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Survival Status, Pre-post Treatment Quality of life, Sexual and Psychosocial Experience among Cervical Cancer Patients

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DEDICATION

This dissertation is dedicated to all Ethiopian women who have suffered from cervical cancer sequelae and lost their lives.

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ACRONYMS AND ABRREVATIONS

ADC	Adenocarcinoma
AHR	Adjusted Hazard Ratio
ASIR	Age Specific Incidence Rate
ASMR	Age Specific Mortality Rate
CI	Confidence Interval
CIN	Cervical Intraepithelial Neoplasia
CHR	Crude Hazard Ratio
EORTC QLQ-CX	European Organization of Research and Treatment for Cancer
FIGO	International Federation of Gynecology and Obstetrics
GLOBOCAN	Global Burden of Cancer
HPV	Human Papilloma Virus
hrHPV	High-risk Human Papilloma Virus
LMIC	Low- and Middle-Income Countries
LBC	Liquid-Based Cytology
MOH	Ministry of Health
MMR	Mixed-Methods Research
QOL	Quality of Life
HRQOL	Health Related Quality of Life
IQR	Interquartile Range
RR	Relative Risk
RS	Relative survival
TASH	Tikur Anbessa Specialized Hospital
SCC	Squamous Cell Carcinoma
SCJ	Squamocolumnar Junction
SPSS	Statistical Package for Social Scientists
SR	Survival Rate
VIA	Visual Inspection Acetic Acid
WHO	World Health Organization

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ABSTRACT

Background and Rationale: In 2020, there were over 604,000 new cases of cervical cancer worldwide and over 342,000 deaths from the disease. In Eastern and Middle Africa, cervical cancer is the most common cancer. In Ethiopia, current statistics indicate that cervical cancer is the second most commonly diagnosed cancer and is the leading cause of cancer-related death in women. Cervical cancer survival rates vary throughout the world and are commonly associated with the country's development status. As survival rates of cervical cancer patients increase, their quality of life becomes a more important issue. Understanding the experience and recovery process of cervical cancer survivors is essential to bring attention to their sexual and psychosocial needs.

Objective: This study was aimed to assess the survival status, pre- & post-treatment quality of life, sexual and psychosocial experiences of women with advanced stage cervical cancer and their partners at Tikur Anbessa Specialized Hospital.

Methods and materials: An explanatory sequential mixed methods design was utilized. Quantitative method was employed in Paper 1 & Paper 2 using a prospective cohort design. Qualitative method, on the other hand, was utilized in Papers 3 & 4 employing a phenomenological design. A total of 180 women with advanced stage cancer were recruited and followed for one year. The data collection was categorized into three phases. During phase I, baseline information on sociodemographic characteristics, reproductive history, pathological and clinical characteristics, treatment start date, diagnosis date, co-morbidities and pre-treatment QoL were collected (Papers 1 & 2). After six months of phase I data collection, phase II data were collected. Post-treatment QoL and qualitative data collection were carried out in this phase (Papers 3 & 4). Phase III data collection took place at the end of the cohort study, one year following each participant's enrollment. During this phase, survival status data were collected (Paper 1). The study period was from January 10/2022 to September 20/2023. Quantitative data entry and analysis were completed in SPSS version 29. Descriptive statistics were used to examine participant characteristics. The Kaplan-Meier procedure, log-rank test, bivariate and multivariate Cox regression (Paper 1), Kolmogorov-Smirnov and the Shapiro-Wilk tests (Paper 2) were computed. The audio record of qualitative data was transcribed, translated and coded. The identified codes were sorted into different subthemes. Finally, the subthemes were organized into themes. The data was analyzed with the assistance of MAXQDA software (Papers 3 & 4).

Results: For patients in FIGO stage IVB, the estimated mean survival time at one-year follow-up was 5.706 months (95% CI: 3.785-7.627), whereas for those in stages II & III, it was 11.537 months (95% CI: 11.199-11.887) ($P < 0.001$). Patients with anemia had an estimated mean survival time of 7.235 months (95% CI: 5.248-9.222), which is significantly ($P < 0.001$) less than those without anemia. When global health status QoL was compared before and after cancer therapy, the median score increased from 66.67 [47.92-75] to 83.33 [66.67-83.33], which was statistically significant. Women with a poor QoL score in terms of global health had a 4.01 times higher chance of dying compared to those with high global health QoL scores ($P = 0.015$). The majority of women identified their main experiences with sexual problems were pain, bleeding, and a lack of interest. Women reported that conflicts about sex were one of the main sources of disagreement with their husbands. One of the main challenges raised by women was the dearth of information on sexual health.

Conclusions: The one-year cumulative survival rate among advanced stage cervical cancer patients was 77%. Global health QoL and the majority of functional QoL scores significantly improved following six months of cancer treatment, but there was no discernible change in terms of sexual enjoyment, sexual function, or activity. Sexual functioning was immediately impacted by the physiological changes that people with cervical cancer experience after undergoing cancer therapy. Consequently, these altered sexual function-related physiological states have more detrimental effects on survivors' psychological health. Psychosocial support plays a critical role in mitigating adverse psychological reactions in patients with cancer. Most male partners had supported their female partners in diverse ways during the treatment and follow-up process.

Recommendations: Women in the community ought to get education regarding the prevention, screening, and treatment of cervical cancer. Beyond the Tikur Anbessa Specialized Hospital Oncology Center, focus should be placed on expanding radiotherapy centers throughout the country. Sexual counselling must be taken into account in every facet of cervical cancer treatment.

Key words: Survival status; advanced stage; cervical cancer; pre-treatment; post-treatment; quality of life; psychosocial; Sexual experience; male partners; qualitative; Ethiopia

CHAPTER 1: INTRODUCTION

Background and Justification

Cervical cancer is a malignant epithelial growth that develops in the uterine cervix. The majority of cervical cancer cases can be prevented by receiving regular screenings, treating precancerous lesions, and receiving the human papilloma virus (HPV) vaccination. Cervical cancer, however, continues to be the fourth most frequent disease in women worldwide because of insufficient screening programs in many parts of the world (1). The primary cause of cervical pre-cancer and cancer is persistent or chronic infection with one or more of the “high-risk” (or oncogenic) types of human papillomavirus (HPV). HPV is the most common infection acquired during sexual relations, usually early in sexual life (2).

Determining the extent and location of cancer in the body is known as cancer staging. Based on the size of the initial (primary) tumor and the degree to which the disease has spread throughout the body, indicates the severity of the cancer. Determining the cancer's stage aids in developing a prognosis and a treatment strategy for each patient (3). The overall survival and recurrence probability are linked to the International Federation of Gynecology and Obstetrics (FIGO) tumor staging system (4). Depending on the patient's condition and the stage of their cervical cancer, therapies such as radiation therapy, chemotherapy, or a combination of these may be administered. When cervical cancer is detected in its early stages, it can be treated with radiation therapy or surgery; however, most late-stage tumors require a combination of treatments (4–6).

The term "survivor" describes the life of a person after diagnosis of the disease (4). Globally, cervical cancer survival rates differ and are frequently linked to a nation's level of development (5). Survivorship care is a crucial part of providing high-quality care for patients at every stage of the cancer continuum, in addition to early detection and standard therapies. Survival studies measure the overall performance of a group of patients in terms of quality and quantity of life after diagnosis or treatment. (6). As survival rates of cervical cancer patients increase, their quality of life (QOL) becomes a more important issue (12).

Cervical cancer treatments affect the lives of surviving women to a varying degree in terms of physical, sexual, and psychosocial functioning. With increasing survival rates of cervical cancer patients, health-related quality of life (HRQoL) in survivors becomes a more important issue. QOL is known to be impacted by the disease as well as by the treatments (4). Conceptually, HRQoL is a state of functional, physical, psychological, and social/family well-being (4). Improving QoL is crucial as advancements in the diagnosis and treatment of cancer have increased the life expectancy of cancer survivors and provided some survival benefits (5). Furthermore, reduced QoL in the area of sexual functioning among long-term cancer survivors suggests that special attention should be paid to problems in this area to counteract treatment-related impairments that negatively affect QoL, emotional well-being, and relationships (6).

Cervical cancer survivors face physical, psychological, and marital concerns after cancer treatment, regardless of whether they engage in sexual activity or not. The primary factors influencing the psychosexual well-being of women who survived cervical cancer were personal beliefs and support from their spouses (7). Cervical cancer affects all aspects of a woman's health, including sexual function and physical well-being (8).

Literature review

Understanding of cervical cancer

Cancer is a broad category of illness that can originate in nearly any organ or tissue in the body when aberrant cells proliferate out of control, cross normal boundaries to invade other body parts, or spread to other organs (9). We refer to these abnormal cells as tumor cells, malignant cells, or cancer cells. Many cancers can be further identified by the name of the tissue from where the abnormal cells originated, as can the abnormal cells that make up the cancer tissue (10). The latter process, known as metastasis, is a primary contributor to cancer-related deaths. Other frequent names for cancer are neoplasm and malignant tumor. A tumor is any space-filling group of cells that may or may not be cancerous. There are two types of tumors or neoplasms: benign and malignant. Benign tumors remain contained in the original tissue, while malignant cancers have the ability to spread to other organs. Secondary growths or metastases are a serious complication to any treatment of cancerous cells (9,10).

The cervix, which is the lowest point of the uterus, is a cylindrical structure made of epithelium and stroma. There are two forms of epithelium that coat the surface of the cervix: columnar and squamous. Squamous epithelium lines the ectocervix, which projects into the vagina. Columnar epithelium lines the endocervical canal, which connects the internal and external os (11,12).

The multilayered stratified squamous epithelium is made up of progressively flatter cells. Normally, it covers the majority of the vagina and ectocervix. The columnar epithelium, which varies in length on the ectocervix, lines the cervical canal. It is made up of one layer of tall cells that are positioned on top of the basement membrane. The squamous and columnar epithelia have differing thicknesses, the squamocolumnar junction (SCJ) appears as a step-like line. The woman's age, hormonal state, history of birth trauma, pregnancy status, and usage of oral contraceptives all affect where the original SCJ is located (13). The ectocervical or endocervical mucosa in the transformation zone, the region of the cervix between the old and new squamocolumnar junction, is the site of origin for almost all cases of cervical carcinoma (11).

There are two main histopathological subtypes of cervical cancer: adenocarcinoma and squamous cell carcinoma (SCC). Adenocarcinoma arises from glandular cells in the endocervix that generate mucus, whereas SCC develops from squamous cells in the ectocervix and makes up about 75% of cervical carcinoma cases (14). Cervical intraepithelial neoplasia (CIN) is the term for precursor lesions that occur in the cervical epithelium after HPV infection and cause dysplastic alterations in squamous cells that advance SCC (14,15). After exposure, most HPV infections go away in a few years, and only 10–20% of persistent infections have the potential to cause cervical cancer (16).

Cervical epithelial cells that are infected with HPV and change over time, becoming highly dysplastic. The degree of dysplasia is used to grade the degree of change. CIN1 is characterized by the presence of dyskeratotic (individual cell keratinization), binucleate (cells with an expanded and irregular nucleus with a perinuclear halo), and koilocyte (cells with an irregular nucleus). Roughly two thirds of the epithelium are affected by heterogeneous lesions that indicate CIN2. However, CIN3, which involves more than two thirds of the epithelium, is a sign of severe dysplasia. (15).

The "necessary" cause of cervical cancer is thought to be caused by approximately 15 strains of high-risk HPV (hrHPV) (11). Persistent HPV infection is defined as the presence of the same type-specific HPV DNA on repeated sampling after 6–12 months. HPV types 16, 17, 18, and 45 account for 71% of the estimated 604,000 new cases of cervical cancer that occur each year worldwide; HPV types 31, 33, 45, 52, and 58 account for the remaining 19% of cases (17,18). It is widely known that over 90% of incident HPV infections resolve within two years of infection and only affect approximately 10% of women (19).

Stages of cervical cancer

The parametrium, vagina, uterus, and other organs, such as the bladder and rectum, are all directly affected by invasive cervical cancer. Additionally, it travels via the lymphatic channels to the obturator, external iliac, internal iliac, and regional lymph nodes before reaching the para-aortic and common iliac nodes. Distant metastasis to the liver, lungs, and skeleton is a late event (11).

Determining the extent and location of cancer in the body is known as cancer staging. The FIGO staging systems are determined by the International Federation of Gynecology and Obstetrics. FIGO staging was updated by the FIGO Gynecologic Oncology Committee in 2018.

FIGO Stage I: The carcinoma is strictly confined to the cervix uteri (extension to the corpus should be disregarded)
Stage IA: Invasive carcinoma that can be diagnosed only by microscopy, with maximum depth of invasion <5 mm
IA1: Measured stromal invasion <3 mm in depth
IA2: Measured stromal invasion ≥3 mm and <5 mm in depth
Stage IB: Invasive carcinoma with measured deepest invasion ≥5 mm (greater than stage IA), lesion limited to the cervix uteri
IB1: Invasive carcinoma ≥5 mm depth of stromal invasion and <2 cm in greatest dimension
IB2: Invasive carcinoma ≥2 cm and <4 cm in greatest dimension
IB3: Invasive carcinoma ≥4 cm in greatest dimension
FIGO Stage II: The carcinoma invades beyond the uterus, but has not extended onto the lower third of the vagina or to the pelvic wall
IIA: Involvement limited to the upper two-thirds of the vagina without parametrial involvement
IIA1: Invasive carcinoma <4 cm in greatest dimension
IIA2: Invasive carcinoma ≥4 cm in greatest dimension
IIB: With parametrial involvement but not up to the pelvic wall
FIGO Stage III: The carcinoma involves the lower third of the vagina and/or extends to the pelvic wall and/or causes hydronephrosis or non-functioning kidney and/or involves pelvic and/or paraaortic lymph nodes
Stage IIIA: Carcinoma involves the lower third of the vagina, with no extension to the pelvic wall
IIIB: Extension to the pelvic wall and/or hydronephrosis or non-functioning kidney

IIIC: Involvement of pelvic and/or paraaortic lymph nodes, irrespective of tumor size and extent
IIIC1: Pelvic lymph node metastasis only
IIIC2: Paraaortic lymph node metastasis
FIGO Stage IV: The carcinoma has extended beyond the true pelvis or has involved (biopsy proven) the mucosa of the bladder or rectum. A bullous edema, as such, does not permit a case to be allotted to stage IV
Stage IVA: Spread of the growth to adjacent organs
Stage IVB: Spread to distant organs.

Cervical Cancer Screening and Prevention

HPV vaccination; and screening for precancerous lesions are two major strategies for prevention and early detection of cervical cancer. As a result, HPV vaccination as prophylaxis should target girls between the ages of 10 and 14 women before the commencement of sexual activity (14).

Effective cervical screening methods have been applied in a variety of contexts, and include cytology (Pap smears), liquid-based cytology (LBC), HPV testing, and, in low and middle income countries (LMICs), visual inspection with acetic acid (VIA) (21). One minute after applying 3%–5% freshly prepared acetic acid to the cervix, VIA screening looks for acetowhite lesions. Due to the feasibility of using acetic acid, many low-income countries in Sub-Saharan Africa, including Ethiopia, have adopted it extensively in clinical settings (22).

Cervical Cancer Treatments

Cervical cancer treatment options include surgery, radiotherapy and chemotherapy, and these may be used in combination (11).

Surgery

Cone biopsy is the removal of a wide circle of tissue that surrounds the opening of the uterus and includes the lower portion of the cervical canal.

Simple hysterectomy is the surgical removal of the entire uterus, including the cervix, either through an incision in the lower abdomen or through the vagina with or without using laparoscopy.

Radical hysterectomy removes tissue to the side of the uterus and often lymph nodes in the pelvis and around the aorta.

Salvage surgery consists of radical hysterectomy including removal of a portion of the upper vagina to decrease chances of cancer recurrence.

Palliative surgery is sometimes done in advanced cancer to relieve obstruction of the bowel, or to treat fistulae (abnormal channels between the vagina and the urinary organs or rectum) that result from radiation or extension of the primary disease.

Radiotherapy

Radiotherapy uses sophisticated equipment to produce invisible rays. It is similar to a ray of light but with higher energy that is beamed onto the cancer and surrounding affected areas. The rays penetrate the body and destroy cancer cells so that the cancer is fully or partially eliminated. Destroyed cancer cells are eliminated from the body.

Primary radiotherapy (with or without chemotherapy) is used with curative intent, for women with cancer at stage IIA2 or greater. It may be offered to women with cancers greater than 4 cm in diameter confined to or spread beyond the cervix.

External-beam radiotherapy, or teletherapy, uses radiation originating from a machine located outside the body

Internal radiotherapy, also called brachytherapy, uses radiation originating from radioactive material placed inside the vagina, close to the cancer.

Chemotherapy

Chemotherapy is the administration of repeated treatments with toxic drugs. A series of several treatments with one or more chemicals is given intravenously to kill rapidly dividing cells (a hallmark of all cancers). Chemotherapy is used first in women with very large and bulky tumours, to reduce the cancer size, and then followed by radiotherapy. Treatment is done in this sequence because cancer is shown to respond better to radiation when the tumour is less bulky. Palliative chemotherapy is sometimes used, after careful consideration of the expected benefits versus the adverse side-effects, to relieve symptoms in women with widespread metastasis to liver, lung and bone.

