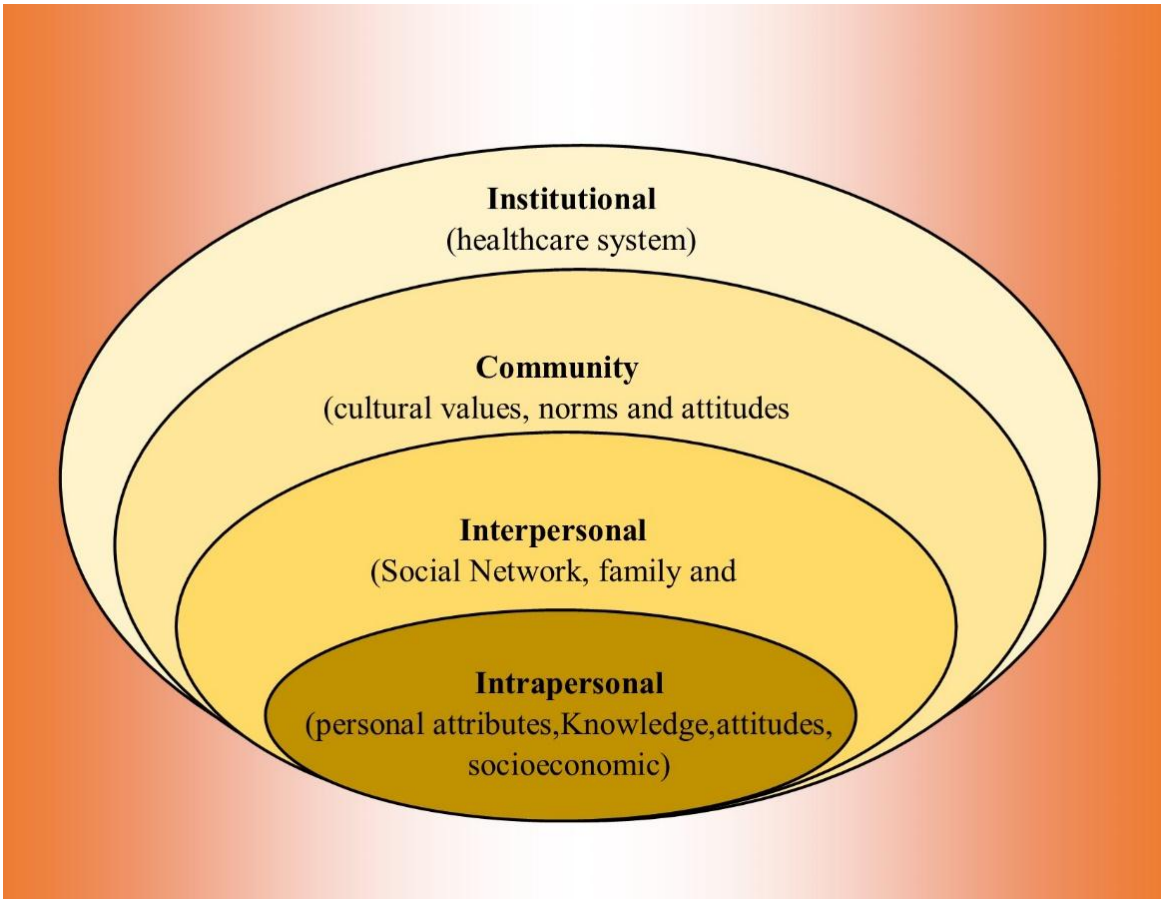


Figure 1: Social Ecological Model

Application of the theoretical framework

This study was guided by the first key concept (multiple level of influence) of the SEM which has five levels but this study will only focus on four constructs which are intrapersonal, interpersonal, community and institution levels. Lived experiences of cervical cancer patients are shaped by their interaction with their surrounding environment. The SEM

illustrates how various factors interact to shape experiences of cervical cancer survivors. By understanding the interaction of these factors, interventions can be tailored to address the specific needs of cervical cancer survivors at multiple levels, promoting their well-being and improving overall outcomes.

An individual's personality traits, knowledge, attitude, and beliefs about cervical cancer (intrapersonal level factors) have an impact on the experiences of cervical cancer patient. Knowledge, attitudes and beliefs influence an individual's perceptions of their illness and the importance of their treatment in controlling their disease (61).

Interpersonal level factors such as interactions with family and friends and healthcare determine how an individual relate with their cervical cancer diagnosis. Positive family interactions and supportive healthcare practices can enhance positive coping mechanisms while absence of these can exacerbate the challenges cancer patients meet (62,63).

Community level factors such as cultural norms and religious beliefs have an impact on lived experiences of cervical cancer patients. Cultural beliefs regarding cancer and religious beliefs shape how an individual may interpret their cervical cancer illness trajectory (64,65).

Institutional factors such as availability of resources within the health system, healthcare provider's knowledge and attitudes towards cervical cancer have, health education systems have an impact on how an individual perceive their diagnosis of cervical cancer (66).

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Introduction

This chapter presents literature from publications related to experiences of cervical cancer survivors. The review focused on four objectives pertaining to this study: Intrapersonal experiences of cervical cancer survivors, interpersonal experiences of cervical cancer survivors, community experiences of cervical cancer survivors and institutional experiences of cervical cancer survivors.

2.2 Intrapersonal Experiences of Cervical Cancer Survivors

Compared to the general women population, cervical cancer survivors often experience lower health related quality of life as they are met with physical, economic, sexual, social, and emotional functioning problems throughout their illness trajectory (67–71).

Cervical cancer survivors often struggle with the long-term effects of treatment, including fatigue, pain, exhaustion, nausea, vomiting and appetite loss (72). A study conducted among Nordic women revealed that diagnosis and treatment of cervical cancer altered the normal functioning in their bowel and urinary systems (73). The study also revealed that women presented with lymphedema post treatment and this negatively affected their everyday life (73). In another study conducted to explore the physical and psychosocial being of women after cervical cancer treatment revealed that due to the diagnosis and treatment of cervical cancer survivors experienced pain and sensitivity loss during intimacy (74). The same study also showed that women experienced fatigue and treatment related neuropathy which negatively impacted their everyday being (74). In a similar study conducted to explore physical and psychosocial functioning after diagnosis and treatment of cervical cancer showed that cervical cancer diagnosis is shocking to the individual and it also entails loss of control over one’s life (74). In another study conducted to explore the experiences of the journey of cervical cancer survivors, results revealed that the diagnosis of cervical cancer brought mixed feelings on the patient such as hopelessness, self-guilt and optimism for better

life (75). Other studies conducted have shown that cervical cancer diagnosis and treatment causes depression, anxiety and impaired cognitive functioning in survivors (76–78). These changes often exacerbate the burden of living with cervical cancer among the survivors. Diagnosis of cervical cancer also has a significant impact on economic aspects of the survivors. Studies conducted have revealed that cervical cancer patients face financial challenges such as increased out-of-pocket expenditures to cover cancer medications, diagnostics, caregiver expenses, travel expenses, and lodging causing them to skip hospital appointments and delay in initiating cancer therapy thus negatively impacting their experiences (79–81).

Several studies conducted in SSA revealed that diagnosis and treatment of cervical cancer causes several disruptions in a woman's life which increases their suffering. A study conducted in Tanzania revealed that women experience suffering in form of self -guilt and worry due to cervical cancer diagnosis and treatments effects (66). Participants from the Tanzanian study revealed that symptoms of vaginal discharge worried them and the side effects from treatment made their diagnosis worse (66). The Tanzanian study also showed that women experienced loss of their ability to generate income which impacted them negatively economically (66). A study conducted in Ghana showed that women undergoing cervical cancer treatment experience debilitating treatment related effects which causes negative experiences to them (82). These experiences mostly affect them negatively in their life course.

Research on the intrapersonal experiences of cervical cancer survivors in Malawi is scarce. It is likely that cervical cancer survivors in Malawi also face different experiences as those patients elsewhere face due to differences in social and geographic contexts.

Further research is needed to identify the specific intrapersonal experiences faced by cervical cancer survivors in Malawi. This research can enhance the empathy of care in providing compassionate care to cervical cancer survivors.

2.3 Interpersonal Experiences of Cervical Cancer Survivors

Though often curable with early diagnosis and treatment, diagnosis of cervical cancer has a significant impact on interpersonal relationships of the survivors (83). The diagnosis of cervical cancer and the treatment side effects have the potential to alter survivors interactions with others close to them (84). Women diagnosed and treated for cervical cancer experience disrupted social functioning. Cervical cancer patients often experience body image disturbance, sexual functioning disturbances, perceived identity change, altered emotional well-being (74,85,86). These experiences alter their social interactions and this influence their experiences negatively.

Other studies have also uncovered that cervical cancer patients are faced with behavioral dysfunction, role changes, and lack of information on management strategies for physical morbidities which alters their interactions with other individuals (87–89). In a study to explore the physical and psychosocial well-being of women after cervical cancer treatment conducted by Millet et al (74), participants revealed that lack of pear support heightened their disease and treatment burden and this made them feel alone thus making their experiences bad. Similarly, Wang & Feng's (90) research on cancer related psychosocial challenges showed that cancer patients have challenges in maintaining healthy relationships as diagnosis of cancer disturbs their social relations with family and the community because they feel alone in the situation. Contrary to the results of Wang and Feng, Sekse et al (73) conducted a systematic review on psychosocial experiences of cervical cancer survivors and the results showed that cervical cancer survivors adapted well to their diagnosis and treatment due to support from spouses and other close family members and this made them have positive experiences throughout their illness trajectory.