Combination cancer treatments

Since combination therapies are more likely to inhibit multiple and/or redundant signaling pathways that are essential to the survival of cervical cancer cells, they may be preferable to monotherapies. In addition, combining therapeutic strategies reduces the intensity, cost, number of cycles, and adverse effects associated with high doses of monotherapy. Chemotherapy is often used in combination with radiotherapy to treat cervical cancer and this reduces tumour volume, inhibits micro metastasis/metastasis, prevents damage repair and drug resistance, and increases radiosensitivity of hypoxic cells in the cervix (22,23).

Survival Status and associated factors

The survival rates of women with cervical cancer differ greatly between nations; those in North America, Europe, Australia, and New Zealand have greater rates of survival than those in LMIC (24). The 5-year survival rate, for instance, is reportedly 13% in Uganda and 22% in the Gambia, compared to 79% in South Korea and 67% in China (25). The survival rates of cervical cancer also differ within nations, with rural women typically having lower rates.

While poor countries have the lowest survival rates, developed countries often have higher rates. According to an analysis of over 25 million cancer cases registered in 67 countries' national information systems between 2005 and 2009, developed nations like the United States (62.8%), Japan (66.3%), and Australia (67.1%) had higher cancer-related survival rates compared to developing nations like South Africa (54.9%), and Chile (50.9%). According to various studies, the five-year survival rate was 84% in Brazil (26), 62% in India (25), 71.1% in Malaysia (27) and 48.1% in India (28).

The low rate of survival in India is a result of several factors, including a lack of knowledge, insufficient screening resources, advanced cancer diagnosis, and difficulty accessing reasonably priced therapy. According to an Indian study, the most frequent characteristics linked to the survival of cervical cancer patients were age at diagnosis, education, parity, smoking, staging, and age at menopause (29). There are significant differences in survival between different regions of India, especially in urban vs. rural areas. In a study conducted in Malaysia, age continued to be an important determinant of the survival rate from cervical cancer (27). According to Kaverappa et al, survival rates are higher in urban areas (57.3%) compared to rural ones (54.7%) (29). This is likely the result of improved cancer health services in urban areas that are more easily accessible for diagnosis and treatment. Another study demonstrated that survival is associated with stage at diagnosis; 5-year survival decreased significantly as the stage at diagnosis increased (30). This pattern was also evident in a study conducted by Jayant and his colleagues where stage IA patients had a 5-year survival rate of 95.1%, whereas stage IV patients had a 5-year survival rate of 5.3% (25).

Compared to patients of age ≤30, those with age ≥60 and age of 50–59 years at presentation were approximately 6 and 5.4 times more likely to die, respectively. Evidence showed that compared to women with early clinical stage I, those with FIGO stages IV and III were approximately 12 and 7.4 times more likely to die, respectively (31).

Compared to women with no medical history or few or no births, having a medical history that includes any medical condition and number of parities were linked to worse survival rates. According to a study by Nartey and colleagues, cervical cancer survival is worse in the presence of any comorbidity. Furthermore, women with adenocarcinoma (ADC) had a higher risk of dying during follow-up when compared to women with squamous cell carcinoma (SCC) of the cervix (32).

In comparison to patients without anemia, those with moderate anemia had a considerably greater survival rate. Baseline anemia independently indicated a higher risk of death (31,33). Patients with anemia were 1.65 times more likely to die at high risk than those without anemia (34).

Cancer survival is significantly predicted by quality-of-life results. According to Ashing-Giwa et al. quality of life factors, particularly the physical, functional, and mental health dimensions are linked to survival (35).

Quality of life (QoL) among cervical cancer patients

QoL is defined as a person's self-reported perception of physical, psychosocial, and sexual well-being. QoL is crucial as advancements in the diagnosis and treatment of cancer have increased the life expectancy of cancer survivors (5). Cervical cancer patients need to go through a number of long-term therapies and follow-up exams after being diagnosed with the disease in order to increase survival and prevent recurrence. In order to properly care for patients with cervical cancer and to tailor their therapy, it is crucial to assess their QoL (36,37). The assessment of QoL following treatment becomes imperative as survival rates progressively increase and as distinct treatment modalities are known to have varying effects on QoL (38). The measurement of QoL has become essential to patient treatment due to the expansion of health concepts beyond traditional indicators of morbidity and mortality.

The illness and its treatment have significant impact on survivors, most notably on QoL. The QoL of these patients and their families may be impacted by the illness's type and course of treatment.(39). Patients with cervical cancer experience changes in their physical and emotional health, which ultimately impacts their QoL (40). Despite advancements in cervical cancer detection and treatment, survivors of the disease face significant challenges, most notably with regard to QoL (41). The burden of cervical cancer and its effects on patients make it necessary to evaluate baseline QoL prior to treatment (42).

The QoL assessment instruments that are currently available are generic, survivor-specific, or cancer-specific. The generic questionnaires were created to evaluate general aspects of QoL; the cancer-specific instruments evaluate the overall QoL of cancer patients, with instruments specific to the type of cancer. Three scales exist for measuring cervical cancer related QoL: the Quality-of-Life Instruments for Cancer Patients-Cervical Cancer (QLICP-CE), the Functional Assessment of Cancer Therapy-Cervix (FACT-Cx), and the EORTC Quality of Life Questionnaire-Cervix–24items (QLQ-Cx24)/QLQ-Cx30 items (43).

Prior to starting therapy for cervical cancer, post-treatment QoL is a crucial consideration (44). Women should be aware that receiving multiple treatment modalities for early-stage cervical cancer might result in significant alterations to their QoL. The importance of late adverse events is highlighted by the long-term survival of young patients with cervical cancer, particularly in light of the growing number of younger patients (45).

In a Brazilian study, women with locally advanced cervical cancer showed improvements in the majority of QOL domains following treatment. There was also a decline in menopausal symptoms, peripheral neuropathy, and satisfaction of sexual activities (46). According to a Lithuanian study, women who have survived cervical cancer often have a decent QoL in terms of their symptom experience. However, following chemotherapy and radiation therapy, these women seldom engage in sexual activity or find pleasure in it (38).

For patients with any type of gynecological cancer, sexuality is a significant factor and an essential one in determining their QoL. A study conducted by the Brazilian Institute for Cancer Control found that sexual functioning was significantly altered in women with cervical cancer (47).

Sexual and psychosocial experiences of women and their partners

Cervical cancer is particularly notable for its association with sexual dysfunction and challenges in intimate relationships, distinguishing itself from other gynecological cancers (48). This is because, treatments for cervical cancer can result in multiple side-effects that impact sexual functioning and sexual relationships including dyspareunia, shortened vagina, reduced vaginal elasticity, and diminished vaginal lubrication (49). These physical issues can result in reduced sexual desire, loss of connection with the spouse, and lack of confidence (50).

Further, the disease and treatment have psychological sequalae like anxiety, fear of sexual performance, guilt, and depression (51). Women who have undergone treatment for cervical cancer seek love and make a conscious effort to integrate their marital lives and romantic desires with the joy that comes from having sex. In order to improve one's perspective on sexuality, support from the partner is essential (52). The divorce rate is higher among women with cervical cancer than among all other cancer survivors and is primarily due to the patient and her spouse’s lack of sexual desire and fulfillment (53).

Psychosocial issues, such as anxieties about the illness, inability to make plans, and poor life quality, can longer for up to two years after treatment (54). In underdeveloped countries, especially in Sub-Saharan Africa, women who have cervical cancer face numerous challenges, such as inadequate access, lack of high-quality healthcare and lack of psychosocial support (55).

Men play a vital role in lowering the incidence of cervical cancer (56). This might be accomplished by offering education that would provide people the necessary understanding of the illness, which would help to remove barriers to screening and treatment (57). Additionally, men have a critical role in the prevention of cervical cancer, and it is anticipated that increased awareness of the disease will change men's health-related behaviors and attitudes. According to studies, the majority of men are unaware of cervical cancer, and some even think that males are not responsible for women's cervical cancer (58,59). Men participate in their partners' reproductive health experiences including cervical cancer care and follow-up in a variety of ways from financial support to transportation (58). Furthermore, male partners also have a significant impact on cervical cancer care and follow-up decision making, and psychosocial support (60).

Quantitative research has shown that a far higher proportion of gynecological cancer survivors (including cervical cancer) report needing psychosexual healthcare compared to those who actively seek treatment (8). Psychosexual care is common among patients and partners, but information and treatment are typically scarce. Psychosexual support should go beyond physical sexual functioning and should take sexual distress into account.

Statement of the problem

Cervical cancer is still one of the most common cancers in women worldwide, being the fourth most common after breast, colorectal, and lung cancer (11). Globally, there were over 342,000 deaths and over 604, 000 new cases of cervical cancer in 2020 (61). Approximately 85% of new cases and 90% of deaths, respectively, take place in low- and middle-income countries. Sub-Saharan Africa has the highest regional incidence and mortality of cervical cancer, with rates highest in Eastern Africa (40.1 cases and 28.6 deaths per 100,000 population) (61). Ethiopia is likewise confronting a significant cervical cancer burden (62). Ethiopia is expected to have 15,300 new cases of cervical cancer by 2040, up from an anticipated 7,500 occurrences in 2020. Similarly, on an annual basis, the disease's death toll will rise from 5,340 in 2020 to 11,000 in 2040 (21).

Cervical cancer typically affects younger women more frequently than other gynecological malignancies, with a mean age of about 50 years. Those who are cured can expect an extra 25 to 30 years of life expectancy after treatment; as a result, they will have to learn to live with the damage brought by cervical cancer and its treatment for a long period of time (5). A significant side effect of treatment is sexual dysfunction; research indicates that 23 to 70% of women who have survived cervical cancer report having issues with their ability to have sexual relations (63).

Cervical cancer treatments could also result in multiple side-effects that impact sexual functioning and sexual relationships including dyspareunia, shortened vagina, reduced vaginal elasticity, and diminished vaginal lubrication (49). These physical issues could lead to reduced sexual desire, loss of connection with the spouse, and lack of confidence (50). Further, there may also be psychological sequalae like anxiety, fear of performance, guilt, and depression (51).

Cancer is sometimes referred to as a "we-disease" since it is well acknowledged that both the patient and their family caregivers are impacted by the disease and its treatment. This is especially true if the patient's spouse serves as the primary caretaker. Cancer impacts the couple collectively, rather than individually, to differing degrees (64). Being the partner of a person diagnosed with cancer means facing new challenges and responsibilities emotional, social and practical (65). The majority of cervical cancer sufferers are unable to work, which costs the family economically (6).

There are several gaps in the literature related to women with cervical cancer in Ethiopia. First, while several studies have been published related to screening and risk factors of cervical cancer for women in Ethiopia, survival rate studies are just beginning to emerge, and still limited by retrospective design. Furthermore, little is known about survival status after cancer treatment has started. Second, there is limited research evaluating the QoL of cervical cancer survivors in Ethiopia who have been diagnosed in advanced stages, and studies are lacking on pre- post-treatment QoL. To address these gaps, this dissertation assessed the survival status of women with advanced stage cervical cancer; evaluated the pre-treatment and post-treatment QoL of women with advanced stage cervical cancer; and also discussed the psychosocial and sexual experiences of women with advanced stage cervical cancer and their partners.

Significancy of the study

Survival studies measure the overall performance of a group of patients in terms of quality and quantity of life after diagnosis or treatment (66). Survival statistics are the most used measures to estimate cancer patients' prognosis and the likely course of their disease and are of great interest to patients, clinicians, researchers, and policy makers. QoL among cervical cancer patients also plays a significant role in exploring pertinent precautions and in evaluating the quality of medical health service. QoL data can serve as an indicator of a patient's general health and functioning, as well as an additional means of monitoring for cancer survivors during normal follow-up (67).

Assessing QoL is potentially valuable in identifying patients' problems and addressing them in existing health systems. A deeper understanding of pre- and post- treatment QoL may help in providing appropriate psycho-oncological care for cervical cancer patients throughout the diagnosis and treatment trajectory.To raise awareness of the sexual and psychosocial needs of cervical cancer survivors, it is crucial to comprehend their experience and recovery process (68). Understanding psychosexual support, which can address concerns such as sexual distress, relationship satisfaction, and the partner's viewpoint, is helpful for providing more helpful and comfortable information on how relationships and sexuality are affected by cervical cancer.

Furthermore, this study will provide valuable reference material for epidemiologists, health policy makers and researchers.

Research question and objective

Research question

1. What is the survival rate after cancer treatment among advanced stage cervical cancer patients?
2. What are factors associated with the survival status of cervical cancer patients?
3. What is the QoL of women with advanced stage cervical cancer before receiving cancer treatment?
4. Is there improvement in QoL domains after cancer treatment?
5. Is there a relationship between QoL and survival status among cervical cancer patients?
6. What are factors associated with post-treatment QoL?
7. How do cervical cancer patients experience sexual and psychosocial issues?
8. How do male partners of cervical cancer patients experience sexual and psychosocial issues?

General objective

To assess survival status, pre- & post-treatment QoL, sexual and psychosocial experiences of women with advanced stage cervical cancer and their partners at Tikur Anbessa Specialized Hospital.

Specific objectives

1. To determine the survival status of women with advanced stage cervical cancer at Tikur Anbessa Specialized Hospital.
2. To assess pre-and post-treatment QoL of women diagnosed with advanced stage cervical cancer at Tikur Anbessa Specialized Hospital.
3. To understand the sexual and psychosocial experiences of women with advanced stage cervical cancer at Tikur Anbessa Specialized Hospital
4. To explore the sexual and psychosocial experiences of male partners of cervical cancer patients at Tikur Anbessa Specialized Hospital

Methods and materials

Study Area

Ethiopia is the second most populated African country next to Nigeria. This study was conducted at the Oncology Center of Tikur Anbessa Specialized Hospital which is found in Addis Ababa, the capital city of Ethiopia. Tikur Anbessa Specialized Hospital (TASH) is the largest referral hospital in Ethiopia. The oncology center of TASH provides chemotherapy, radiation therapy and other supportive and palliative services. It is the major center for cancer care, early detection, prevention, standard treatment and palliative care in Addis Ababa and it is the only cancer center in Ethiopia.

Study method

A mixed quantitative and qualitative study method was conducted. Mixed-methods research (MMR) combines quantitative and qualitative concepts and methodologies into a single study (69). The complexity of public health issues calls for research methodologies that integrate quantitative and qualitative methodologies in different ways. Employing this combined approach could lead to a more nuanced understanding of the study question (70).

Study Design

An explanatory sequential mixed methods design was employed. There are 3 types of mixed method designs: exploratory sequential, explanatory sequential, and convergent designs. The explanatory design begins with a quantitative data collection and analysis phase, which informs the follow-up qualitative phase. This design was selected because it allows for the initial quantitative data to be elaborated on and contextualized by the qualitative data. It starts with quantitative research, which is then analyzed, and then utilizes qualitative research to develop deeper into and provide richer explanations for the results (69).

Quantitative method

Paper 1 and Paper 2: *Study design:* A prospective cohort study was employed.

Qualitative method

Paper 3 and Paper 4: *Study design:* A phenomenological study design was employed.

Sample size determination

The sample size was determined based on the objective and analysis model used. The sample sizesfor papers 1 and 2 were calculated using STATA^{TM} and G*power software.

Paper 1: To determine the sample size required to assess the survival status of women with advanced stage cervical cancer a Cox model was planned to compare survival curves between two groups within the Cox Proportional Hazard model framework. The assumptions included a power of 80%, a proportion of events (one-year non-survival proportion) of 7.89%, a proportion of one-year censored cases (one year survival) of 92.11% (31) and two-tailed level of significance of 5%. Based on these considerations, a total sample size of 180 participants was determined.

Paper 2: To assess pre-and post-treatment QoL of women diagnosed with advanced stage cervical cancer at Tikur Anbessa Specialized Hospital. The assumptions for this analysis included consideration of Wilcoxon signed-rank analysis, with a power of 80%, a medium effect size of 0.3 (71), and a two-tailed level of significance set at 5%. Based on these criteria, a total sample size of 166 patients was determined.

Paper 3: A total of 23 women were selected. The final number of participants was determined by data saturation. Data saturation was assessed based on the informational redundancy of the data, which was deemed to have been attained at the point where no new categories or information were collected.

Paper 4: A total of 15 male partners who came to the hospital with their partners were recruited purposively.

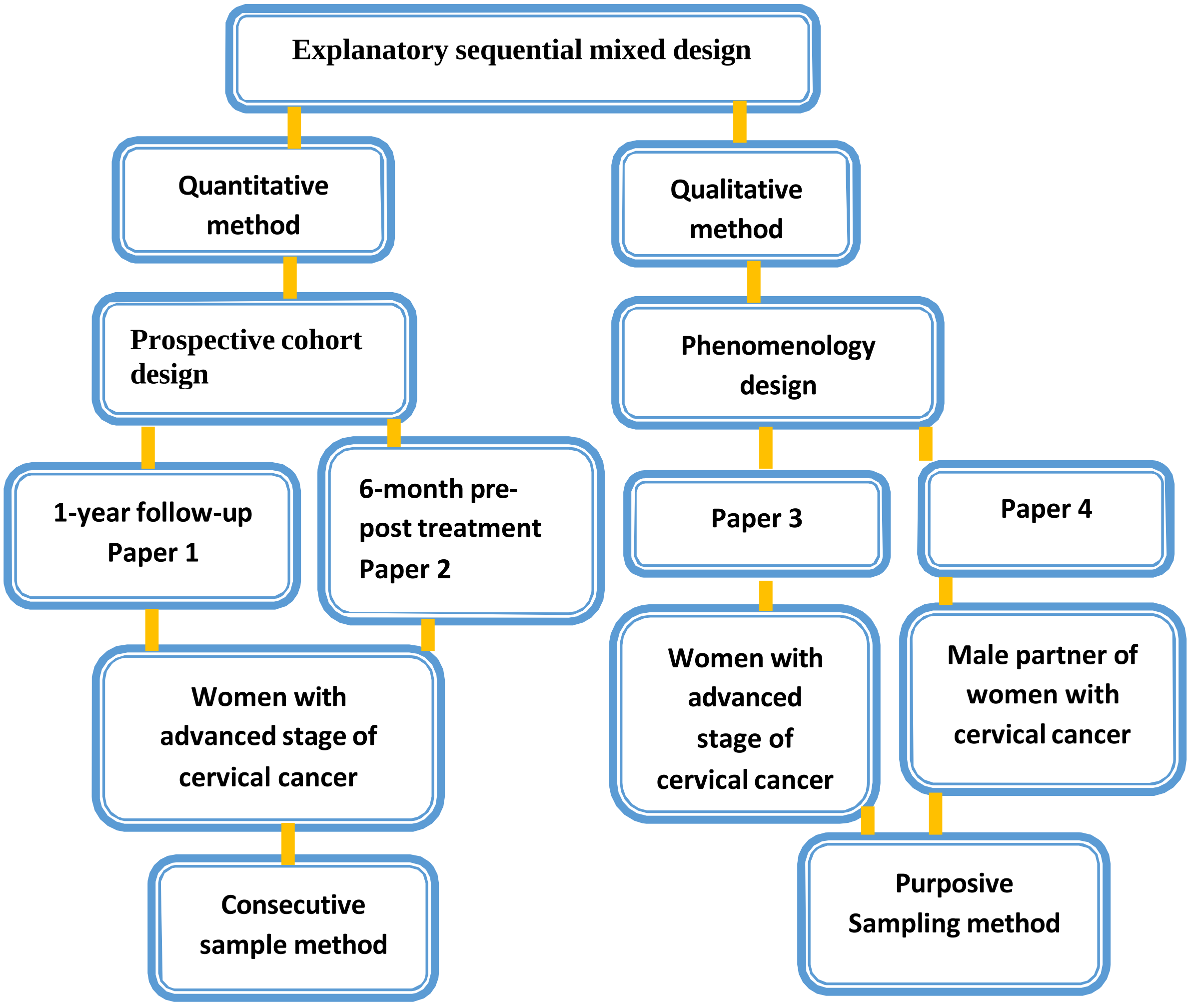

Figure 1: Summary of study design, study participants and sampling techniques

Recruitment, Data Collection Tool and Techniques

Paper 1: At the onset of cancer treatment, patients with histologically confirmed cervical cancer were enrolled in a consecutive manner between January 10, 2022, and September 20, 2022. The inclusion criteria were patients with advanced stage cervical cancer (FIGO stage IIB-IVB), and patients who started any cancer treatment during the recruitment period of the study (surgery, radiotherapy or chemotherapy). The exclusion criteria were patients who were already receiving direct cancer treatment, patients who didn't consent to participate, and patients who were critically ill. During recruitment, baseline information on sociodemographic characteristics, reproductive history, pathological and clinical characteristics, treatment start date, diagnosis date, and co-morbidities were collected through interviews and from the patient's chart. One year from the date of enrollment, participants were interviewed by telephone. In cases of death, the patient's husband or relatives were contacted. The last interview was conducted on September 20, 2023. A data abstraction tool was designed and assessed by a senior oncologist. It has five parts: (See APPENDIX A1)

(1) Sociodemographic and socioeconomic status characteristics;
(2) Reproductive history;
(3) Pathological and clinical characteristics;
(4) Treatment type and co-morbidities;
(5) Observational prospective follow up information

Paper 2: Participants who were consecutively recruited just prior to the start of their cancer treatment for paper 1 were also assessed for pre-post treatment QoL. Eligible patients were at FIGO stage IIB to stage IVB, enrolled for any cancer treatment, and willing to participate in the study. Data was collected using interviewer based standardized QoL questionnaires. During the pre-treatment interview, sociodemographic characteristics, clinical characteristics, type of cancer treatment, and comorbidities were additionally collected. Patients were re-interviewed six months after the pre-treatment interview to evaluate post-treatment QoL. Post-treatment interviews ended on March 20, 2023.

A standardized tool, the European Organization for Research and Treatment of Cancer core questionnaire (EORTC QLX-CX30) and the cervical cancer module (EORTC QLX-CX24) were used. The EORTC CX30 questionnaire is an integrated tool for assessing health related QoL of cancer patients and has 30 items. It includes five functional scales, three symptom scales, a global health status scale and six single items (72). Cronbach's alpha coefficient scores for the EORTC QLQ-CX30 ranged from 0.72 to 0.95. (73). (See APPENDIX A2)

The cervical cancer module (EORTC QLQ-CX24) was developed in a multicultural, multidisciplinary setting to supplement the EORTC QLQ-CX30 core questionnaire. It has 24 items. It incorporates 3 multi-item scales to assess symptom experience, body image, and sexual/vaginal functioning. In addition, 6 single items assess lymphoedema, peripheral neuropathy, menopausal symptoms, sexual worry, sexual activity and sexual enjoyment (43). Cronbach's alpha coefficients range from .72 to .87 for the subscales suggesting high internal consistency (symptom experience, 0.72; body image, 0.86; sexual/vaginal functioning 0.87) (74) (See APPENDIX A3).

The English language EORTC CX 30 and 24 tools were translated into Amharic language. Cronbach's alpha's for the translated versions ranged from 0.70–0.84 (75). In our study, we used this validated Amharic language version tool to assess pre-treatment and post-treatment QoL among advanced staged cervical cancer patients.

Paper 3: In-depth interviews were conducted using an interview guide (Paper 3 Table 1). To provide privacy and an opportunity to deeply reflect on their experiences, each woman was interviewed alone. Every day, thorough notes were assessed, and the recorded speech data were transcribed verbatim. The inclusion criteria included age under 50 years, at least one-year post cancer diagnosis, and willingness to explore and describe their experiences.

Paper 4: An in-depth interview was conducted. Data was collected from May 10-25/2023. Women who came for their appointments at the outpatient department of the oncology center were screened for accompanying male partners. Data was collected until saturation was achieved. The inclusion criteria included being a male partner of a cervical cancer patient who was diagnosed for at least one-year, age under 50 years, and willingness to explore and describe their experiences.

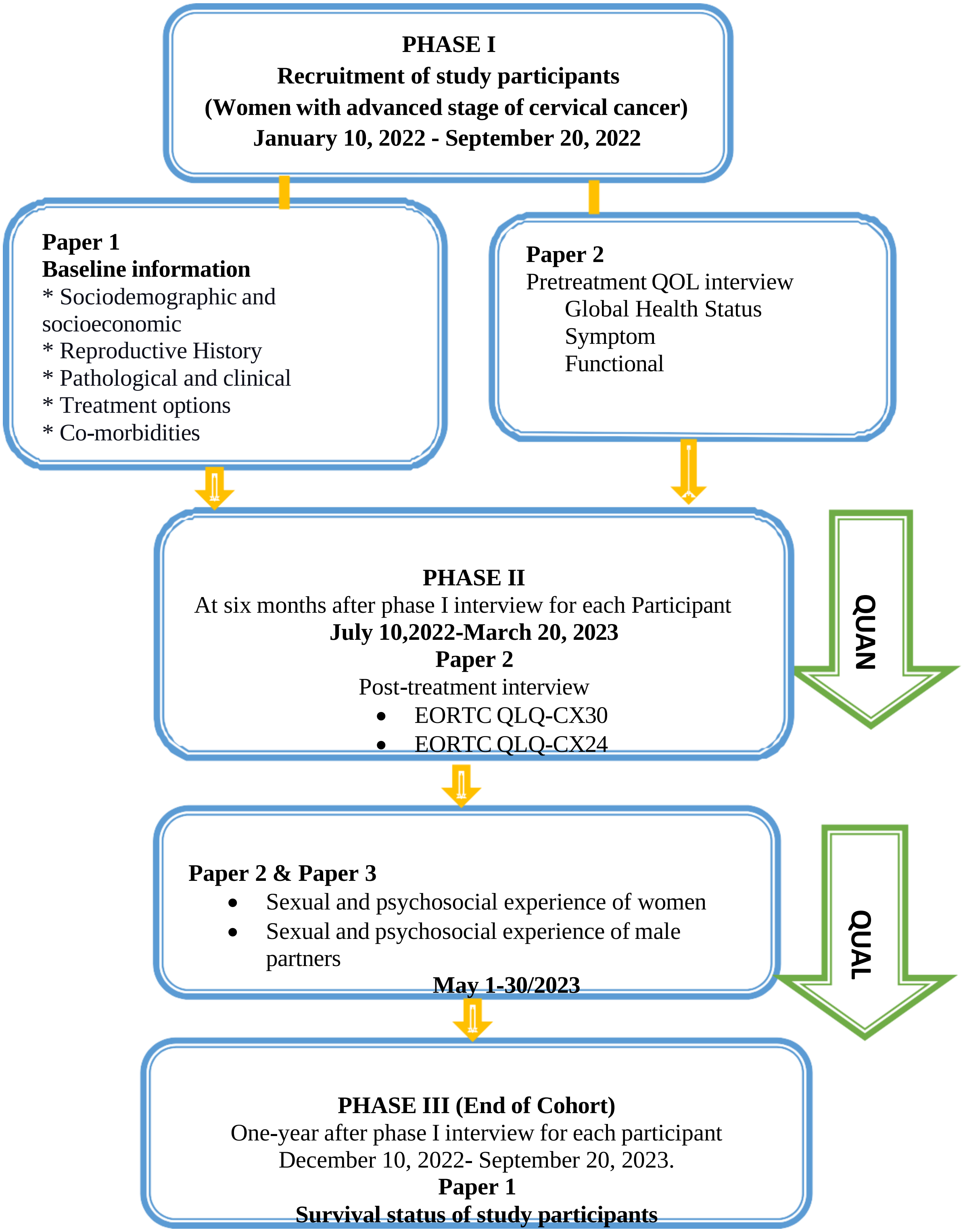

Figure 3: Summary of study participant recruitment, data collection, and timing

Study Variables and Measurement

Paper 1

Dependent Variables

- Survival status

Independent variables

- Sociodemographic and socioeconomic factors (age, residency, occupation, level of income, marital status)
- Reproductive history (age at first sexual intercourse, age at first marriage, age at first pregnancy, parity, number of children, age at menopause, use of oral contraception)
- Treatment type
- Time since diagnosis
- Waiting time for treatment
- Stage of cancer
- Co-morbidities

***Survival status*:** Survival status is defined as the outcome of women at the end of cohort and was dichotomized into *censored* and *event* (*death)*. The participants in the study were followed from the start of their cancer treatment until their last known date of contact, their death, or the end of the study (September 20, 2023). The final status determination was completed a year following study participants' recruitment. Those who were alive on the final follow-up date were considered as censored. The occurrence of death after enrollment on the study and at any time during the follow-up period was considered as *event (death)*. From the total of 180 cervical cancer patients, there were 7 lost to follow-up and these were considered as censored. The overall survival was calculated as the duration in months from start of cancer treatment to death.

Event: Death of cervical cancer patients is an event of interest.

Censored: Patients who are lost to follow up, not due to death, and survived up to the end of study period.

Paper 2

Dependent Variables

- QoL (pre-treatment and post-treatment)

Independent Variables

- Age

- Residency
- Occupation
- Level of Income
- Marital status
- Type of treatment
- Stage of cancer
- Comorbidities
- Waiting time for cancer treatment

The QLQ-C30 is composed of both multi-item scales and single-item measures (See Table 1). Each of the multi-item scales includes a different set of items - no item occurs in more than one scale. All of the scales and single-item measures range in score from 0 to 100. ***A high scale score*** represents a higher response level. Thus, a high score for a functional scale represents a high / healthy level of functioning, a high score for the global health status / QoL represents a high QoL, but a high score for a symptom scale / item represents a high level of symptomatology / problems.

The principle for scoring these scales is the same in all cases:

1. Estimate the average of the items that contribute to the scale; this is the raw score.
2. Use a linear transformation to standardize the raw score, so that scores range from 0 to 100; a higher score represents a higher ("better") level of functioning, or a higher ("worse") level of symptoms.

Table 1: Scoring the QLQ- CX30 questionnaire to assess pre-treatment & post-treatment quality of life among women with advanced stage cervical cancer

Variable	Item Number	Item range
EORTC CX30		
Global Health Status		
Global health status/QoL	29,30	6
Functional scales		3
Physical functioning	1 to 5	3
Role functioning	6,7	3
Emotional functioning	21 to 24	3
Cognitive functioning	20,25	3
Social functioning	26,27	3
Symptom scales / items		
Fatigue	10,12,18	3
Nausea and vomiting	14,15	3
Pain	9,19	3
Dyspnea	8	3
Insomnia	11	3
Appetite loss	13	3
Constipation	16	3
Diarrhea	17	3
Financial difficulties	28	3

Item range is the difference between the possible maximum and the minimum response to individual items; most items take values from 1 to 4, giving a range of 3.

Scoring

1) Raw score

For each multi-item scale, calculate the average of the corresponding items.

$$Raw\ Score = RS = \left\{\frac{(I_1 + I_2 + \ldots + I_n)}{n}\right\}$$

Then for **Functional scales**

$$Score = \left\{1 - \frac{(RS - 1)}{range}\right\} \times 100$$

Symptom scales / items and Global health status / QoL

$$Score = \{(RS - 1)/range\} \times 100$$

The Cervical Cancer Module is a supplementary questionnaire module to be employed in conjunction with the QLQ-C30. The QLQ-CX24 incorporates 3 multi-item scales to assess symptom experience, body image, and sexual/vaginal functioning. In addition, 6 single items assess lymphoedema, peripheral neuropathy, menopausal symptoms, sexual worry, sexual activity and sexual enjoyment. The scoring approach for the QLQ-CX24 is identical in principle to that for the symptom scales/single-items of the QLQ-C30 (See Table 2).

Table 2: Scoring the QLQ- CX24 questionnaire to assess pretreatment & posttreatment quality of life among women with advanced stage cervical cancer

	Scale	**Number of items**	**Item range***	**EORTQLQCX24 Item number (Appendix B)** $(I_1, I_2, I_3 \ldots I_n)$
Symptom Scales/Items				
Symptom Experience	SE	11	3	31-37,39,41-43
Body Image	BI	3	3	45-47
Sexual/Vaginal Functioning	SV	4	3	50-53
Lymphoedema	LY	1	3	38
Peripheral Neuropathy	PN	1	3	40
Menopausal Symptoms	MS	1	3	44
Sexual Worry	SXW	1	3	48
Functional Items**				
Sexual activity	SXA	1	3	49
Sexual Enjoyment	SXE	1	3	54

Interpretation: All of the scales and single-item measures range in score from 0 to 100. A high score for the symptom scales/single-items represents a high level of symptomatology or problems, whereas a high score for the functional single-items represents a high level of functioning.

Scoring

1. Raw score for each multi-item scale, calculate the average of the corresponding items.

$$Raw\ Score = RS = \left\{\frac{(I_1 + I_2 + \ldots + I_n)}{n}\right\}$$

2. Linear Transformation to obtain the score S, standardize the raw score to within a 0 – 100 range by using the following transformation.

For both the symptom and the functional scales / single items.

$$S = \left\{\frac{(RS-1)}{range}\right\} \times 100 \ ,$$

Furthermore, global health QoL, Symptom domain QoL and functional domain QoL were categorized. Based on other published works, the functional domain, the symptom domain, and global health status were categorized as "good," "moderate," and "poor" for comparison's sake (16, 17). The functional domain and global health status were categorized as "good" with a median score of greater than 66.7, "moderate" with a median score of 33.4–66.6, and "poor" with a median score of less than 33.3. The symptom domain was classified as “less symptomatic” with median score of below 33.3, as “moderately symptomatic” with a median score of 33.4-66.6 and as “very symptomatic” with a median score of above 66.7.