Among studies conducted in SSA, a study conducted in Uganda revealed that cervical cancer treatment left women anxious in regard to their inability to satisfy their spouses conjugal needs and their child bearing ability in the future which made the have negative experiences(91). In Ghanaian based studies, stress, depression and social isolation as a result of altered body image, social and family functioning were identified as some of the experiences that cervical cancer patients face and this negatively affected their quality of life

(92,93). In a study conducted in Tanzania on experiences and caring needs of women diagnosed with cervical cancer, results revealed that survivors faced social isolation due to stigma and inadequate familial support which negatively affected their coping with the disease (66). On a different note, Kedebe et al (94) conducted a research on psychosocial experiences and needs of cervical cancer survivors and the study results revealed that familial support helped survivors cope with the disease and its treatment thus giving them better experiences and coping. Concurring with the results from Kedebe et al, Dirar et al (49) conducted a study to assess the experiences and social needs of women in Ethiopia. The results showed that family support and care from spouse was a vital tool in coping and adapting to their disease situation.

Information on the interpersonal experiences of cervical cancer survivors in Malawi is not available. It is possible due to geographical differences cervical cancer survivors in Malawi may face different interpersonal experiences as those patients elsewhere face.

Further research is needed to identify the specific interpersonal experiences of cervical cancer survivors in Malawi. This research can inform the development of patient sensitive interventions that promote resilience among cervical survivors.

2.4 Community Experiences of Cervical Cancer Survivors

The trajectory of cervical cancer diagnosis, treatment and beyond treatment is a complex one which is often heightened by social, cultural and economic factors.

A study conducted in Chitwan in Nepal on experiences of cervical cancer survivors, participants revealed that they faced stigma and discrimination from community members due to their diagnosis of cervical cancer (95). Results from the Chitwan Study also revealed that cervical cancer survivors faced financial constraints as a result of community stigma due to the symptoms of the disease and this made them not cope well with the disease (95). In another study conducted on Black, Latin and Chinese American cervical cancer survivors, results showed that both stigma and social support strengthened their faith allowing them to cope positively with their diagnosis (96).

Among studies conducted in SSA, a study conducted in Tanzania explored the experiences of cervical cancer survivors and the results showed that stigma and discrimination were significant challenges that cervical cancer survivors faced in their communities and this did not help them to cope with the disease (66). Religious faith, and traditional healing practices helped Tanzanian cervical cancer survivors cope with their disease offering them better experiences (66). Similarly, another study conducted in Tanzania revealed that being affiliated to a religious grouping was a source of support for patients with cervical cancer and this offered them help to navigate the negative experiences of living with cervical cancer (97).

A study conducted in Malawi on Cancer-Related Stigma which investigated the impact of stigma on Malawian cancer survivors, including those with cervical cancer. Survivors expressed fear of isolation, discrimination, and blame as experiences they faced in their communities and this exacerbated their suffering. The survivors found that support groups helped them cope with their disease and have better experiences (98).

There is need to explore further on the community experiences specific to cervical cancer survivors in Malawi to ascertain the importance of community support to enhance the well-being of cervical cancer patients in their communities.

2.5 Institutional Experiences of Cervical Cancer Survivors

Even though there has been improvement in screening, diagnosis and treatment, cervical cancer remains as a huge public health concern overwhelming the health system and thus subjecting survivors to different experiences.

An Indian study done to explore cervical cancer patient's satisfaction during hospital care found that survivors received sub-standard care due to lack of good communication between hospital departments, shortage of human and material resources and long waiting hours before physician review and made their experiences worse.(99).

Among studies done in SSA, studies conducted in Ghana and Ethiopia showed that cervical cancer patients were met with delays during diagnosis and treatment, others received wrong

diagnosis and they felt that health care professionals lacked in the knowledge about their disease which left them dissatisfied with their care (49,82,100). Contrary to the findings of Ghana and Ethiopia studies, a study conducted in South Africa found that patients were satisfied with the oncology services they received at the hospital they were attending thus experiencing improved quality of life(101).

In Malawi studies on the institutional experiences of cervical cancer survivors are not available highlighting the need to conduct further research to uncover the specific experiences. Conducting this study will provide insights on the needs of cervical cancer and enable healthcare providers to improve provision of care to cervical cancer patients thus improving their quality of life.

2.6 Conclusion

The experiences of cervical cancer survivors may vary between LMICs and the high-income regions as survivors in other countries may experience a better life than in Malawi. While considerable research has examined the experiences of cervical cancer survivors on a global scale, a significant gap exists in understanding the specific lived experiences cervical cancer survivors in Malawi. There is a need to explore how cervical cancer survivors navigate their illness journey in Malawi.

CHAPTER THREE

3.0 METHODOLOGY

This chapter explains the research methodology that was used in conducting this study. This section covers the study design, study site, population and sampling procedures. Data collection methods, data collection tool and data management procedures are also described in detail in this section.

3.1 Study Design

A Phenomenological qualitative design was utilized in this study. Phenomenological design involves organization, collection, analysis and interpretation of narratives obtained from individuals who have firsthand experience of phenomenon under study (102). The Phenomenological approach was best suited for this study as it emphasizes on understanding hidden meaning and core components of human experiences whilst also aiming to understand how individuals living with cervical cancer interpret their experience and that of the world around them. This research documented a range of experiences faced by survivors diagnosed and living with cervical cancer.

3.2 Study site

The study was conducted at the Malawi National Cancer Centre (MNCC) situated in the city of Lilongwe in the central region of Malawi. Lilongwe district covers 727.79 square kilometers. The district borders north with Dowa, east Salima, west Mchinji and south with Dedza districts. The MNCC largely receives patients from the central region districts of Malawi namely: Nkhotakota, Kasungu, Dowa, Mchinji, Dedza, Salima, Ntchisi, Ntcheu and Lilongwe. The MNCC was chosen as the study area as it is the country's national referral treatment center for patients offering comprehensive cancer treatment. The center treats about 7000 cancer patients per year. The cancer center has 46 nurses, 16 doctors, 6 specialist doctors, and 3 nurse specialists. The center collaborates to offer specialized pathology, adult medical oncology, pediatric haemato-oncology, all-inclusive palliative care, and oncology research services. the cancer center ha 1 female ward, 1 male ward, 1 pediatric ward that run

24 hours. It also has the consultation department, chemotherapy department and radiology department that operate as out-patient departments.

3.3 Study Population

The study recruited cervical cancer survivors aged 18 years and above. The survivors were those that were histologically diagnosed with cervical cancer, received cervical cancer treatment for at least three months up to those on follow up care. The study only recruited survivors who had made informed consent to participate in the study.

3.4 Eligibility criteria

3.4.1 Inclusion Criteria

Survivors aged 18 years and above who had received cervical cancer treatment for at least three months up to follow up participated in this study. These survivors were selected as they had the experiences of both diagnosis and treatment of cervical cancer (103).

3.4.2 Exclusion criteria

Survivors who were mentally unstable were excluded from this study.

3.5 Sampling and sample size

The study utilized purposive sampling technique to collect information from the participants. The selection process involved selecting survivors who had knowledge and experience of the phenomena under study. The researcher purposively selected survivors with rich information to help the researcher answer the research questions. To increase variation in the study, the selection criteria included diversity in age, marital status, and education backgrounds of the survivors. The predetermined sample for this study was 15 participants, however the sample size was 12 participants. The sample size was determined by data saturation principle (104). Data saturation is when no new information can be obtained by conducting more interviews. Survivors were invited to participate in the study on the day of their review date with the doctor. The researcher recruited the survivors by reviewing the NCC's cancer registry to identify eligible patients to participate in the study. After identifying the patients, the researcher crosschecked with the files of the patient available on the day of review. survivors

were then individually approached and invited to participate in the study upon being cleared as eligible to participate in the study.

3.6 Data Collection Methods

A description about the study preceded obtaining informed consent. The study only recruited survivors who had provided an informed consent to participate in the study. To obtain informed consent, the study purpose, benefits, risks and utilization of the data were explained to the survivors clearly. Each cervical cancer survivor was interviewed individually to explore their lived experiences. In-depth interviews were conducted in a pre-booked room which offered quietness, participant comfortability and privacy at the research site. Survivors were then asked questions by the principal investigator utilizing semi-structured interview guide during the interview time. The interviews were conducted in the Malawi local language, Chichewa and the interviews lasted between 30 to 45 minutes.

One research assistant (RA) with qualitative data collection experience was hired to help with collecting data for the study. The RA had an oncology nursing background, was able to speak Chichewa and underwent a training for a period of two days. The training was comprehensive covering objectives of the research, ethical issues and interview process. The training was done to make sure the data collection was thorough with ethical issues taken into greater consideration. Attributes such as experience, professionalism, interview and language skills and team work capability influenced the hiring of the RA.