Data Management and Analysis

Data quality assurance

Numerous steps were taken to ensure data quality, from data abstraction design, adopting validated a standardized questionnaire for data analysis and interpretation of findings. The interview was conducted in Amharic, Ethiopia’s official language. The abstraction tool for the first paper was reviewed by senior experts in the field. Further, a pretest was done. Data was collected for 20 cervical patients before the actual data collection. Necessary modification then, was made based on the pre-test findings. A validated standardized questionnaire was used for paper 2. The English version was translated to Amharic and the Amharic version was validated. To maintain reflexivity and prevent the investigators' own opinions from influencing the study data, It was meticulously reviewed interview transcripts, cross-referenced codes with the raw data, and validated findings with participants' perspectives. It was ensured an adequate sample size and finalized data collection upon reaching saturation. Data collectors working at Oncology center were trained for two days before actual data collection. A training manual was developed for facilitation. Every day, the data were assessed for completeness, and any issues that arose throughout the data collection process were addressed appropriately. Upon completion of data management, storage, cleaning, and analysis, each completed data collection form was reviewed for accuracy and consistency.

Data analysis

Paper 1: Data entry and analysis were done with SPSS version 29 (15). Descriptive statistics were used to examine participant characteristics. The Kaplan-Meier procedure and log-rank test were used to estimate the duration of survival. Bivariate and multivariate Cox regression analyses were computed for predictor variables with survival status. Predictor variables with a significance level of 0.25 were included in a multivariate Cox proportional hazard model. Both the crude hazard ratio (CHR) and the adjusted hazard ratio (AHR) were used to determine predictor variables, with confidence levels set at 95% and statistical significance at a p-value < 0.05. The event was defined as the "death of cervical cancer patients," and the censored group was defined as "patients who survived until the end of the cohort period" and "patients who are lost to follow-up."

Paper 2: Data was entered, cleaned and analyzed using SPSS version 29 software (76). Descriptive statistics was performed to analyze sociodemographic characteristics such as age, education level, marital status, and clinical traits such as cancer stage and treatment types. Before data analysis, a normality test was performed. The Kolmogorov-Smirnov and the Shapiro-Wilk tests showed that normality assumptions were not satisfied. Therefore, non-parametric tests, the Wilcoxon ranked test was used to assess differences in pre-treatment and post-treatment QoL. Values are presented in mean, median, standard of deviation and interquartile range. The Mann Whitney U test was used to assess differences in post-treatment QoL by sociodemographic and clinical characteristics. Statistical significance was determined with *p*-values < 0.05 and 95% confidence interval.

Paper 3 & 4: The audio record was transcribed using verbatim approach, and the researcher read through all the qualitative data (transcripts and notes) several times to get an overall feeling for them. The transcribed interview was translated into English. The Then returning to each transcript, significant statements that pertained directly to the male partners' psychological, social and sexual experience of contracting was identified and extracted. Subsequently, the texts were divided into meaningful units made up of important words from the transcripts. Codes that were created inductively as they emerged from the data and deductively from the interview guide. The identified codes were sorted into different categories/subthemes. Finally, the subthemes were organized into themes. The data was analyzed with the assistance of MAXQDA software (77).

Ethical consideration

Data was collected after ethical clearance was obtained from the Institutional Review Board of Addis Ababa University College of Health Sciences (IRB 057/21/Nursing). A trained data collector informed eligible patients about the objectives and purposes of the study, the benefits of the study and the requirement of a follow-up interview one-year post-enrollment. Patients were encouraged to ask questions to clarify any issues before deciding whether to participate. Study participants were enrolled when they agreed to participate in the study including participation in the one-year follow-up interview, use of medical records and possible phone contact for follow-up, and signed the informed consent form. Informed consent was obtained for both quantitative and qualitative study before enrolment.

During the training of data collectors, ethical issues were addressed as an essential component of the research. Privacy and confidentiality were maintained by avoiding the use of identifiers and restriction of data access. The principal investigator ensured that the collected raw data was kept safe and confidential, locked in a secure location with password protection implemented for all files. Names of participants were not recorded in study records and data were reported in a manner that preserves participant anonymity and prevents the identification or linkage of the participants with the information. There were no risks for the participants apart from the time spent during interview. The interviews were conducted in private rooms. The participants have the right to refuse or withdraw from the study at any time. Refusing to participate did not affect their treatment at the hospital in any way. It was also explained that there was no direct benefit to them for their participation in the study but the output of the study would benefit mothers, health facilities, researchers, policy makers and the community. Confidentiality was assured by using study ID codes. During data collection all precautions for the prevention of COVID 19 were implemented. Strict adherence to the use of face masks, hand hygiene and maintaining physical distance was observed during all face-to-face interviews.

Scope and Limitation of the study

The scope of this study was limited to a one-year follow-up period, preventing comparisons or discussions beyond the one-year survival rate. Additionally, a few participants in this cohort study did not receive or did not complete cancer treatment, necessitating their exclusion from the analysis of overall survival rate and median survival time.

Structure of dissertation

This dissertation is written as paper-based dissertation according to Addis Ababa University guidelines (78). It is structured into six chapters.

- Chapter 1: Introduction.
- Chapter 2: Paper 1: This paper is objective 1 of the study and published in the International

Journal of Women Health.

- Chapter 3: Paper 2: This paper is objective 2 of the study and published in the Journal of Cancer Management and Research.
- Chapter 4: Paper 3: This paper is objective 3 of the study. It is under revision following reviewers' comments in the journal of BMC Reproductive Health.
- Chapter 5: Paper 4: This paper is objective 4 of the study and is under-peer-review in the International Journal of Qualitative Research.
- Chapter 6: Synthesis

CHAPTER TWO: PAPER 1

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ORIGINAL RESEARCH

Survival Status and Predictors Among Women with Advanced Stage of Cervical Cancer

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Background: Cervical cancer is one of the leading causes of cancer death in women, even though it is a preventable disease. Most deaths occur in low- and middle-income countries. In addition to early detection and receipt of standard treatments, survivorship is an important component of high quality of care across the cancer continuum.

Objective: To assess the survival status of advanced-stage cervical cancer patients after cancer treatment has started.

Methods and Materials: A one-year prospective cohort study was employed to assess the survival status of women with advanced stages of cervical cancer. A total of 180 cervical cancer patients were recruited, and the study was conducted from January 10, 2022, to September 20, 2023. Data entry and analysis were done in the SPSS 29 version. Descriptive statistics were used to examine participant characteristics. The Kaplan-Meier procedure and log rank test were used to estimate the duration of survival. Bivariate and multivariate Cox regression analyses were computed for predictor variables with survival status.

Results: Patients receiving cancer treatment at FIGO stages IVA and IVB had survived by 56% and 24%, respectively, whereas patients receiving treatment at stages IIB and IIIA had survived by 100%. The estimated mean survival time at one-year follow-up was 5.706 months (95% CI: 3.785–7.627) for patients with FIGO stage IVB, but 11.537 months (95% CI: 11.199–11.887) for those with stages II and III ($P < 0.001$). Women over 60 years old had a 1.5-fold higher risk of death than those under 60 (HR: 1.482, $P = 0.040$).

Conclusion: The one-year cumulative survival rate among advanced-stage cervical cancer patients was 77%. Major factors associated with survival were age, cancer stage, the presence of anemia, and waiting time for treatment.

Keywords: survival status, advanced stage, cervical cancer, tikur anbessa specialized hospital, Ethiopia

Background

Globally, there were over 342,000 deaths and over 604,000 new cases of cervical cancer in 2020.[1] The effects of cervical cancer vary depending on the region; evidence indicates that over 85% occurs in low- and middle-income countries.[2] Sub-Saharan Africa has the greatest regional incidence and mortality rates, with higher rates in Eastern, Southern, and Middle Africa.[1] Ethiopia is likewise confronting a significant cervical cancer burden.[3] Ethiopia is expected to have 15,300 new cases of cervical cancer by 2040, up from the anticipated 7,500 occurrences in 2020. Similarly, on an annual basis, the disease's death toll will rise from 5340 in 2020 to 11,000 in 2040.[4]

The main factor contributing to cervical precancerous lesions and cancer is persistent human papillomavirus infection.[5] Adenocarcinomas, which occur in the glandular columnar layer of the endocervix, account for 10% of cervical cancer cases. Squamous cell tumors, which mostly affect the transformation zone of the ectocervix, account for 90% of cervical cancer cases.[6]

Worldwide cervical cancer survival rates vary and are often associated with the level of country development.[7] Additionally, cervical cancer survival rates vary by race and subregion throughout the African continent. Tumor stage, histology, geographic location, and access to high-quality healthcare all affect survival rates.[8] The tumor stage is the main

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indicator of the prognosis for cervical cancer. The International Federation of Gynecology and Obstetrics (FIGO) staging system for tumors is associated with overall survival and the probability of recurrence.[9]

The majority of patients in developing countries, such as Ethiopia, present late and have advanced stages of cancer. Their prognosis is significantly worse and may require a combination of treatments, such as radiation, chemotherapy, and surgery. Surgery is the main treatment for cervical cancer at stage IIA or lower, whereas chemo-radiation is used to treat the cancer when it has progressed to stage IIB or above.[10]

Survival studies measure the overall performance of a group of patients in terms of quality and quantity of life after diagnosis or treatment. Survivorship care is a critical part of providing high-quality care for patients at all stages of the cancer continuum, in addition to early diagnosis and standard treatments.[11] In Ethiopia, several studies are related to screening and risk factors for cervical cancer. In Ethiopia, survival studies are beginning to emerge but are limited by retrospective design. Little is known about survival status after cancer treatment starts. This study aimed to assess the survival status of advanced-stage cervical cancer patients after cancer treatment had started.

Methods and Materials

Study Design and Sample

A prospective cohort study was employed to assess the survival status of women with advanced stages of cervical cancer. It was carried out at the Tikur Anbessa Specialized Hospital Oncology Centre, located in Ethiopia's capital city of Addis Ababa. Approximately 400,000 in-patients and out-patients receive diagnosis and treatment annually from Tikur Anbessa Specialized Hospital (TASH), the largest referral hospital in Ethiopia. TASH's oncology center offers radiation therapy, chemotherapy, and other supportive and palliative medical services. A total of 180 patients with advanced stages of cancer were recruited.

Recruitment and Baseline Data Collection

At the onset of cancer treatment, 180 patients with histologically confirmed cervical cancer were enrolled in consecutive manner between January 10, 2022, and September 20, 2022. During the recruitment, baseline information on socio-demographic characteristics, reproductive history, pathological and clinical characteristics, treatment start date, diagnosis date, and co-morbidities was collected through interviews and from the patient's chart. Participants were interviewed after one year from the date of enrollment by telephone. In cases of death, the patient's husband or relatives were contacted. The last interview was conducted on September 20, 2023.

Data Analysis

Data entry and analysis were done using SPSS version 29.[12] Descriptive statistics were used to examine participant characteristics. Kaplan-Meier procedure and Log rank test were used to estimate the duration of survival. Bivariate and multivariate Cox regression analyses were computed for predictor variables with survival status. Predictor variables with a significance level of 0.25 were included in a multivariate Cox proportional hazard model. Both the crude hazard ratio (CHR) and the adjusted hazard ratio (AHR) were used to determine predictor variables, with confidence levels set at 95% and statistical significance at a p-value less than 0.05. The event was defined as the "death of cervical cancer patients", and the censored group was defined as "patients who survived until the end of the cohort period" and "patients who are lost to follow-up".

Results

Socio-Demographic Characteristics and Reproductive Health History

A total of 180 advanced-stage cervical cancer patients were enrolled to follow their survival status one year after beginning treatment. Of these, 51.1% were between the ages of 45 and 59, and 28.3% were older than 60. Half of them had no formal schooling. The majority were housewives (Table 1).

Table 1 Socio-Demographic Characteristics of Participants

Variable	N (total=180)	Death n (%)	Censored n (%)	X^2 (P-value)
Age				
30–40 years	37	9 (24.3)	28 (75.7)	7.174 (0.028)
45–59 years	92	19 (20.7)	73 (79.3)	
Above 60 years	51	21(41.2)	30 (58.8)	
Educational Level				
No formal education	95	26 (27.4)	69 (72.6)	0.998 (0.824)
Elementary completed	47	13 (27.7)	34 (72.3)	
High school completed	30	9(30)	21 (70)	
College/university completed	8	1 (12.5)	7 (87.5)	
Occupation				
Housewife	154	42 (27.3)	112 (72.7)	0.899 (0.826)
Governmental employee	8	2(25)	6 (75)	
Self-employed	18	5 (31.1)	13 (69.9)	
Marital status				
Single	25	8(32)	17 (68)	0.807 (0.937)
Married	73	19(26)	54 (74)	
Divorced	27	7 (22.2)	21 (77.8)	
Widowed	55	15 (28.8)	39 (71.2)	
Region				
Amhara	56	16 (28.6)	40 (71.4)	2.719 (0.843)
Oromia	47	10 (21.3)	37 (78.7)	
Addis Ababa	56	18 (32.1)	38 (67.9)	
SNNPR	14	3 (21.4)	11 (78.6)	
Tigray	7	2(25)	5 (75)	
Monthly Income				
Less than 5125 ETB	156	44 (28.2)	112 (71.8)	0.571 (0.450)
More than 5126 ETB	24	5 (20.8)	19 (79.2)	
Living with				
Alone	11	2 (18.2)	9 (81.2)	1.922 (0.166)
With families	170	47 (28.6)	123 (71.4)	

For 32.2% of the participants, the age of their first sexual contact was under 15 years, and for 36.1% of the participants, the age of their first marriage was between 9 and 15 years old. For the majority of participants, the age range for their first pregnancy was 15 to 19 years (Table 2).

Clinical Characteristics

Out of all the participants, 49.4% began cancer treatment within 1–6 months of the date of diagnosis, while 19.4% waited longer than 12 months to begin cancer treatment. From the total participants, most of them were treated with radiotherapy (n = 62) and chemotherapy (n = 88) treatments. Eleven, however, died while waiting for treatment, and three did not begin treatment until the end of this study. The 14 patients who did not receive cancer treatment were not included in the survival analysis. Anemia was present in 10.2% of cases, while HIV/AIDS was present in 12% of cases. Treatments with radiation and chemoradiotherapy were 34.4% and 48.9%, respectively. The vast majority of participants were in FIGO stages III and IV (Table 2).

Survival Status

Following their enrollment, 180 patients in FIGO stages IIB to IVB were followed for a year. Of these, 14 did not receive cancer treatment. There were 49 deaths overall. Additionally, seven participants were censored because they were lost to follow-up.

Table 2 Reproductive History and Clinical Characteristics of Participants

Variable	N (180)	Deaths	Censored	X^2 (P-value)
Age at first sexual intercourse				
11–15 years	58	17 (29.3)	41 (70.7)	0.193 (0.908)
16–19 years	68	18 (26.5)	50 (73.5)	
Above 20 years	54	14 (25.9)	40 (74.1)	
Age at first marriage				
9–15 years	65	18 (27.7)	47 (72.3)	0.026 (0.987)
15–19 years	62	17 (27.4)	45 (72.6)	
Above 20 years	54	14 (26.4)	39 (73.6)	
Parity				
Nulliparous	13	6 (46.2)	7 (83.8)	6.488 (0.039)
Less than 4	75	25 (33.3)	50 (66.7)	
More than 4	92	18 (19.6)	74 (80.4)	
Use of oral contraception				
Yes	41	13 (31.7)	28 (68.3)	0.539 (0.463)
No	139	36 (25.9)	103 (74.1)	
Age at first Pregnancy	99			
15–19 years	81	27 (27.3)	72 (72.7)	0.000 (0.987)
Above 20 years		22 (27.2)	59 (72.8)	
Menopause				
Yes	118	27 (22.9)	91 (77.1)	
No	62	22 (35.5)	40 (64.5)	3.258 (0.071)
Waiting time for treatment				
Less than 12 months	131	28 (21.4)	103 (78.6)	20.777 (< 0.001)
Above 12 months	35	10 (28.6)	25 (71.4)	
Not taken	14	11 (78.6)	3 (21.4)	
Comorbidities				
Anemia	29	18 (62.1)	11 (37.9)	26.073 (< 0.001)
HIV/AIDS	22	7 (31.8)	15 (68.2)	
Others	24	8 (33.3)	16 (66.7)	
None	105	16 (15.2)	89 (84.8)	
Histopathology				
Squamous	173	47 (27.2)	126 (72.8)	0.007 (0.935)
Adenocarcinoma	7	2 (28.6)	5 (71.4)	
Treatment				
Radiotherapy	62	16 (25.8)	46 (74.2)	20.770 (< 0.001)
Chemoradiotherapy	88	18 (20.5)	70 (79.5)	
Chemoradiotherapy plus surgery	16	4(25)	12 (75)	
Not taken	14	11 (78.6)	3 (73.4)	
FIGO Stage at treatment				
Stage II B	45	0 (0)	45 (100)	57.297 (< 0.001)
Stage III A	7	0 (0)	7 (100)	
Stage III B	14	2 (14.3)	12 (87.7)	
Stage III C	49	10 (20.4)	39 (79.6)	
Stage IV A	46	22 (47.8)	24 (52.2)	
Stage IV B	19	18 (78.9)	4 (21.1)	

Out of 166 people who received cancer treatment, overall survival was achieved by 77% (Table 3; Figure 1). Patients at FIGO stages IVA and IVB survived by 56% and 24%, respectively, by the end of the one-year follow-up period, whereas patients at stages IIB and IIIA survived by 100% (Table 4).

Table 3 Life Table After Cancer Treatment Started Among Advanced Stage of Cervical Cancer Patients

Month	Number at Start	Withdrawn Within Interval	At risk	Deaths/ Events	Prob of Death	Prob of Surviving	Cumulative Surviving of Interval
0	166	0	166	0	0.00	1.00	1.00
1	166	0	166	3	0.02	0.98	0.98
2	163	0	163	6	0.04	0.96	0.95
3	157	0	157	6	0.04	0.96	0.91
4	151	0	151	0	0.00	1.00	0.91
5	151	0	151	8	0.05	0.95	0.86
6	143	0	143	4	0.03	0.97	0.84
7	139	0	139	2	0.01	0.99	0.83
8	137	0	137	4	0.03	0.97	0.80
9	133	0	133	4	0.03	0.97	0.78
10	129	0	129	1	0.01	0.99	0.77
11	128	0	128	0	0.00	1.00	0.77
12	128	128	64	0	0.00	1.00	0.77

Note: Patients who did not take treatment (n=14) were excluded.

In FIGO stage IVB, the cumulative one-year survival rate was 24%, while in stage IIB, it was 94%. At one-year follow-up, the estimated mean survival time for patients with FIGO stage IVB was 5.706 months (95% CI: 3.785–7.627), but for patients with stage II and III, it was 11.537 months (95% CI: 11.199–11.887) (P < 0.001) (Table 5) and (Figure 2).

Patients with anemia had an estimated mean survival time of 7.235 months (5.248–9.222), which is significantly (P < 0.001) less than those without anemia, who had an estimated mean survival time of 10.926 months (95% CI: 10.411–11.441). (Table 5) (Figure 3).

The cumulative one-year survival of patients who did not receive treatment was 21%. The estimated mean survival time among patients who did not receive cancer treatment was 6.786 months (95% CI: 4.844–8.727), which is significantly less than patients who received cancer treatment (P = 0.002) (Table 6, Figure 4).

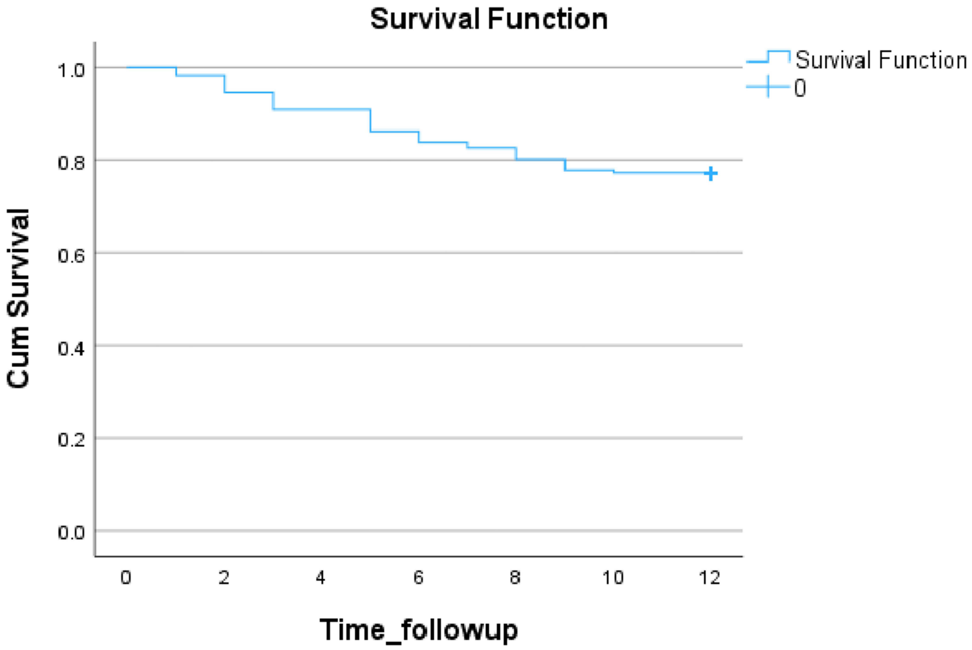

Figure 1 Overall survival (OS) curve among women with advanced-stage cervical cancer.
Note: The median survival time among participants with advanced stage cervical cancer after 12 months follow up was 10.392 months (95% CI 9.903-10.880).

Table 4 Survival Time of Cervical Cancer Patients After Treatment by FIGO Stage

FIGO Stage	Month	Number at Start	Withdrawn Within Interval	At risk	Deaths/ events	Cumulative Survival
IIB	12	45	45	22	0	1.00
IIIA	12	6	6	3	0	1.00
IIIB	12	12	11	5.5	1	0.92
IIIC	12	45	39	19.5	6	0.87
IVA	12	41	23	11.5	18	0.56
IVB	12	19	4	2	15	0.24

Note: Patients who did not take treatment (n=14) were excluded.

Table 5 Estimated Mean Survival Time in Months and Cumulative One-Year Survival by Socio-Demographic and Clinical Characteristics

Variable	Estimated Mean Survival Time in Months (95% CI)	Log-rank (Mantel-Cox test)	Cumulative 1-Year Survival Rate
Age			
30–44 years	11.053 (10.267–11.836)	0.002	84%
45–59 years	10.808 (10.147–11.469)		78%
Above 60 years	9.240 (8.211–10.269)		60%
FIGO stage			
IIB & III	11.537 (11.199–11.887)	< 0.001	94%
IV A	9.317 (8.224–10.410)		56%
IV B	5.706 (3.785–7.627)		24%
Treatment			
Radiotherapy	10.242 (9.420–11.063)	< 0.001	74%
Chemoradiotherapy (CCT)	10.489 (9.284–11.153)		80%
CCT plus surgery	10.438 (8.978–11.897)		75%
Not taken	6.786 (4.844–8.727)		21%
Comorbidities			
Anemia	7.235 (5.248–9.222)	< 0.001	41%
HIV/AIDS	10.300 (9.037–11.563)		70%
DM	10.455 (8.417–12.492)		82%
Others	10.100 (8.055–12.145)		70%
None	10.926(10.411–11.441)		84%
Treatment waiting time by stage			
>12 months in stage IIB & III	11.682 (11.073–12.291)	0.650	95%
<12 months in stage IVA	9.485 (8.276–10.6940		58%
>12 months in stage IVA	8.625 (6.128–11.122)		50%
<12 months in stage IVA	5.833 (3.242–8.424)		33%
>12 months in stage IVB	5.400 (3.200–7.600)		0%

Note: Patients who did not take treatment (n=14) were excluded except for "treatment" variable.

Among patients over 60 years, the estimated mean survival time was 9.240 months (95% CI: 8.211–10.269), and the cumulative one-year survival rate was 60%, which is significantly lower than that of the other age groups (Table 5, Figure 5).

Predictors of Survival Status

Age, cancer stage, comorbidities, treatment waiting time, and receiving cancer treatment were found to be the important factors linked with survival status in both univariate and multivariate Cox regression models.

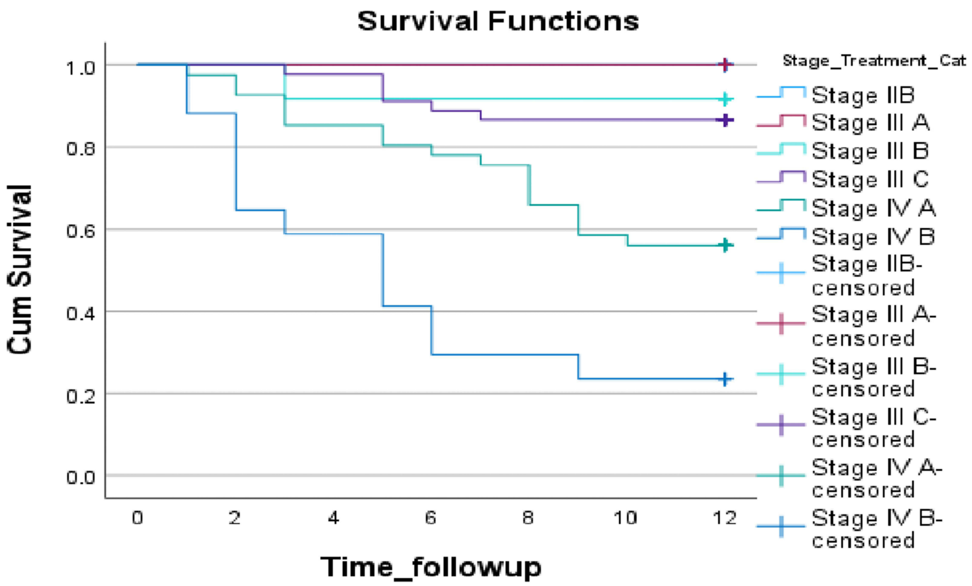

Figure 2 Kaplan-Meier survival curve according to FIGO staging.

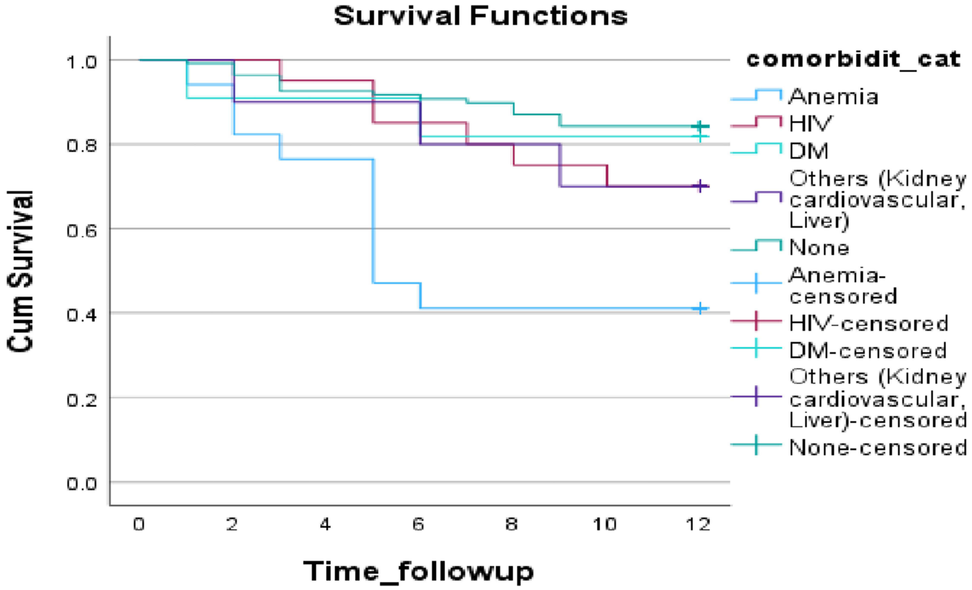

Figure 3 Kaplan-Meier survival curve according to comorbidity.

A statistically significant correlation was found (P = 0.028) between participant age and survival, as determined by the chi-square test (Table 1). There was a 1.5-fold risk of death difference between women over 60 and those under 60 (HR: 1.482, P = 0.040) (Table 6).

A significant association between the presence of comorbidity and survival status was identified among patients with cervical cancer (P < 0.001) (Table 2). Compared to women without anemia, anemic women had over four times the increased risk of dying (HR: 2.389, P = 0.038) (Table 6).

Discussion

The main objective of this study was to prospectively assess the precise one-year survival status of advanced stage cervical cancer patients following the initiation of cancer treatment. Overall, 77% of patients survived their first year following cancer treatment, according to this study. Similarly, 74% of 1-year survivors were reported in a multi-national

Table 6 Cox Regression Model for Factors Associated with Survival Status Among Patients with Advanced Stage Cervical Cancer

Variable	Univariate Cox Model HR $_{\text{Crude}}$	P-value	Multi-Variate Cox HR $_{\text{Adj}}$	P-value
Age				
Less than 60 years	1		1	
Above 60 years	2.115	0.010	1.482	0.040
Comorbidities				
No	1		1	
Anemia	3.095	< 0.004	2.389	< 0.038
HIV/AIDS	1.108	0.074	1.727	0.533
Others	1.805	0.193	1.426	0.233
FIGO stage				
Stage II B & III	1		1	
Stage IVA	5.412	< 0.001	4.955	< 0.001
Stage IV B	13.423	< 0.001	10.376	< 0.001
Cancer Treatment				
Radiotherapy	1		1	
Chemoradiotherapy	0.780	0.470	0.815	0.568
Chemoradiotherapy plus surgery	0.946	0.921	1.180	0.774
Not taken	4.085	< 0.001	4.869	0.004
Waiting time for cancer treatment				
Less than 6 months	1		1	
6–12 months	1.228	0.573	1.387	0.372
More than 12 months	1.852	0.065	1.911	0.050

population study involving seven sub-Saharan nations.[13] A study conducted in Uganda reported a one-year survival rate of 78.5% among patients who did not get radiotherapy. This may be due to the study design which included patients at all stages.[14] An earlier study, conducted in Ethiopia ten years ago, found that the one-year survival rate for patients treated with radiation therapy and/or surgery was 90.4%, a significantly higher rate than the current study. This variation may be due to fact that all cancer stages were included.[15] Similar to this, a previous retrospective study carried out in Ethiopia found that one-year survival rate was 92.11%, much higher than our findings. This discrepancy may be explained by the patients' cancer stages, the study period, or different study designs.[16] On the other hand, a substantially lower one-year survival rate 58.6% was reported in a Zimbabwean study involving patients who did not get treatment.[17]

The survival rate for women over 60 is significantly lower than that of women under 60. This is inconsistent with studies conducted in Brazil[18] and Netherlands[19] which identified no association between age and survival status. The inconsistency may be explained by the fact that the majority of the patients in these studies received curative therapies. On the other hand, there are plenty of studies that revealed that the significancy association between age and survival.[14,16,20–26]

The present study showed that survival status is highly affected by stage of cancer. This is supported by many articles.[14–16,26,27] Our study adds to the evidence pointing to the need for low- and middle-income countries to develop systems that encourage early cancer diagnosis in order to increase population-level survival.[28] A systematic review and meta-analysis showed that prevalence of late-stage presentation among cervical cancer patients in Africa was 62.60% (95% CI 54.83–70.37).[29] In Ethiopia, the majority of cervical cancer patients still appear at advanced stages of the disease. One of the most significant prognostic factor is stage at diagnosis, which links early detection with greater odds of survival.[15,18,30] One study conducted in Ethiopia found that longer patient intervals (the time interval between the date the patient noticed the first symptom and the date of the biopsy report) are associated with more advanced FIGO-stages at diagnosis. Rural women typically have longer patient intervals. This could be due to a lack of knowledge about cervical

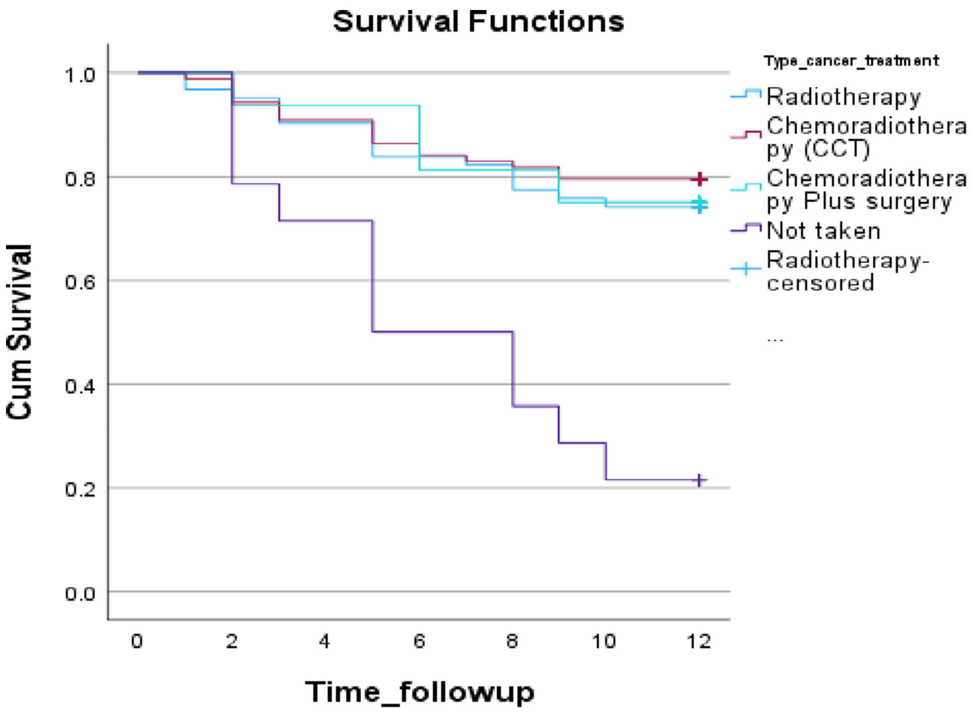

Figure 4 Kaplan-Meier survival curve according to type of cancer treatment.