3.7 Data Collection Tool

Data for this study was collected from survivors using semi structured interview guide which was developed based on literature review and modified to suit the study's specific objectives. The interview guide was adapted from a study similar to this conducted in Puducherry(105). The interview guide consisted of two sections. Section I aimed at capturing socio-demographic characteristics of the survivors while as section II focused on stem questions and probes which sought to answer the major research question thus what are the lived experiences of cervical cancer survivors at the MNCC. The interview guide and informed consent were translated from English to local language (Chichewa), for ease of

communication with participants. Reverse translation from Chichewa to English of the collected transcribed data was done to ensure accuracy and representation of the participant's voice.

A digital voice recorder was used to capture the conversations that were held with the survivors. Non-verbal cues were captured by taking field notes to complement on audio recorded data during the interviews. The data collection tool was refined along the way to generate the desired responses from the participants. Data was collected from March 2024 to April 2024.

3.8 Data Management

Data in the form of written records were kept and transported in sealed envelopes. Data in soft copy was kept in a password protected hard drive to prevent unauthorized access to participants' information.

3.9 Data Analysis

Audio recorded interviews were transcribed verbatim. Data analysis was done utilizing the six step approach of thematic analysis developed by Braun and Clarke(106). Thematic Analysis is a systematic method that identifies, analyzes and reports meanings of themes within data. Data collection was done concurrently with data analysis. The researcher started by familiarizing with the data set to gain deeper understanding of the survivor's experiences. This was done without the researcher pre-imposing her ideas about the subject under study.

Data familiarization was done through conducting interviews, verbatim transcription of the audios, reverse translation of transcripts from Chichewa to English and reading and rereading of the transcribed data. Transcripts were analyzed deductively. The researcher generated codes from meaning units of the transcripts to capture important characteristics of cervical cancer survivor's experience. To effectively code, framework analysis was meticulously done which ensured all data points were captured. A coding book was developed in an excel sheet. All topics emerging from the data set were identified and written down in the code book as codes. The codes were then grouped into similar topics and this gave rise to sub-themes. All sub-themes with similar codes were used to develop themes as shown in table 1

and 2 below. A second nurse researcher with expertise in qualitative research (the researcher's supervisor) reviewed the data set and discussed codes, sub-themes and themes with the researcher thus arriving at the final consensus.

Table 1: Coding process

Interview Extract	Codes
…after I was told that it is cervical cancer, I was sad. I had thoughts of fear, especially thinking about how this cancer is not curable, I had to stop doing business as I was not able to run the business and at the same time attend to the hospital for my care, I could not farm to get money for home development. This was mostly because I was thinking that I could die plus also I did not have the energy for me to carry out such activities due to the nature of the medication I was receiving which was making me weak	• **Cervical cancer diagnosis brought sadness** • **Fear of disease incurability** • **Loss of hope due to diagnosis** • **Inability to cope with home activities** • **Loss of business due to diagnosis** • **Cancer treatment causing weakness**

After generating codes, the patterns of codes with a similar meaning were grouped to generate sub-themes that aligned with the pre-determined themes (deductive reasoning). Pre-determined themes were further refined to reflect the complex aspects of cervical cancer survivors.

Table 2: Sub-themes and themes generation

Code	Sub-theme	Theme
• Inability to cope with home activities • Disruption of home routines due to treatment • Experiencing numbness in hands and legs • Experiencing nausea and vomiting • Treatment improved cancer symptoms	• Reported physical effect of the disease and its treatment on an individual	• Interpersonal experiences of cervical cancer survivors

3.10 Trustworthiness

Throughout the research process, trustworthiness is a crucial consideration since it indicates the rigor of the investigation. In qualitative research, trustworthiness is measured by a number of factors, such as authenticity, transferability, authenticity, confirmability, and dependability(107). In order to enhance trustworthiness in this study, Guba's constructs of ensuring trustworthiness thus credibility, dependability, confirmability, and transferability were applied(107).

3.10.1 Credibility

Credibility is the confidence in the correctness of the data and interpretations of it by other people(107). Ensuring credibility involves performing the study in a way that enhances the findings of the study and putting procedures in place to prove correctness to outside readers(107). To ensure credibility, the researcher engaged participants in prolonged interviews, encouraging them to give more details in their responses. Adding to that persistent observation during developing codes, concepts and refining predetermined themes helped the researcher to accurately describe the data characteristics(108). The researcher

constantly read and reread and analysed the data, theorized about the meaning, and revised the concepts accordingly until the findings provided the intended depth of insight(108)**..**

3.10.2 Dependability

Dependability refers to the consistency of data across conditions and throughout time(107). To enhance dependability, the methodology for the research study has been fully described to allow other researchers to follow through and determine if the same results can be generated. An interview guide was also utilized ensuring that participants were not be asked different questions.

3.10.3 Confirmability

Pertains to objectivity, which is the possibility of two or more independent individuals agreeing on the accuracy, significance, or interpretation of the evidence(107). The interpretation of the study results was not based on the researcher's own preferences or viewpoints, but rather was grounded in the data. The focus was on the interpretation process embedded in the process of analysis in concert with the supervisor. A complete set of notes on decisions made during the research process, reflective thoughts, sampling, research materials developed, emergence of the findings and information about the data management was submitted to the supervisor to enable her to verify the transparency and findings of the study path.

3.10.4 Transferability

Transferability is the degree to which qualitative research can still generate the same results if conducted on different people or environments(107). Rich accounts of the methodology and descriptive data on participants has been given to allow the reader to evaluate the extent to which the results may be applicable in other settings**.**

3.11 Ethical Considerations

Ethical approval was sought from the Research and Ethics Committee of the Muhimbili University of Health and Allied Sciences; Ref.No.DA.282/291/01.C/2090. Permission to conduct research at MNCC was obtained from Kamuzu Central Hospital Ethics Committee;

Ref: nhsrc/2024. Ethical approval was also sought from National Health Services Research Committee of Malawi; Protocol # 24/02/4375. Study participants were recruited after obtaining an informed consent by signing an informed consent form which provided details of the participants' right to participate and withdraw from the study, risks, benefits, and an audio recording of the interview. Participants' identities were kept anonymous and the researcher made sure that participants confidentiality was kept throughout the study.

CHAPTER FOUR

4.0 RESULTS

4.1 Social demographic data of the survivors

The qualitative study involved twelve (12) cervical cancer survivors at the National Cancer Center in Malawi, aged between 42 and 76. Participants included six businesswomen, four farmers, and two retired professionals who were an education specialist and a teacher. Educational backgrounds varied, with four having primary education, three secondary education (Form 4), three with no formal education, one holding a primary teaching certificate, and one an MSC degree. Out of 12 participants five (5) were married Six (6) were widowed, and one(1) divorced. See Table 3.

Table 3: The social demographic characteristics

Participant Serial number	Age	Occupation	Education Status	Marital status	Residence	Time since diagnosis of disease
P1	50	Business woman	Primary level STD3	Married	Chitedze-Lilongwe	4 months
P2	49	Business woman	Form 4	Married	Jenda-Kasunga	12 months
P3	56	Business woman	Primary level STD8	Married	Area 23-Lilongwe	8 months
P4	59	Farmer	Primary level STD6	Widowed	Dedza	6 months
P5	62	Farmer	Never attended formal education	Widowed	Mchinji	15 months
P6	56	Business woman	Never attended formal education	Married	Lilongwe	48 months

P7	62	Farmer	Never attended formal education	Widowed	Dedza	13 months
P8	42	Business woman	Form 4	Divorced	Mchinji	9 months
P9	58	Business woman	Form 4	Widowed	Kabudula-Lilongwe	8 months
P10	76	Retired Education Specialist	MSC	Widowed	Area47 - Lilongwe	17 months
P11	69	Retired teacher	Primary Teaching Certificate	Widowed	Area12 Kauma - Lilongwe	7 months
P12	46	Farmer	Primary level STD8	Married	Mponda-Dowa	5 months

4.2 Themes and Subthemes emerged from the study

The study involved cervical cancer survivors who were on active treatment for at least three months and follow-up. Survivors were asked several questions pertaining to their experiences as cervical cancer survivors at the intrapersonal, interpersonal, community and institutional levels. From the analysis four themes were developed with their sub-themes (Table 4).

Table 4: Subthemes and Themes

THEME	SUB-THEME
Intrapersonal experiences of cervical cancer survivors	a) Reported physical effect of the disease and treatment b) Financial impact disease and associated treatment c) Emotional experiences of individuals living with cervical cancer d) Coping mechanisms employed survivors
Interpersonal experiences of cervical cancer survivors	a) Reported Changes in social relationship b) Support from family and friends c) upset in sexual relationships
Community experiences of survivors	a) community treatment towards cervical cancer survivors b) community misconceptions about cervical cancer c) community value for life
Institutional experiences of cervical cancer survivors	a) Positive institutional experiences b) Challenges with healthcare

4.2.1 Intrapersonal Experiences of Cervical Cancer Survivors

In a pre-determined theme, survivors were asked on how the diagnosis of cervical cancer affected their personal life. Four sub-themes were developed from the findings: a) Reported physical effect of the disease and its treatment on an individual, b) Financial impact of

cervical cancer and its treatment on an individual, c) Emotional experiences of individuals living with cervical cancer, d) Coping mechanisms employed by cervical cancer survivors.

a) Reported Physical Effects of Disease and Treatment

Participants reported wide range of physical effects that happened to them during the course of their illness which were due to disease itself which changed their life in various aspects. The most reported symptoms included general body weakness and fatigue which greatly impacted participants' daily lives, affecting their ability to perform routine tasks. One survivor shared,

"*…after I noticed the signs, I was experiencing general body weakness and fatigue. I did not have the energy and capability to cope with the activities I used to do. Things would just delay things at home" (p11)*

Survivors also reported various side effects from cervical cancer treatment. These side effects included changes in body organ functioning. One woman narrated,

"*…once I received treatment, I could get up to two weeks without being able to properly use my legs and arms due to numbness. When walking I would drag my feet as they felt heavy, my hands would shake that I could not hold things properly without having them falling off." (p2)*

Survivors also shared that treatment side effects like nausea, vomiting, and diarrhea made them feel like dying due to lack of strength;

"I used to experience a lot of medication side effects like nausea, vomiting, and diarrhea. These side effects made me feel like I was dying as I was left feeling dizzy and without strength." (p3)

Despite the challenges, many survivors reported on the benefits of treatment. Survivors noted improvements in their physical health and physical capabilities in their everyday lives. The following participant excerpt explains:

"Now that I am on follow up after finishing the cycles for chemotherapy, I have seen that I have regained my strength. Now I am able to do my household chores without delay. Back home I have a project where I am building a house, and I am able to even carry the bricks to the brick layers."(p11)

b) Financial Impact of Disease and Associated Treatment

Survivors explained how the disease and its treatment affected them to the point of not being able to run their businesses causing disruptions in their financial citing difficulties in providing for basic needs and hospital transport.