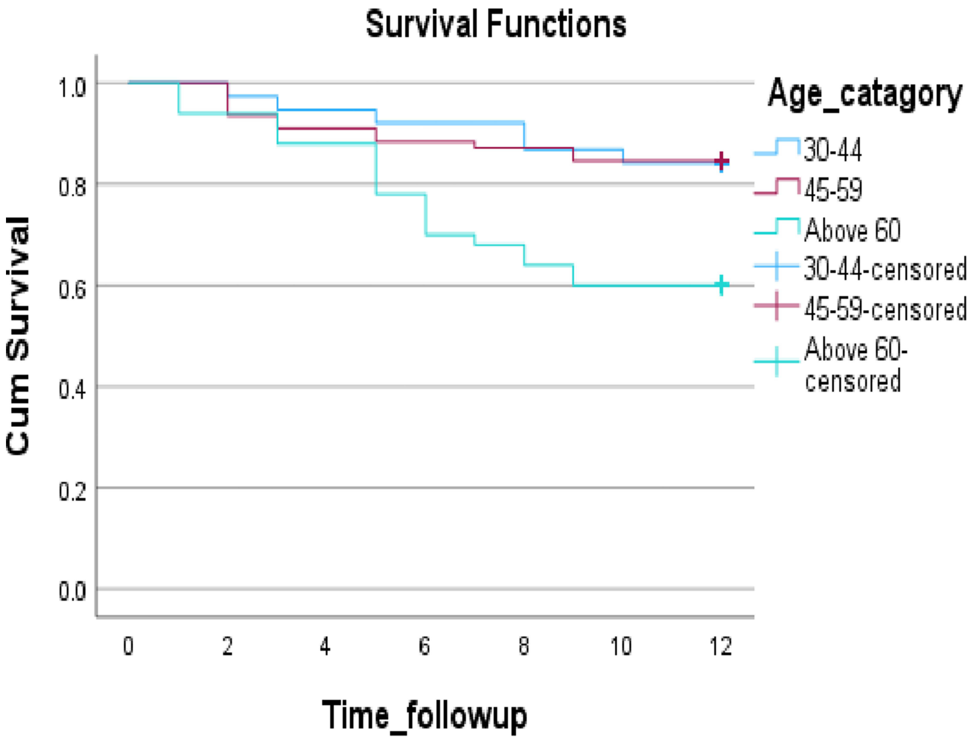

Figure 5 Kaplan-Meier survival curve according to age.

cancer and the symptoms that go along with it, or it could be because rural areas of the nation lack access to quality healthcare and medical professionals.[30] Furthermore, another study conducted in Ethiopia showed that the primary cause of cervical cancer diagnosis at an advanced stage is non-engagement in care or screening.[31]

Our study revealed that not receiving cancer treatment and having to wait longer for treatment had a higher risk of death. This finding is comparable to others studies.[25,32,33] According to international guidelines, radiation therapy for cervical cancer should begin within 60 days of the diagnosis being confirmed for optimal care and outcomes.[34,35] Waiting time for treatment is linked to poor survival and tumor growth. The consequence of disease progression to later stages while awaiting radiation therapy is a higher number of women entering palliative care, which is associated with a high cost of care, poor quality of care, and lower survival rates.[36–38]

A key finding in our study is the association between survival status and the presence of anemia. Anemia increased the risk of death in both univariate and multivariate regression analyses. This finding is supported by other articles.[16,25,27,39] Patients with cervical cancer may have anemia for a variety of reasons, including bleeding from the tumor, tumor invasion of the bone marrow, tumor-induced malnutrition, aberrant iron metabolism, impaired renal function, and compromised bone marrow function.[40] The effectiveness of treatment, particularly radiotherapy, appears to be directly impacted by low hemoglobin levels. This is likely because reduced tissue oxygenation results in a reduction in radiosensitivity.[41]

In our study, HIV, however, was not significantly associated after controlling for age and stage of cancer in multivariate analysis. While some studies have reported an association between HIV/AIDs and survival[25,42,43] findings from other studies in Uganda and Ethiopia align with ours.[14,39] HIV is thought to increase the incidence of cervical cancer mainly by raising the chance of getting the first precancerous lesion due to a decreased ability to clear high-risk HPV infections and the necessary infection of cervical basal cells.[44,45] However, it is unlikely that these mechanisms will have an impact on survival once the cancer develops.[46]

Limitation, Strengthen and Recommendations

Some limitations were observed in this study. First, the investigation was limited to a one-year follow-up period, preventing comparisons or discussions beyond the one-year survival rate. Additionally, few participants in this cohort study did not receive or complete cancer treatment, necessitating their exclusion from the analysis of the overall survival rate and median survival time. On the other hand, using a prospective cohort and primary data collection is the strength of the study.

Research recommendations that include a prospective cohort and/or clinical trials are encouraged to reduce biases resulting from retrospective studies, particularly in a country like Ethiopia where there is no cancer registry. It is necessary to investigate factors related to survival in the context of Ethiopia further and to prospectively determine the accurate survival rate. In sub-Saharan Africa, there have been notable improvements in the screening, diagnosis, and treatment of cervical cancer patients; nonetheless, more work remains.[47] It has been demonstrated that early identification, and screening are beneficial in low-resource environments. And, Immunization against HPV has emerged as a potential primary preventive measure.[48] Ethiopia launched the HPV vaccine, a quadrivalent immunization, for the first time in 2018.[3] However, because the available approach was not well-utilized, insufficient screening opportunities, patients typically appear with symptoms later-stage.[15] A systematic review and meta-analysis showed that in Ethiopia, the pooled estimate of adolescents' vaccination uptake of at least one dose of HPV vaccine was 55%. This is a low rate and indicates the significant gap comparing to the WHO plan of having 90% of girls should be fully vaccinated by the age of 15 years.

Conclusion

Due to inadequate access to effective management, particularly in low- and middle-income countries, advanced cervical cancer is one of the leading causes of cancer-related mortality among women. This study identified advanced cervical cancer survival rates and associated factors in Ethiopia. The one-year cumulative survival rate among advanced-stage cervical cancer patients was 77%. The mean time of survival after 12 months was 10.392 months. The percentages of patients who survived cancer treatment for stages IIB, IIIA, IIIB, IIIC, IVA, and IVB were 100%, 100%, 92%, 87%, 56%, and 24%, respectively. Patients who received cancer therapy had a survival rate of 70–80%, compared to 21% for those who did not. Major factors associated with survival were age, cancer stage, the presence of anemia, and longer treatment waiting times.

Data Sharing Statement

Data are available upon reasonable request from the corresponding author.

Ethical Statement

Data was collected after ethical clearance was obtained from the Institutional Review Board of Addis Ababa University College of Health Sciences (IRB) (057/21/Nursing). The study was conducted in accordance with the Declaration of Helsinki. A trained data collector verbally informed eligible patients about the objectives and purposes of the study, the benefits of the study, and the requirement of a follow-up interview one-year post-enrollment. Patients were encouraged to ask questions to clarify any issues before deciding whether to participate. Study participants were enrolled when they verbalized their willingness to participate in the study, including participation in the one-year follow-up interview, use of medical records, and possible phone contact for follow-up, and signed the informed consent form.

During the training of data collectors, ethical issues were addressed as an essential component of the research. Privacy and confidentiality were maintained by avoiding the use of identifiers and restricting data access. The principal investigator ensured that the collected raw data was kept safe and confidential, locked in a secure location with password protection implemented for all files. Names of participants were not recorded in study records, and data will be reported in a manner that preserves participant anonymity and prevents the identification or linkage of the participants with the information.

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Author Contributions

All authors contributed to data analysis, drafting, or revising the article, have agreed on the journal to which the article will be submitted, gave final approval of the version to be published, and agree to be accountable for all aspects of the work.

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Disclosure

The authors declared that there was no conflict of interest.

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CHAPTER THREE: PAPER 2

Cancer Management and Research

Elevate Series

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ORIGINAL RESEARCH

Pre- and Post-Treatment Quality of Life Among Patients with Advanced Stage Cervical Cancer at Tikur Anbessa Specialized Hospital, Ethiopia

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Background: The development of health concepts beyond traditional markers of illness and death has made the evaluation of quality of life (QoL) crucial to patient care. Yet, there is little research evaluating the pre- and post-treatment QoL of cervical cancer survivors in Ethiopia.

Objective: This study aimed to assess the pre- and post-treatment QoL of women diagnosed with advanced-stage cervical cancer.

Methods and Materials: A cohort design was conducted at the Tikur Anbessa Specialized Hospital Oncology Center. A total of 166 cervical cancer patients were recruited consecutively. Data was collected through interviews with standardized questionnaires before and after treatment. The Wilcoxon rank test was used to assess the significant differences in pre-treatment and post-treatment quality of life. Additionally, the Mann-Whitney *U*-test was also employed. Statistical significance was determined with p-values <0.05 and a 95% confidence interval.

Results: Women who were in stages IVA and IVB were 24.7% and 10.2%, respectively. Both the global health scale (66.67 [47.92–75] to 83.33 [66.67–83.33]) and the functional domain QoL (66.67 [40–80] to 70 [46.67–86.66]) showed statistically significant improvements from pre-treatment to post-treatment QoL. Women under the age of 45 were found to have higher global health QOL ($P < 0.001$) and functional domain QOL ($P = 0.029$). Women presented in stages II and III had comparatively higher global health QoL ($P = 0.008$) and functional domain QoL ($P = 0.021$).

Conclusion: Global health QOL and the majority of functional quality of life significantly improved following six months of cancer treatment. But there was no discernible change in terms of sexual enjoyment, sexual function, or activity. Age, marital status, the duration since diagnosis, the stage of the cancer, and the presence of comorbidities were the factors that affected the improvement of post-treatment quality of life.

Keywords: pre-treatment, post-treatment, quality of life, cervical cancer, Ethiopia

Background

Cervical cancer is one of the most common cancers in women worldwide, being the fourth most common after breast, colorectal, and lung cancer.[1] According to GLOBOCAN 2020 estimates, there were about 604,000 new cases of cervical cancer worldwide in 2020, with 342,000 deaths annually. Approximately 85% of new cases and 90% of deaths, respectively, take place in low- and middle-income countries. Sub-Saharan Africa has the highest regional incidence and mortality, with rates higher in Eastern Africa (40.1 cases and 28.6 deaths per 100,000 population).[2] Cervical cancer is the second most common type of cancer among women in Ethiopia. Reports from 2018 indicate that there were an anticipated 6294 new cases of cervical cancer each year and 4884 deaths related to the disease.[3]

The incidence and mortality of cancer are rising at an accelerated rate, which can be attributed to various factors such as aging and population growth, as well as shifts in the distribution and frequency of the main cancer risk factors, some of which are associated with socioeconomic status.[4]

The percentage of patients diagnosed with cervical cancer varies based on the disease's stage; the majority of patients are found in the mid-to-late stages, and the majority of patients present in the early stages, when treatment is most successful. [5] The staging system for invasive cervical cancer that is most commonly used is the International Federation

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of Gynecology and Obstetrics (FIGO) guideline, which is separated into four stages: I (A, A1, A2, B, B1, B2, and B3), II (A, A1, A2, and B), III (A, B, and C), and IV (A and B). Patients with advanced-stage cervical cancer are in FIGO stages IIB to IVB and may have pelvic or lower back pain, flank pain, and lower limb edema. Furthermore, problems relating to the bowel or bladder, such as pressure changes or the flow of feces or urine through the vagina, indicate invasion of the rectum and bladder, respectively.[6] Surgery, radiation therapy, chemotherapy, or a combination of these treatments may be used to treat patients, depending on the stage of their cervical cancer and the presence of comorbidities. While radiation therapy or surgery can be used to treat cervical cancer in its early stages, combination treatments are necessary for patients presenting with advanced stages of the disease.[1,5,7]

Patients with cervical cancer experience changes in their physical and emotional health, which ultimately impact their quality of life.[8] The measurement of QoL has become essential to patient treatment due to the expansion of health concepts beyond traditional indicators of morbidity and mortality. Despite advancements in cervical cancer detection and treatment, survivors of the disease face significant challenges, most notably with regard to QoL.[9]

The burden of cervical cancer and its effects on patients make it necessary to evaluate baseline QoL prior to treatment.[10] It is established that both the illness and the treatments have an effect on QoL. Appropriate psycho-oncological care for patients with cervical cancer throughout diagnosis and therapy may be made easier with a deeper understanding of pre- and post-treatment quality of life. However, there is a dearth of research assessing the quality of life (QoL) prior to and following therapy for patients with advanced cervical cancer in Ethiopia. Thus, this study was aimed at assessing the pre- and post-treatment quality of life of women diagnosed with advanced-stage cervical cancer.

Methods and Materials

Study Design and Setting

This study was a cohort design to assess QOL among advanced-stage cervical cancer patients who received cancer treatment at the Tikur Anbessa Specialized Hospital Oncology Center. Tikur Anbessa Specialized Hospital is one of the biggest referral hospitals and the only oncology center in Ethiopia.

Population and Data Collection Procedure

A total of 166 patients with clinically diagnosed advanced cervical cancer were included. Participants were consecutively recruited just prior to the start of the cancer treatment during the period from January 10, 2022, to September 20, 2022. Data were collected using interviewer-based, standardized questionnaires. During the pre-treatment interview, socio-demographic characteristics, clinical characteristics, type of cancer treatment, and comorbidities were additionally collected. Patients were re-interviewed six months after the pre-treatment interview to evaluate post-treatment QoL. Post-treatment interviews ended on March 20, 2023. The inclusion criteria were cervical cancer patients who were diagnosed as advanced stage of cervical cancer (FIGO stage of IIB-to-stage IVB), patients who were enrolled in any cancer treatment, and patients who were willing to participate in the study. Cervical cancer patients who were in the early stages of cancer and patients who did not begin any cancer treatment were excluded. Validated questionnaires were used, and the data collection was continuously supervised. Two days of training were given to data collectors. Daily evaluation of the data for completeness and encountered difficulties at the time of data collection were attended accordingly. All completed data collection questionnaires were examined for completeness.

Data Collection Tool

A standardized tool, the European Organization for Research and Treatment of Cancer (EORTC) core questionnaire (CX 30) and the cervical cancer module (CX 24), were used. The EORTC CX30 questionnaire is an integrated tool for assessing the health-related QoL of cancer patients and has 30 items. It includes five functional scales, three symptom scales, a global health status scale, and six single items. All of the scales and single-item measures range in score from 0 to 100. A higher score on the scale indicates a higher response level. Therefore, a high score on the global health status scale indicates a good quality of life; a high score on the functional scale indicates a high or healthy level of functioning; and a high score on the symptom scale indicates a high degree of symptomatology/problems.[11] Cronbach's alpha coefficient scores for the EORTC QLQ-C30 ranged from 0.72 to 0.95.[12]

The cervical cancer module (EORTC QLQ-CX24) was developed in a multicultural, multidisciplinary setting to supplement the EORTC QLQ-C30 core questionnaire. It has 24 items. It incorporates 3 multi-item scales to assess symptom experience, body image, and sexual/vaginal functioning. In addition, 6 single items assess lymphoedema, peripheral neuropathy, menopausal symptoms, sexual worry, sexual activity, and sexual enjoyment. Similar to the EORTC CX30, all of the scales and single-item measures range in score from 0 to 100. A high score on the symptom scales or single items indicates a high degree of problems or symptomatology, while a high score on the functional single items indicates a high degree of functioning[13] Cronbach's alpha coefficients range from 0.72 to 0.87 for the subscales, suggesting high internal consistency (symptom experience, 0.72; body image, 0.86; sexual/vaginal functioning, 0.87).[14]

The English-language EORTC CX 30 and 24 tools were translated into Amharic. Cronbach's alpha's for the translated versions ranged from 0.70 to 0.84.[15] In our study, we used this validated Amharic language version tool to assess the pre-treatment and post-treatment QoL among advanced-stage cervical cancer patients.

Data Analysis

Data was entered, cleaned, and analyzed using SPSS version 29 software.[16] Descriptive statistics were performed to analyze sociodemographic characteristics such as age, education level, marital status, and clinical traits such as cancer stage and treatment types. Before data analysis, a normality test was performed. The Kolmogorov-Smirnov and the Shapiro-Wilk tests showed that normality assumptions were not satisfied. Therefore, non-parametric tests, such as the Wilcoxon ranked test, were used to assess differences in pre-treatment and post-treatment QoL. Values are presented in mean, median, standard deviation, and interquartile range. The Mann-Whitney *U*-test was used to assess differences in post-treatment QoL based on sociodemographic and clinical characteristics. Statistical significance was determined with *p*-values <0.05 and a 95% confidence interval.

Furthermore, global health QoL, symptom domain QoL, and functional domain QoL were categorized. Based on other published works, the functional domain, the symptom domain, and the global health status were categorized as good, "moderate, and poor for comparison's sake.[16,17] The functional domain and global health status were categorized as "good" with a median score of greater than 66.7, "moderate" with a median score of 33.4–66.6, and "poor" with a median score of less than 33.3. The symptom domain was classified as "less symptomatic" with median score of below 33.3, as "moderate symptomatic" with median score of 33.4–66.6 and as "very symptomatic" with median score of above 66.7

Results

Sociodemographic and Clinical Characteristics of Participants

A total of 166 women with advanced-stage cervical cancer participated in this study. Participants' mean age was 52.33 years, with a standard deviation of 10.16 years and a range of 30–81 years. From these, 31.9% were 50–59 years of age. Most were housewives; more than half had no formal education, 42.2% were married, 70% reported no alcohol consumption, and 81% reported no regular exercise.

The most common histologic type was squamous cell carcinoma (96.2%). Twenty-five percent and 10.2% of women were in FIGO stages IVA and IVB, respectively. Thirty-seven percent and 53% of cervical cancer patients were treated with radiotherapy and chemoradiotherapy, respectively. Anemia and HIV/AIDS accounted for 21.1% and 12% of the co-morbidities, respectively (Table 1).

Pre-Treatment Quality of Life

Higher values in the functional and global health status domains suggest a higher quality of life, according to the scoring manual, while higher values in the symptom category indicate an a symptomatic or health problem issue. The interquartile range (IQR) for women's global health status before to treatment was [41.67–75], with a median score of 58.33. The functional domain yielded higher scores for physical functioning (63.33 [40–80]) and cognitive functioning (66.67 [33.33–66.67]), respectively.

Table 1 Sociodemographic and Clinical Characteristics of Participants (n = 166)

Variable	N	%
Age		
Above 60 years	50	30.1
50–59 years	53	31.9
40–49 years	46	27.7
30–39 Year	17	10.2
Educational Level		
No formal education	86	51.8
Elementary completed	44	26.5
High school completed	28	16.9
College/university completed	8	4.2
Occupation		
Housewife	*141*	84.9
Self-employed	*17*	10.2
Governmental employee	*8*	4.8
Marital status		
Married	*70*	42.2
Widowed	*47*	28.3
Divorced	*25*	15.1
Single	*22*	13.3
Separated	*2*	1.2
Religion		
Orthodox Christian	*108*	65.1
Muslim	*33*	19.9
Protestant	*21*	12.7
Others	*4*	2.4
Monthly Income		
500–5,000 ETB	*107*	64.5
5,000–10,000 ETB	*48*	28.9
More than 10,000 ETB	*11*	6.6
Alcohol Drinking		
Yes, everyday	*9*	5.4
Yes, 1–2 days every week	*6*	3.6
Yes, sometimes	*36*	21.7
No	*115*	69.3
Exercise		
Never	*135*	81.3
Yes, sometimes	*24*	14.5
Yes, everyday	*7*	4.2
Living with		
Alone	*9*	5.4
With families	*150*	90.4
With relatives	*7*	4.2
Histopathology		
Squamous	160	96.4
Adenocarcinoma	6	3.6
FIGO stage		
Stage IIB	45	27.1
Stage IIIA	6	3.6
Stage IIIB	12	7.2
Stage IIIC	45	27.1
Stage IVA	41	24.7
Stage IVB	17	10.2

(*Continued*)

Table 1 (Continued).

Variable	N	%
Known co-morbidities		
None	90	54.2
Anemia	35	21.1
HIV	20	12
Others	21	12.6
Type of treatment		
Chemoradiotherapy	88	53
Radiotherapy	62	37.3
Chemoradiotherapy +Surgery	16	9.6

Notes: Others include DM, kidney, liver and cardiovascular disease.

The EORTC QLQ-C30 tool's symptom domain revealed that fatigue (55.56 [33.33–66.67]), constipation (66.67 [0–100]), and financial difficulties (66.67 [0–100]) scored higher than the other symptoms, whereas the median score of symptom experience using EORTC CX24 was 39.39 [21.21–54.55] (Table 2).

Table 2 Pre-Treatment QOL of Women with Advanced Cervical Cancer Using EORTC CX30 and CX24 (n = 166)

Variable	Item Number	Median [Interquartile Range] (IQR)
EORTC CX30		
Global Health Status		
Global health status/QoL	29.30	58.33 [41.67–75]
Functional scales		
Physical functioning	1 to 5	63.33 [40–80]
Role functioning	6.7	50 [33.33–66.67]
Emotional functioning	21 to 24	45.83 [33.33–75]
Cognitive functioning	20.25	66.67 [33.33–66.67]
Social functioning	26.27	50 [33.33–66.67]
Symptom scales		
Fatigue	10,12,18	55.56 [33.33–66.67]
Nausea and vomiting	14.15	16.67 [0–33.33]
Pain	9.19	50 [33.33–83.33]
Dyspnea	8	0 [0–33.33]
Insomnia	11	0 [0–66.67]
Appetite loss	13	33.33 [0–66.67]
Constipation	16	66.67 [0–100]
Diarrhea	17	0 [0–33]
Financial difficulties	28	66.67 [0–100]
EORTC CX24		
Symptom Domain		
Symptom Experience	31 to 37, 39, 41–43	39.39 [21.21–54.55]
Lymphoedema	38	0 [0–33.33]
Peripheral Neuropathy	40	0 [0–66.67]
Menopausal Symptoms	44	33.33 [0–66.67]
Sexual Worry	48	0 [0]
Functional Domain		
Body Image	45–47	33.33 [11.11–66.67]
Sexual Activity	49	0 [0]
Sexual Enjoyment	54	0 [0]
Sexual/Vaginal Functioning	50–53	33.33 [25–58.33]

Post-Treatment Quality of Life

Six months after the pre-treatment interview, post-treatment QoL was evaluated. Thirty-two deaths were recorded within six months post-treatment. As a result, 134 individuals were interviewed in the post-treatment phase.

The median global health score after cancer treatment was 83.33 [66.67–83.33]. Physical functioning had the highest score (70 [46.67–86.66]) among the functional domains of the EORTC QLQ-C30 tool. Pain (50 [16.67–66.67]) and fatigue (55.55 [22.22–77.78]) scored highest in the symptom domain. According to the EORTC QLQ-CX24, sexual/vaginal functioning had the highest value of 33.33 [33.33–41.67] among the functional domains, and symptom experience had the highest value of 15.15 [6.06–36.36] in the symptom domain (Table 3).

Comparison of Pre-Treatment and Post-Treatment Quality of Life

In order to assess the quality of life before and after treatment, individuals with cervical cancer who died within the first six months (n = 32) were not included in the analysis of pre-treatment QoL.

A comparison of the global health status prior to and after cancer treatment showed statistically significant improvement in their median score, which was from 66.67 [47.92–75] to 83.33 [66.67–83.33]. This difference was significant according to the Wilcoxon rank test ($p < 0.001$).

Table 3 Post-Treatment QOL of Women with Advanced Cervical Cancer Using EORTC CX30 and CX24 at TASH, 2022 (n = 134)

Variable	Item Number	Median (IQR)
EORTC CX30		
Global Health Status		
Global health status/QoL	29.30	83.33 [66.67–83.33]
Functional scales		
Physical functioning	1 to 5	70 [46.67–86.66]
Role functioning	6.7	66.67 [50–66.66]
Emotional functioning	21 to 24	66 [50–66.66]
Cognitive functioning	20.25	66.67 [50–83.33]
Social functioning	26.27	66.67 [33.33–83.33]
Symptom scales		
Fatigue	10,12,18	55.55 [22.22–77.78]
Nausea and vomiting	14.15	33.33 [0–50]
Pain	9.19	50 [16.67–66.67]
Dyspnea	8	0 [0–33.33]
Insomnia	11	0 [0–66.67]
Appetite loss	13	33.33 [0–66.67]
Constipation	16	0 [0–33.330]
Diarrhea	17	0 [0]
Financial difficulties	28	66.67 [33.33–100]
EORTC CX24		
Symptom Domain		
Symptom Experience	31 to 37, 39, 41–43	15.15 [6.06–36.36]
Lymphoedema	38	0 [0–33.33]
Peripheral Neuropathy	40	0 [0–33.33]
Menopausal Symptoms	44	0 [0–33.33]
Sexual Worry	48	0 [0]
Functional Domain		
Body Image	45–47	11.11 [0–44.44]
Sexual Activity	49	0 [0–33.33]
Sexual Enjoyment	54	0 [0–33.33]
Sexual/Vaginal Functioning	50–53	33.33 [33.33–41.67]

Based on the EORTC QLQ-C30 functional domain, women showed statistically significant improvement on all functional scales from the pre-treatment period. The functional domain increased from 66.67 [40–80] to 70 [46.67–86.66].

On the other hand, it was found that the value in the body image functional domain significantly decreased from the pre-treatment phase (33.33 [11.11–66.67]) to the post-treatment phase (11.11 [0–44.44]), rather than increasing. Furthermore, sexual enjoyment and sexual activity did not show any improvement (Table 4).

Before receiving treatment, the global health status of over half of participants (52.1%) was moderate, and 29.1% was good. Following treatment, participants with good global health status increased to 62.7% and participants with moderate global health status decreased to 34.2% (Figure 1).

Participants were asked for their sexual engagement to respond as "not at all", "a little bit", "a quite bit" and "very much". During pre-treatment interview, most of women (80.6%) reported "not at al", 5.7% of them responded as "a little bit", 2.2% of them said "quite bit" and only 1.5% of them said "very much". Similarly, during post-treatment interview, 74.1% of them responded as "not at all", and 1.2% said as "very much". Women who reported no sexual enjoyment were 93.2% during pre-treatment interview and 88.6% during post-treatment interview (Figure 2).

Table 4 Comparison of Pre-Treatment and Post-Treatment Quality of Life Among Women with Advanced Stage of Cervical Cancer

Variable	Item Number	Pre-Treatment	Post-Treatment	P-value
EORTC CX30				
Global Health Status				
Global health status/QoL	29.30	66.67 [47.92–75]	83.33[66.67–83.33]	< 0.001
Functional scales				
Physical functioning	1 to 5	66.67 [40–80]	70 [46.67–86.66]	< 0.001
Role functioning	6.7	50 [33.33–66.67]	66.67 [50–66.66]	< 0.001
Emotional functioning	21 to 24	50 [33.33–75]	66 [50–66.66]	< 0.001
Cognitive functioning	20.25	66.66[33.33–66.67]	66.67 [50–83.33]	<0.001
Social functioning	26.27	50 [33.33–70.83]	66.67[33.33–83.33]	< 0.001
Symptom scales / items				
Fatigue	10, 12, 18	44.44[22.22–66.67]	50 [22.22–77.78]	0.548
Nausea and vomiting	14.15	16.67 [0–33.33]	16.67 [0–33.33]	0.724
Pain	9.19	50 [16.67–83.33]	50 [16.67–66.67]	<0.001
Dyspnea	8	0 [0–33.33]	0 [0–33.33]	0.008
Insomnia	11	33.33 [0–66.67]	0 [0–66.67]	< 0.001
Appetite loss	13	33.33 [0–66.67]	33.33 [0–66.67]	0.448
Constipation	16	50 [0–100]	0 [0–33.33]	< 0.001
Diarrhea	17	0 [0–33.33]	0 [0]	0.686
Financial difficulties	28	66.67 [0–100]	66.67 [33.33–100]	0.002
EORTC CX24				
Symptom Domain				
Symptom Experience	31 to 37, 39, 41–43	36.36[20.45–51.52]	15.15[6.06–36.36]	< 0.001
Lymphoedema	38	0 [0–33.33]	0 [0–33.33]	0.052
Peripheral Neuropathy	40	0 [0.0–66.67]	0 [0–33.33]	0.543
Menopausal Symptoms	44	33.33 [0–66.67]	0 [0–33.33]	< 0.001
Sexual Worry	48	0 [0]	0 [0]	0.382
Functional Domain				
Body Image	45–47	33.33[11.11–66.67]	11.11 [0–44.44]	< 0.001
Sexual Activity	49	0 [0]	0 [0–33.33]	0.109
Sexual Enjoyment	54	0 [0–33.33]	0 [0–33.33]	0.564
Sexual/Vaginal Functioning	50–53	33.33 [25–58.33]	33.33[33.33–41.67]	0.078

Note: P value by Wilcoxon signed rank test.

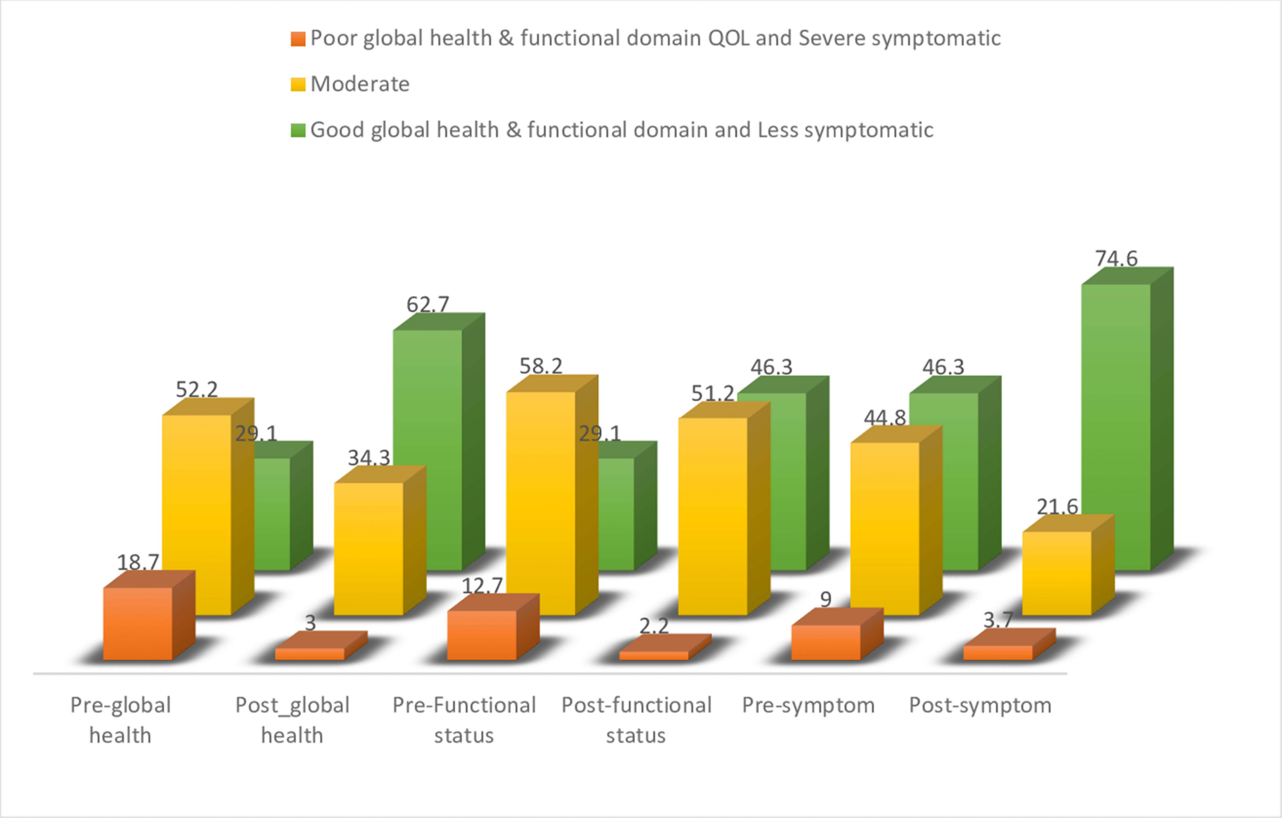

Figure 1 Comparing Pre-treatment and Post-treatment global health, functional domain and symptom experience among women with advanced stage of cervical cancer.

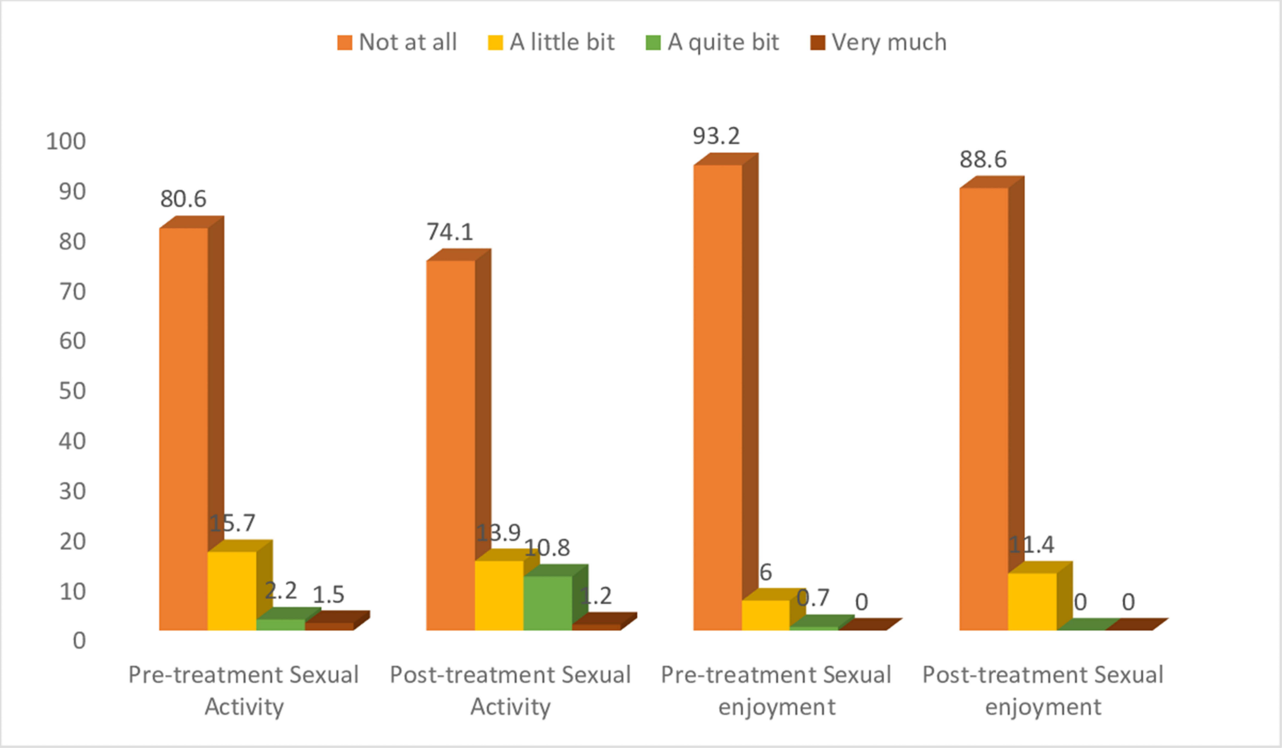

Figure 2 Comparing Pre-treatment and Post-treatment by sexual activity and sexual enjoyment.