"*I used to own a business which would help fend for my family, now this disease and its medication leave me feeling weak most of the times and that has caused my business to stand still, it is difficult to find food, clothe the family and even pay fees for the children. There are times that we fail to find money that I should use for transportation to the hospital for mu appointments."(p1).*

Others also narrated that due to their inability to source money, they are struggling financially up to the point of selling home items to cover for hospital transportation costs. One respondent expressed:

"*Cervical cancer also changed my life financially; I cannot do the activities that used to bring me money as before. Now I have sold most of the items that I used to own at home just for me to be able and cater for my transport needs to the hospital. I am struggling financially."(p6).*

c) Emotional Experiences of an Individual Living with Cervical Cancer

The emotional toll of cervical cancer was profound, with feelings of fear, anxiety, and depression commonly reported. Survivors mentioned experiencing these emotions mostly after their diagnosis. one participant stated:

" This diagnosis gave me fear and anxiety; I had questions whether I will continue with this life or die, it was just too much for me to bear at the time. I was depressed for weeks"(p7)

Survivors also expressed that upon being told that they had cancer they were sad, surprised and worried about their lives.

" I was sad and surprised after being told its cancer. I had so much worry because this is something strange. When people hear about it, they equate it to death and I was worried that I might die just soon. Like everyone else who has received bad news, sadness is part of it."(p12)

d) Coping Mechanisms Employed by Survivors

Survivors reported employing various coping mechanisms to manage their diagnosis and treatment. Accepting the diagnosis and religious faith helped the survivors to cope with their diagnosis. One woman explained,

"I accepted this diagnosis as it was already in my body. I look at it as nothing new because these things were written in the bible that there shall be strange disease upon us in the last days. Whether with disease or without disease all we wait for is death on this earth."(p4)

Survivors also reported that hearing other patient stories gave them hope and helped them to cope with the disease

"After I met my fellow patients, my spirit was uplifted. Hearing their stories encouraged me not to lose hope. Some patients gave me examples of them, they told me the length of time that they have had the diagnosis and this gave me hope and helped me cope better."(p1)

The survivors also shared that resolving not get hurt by bad comments from people, staying alone and protecting children from hurt help them cope

"I resolved to not get offended by hurtful and mocking things that people say. It is for the sake of my peace of mind and better functioning of my body. I choose to lock my door and just be by myself. I even told my children not to get hurt by such things being said."(p8)

4.2.2 Interpersonal Experiences of Cervical Cancer Survivors

In another predetermined theme, survivors were asked on how their diagnosis impacted their social relationships. Three sub-themes emerged from the analysis under this theme: a)

Reported changes in social interactions, b) support from family and friends, c) stigma and discrimination from close friends, d) Upset of sexual relations

a) Reported Changes in Social Interactions

Survivors expressed that their cancer diagnosis brought a change in their interactions with family and friends. Some survivors described that the situation created a greater sense of closeness with family and friends.

"*My interactions with my children did not change for the worse but for the better. They check on me frequently making sure I am ok. My relatives also know that I am sick, they show me love even more. When it comes to my friends, despite knowing that I have cancer they show up at my house just to cheer me up."(p10)*

Other survivors also narrated how cervical cancer negatively impacted their relationships and interactions with family and friends.

"I and my children….phew… we do not interact well. They insult me almost on daily basis, they are not nice to me. They say a lot of bad things which a child cannot say to her parent. They talk as if I got the disease deliberately? I feel like they do not care about me and I feel like they would be happy if I die because I am a burden to them" (p5).

Stigma and discrimination were also prominent issues faced by cervical cancer survivors among their friends. One survivor showed this response by saying

" My friends shun me. when I approach them to maybe chat with them, I find they would leave one by one. They say I stink and smell as if I do not take care of myself the way a woman should, they do not want to associate with me."(p1)

b) Support from Family and Friends

Survivors were asked on how they looked at the support given by family and friends. Some survivors expressed that their families and friends offered them support in form of practical help and finances.

"My husband took the leading role of helping me seek help in the hospitals. My husband and children provide for our financial needs at home, the children do household chores. My friends come to check on me and encourage me to continue with treatment it shows I am not alone."(p6)

Other survivors reported facing abandonment and lack of support from their family and friends acknowledging how their families distanced themselves after learning that they have been diagnosed with cervical cancer.

"After it was known that I have cervical cancer, my relatives abandoned me. I do not know why they abandoned me but I just realized that they keep their distance and they do not want to associate with me. I do not have anyone to support me in terms of money and food."(p5)

c) Upset In Sexual Relationships

Survivors reported changes in their intimate relationships citing that it as challenging for them to meet the sexual needs of their husbands which left them feeling useless to their husbands. One survivor shared:

" We stooped having sexual intercourse with my husband ever since the problem of cervical cancer came in. Each time, we try to have sex, we notice that I am bleeding. This issue of not having sexual intercourse makes me feel I am not enough for him as a wife. I cannot take care of his needs in the bedroom and to some extent I feel useless to him"(p6).

Additionally, other survivors reported that their diagnosis has caused their husbands to have extramarital affairs depicting that the wife is no longer useful.

"Due the diagnosis of cervical cancer my husband started having open extra marital affairs even though we stay together. It shows that I have no use to him right now because I cannot provide for his sexual needs"(p3)

4.2.3 Community Experiences of Survivors

Survivors were asked on how the community treated them after their cervical cancer diagnosis in this predetermined theme 3 sub-themes emerged; a) Community treatment

towards cervical cancer, b) Community misconceptions about cervical cancer, c) Community value for life

a) **Community Treatment Towards Cervical Cancer Survivors**

Survivors expressed that they faced lack of understanding from the community about their situation. This is evident from the following participant excerpt:

"The community at large has different levels of understanding. There are others who do not really get concerned when one is sick, you find instead of sympathizing with you. I do not know whether it is because of the area I am staying, it is in the village, when people are passing by my house sometimes, I may just hear them scream that she has cancer!!!."(p8)

b) **Community Misconceptions About Cervical Cancer**

Survivors who participated in this study reported that community misconceptions about cervical cancer were common. One survivor explained how community members believed that cancer is from witchcraft by saying:

"In the communities, there is this thinking that cancer is a form of disease which comes because someone has been bewitched. I wasted time seeking traditional help than going to the hospital because of this belief "(p1).

Survivors also mentioned on encountering incorrect beliefs about the disease citing that the community attached cancer diagnosis to promiscuity .

"The community sometimes perceive that one would get cervical cancer mostly because they have been promiscuous. Some perceive the patient as the worst sinner. The community associates cervical cancer only with people who sleep around with a lot of men."(p8)

Additionally, survivors described that the community attitude toward cervical cancer is it can be spread by contact at the same time there is attachment of suffering from the disease with immediate death. one woman explained by saying;

"The society also has the attitude that cervical cancer can be spread through contact or breathing the same air. There is also this perception that cancer is a killer disease more than HIV/AIDS and once an individual has the disease, he/she will die in no time"(p3)

c) **Community Value for Life**

Despite the misconceptions and bad treatment from community, some survivors expressed how the community at large has shown value for their lives. One participant narrated:

"My church groups have helped me a lot. They come to check on me, encourage me with the word of God and we pray together. Sometimes the church groups contribute some money for food and hospital transportation so I should find help and be better, it shows my life is valuable."(p7)

Additionally, other survivors shared how community groups showed that they care for their well-being by relieving them of some physical duties to focus on their recovery.

"The women groups which I belong to even go as far as fetching water for me so that I should bath or use around my house. When they find that my surrounding is not clean, the offer help allowing me to focus on recovery. This shows to me that they care about my well-being."(p4)

4.2.4 Institutional Experiences of Cervical Cancer Survivors

In another predetermined theme, survivors were asked on what their experiences were in the hospital. Two sub themes were developed: a) positive institutional influences, b) negative institutional influences

a) Positive Institutional Experiences

Survivors generally expressed satisfaction with the healthcare services they received. Survivors shared on how dedicated and attentive the healthcare workers were in treating them. One woman shared:

"*I am satisfied with the care that I am receiving. The people pay attention to my concerns and help me in time. There was a time I had lost a lot of blood, upon reaching here they made*

everything possible to stop the bleeding and I was transfused. People working in the hospital are dedicated to saving lives of patients"(p1).

Survivors also reported positive interactions with their healthcare providers, noting their respectful and understanding approach:

"*Generally, these people working in the hospital interact with us as their fellow human beings, they treat us with respect and understanding. Sometimes you find they joke with us and this makes the hospital a better place and we sometimes forget that we are patients" (p11).*

b) Challenges with Healthcare

Even though survivors expressed satisfaction with the healthcare they received citing disease recurrence, restarting treatment and missing patient records as some of the challenges they meet. The following excerpt shows this response so well:

"I am not completely satisfied with the care because there are reported cases of disease recurrence. It leaves me unsatisfied…sometimes at the doctor's consultation, it takes long for you to be seen. We sometimes face delay due to missing lab results or even files."(p2)

Survivors also narrated that they were met with other healthcare workers who treated them roughly sometimes while receiving care.

"Well, the people we would meet at the main hospital for cervices like radiology, pharmacy and laboratory would sometimes be rough in the way the handle and talk to us as patients. I would sometimes just choose to get these services at a private center and bring the results to the doctor"(p10)

Other survivors also narrated how the long distance to the cancer canter was a challenge for them to get the required help. One survivor lamented:

"*The distance we travel from home to get help her is just too long, and requires a lot of money for transport. When we fail to find the money, we just resort to miss the appointment because the distance is not walkable."(p8)*

Even though they hope to come and hope to receive treatment at the hospital survivors narrated that they are met with situations where they are being told that medication is out of stock and they return back home without being treated. One survivor explained by saying;

"You know there are times when you come to the hospital and only to be told that your chemotherapy is out of stock. It is bad for us mostly because we miss our doses and spend our transport money for nothing,"(p8)

CHAPTER FIVE

5.0 DISCUSSION

5.1 Introduction

This chapter discusses the principal findings of the study, discussion in relation to other studies, strengths and weaknesses of the study, implications of this study as well as recommendations.

5.1.1 Discussion in relation to other studies

The discussion in this sub-section focuses on the four specific objectives: intrapersonal experiences, interpersonal experiences, community experiences and institutional experiences of cervical cancer survivors.

5.1.2 Intrapersonal Experiences

The findings of this study reported that survivors experienced physical disruption which manifested in form of general body weakness, fatigue, body organ functioning changes, nausea, vomiting and diarrhea. Lacking strength and inability to perform routine tasks was also found to be a concern among the participants. Consistent findings were also reported by Dirar et al(49), in study conducted in Ethiopia on experiences of cervical cancer patients during follow-up care. The study revealed that women faced significant physical disruptions which limited their ability to carry out activities of daily living due to cervical cancer and its treatment(49). Similar to these findings, a study conducted in Tanzania also reported that cervical cancer patients experienced physical sufferings which made them not adjust well to their situation(66). Despite the physical disruption brought by the disease and its associated treatments, participants reported that that treatment alleviated their symptoms. Similarly, Millet et al (74), in a study to explore the physical and psychosocial well-being in the short and long term after treatment for cervical cancer found that participants reported improved physical well-being after treatment and this encouraged the patients to adhere to treatment with the hope of regaining their physical abilities(74). The participants in the current study

also reported on experiencing financial disruptions due to their inability run their businesses or do farm work. This caused some participants to sell their assets in attempts to get treatment. The financial disruption was compounded by increased demand for money to cover hospital transportation and provide for their basic needs at the same time. This situation may cause negative psychological consequences causing delays in the healing process. Chona et al(66) presented similar findings stating that cervical cancer reduced the ability of women to generate income imposing constant stress on them. Concurring also with these findings, Natuhwera et al(109) conducted a study in rural Ghana which revealed that cervical cancer causes debilitating economic hardships for women and their families by reducing their productivity and in turn making poverty worse. Emotional toll was also reported to be experienced by participants in this study. These findings are consistent with findings from studies done by Hughes et al (110), Binka et al(92) and Chona et al(66) where participants reported emotional distress in form of sadness, fear of disease recurrence, fear of death and depression upon receiving the news about their diagnosis. This has an impact on how well an individual may cope with the disease to improve adaptation, survival and well-being of the survivors(49). Participants in this study expressed on how accepting the diagnosis, religious faith, hearing other patient stories, support from family and friends and living in isolation helped them cope. On the same note, Ambikile et al(97), reported that religious faith, social support and isolation were common coping mechanisms employed by cervical cancer survivors in low resource settings. According to Bingo et al(111) spirituality, maintaining positive outlook and support from close family influences positive quality of life and reduces the cancer burden among patients(111).

5.1.3 Interpersonal Experiences

The women in this study reported on experiencing changes in their social relationships. Women reported on how cervical cancer diagnosis strengthened the love and bond in their families. This closeness improved the quality of life as the survivors felt that they were accepted by their families. The findings from this study correlate with those from a study done in Indonesia which showed that strong family relationships improves the patients quality of life thus emphasizing on need for hospital institutions to encourage family

engagement in provision of care to cancer patents(112). On the other hand, some women experienced disruption in social relationships explained by intolerance of family and friends and stigma from friends in such situations. Other studies have also reported on disrupted social relations which exacerbated the burden of the disease(92,113). The studies reported that social disruption increases the disease burden among the patients which reduces their quality of life. Some survivors in this study reported on experiencing abandonment and lack of support from their families and friends. This heightened their burden of living with the disease. Findings from a study done by Colter(114), on a group of young cancer patients showed that lack of support and abandonment has negative impact on the mental and physical health of cancer survivors. The current study also revealed that some women suffered upsets in their sexual lives which caused their partners to engage in extra marital affairs openly leaving the women feeling useless. The findings correlate those of Binka et al(92), who conducted a study to explore the experiences of cervical cancer patients in rural Ghana which found that inability to engage with sexual intercourse with their partners caused them low self-esteem, isolation and constant distress. There is need for male partner involvement in provision of care to these patients to promote empathy.

5.1.4 Community Experiences

This study revealed that survivors experienced negative treatment inform of mocking behavior from community. Adding on that, misconceptions that cervical cancer is a result of promiscuity, believing that cervical cancer can be transmitted through social contact and attaching cervical cancer to immediate death drives stigma towards survivors which impacts them negatively. This is consistent with findings from a study done in Chitwan, Nepal which explored qualitatively on the experiences of cervical cancer survivors(95). The study in Chitwan found that misconceptions relating to cervical cancer increase stigma, discrimination and mocking behaviors towards the survivors in the community(95). Participants in the current study also reported that some cultural beliefs like that cervical cancer is a result of being bewitched within the communities caused them to seek professional care late. In support of this evidence, Lee et al(65) in their study on exploring the complicity of cervical cancer screening in Malawi found that culture and society may

cause delay in seeking orthodox medicine which compounds the burden of the disease. In contrast, other participants experienced that the community valued their lives by providing them with hospital transportation and relieving them of some physical duties to focus on their recovery which made them feel that they were an important entity of the community, no evidence was found in literature to support these findings.

5.1.5 Institutional Experiences

The qualitative findings from this study indicated that there are positive influences within the healthcare system which are essential for improving the livelihoods of cervical cancer survivors. Most of the women described that they were satisfied with the care they received from the hospital. Participants described that the healthcare workers were dedicated, attentive and at the same time treated the patients with respect and empathy. This type of care improves overall patient experiences and outcomes of care. These findings are corroborated by a study conducted in South Africa which revealed that staff attitude has an impact on successful recovery of patients from terminal and chronic illnesses(101). On the contrary, some participants experienced receiving unsatisfactory care citing disease recurrence, missing patient records, harsh treatment by other healthcare workers, medication stock outs and long distances to treatment center as some of the challenges they met in their course of seeking care. These factors have a negative impact on individual patient outcomes. These findings are consistent with those from a study done in Ethiopia which explored on the experiences of cervical cancer patients during follow-up care. The findings of the study highlighted that negative institutional experiences can lead to adjustment difficulties in patients(49).

5.2 Strengths

Cervical cancer is a significant health issue in Malawi, with limited existing research on the experiences of survivors. This study provides a unique perspective and contributes valuable data currently missing.

5.3 Limitations

The study only employed in-depth interviews and the results of the study could not be triangulated. The study also used a theoretical framework which may have caused

confirmation bias and theoretical blindness to generate results on experiences of cervical cancer survivors in other centers in Malawi.

5.4 Conclusion

This study highlights the significant impact of cervical cancer on survivors in Malawi, encompassing intrapersonal, interpersonal, community and institutional changes.

Survivors and their communities lack knowledge about cervical cancer, leading to delayed diagnosis and treatment. Participants pointed out physical disruption due to disease and treatment causing physical limitations. Financial strain resulted mostly from treatment costs and inability to work. The diagnosis caused emotion distress which manifested in form of fear, sadness and anxiety. The diagnosis also had varying impact on social interactions where participants experienced strengthened relationships while others experienced disruption on social interactions. Supportive family, religious faith and other patient narratives were some of the coping mechanisms employed by the participants. Misconceptions about cervical cancer led to social isolation, stigma and discrimination among family friends and community at large. Also varied healthcare experiences were noted as some participants received good quality care while others faced challenges.

5.5 Recommendations

Recommendations for Improving the Experiences of Cervical Cancer Survivors in Malawi

Practice

There is need for comprehensive patient education on risk factors, symptoms, prevention, treatment options, and available support services. Establishment of patient support groups to provide emotional support, information sharing, and a sense of community for survivors should also be incorporated.

Hospitals are also encouraged to involve families in patient care to strengthen support networks and improve communication. Hospitals also need to conduct community outreach

programs to raise awareness about cervical cancer, dispel myths, and promote empathy for survivors.

Training

There is need for provision of training for healthcare professionals on cervical cancer, including symptom management, treatment options, and the importance of compassionate care. Healthcare professionals also need to be trained on culturally sensitive and respectful of survivors' beliefs and values to provide comprehensive care.

Policy

Reinforcing government-led public education programs to raise awareness about cervical cancer prevention and early detection. There is need to ensure adequate and consistent supplies of essential drugs for cervical cancer treatment and management in hospitals.

Future Research

Research can be conducted to explore the spiritual needs of cervical cancer survivors and develop appropriate interventions to address them. Also, studies can be done on disparities in cervical cancer outcomes and access to care among different population groups in Malawi.

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Appendix I. Consent form (English version)

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED HEALTH SCIENCES DIRECTORATE OF RESEARCH AND PUBLICATIONS

ID. NO _____ **Consent Form for Participating in a Research Study**

My name is **Chisomo Mtima,** a postgraduate student; pursuing a Master of Science in Oncology Nursing at Muhimbili University of Health and Allied Sciences (MUHAS) in the School of Nursing. I am researching on the lived experiences of cervical cancer survivors at the Malawi National Cancer Center.

The aim of the Study

This study aims to explore the lived experiences of cervical cancer patients receiving care at the Malawi National Cancer Center, Lilongwe Malawi.

The findings of this study will provide rich contribute will contribute to raising awareness about the experiences of cervical cancer survivors receiving care at the Malawi National Cancer Center thus providing a platform for their voices to be heard creating a more compassionate and supportive environment for cervical cancer survivors.

Procedure

I would like you to participate in this study. You are selected because you are among the patients who have completed cervical cancer treatment for more than three months. If you choose to participate you will be interviewed for about 45 minutes and will be audio recorded in order not to miss any information as the researcher cannot be quick enough to write everything you say.

Confidentiality

All responses will be kept confidential. This means that your responses will only be used for research and shared with MUHAS when necessary. I will ensure that any information

included in my report does not identify you as the respondent. No names will be included both during the interview and reporting findings.

Right to refuse or withdraw

It is your choice to participate in this study. Also, you don't have to talk about anything you don't want and you may stop the interview at any time for any reason without any repercussions. However, I encourage you to participate because your experience is very important in this study.

Benefits

Participating in this study may not benefit you personally, but your participation might provide useful information that will benefit others and improve the quality of life and positive health outcomes for you, your peers, and the health care system.

Risks

There will be no harm to you as a result of participation in this study although due to the nature of this study you might experience emotional discomfort when sharing your experience. If you experience any emotional discomfort, I will request the mental health specialist practicing at this cancer center to see you. This service shall be free of charge and this will only be done with your permission.

Whom to Contact

In case of any inquiry please contact the researcher, **Chisomo Mtima** from MUHAS, P. O. BOX 65001, Dar es Salaam, mobile number 0994 105 050. If you ever have questions about your rights as a participant, you may contact the Director of Research and Publications, at MUHAS. P.O. Box 65001, Dar es Salaam-Tanzania.

Signature

Do you agree to participate? Put a tick in the appropriate box

Participant agrees ☐ participant does NOT agree ☐

I, …….. have read the contents of this form and understood. My questions have been answered; I agree to participate in this study.

Signature of participant_____Date_____

Signature of researcher_____

Date_____

Appendix 2 Fomu Ya Chilolezo (Chichewa version)

NTHAMBI YAKAFUKUKUFUKU NDI KUSINDIKIZA MABUKU PA MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED HEALTH SCIENCES

NAMBALA YA ID. ☐ **Chikalata chopemphera chilolezo kuti mutenge nawo mbali pakafukufuku**

Dzina langa ndi **Chisomo Mtima,** ochita maphunziro a ukachenjede wa maphunziro a Unamwino Pamatenda a Khansa pa Muhimbili University of Health and Allied Sciences (MUHAS) maka munthambi ya maphunziro a unamwino. Ndikuchita kafukufuku pazomwe amayi omwe akudwala khansa yakhomo lachiberekero amakumana nazo pachipatala cha Malawi National Cancer Center.

Cholinga cha kafukufukuyu

Kafukufukuyu akufuna kuunikira pazomwe amayi omwe akudwala khansa yakhomo lachiberekero amakumana nazo pa Malawi National Cancer Center, ku Lilongwe, Malawi. Zotsatira zakafukufukuyu zithandiza kudziwa mavuto omwe odwala matenda a khansa yakhomo lachiberekero amakumana nawo. Zotsatira zakafukufukuyu zidzathandiziranso kutukula ntchito zophunzitsa anthu zokhudzana ndi umoyo wa anthu omwe adadwalapo nthenda yakhansa yakhomo lachiberekero omwe amalandira chithandizo pachipatala cha Malawi National Cancer Center mwa ichi zidzapereka mpata kwa amayiwa kuti amvedwe zomwe zidzabweretse mwayi wokonza malo otetezeka ndi ofunda kwa amayi omwe anadwalapo khansa yakhomo lachiberekero.

Ndondomeko

Ndikufuna kuti inuyo mutatenga nawo mbali mukafukufukuyu. Mwasankhidwa chifukwa ndinu mmodzi mwaamayi omwe alandirapo chithandizo pamatenda a khansa yakhomo lachiberekero kwa miyezi yoposa itatu. Ngati mungasankhe kutenga nawo mbali m'kafukufukuyu ticheza nanu pokufunsani mafunso kwa mphindi zosachepera makumi anayi ndi zisanu (45) ndipo pokambirana nanu tizikutepani mawu ndi cholinga choti tisaphonye zomwe muzidzafotokoza pakuti wochita kafukufukuyu sangakwanitse kulemba chilichonse chomwe mufotokoze.

Chinsinsi

Mayankho onse adzasungidwa mwachinsinsi. Izi zikutanthauza kuti mayankho anu adzagwiritsidwa ntchito pakafukufukuyu basi ndipo adzagawidwanso kwa a yunivesite ya MUHAS ngati kudzafunike kutero. Ndidzaonetsetsa kuti uthenga ulionse omwe udzaikidwe muzotsatira zakafukufukuyu usadzakutchuleni dzina lanu ngati mmodzi yemwe anatenga nawo mbali pakafukufukuyu. Mayina anu sadzagwiritsidwa ntchito pokambiranapo komanso muzotsatira zakufukufukuyu poonetsetsa kusunga chinsisi chanu.

Ufulu wokana kapena kusiyira panjira

Ndi chisankho chanu kutenga nawo mbali mukafukufukuyu. Komanso simudzakakamizidwa kunena zinthu zimene simukufuna kunena ndipo muthanso kuimitsa panjira zokambirana zathu nthawi ina iliyonse pachifukwa chilichonse ndipo simudzalandira chilango. Komabe, ndikukulimbikitsani kuti kutenga nawo mbali m'kafukufukuyu chifukwa zomwe mwakumana nazo ndi zofunikira pakafukufukuyu.

Phindu

Kutengapo gawo / kuthandizira pakafukufukuyu kutha kusakuthandizani inu pa inu nokha, koma kuthandizira kwanu kukhonza kupereka uthenga ofunikira omwe udzathandize ena komanso kupititsa patsogolo miyoyo ndikubweretsa umoyo wathanzi pa moyo wanu, amnzanu komanso ndondomeko za umoyo.

Ziphinjo

Sipakhala chophinja chilichonse pa inu chifukwa chotenga nawo mbali pakafukufuku ameneyu ngakhale kuti pena mukhoza kukhala okhudzika ndi chikumbu mtima chifukwa

cha zinthu zomwe munadutsamo pa nthawi yomwe mukudwala nthendayi. Ngati mungakhale okhudzika ndi chikumbu mtima, pali dongosolo loti mutha kuonedwa ndi kadaulo wa malingaliro amngwiro kuti akuthandizeni. Izi zidzachitika popanda inu kulipira kalikonse ndipo izi zidzachitika ndi chilolezo chanu.

Mungayankhule ndi yani

Ngati mungakhale ndi funso yankhulanani ndi ochita kafukufukuyu, **Chisomo Mtima** wa ku MUHAS, P. O. BOX 65001, Dar es Salaam, nambala yake yalamya ndi **0994 105 050**. Ngati mudzakhale ndi funso lokhudzana ndi ufulu wanu ngati wotenga mbali pakafukufukuyu, mutha kuyankhulana ndi Wamkulu wa Zakafukufuku ndi Kusindikiza Mabuku, pa MUHAS. P.O. Box 65001, Dar es Salaam-Tanzania.

Sayini

Mwalola kutenga nawo mbali? Chongani mubokosi loyenera

Wotenga nawo mbali wavomera ☐ Wotenga nawo mbali wakana ☐

Ine, ……... ndawerenga uthenga womwe uli mu ndondomekoyi ndipo ndamvetsetsa. Mafunso anga ayankhidwa; ndikuvomera kutenga nawo mbali m'kafukufukuyu.

Sayini yawotenga mbali_____Tsiku_____

Sayini yawochita kafukufuku _____

Tsiku_____

Appendix 3: Data Collection Tool; In-Depth-Interview-Guide (English version)

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED HEALTH SCIENCES

DIRECTORATE OF RESEARCH AND PUBLICATIONS

Title: Lived Experiences of Cervical Cancer Survivor's Throughout Illness Trajectory at the Malawi National Cancer Center

Basic Information about the Interview:

Thank you for your participation in this interview. Your insights are invaluable as we aim to enrich our understanding of lived experiences of cervical cancer survivors throughout their illness trajectory at the Malawi National Cancer Center. Your experiences and viewpoints are crucial to better understand the unique needs of cervical cancer survivors in Malawi. Today's conversation will contribute significantly to facilitate the initiation of targeted interventions to improve their quality of life of cervical cancer survivors in Malawi.

Purpose of the Interview: To explore the lived experiences of cervical cancer survivors throughout illness trajectory at the National Cancer Center in Malawi. Within this context, the objectives include understanding the intrapersonal, interpersonal, institutional and community experiences of cervical cancer survivors. Through these objectives, we aim to gain a comprehensive insight into the complex dynamics surrounding experiences of cervical cancer patients at the Malawi National Cancer Center.

Time of Interview:

Date:

Name of Interviewer:

IDI Number:

Recording and Storing Information

This interview will be audio-recorded for research purposes. All information collected will be stored securely on a computer accessible only with a password, limited to the project coordinator.

Introduction

1. Introduce Yourself: Provide your name, role, and affiliation with the study.
2. Explain the Purpose of the study: Clarify that the interview focuses on

.

3. Obtain Informed Consent: Request the interviewee's signature on the informed consent form.
4. Describe the Interview Structure: Outline the interview format, including audio recording, taking notes and assure confidentiality and anonymity.
5. Ask for Questions: Invite the interviewee to ask any questions or seek clarification.

Semi-Structured interview guide

Objective: *Exploring lived experiences of cervical cancer survivors throughout illness trajectory*

Demographic Information of the Participants

Participant	Age	Occupation	Education status	Marital status	Residence
P1					
P2					
P3					
P4					
P5					
P6					
P7					
P8					
P9					
P10					

P11					
P12					

Interview Content Questions

- Dear participant, we will discuss on your experiences of living with cervical cancer, how you perceive it personally, your experiences with people close to you, the community and at the hospital during your care its causes

1. Please would you tell us [me] about your understanding of cervical cancer?
   - ✓ Probe: what is cervical cancer, what causes it?
   - ✓ Probe: What are the risk factors of cervical cancer?
   - ✓ Probe: Who is at risk of cervical cancer?
   - ✓ Probe: How is cervical cancer prevented?
   - ✓ Probe: can cervical cancer be cured?
2. Please, would you tell me how the diagnosis of cervical cancer affect your personal life?
   - ✓ Probe: How did you receive the news about your diagnosis of cervical cancer?
   - ✓ Probe: what did the cervical cancer diagnosis mean to you?
   - ✓ Probe: what changes did you encounter in your body functioning?
3. How did your diagnosis of cervical cancer impact your social interactions?
   - ✓ Probe: How did it change the way you interacted with your family and friends?
   - ✓ Probe: What role did your family and friends played after your diagnosis?
   - ✓ Probe: How did family and friends perceive your cervical cancer diagnosis?
4. Would you please tell me how did the community treat you after your cervical cancer diagnosis?
   - ✓ Probe: What perception/attitudes does your community have about cervical cancer?
   - ✓ Probe: How did the people in the community treat you after your cervical cancer diagnosis?

- ✓ Probe: What role did community groups play after you were diagnosed with cervical cancer?

5. What were your experiences as a cancer patient at the hospital you received treatment?
   - ✓ Probe**:** how was your interaction with healthcare providers during your diagnosis and treatment
   - ✓ Probe: What is your perception of the care you received?
   - ✓ Probe: What were the positive things you experienced?
   - ✓ Probe: What were the negative things you experienced?

Summary (Interviewer summarizes the discussion)

Thank you for your participation. We appreciate for your contribution and time spent to discuss about lived experience of cervical cancer survivor. Do you have any questions? Any suggestions to improve the experiences of cancer survivors?

Appendix 4: Zipangizo Zotolelera Uthenga; Mafunso Otsogolera Zokambirana (Chichewa)

NTHAMBI YAKAFUKUKUFUKU NDI KUSINDIKIZA MABUKU PA MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED HEALTH SCIENCES

Mutu: Umoyo wa Amayi Omwe Anadwalapo Khansa Yakhomo Lachiberekero Nthawi Yolandira Thandizo Malawi National Cancer Center

Chiyambi cha Zokambirana Zathu:

Zikomo kwambiri potenga nawo mbali pakafukufukuyu. Maganizo anu ndi ofunika kwambiri pamene tikufuna kukuza nzeru zathu paumoyo wa amayi omwe akudwala nthenda yakhansa yakhomo lachiberekero panthawi yolandira thandizo pachipatala cha Malawi National Cancer Center. Zomwe munakumana nazo ndi maganizo anu ndi ofunika pofuna kudziwa zosowekera za omwe akudwala khansa yakhomo lachiberekero m'Malawi muno. Kukambirana kwalero zidzathandizira kwambiri pantchito yotukula moyowa amayi omwe anadwalapo khansa yakhomo lachiberekero ku Malawi kuno.

Cholinga cha Zokambirana: Kuunikira pazomwe amayi omwe akudwala khansa yakhomo lachiberekero amakumana nazo polandira thandizo pa chipatala National Cancer Center ku Malawi. Potengera izi, zolinga zake ndi monga kumvetsetsa zochitika mwa anthu, pakati paanthu, pamalo olandilira chithandizo pachipatala, ndi m'dera momwe amayi omwe aakudwala/anadwalapo khansa yakhomo lachiberekero. Kudzera muzolinga zimenezi, tikufuna kudziwa kotheratu zokhudza zinthu zosiyanasiyana zomwe amayi omwe akudwala/anadwalapo khansa yakhomo lachiberekero pa Malawi National Cancer Center.

Nthawi ya zokambirana:

Tsiku:

Dzina la Ochita Kafukufuku:

Nambala ya ID:

Kutepa ndi Kusunga Uthenga

Mawu a zokambiranazi adzatepedwa kuti adzagwiritsidwe ntchito pa zakafukufukuyu basi. Uthenga wonse womwe udzatoleredwe udzasungidwa mwachinsinsi mukompyuta yomwe idzakhale ndi mawu achinsinsi oyiyatsira omwe azidzadziwidwa ndi wotsogolera kafukufukuyu basi.

Chiyambi

1. Dzitchuleni Dzina: Perekani dzina lanu, udindo wanu komanso zomwe mukuchita mukafukufukuyu.
2. Fotokozani Cholinga cha Kafukufuku: Tchulani zomwe kafukufukuyu akufuna
3. Pezani Chilolezo kwa Otenga Nawo Mbali: Pemphani otenga nawo mbali kuti aike sayini pachikalata chopemphera chilolezo.
4. Fotokozani Mmene Zokambirana Ziyendere: Fotokozani dongosolo la zokambirana, kuphatikizapo kutepedwa kwa mawu, kulemba uthenga ndi kusindikiza za chinsinsi ndi kusaululidwa.
5. Perekani mpata wofunsa mafunso: Mupatseni mpata wotenga nawo mbali pakafukufukuyo kuti afunse mafunso kapena apemphe kuti mufotokoze bwino lomwe.

Zotsogolera pa Zokambirana

Cholinga: *Kuunikira pazomwe amayi omwe akudwala/anadwalapo khansa yakhomo lachiberekero anakumana nazo polandira thandizo*

Mbiri ya Wotenga Nawo Mbali Pakafukufuku

Wotenga mbali	Zaka	Ntchito	Maphunziro	Okwatira(wa)/Osakwatira(wa)	Kokhala
P1					
P2					

P3					
P4					
P5					
P6					
P7					
P8					
P9					
P10					
P11					
P12					

Mafunso a pa Zokambirana

- Wokondedwa Mayi, tikambirana za mmene mumakhalira mukudwala khansa yakhomo lachiberekero, mmene mumazionera, mmene munakhalira ndi anthu, anthu a m'dera komanso kuchipatala panthawi yomwe m'malandira thandizo
  1. Mungatiuzeko zokhudza khansa yakhomo lachiberekero?
     - ✓ Funso: khansa yakhomo laciberekero ndi chiyani, chimayambitsa ndi chani?
     - ✓ Funso: Chomwe chimamuika munthu pachiophyezo chodwala khansa yakhomo lachiberekelo ndi chani?
     - ✓ Funso: Amene amakhala pachiopsezo cha khansa yakhomo lachiberekero ndi ndani?
     - ✓ Funso: Khansa yakhomo lachiberekero ingapewedwe bwanji?
     - ✓ Funso: Kodi khansa yakhomo lachiberekero ndiyochizika?
     - ✓ Funso: Kupezeka kwanu ndi khansa ya khomo lachiberekelo kunasintha bwanji umoyo wanu watsiku ndi tsiku?
  2. Mungandiuzeko mmene kupezeka kwanu ndi khansa ya khomo lachiberekero kunasithira moyo wanu watsiku ndi tsiku?

- ✓ Funso: Munaulandira bwanji uthenga wa kupezeka kwanu ndiu khansa ya khomo lachiberekelo?
- ✓ Funso: Kupezeka kwanu ndi khansa ya khomo lachiberekelo kunatanthauza chani mmoyo mwanu?
- ✓ Funso: Kupezeka kwanu ndi khansa ya khomo lachiberekero kunasintha bwanji kagwiridwe ntchito ka thupi lanu?

3. Kupezeka kwanu ndi khansa yakhomo lachiberekero kunakhudza bwanji kakhalidwe kanu ndi anthu?
   - ✓ Funso: Zinasintha bwanji mmene mumakhalira ndi abale anu ndi anzanu?
   - ✓ Funso: Abale anu ndi anzanu anatenga udindo wanji mutauzidwa zoti muli ndi khansa yakhomo lachiberekero?
   - ✓ Funso: Abale anu ndi anzanu analandira bwanji kuuzidwa za nthendako?
4. Mungandiuzeko momwe anthu a m'dera lanu amachezera/kukhalira nanu mutauzidwa zoti muli ndi khansa yakhomo lachiberekero?
   - ✓ Funso: Anthu a m'dera lanu amaitenga bwanji nkhani ya kupezeka kwanu ndi nthenda yakhansa yakhomo lachiberekero?
   - ✓ Funso: Anthu a m'dera lanu amacheza nanu/kukuonani motani atadziwa zoti muli ndi khansa yakhomo lachiberekero?
   - ✓ Funso: Anthu a m'dera lanu anatenga udindo wanji atadziwa za kupezeka kwanu ndi khansa yakhomo lachiberekero?
5. Mudakumana ndi zotani kuchipatala chomwe mumalandirako thandizo?
   - ✓ Funso**:** Ubale wanu ndi anthu ogwira ntchito muchipatala panthawi yokuyezani komanso kukupatsani thandizo unali otani/umakhala otani?
   - ✓ Funso: Mukuona kwanu chithandizo chomwe mukulandira/munalandira ndi chokwanira??
   - ✓ Funso: Zinthu zabwino zomwe munakumana/mukukumana nazo pa nthawi yolandira chithandizo ndi ziti?
   - ✓ Funso: Zinthu zoipa zomwe munakumana/mukukumana nazo pa nthawi yolandira chithandizo n ndi ziti?

Zikomo kwambiri chifukwa chitenga nawo mbali pakafukufukuyu. Ndife othokoza chifukwa chakupereka nthawi yanu ndinso kuthandizira kuyankha mafunso pa zomwe anthu odwala/amene anadwalapo khansa ya khomo lachiberekelo amakumana nazo. Muli ndi mafunso ena alionse? Ngati pali zina zomwe mukona zikhoza kuthandiza kupititsa patsogolo miyoyo ya anthu omwe akudwala/anadwalapo khansa ya khomo lachiberekero?

Appendix 5: Ethical clearance –MUHAS

UNITED REPUBLIC OF TANZANIA

MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

OFFICE OF THE DIRECTOR – RESEARCH, PUBLICATIONS AND INNOVATION

Ref. No.DA.282/298/01.C/2090 Date: 11/03/2024

MUHAS-REC-03-2024-2090
CHISOMO MTIMA
MUHAS

RE: APPROVAL FOR ETHICAL CLEARANCE FOR A STUDY TITLED: LIVED EXPERIENCE OF CERVICAL CANCER SURVIVORS AT THE MALAWI NATIONAL CANCER CENTER

Reference is made to the above heading,

I am pleased to inform you that the Chairman has on behalf of the University Senate, approved ethical clearance of the above-mentioned study, on recommendations of the Senate Research and Publications Committee meeting accordance with MUHAS research policy and Tanzania regulations governing human and animal subjects research.

APPROVAL DATE: 11/03/2024
EXPIRATION DATE OF APPROVAL: 11/03/2025

STUDY DESCRIPTION:
Purpose:

To explore the lived experiences of cervical cancer survivors throughout illness trajectory at the National Cancer Center in Malawi

The approved protocol and procedures for this study is attached and stamped with this letter, and can be found in the link provided: https://irb.muhas.ac.tz/storage/Certificates/Certificate%20-%2015363.pdf and in the MUHAS archives.

The PI is required to:

1. Submit bi-annual progress reports and final report upon completion of the study.
2. Report to the IRB any unanticipated problem involving risks to subjects or others including adverse events where applicable.
3. Apply for renewal of approval of ethical clearance one (1) month prior its expiration if the study is not completed at the end of this ethical approval. You may not continue with any research activity beyond the expiration date without the approval of the IRB. Failure to receive approval for continuation before the expiration date will result in automatic termination of the approval for this study on the expiration date.
4. Obtain IRB amendment (s) approval for any changes to any aspect of this study before they can be implemented.
5. Data security is ultimately the responsibility of the investigator.
6. Apply for and obtain Data Transfer Agreement (DTA) from NIMR if data will be transferred to a foreign country.
7. Apply for and obtain Material Transfer Agreement (MTA) from NIMR, if research materials (samples) will be shipped to a foreign country.
8. Apply for and obtain permission to publish the results from National Institute for Medical Research. The application should be before submitting to a publisher and not concurrently through the email publications@nimr.or.tz.
9. Any researcher, who contravenes or fail to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine as per NIMR Act No. 23 of 1979, PART III section 10 (2)
10. The PI is required to ensure that the findings of the study are disseminated to relevant stake holders.
11. PI is required to be versed with necessary laws and regulatory policies that govern research in Tanzania. Some guidance is available on our website https://drp.muhas.ac.tz/.

Dr. Nahya Salim Masoud,

Chairperson, MUHAS Research and Ethics Committee

University of Health and Allied Sciences
DIRECTOR
Research, Publications & Innovations
P.O. Box 65001

Appendix 6: Ethical approval Malawi

REF. NO. KCH/RESEARCH
TELEPHONE NO.: (265) 753 555
TELE FAX NO.: (265) 756 380

PLEASE ADDRESS ALL COMMUNICATIONS TO: THE HOSPITAL DIRECTOR
E-MAIL: Kch@sdnp.org.mw

Ref : nhsrc/2024

MINISTRY OF HEALTH
KAMUZU CENTRAL HOSPITAL
P. O. BOX 149
LILONGWE
MALAWI
22ND MARCH 2024

The Chairman,
National Health Sciences Research Committee,
P.O. Box 30377,
Lilongwe 3

Dear Sir,

LETTER OF SUPPORT TO CONDUCT A STUDY TITLED"LIVED EXPERIENCES OF CERVICAL CANCER SURVIVORS AT THE MALAWI NATIONAL CANCER CENTRE"

Support is hereby being given to the researcher to go ahead and submit their proposal to your distinguished committee.
We will await your committee's scrutiny of the proposal and feedback.
Many thanks.

KAMUZU CENTRAL HOSPITAL DIRECTOR
02 APR 2024
P.O BOX 149 LILONGWE

Jonathan Ngoma
Hospital Director

Appendix 7: Permission letter –KCH

Telephone: a + 265 789 400
Facsimile: + 265 789 431

All Communications should be addressed to:

The Secretary for Health



In reply please quote No. MED 4/36c
MINISTRY OF HEALTH
P.O. BOX 30377
LILONGWE 3
MALAWI

6th June, 2024

Chisomo Mtima
Muhimbili University

Dear Sir/Madam

RE: PROTOCOL # 24/03/4415: Lived Experiences of Cervical Cancer Survivors at The Malawi National Cancer Centre by Chisomo Mtima of Muhimbili University of Applied Sciences, Dar Es Salaam Tanzania/Kamuzu Central Hospital.

Thank you for the above titled proposal that you submitted to the National Health Sciences Research Committee (NHSRC) for review. Please be advised that the NHSRC has **reviewed** and **approved** the above titled study.

- **APPROVAL NUMBER : 4415**
- The above details should be used on all correspondences, consent forms and documents as appropriate.
- **APPROVAL DATE : 06/06/2024**
- **EXPIRATION DATE : 05/06/2025**
  This approval expires on **05/06/2025**. After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the NHSRC Secretariat should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the NHSRC within 10 working days using standard forms obtainable from the NHSRC Secretariat.
- **MODIFICATIONS**: Prior NHSRC approval using forms obtainable from the NHSRC Secretariat is required before implementing any changes in the protocol (including changes in the consent documents). You may not use any other consent documents besides those approved by the NHSRC.
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the NHSRC using standard forms obtainable from the NHSRC Secretariat.
- **QUESTIONS**: Please contact the NHSRC on phone number *+265 999397913* or by email on mohdoccentre@gmail.com.
- **OTHER**: Please be reminded to send in copies of your final research results for our records (Health Research Database).

Kind regards from the NHSRC Secretariat.

National Health Sciences Research Committee
2024 -06- 06
APPROVED

.....

For: CHAIRPERSON, NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE
Promoting Ethical Conduct of Research[1]

Executive Committee: *Dr. M. Joshua (Chairperson), Dr. F. Sinyiza (Vice-Chairperson)*
Registered with the USA Office for Human Research Protections (OHRP) as an International IRBIRB Number IRB00003905 FWA00005976