Factors Associated with Post-Treatment Quality of Life

Age of Participants

Among the 134 individuals who underwent assessment after cancer treatment, 65.7% were older than 45 years. Women under the age of 45 were found to have higher global health status ($P < 0.001$) and functional domain of quality of life (P 0.029). Likewise, there was a significant difference in the symptoms of fatigue and pain. It was also shown that women under 45 experienced more sexual worry than those over 45 (P 0.038). However, age did not associate with sexual activity or sexual enjoyment (Table 5).

Comorbidities

Forty-five percent of the participants overall had at least one comorbidity. Anemia, HIV/AIDS, diabetes, heart disease, kidney disease, and liver disease were among the comorbidities that were mentioned. Anemia accounted for 21.1% and HIV/AIDS for 12.1% of cases. The global health and functional quality of life of women without comorbidities was significantly higher than that of women with comorbidities (Table 5).

Stage of Cancer

Of the 134 women assessed after treatment, 34 (25.4%) were in FIGO stage IV. For the majority of domain measurements, there was a statistically significant difference in post-treatment quality of life by stage presentation. Compared to women presenting in FIGO stage IV, those in stages II and III had comparatively higher global health ($P = 0.008$) and functional quality of life ($P = 0.021$). When it came to sexual enjoyment, there was no discernible difference between women in stage IV compared to stages II and III ($P = 0.334$), although women presenting in the lower stages experienced higher levels of sexual activity ($P = 0.039$) (Table 5).

Income

The mean monthly family income was 5,000 ETB with a range of 500 to 22,000 Ethiopian Birr (ETB). Global health quality of life was lower for women with monthly incomes of less than 5,000 ETB compared to those with incomes above 5,000 ETB ($P < 0.001$). However, their sexual activity, sexual enjoyment, and emotional functioning did not differ statistically (Table 6).

Marital Status

Of the 134 women who were assessed after treatment, 43.3% were married, 11.2% were single, 15.7% had divorced, 28.4% were widowed, and 1.5% were separated. Global health quality of life did not differ by marital status; however, married women scored higher in the emotional functioning domain of quality of life. Married women also had more sexual worry and higher levels of sexual activity, but there was no significant difference in sexual enjoyment between marital status groups (Table 6).

Table 5 Post-Treatment Quality of Life by Age, Presence of Anemia and FIGO Stage

Variable	**Age**			**Comorbidity**			**FIGO Stage**		
	> 45years	**< 45years**	**P**	**Yes**	**No**	**P**	**Stage IV**	**Stage II & III**	**P-value**
Global Health	70.69±17.90	82.41±9.72	<0.001	72.37±18.01	74.56±16.31	0.018	67.65±18.09	77 ±16.79	**0.008**
Functional	61.07±17	71.60±10.35	0.029	57.89±17.90	69.24±12.29	0.008	59.41±14.11	65.96±15.12	0.021
Pain	47.13±27.84	25.93±22.22	0.242	43.86±27.89	40.35±27.89	0.051	55.39±24.17	39.50±25.25	0.003
Fatigue	57.85±29.45	46.91±37.17	0.012	64.91±27.28	45.61±32.68	0.040	72.22±19.19	49.11±31.63	0.001
Sexual/vaginal	34.20±23.07	26.85±20.74	0.194	35.09±22.14	29.82±23.12	0.281	69.44±30.33	27.99±15.70	0.001
Menopausal	22.98±36.84	11.11±23.57	0.048	19.29±38.99	21.05±29.83	0.070	51.21±41.56	14.66±25.88	0.001
Sexual Worry	64.36±29.45	81.48±33.79	0.038	68.42±32.34	68.42±30.37	0.169	6.50±15.31	36 ±36.31	0.001
Sexual Activity	35.63±28.07	51.85±17.56	0.944	45.61±27.68	33.33±27.68	0.294	4.87 ±14.06	13.86±25.11	0.039
Sexual enjoyment	13.79±16.70	18.51±17.56	0.222	10.52±15.91	19.29±16.90	0.030	7.40 ±14.69	14.52±16.74	0.334

Note: P-value by Mann Whitney *U*-test.

Table 6 Post-Treatment Quality of Life by Family Monthly Income, Marital Status and Time Since Diagnosis

Variable	**Income**			**Marital Status**			**Time Since Diagnosis**		
	<5000ETB>	**5000ETB**	**P**	**Married**	**Others[a]**	**P**	**<12Months**	**>12Months**	**P-value***
Global Health	66.67±17.15	86.64±9.57	0.001	76.01±17.59	73.57±17.55	0.418	78.57±15.59	68±18.77	0.001
Emotional	64.60±21.44	67.45±20.49	0.183	72.55±19.18	61.95±20.74	**0.002**	68.32±19.17	63.50±22.89	0.309
Sexual Worry	58.55±31.33	72.88±37.89	0.018	70.95±36.74	58.33±31.71	0.023	65.87±35.46	61.38±33.32	0.441
Sexual Activity	10.28±22.62	18.07±26.49	0.190	18.09±27.61	9.37±20.91	0.016	60.63±28.29	5.28±16.11	0.001
Sexual enjoyment	10.71±15.85	16.66±17.09	0.217	15.94±17.02	10.66±15.86	0.268	15.55±16.91	9.25±15.36	0.200

Notes: * P-value by Mann Whitney *U*-test, [a] Others includes single, widowed, divorced and separate.

Time Since Diagnosis

Time since diagnosis was over a year for 37.3% of participants and was associated with global health quality of life. Longer time diagnosis was significantly associated with quality of life. Women with time of diagnosis longer than a year had lesser global health quality of life (P < 0.001) (Table 6).

Discussions

Quality of life (QOL) is defined as a person's self-reported perception of physical, psychosocial, and sexual well-being. Survivors' health-related QOL is becoming an increasingly important consideration as the rate of cervical cancer patients' survival increases, and improving QOL is crucial as advancements in the diagnosis and treatment of cancer have increased the life expectancy of cancer survivors.[17]

This study examined the pre- and post-treatment QoL of patients with advanced cervical cancer. Pre-treatment global health median score in the current study was comparable to results reported in South India.[8] In our study, following cancer treatment, there was a considerable improvement in global health status of quality of life. This is consistent with studies conducted in India.[9,10] On the other hand, a study conducted in Austria revealed that following the initial (less than three months) cancer treatment, there was a considerable reduction in global health status QOL. This inconsistency may be due to the fact that the majority of patients in their study underwent surgery and the length of the post-treatment evaluation varied. The same authors, however, reported that after a six-month and year-long follow-up, global health status had improved.[18]

Following cancer treatment, 53% of participants in our study had good global health status scores. This is similar to the results of studies conducted in Tanzania, China, and Iran.[19–22] The present investigation revealed a considerable improvement in physical, emotional, and social functioning following cancer therapy. These findings are in line with research conducted in Austria, Poland, and India.[9,10,18,23] Pain decreased significantly post-treatment; however, fatigue symptoms remained the same which was consistent with a study in Denmark[24] but differed from a study in India where fatigue symptoms also decreased.[9]

Sexual dysfunction problems, such as feeling unable to satisfy their partner's demands or perceiving changes in their partner's sexual interest, are significant sources of distress for women who have survived cervical cancer.[25,26] For cervical cancer survivors, both radiation therapy and major surgery may have medium- and long-term effects on their sexual functioning.[27] In our study, most participants, both pre- and post-treatment, did not have sexual activity. Sexual/vaginal functioning also remained the same between pre- and post-treatment periods. These findings were in line with several studies.[8–10,21,27–30] In the present study very few participants engaged in sexual activity similar to what was found in a study done in Korea.[31] Similarly, a study conducted in Lithuania found that the sexual activity and enjoyment of cervical cancer survivors were particularly low.[32] Related factors have been suggested by numerous studies and include dyspareunia, orgasmic difficulties, dry vagina, and vaginal atrophy, all brought on by the illness and side effects of cancer treatments.[33–36]

Radiotherapy has a greater adverse effect on sexual function than radical hysterectomy with pelvic lymphadenectomy, but more recent research suggests that new radiotherapy methods may not so negatively affect sexual function. Additionally, a study in Tanzania and a systematic review found that the use of combination radiation therapy (external plus brachytherapy) can considerably reduce sexual concern, increase sexual activity, and improve an individual's body image.[35,37]

In the current study, common significant factors associated with post-treatment QoL were age, time since diagnosis, marital status, presence of comorbidity and stage of cervical cancer. This is inconsistent with certain published studies that found no statistically significant variations in QoL ratings between age groups and cervical cancer stages.[32,38] According to this study, time since diagnosis had an impact on cancer survivors' self-reported health state and QOL. Another study found a similar relationship between the time since diagnosis and global health, functional health, and symptom scale.[21,39]

Implication to Clinical Practice

Improving quality of life (QoL) for patients with cervical cancer in low- and middle-income countries is crucial. In order to effectively care for patients with cervical cancer and to tailor their treatment, it is imperative to assess their QOL.[40] Furthermore, current research indicates that QoL data can offer unique predictive information in addition to being useful for evaluating patient well-being and aiding clinicians in making decisions.[41] When planning and evaluating a cancer patient's therapy course, QoL should be taken into account in addition to clinical characteristics.[38] Because this is the first study in Ethiopia to study pre- and post-treatment impacts of QOL, our results provide baseline findings for comparing pre- and post-treatment effects. Numerous studies have been conducted in other countries, however when evaluating participants' self-reported QoL, it is crucial to take into account sociodemographic, cultural, and religious backgrounds.

Limitations and Future Research Recommendations

Particularly in a population such as Ethiopia, where discussing sexuality is not an open conversation, evaluating sexual function, sexual engagement, and sexual enjoyment would be difficult. To comprehend and explore more about sexual issues and experiences, further research using methodologies such as qualitative approaches is encouraged. Furthermore, sexual counselling must to be taken into account in every facet of cervical cancer treatment. The observational method was used to conduct the current investigation. Additional study methodologies beyond observational design should be encouraged to evaluate the pre- and post-treatment impacts involving control groups.

Conclusion

In conclusion, following six months of cancer treatment, there was a significant improvement in global health quality of life. There were also improvements in physical functioning, role functioning, social and emotional functioning. Symptoms of pain and nausea/vomiting did not change, but fatigue decreased. Additionally, there were no noticeable differences in sexual function, sexual activity and sexual enjoyment from pre- to post-treatment phases. The factors that were linked to post-treatment QoL were age, marital status, time since diagnosis, cancer stage, and the presence of comorbidities. In addition to clinical parameters, QoL should be considered while planning and assessing a cancer patient's course of treatment course.

Data Sharing Statement

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

Ethical Statement

Data was collected after ethical clearance was obtained from the Institutional Review Boards of Addis Ababa University College of Health Sciences (IRB (057/21/Nursing). After that, consent was obtained from the oncology center. Eligible participants were informed, by trained data collector, about the objectives and purposes of the study, and the benefits of the study. The study was conducted in accordance with the Declaration of Helsinki. Study participants were included when they stated their willingness to participate in the study and signed on the informed consent.

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Author Contributions

All authors contributed to data analysis, drafting or revising the article, have agreed on the journal to which the article will be submitted, gave final approval of the version to be published, and agree to be accountable for all aspects of the work.

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Disclosure

The authors declared that there is no conflict of interest.

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CHAPTER FOUR: PAPER 3

Sexual and psychosocial experiences of women with advanced-stage cervical cancer at Tikur Anbessa Hospital

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Abstract

Background: Cervical cancer in its advanced stages is difficult to treat and typically results in a terminal diagnosis with palliation rather than cure. In Ethiopia, the majority of women diagnosed with invasive cervical cancer do so at an advanced stage. Women with advanced stages of cervical cancer are treated with radiotherapy or combination treatments, which can result in multiple side effects and impact sexual function. There are also psychological sequelae, such as anxiety, guilt, and depression. To effectively anticipate, comprehend, and address the issues faced by cancer patients, it is crucial to conduct research on psychosocial and sexual concerns. Therefore, this study aimed to understand the sexual and psychosocial experiences of women with advanced-stage cancer.

Methods and Materials: A qualitative phenomenological study was performed at the Tikur Anbessa Specialized Hospital Oncology Center. A total of 23 women with advanced-stage cervical cancer were selected. In-depth interviews were conducted using an interview guide. The recorded data were transcribed using a verbatim approach and then translated into English. The transcribed data was then imported into the qualitative data analysis software package MAXQDA for coding and categorization.

Results: Several codes arose from the synthesis of the women's transcribed interviews, and these codes were subsequently grouped into three themes and subthemes. The most commonly reported sexual problems were pain during sexual intercourse, bleeding or spotting after sexual intercourse, foul-smelling vaginal discharge, and diminished sexual desire. Women reported that it can be challenging for them to start these conversations with providers and that medical providers do not always provide them with information on sexual issues. Most women highlighted how important their partners' psychosocial assistance was to them during difficult times.

Conclusion: Women experienced numerous sexual problems after the onset of cancer symptoms and after undergoing cancer treatment. Patients with cancer will benefit from psychosocial support from their partners, families, and doctors to feel hopeful again.

Keywords: Psychosocial; Sexual; Tikur Anbessa Specialized Hospital; Cervical cancer;

Advanced stage; Ethiopia

Plain English Summary

Psychosexual support address issues such as sexual distress, relationship satisfaction, and the partner's viewpoint in addition to physical sexual functioning. Moreover, it would be beneficial to provide more useful and reassuring information regarding the implications of cervical cancer for relationships and sexuality. Women may better handle the challenges related to sexual activity if their sexual and psychological needs are given greater consideration. Compared to women who get surgery and chemotherapy, radiation therapy patients had higher rates of sexual dysfunction. The psychosocial and sexual experiences of patients with cancer are crucial for improving cancer care and treatment. Most common complaints from women were pain during or following a sexual encounter, bleeding, spotting or vaginal discharge, and decreased libido. Women claim that being among supportive and caring individuals made them feel a lot more alive. On the other hand, women who did not receive psychosocial support expressed fearing their spouse's attitude and felt less confident, useful, hopeful, and attractive.

Introduction

Sexuality is a significant factor in patients' quality of life before, during, and after treatment for cervical cancer (1). Survivorship care increasingly includes consideration of cancer and the adverse effects of treatment (2). Cervical cancer treatment may lead to sexual dysfunction (3). Cervical cancer stands out as the leading factor associated with sexual dysfunction and challenges in intimate relationships (4).

Treatments for cervical cancer can also result in multiple side effects that can impact sexual functioning and sexual relationships, including pain during sexual intercourse, a shortened vagina, reduced vaginal elasticity, and diminished vaginal lubrication (5). These physical issues could result in reduced sexual desire, loss of connection with one's spouse, and lack of confidence (6).
Furthermore, disease and treatment are associated with psychological sequelae such as anxiety, fear of sexual performance, guilt, and depression (7). Women who have undergone treatment for cervical cancer seek love and make a conscious effort to integrate their marital lives and romantic desires with the joy that comes from having sex. To improve one's perspective on sexuality, support from one's partner is essential (8). The divorce rate is greater among women with cervical cancer than among all other cancer survivors and is primarily due to the patient's and her spouse's lack of sexual desire and fulfillment (1).

Psychosocial issues, such as anxieties about the illness, inability to make plans, and poor quality of life, can persist for up to two years after treatment (9). In underdeveloped countries, especially in sub-Saharan Africa, women who have cervical cancer face numerous challenges, such as inadequate access, a lack of high-quality healthcare, and a lack of psychosocial support (10).

To increase awareness of the sexual and psychosocial needs of cervical cancer survivors, it is crucial to comprehend their experience and recovery process (11). The definition of disease, the formation of disease beliefs, and the process of seeking medical advice are all influenced by culture (12). It is imperative for clinicians to increase their awareness of patients' concerns since these can serve as sensitive indicators of instances requiring psychosocial support. To anticipate, comprehend, and address the issues faced by cancer patients, it is essential to investigate both psychosocial and sexual concerns. Therefore, the aim of this study was to explore the sexual and psychosocial experiences of women with advanced-stage cancer who were receiving follow-up care.

Methods and Materials

Design and Context

A phenomenological-qualitative study design was employed. This design was employed because phenomenological studies explain how a phenomenon is understood by multiple people based on their shared experiences. In phenomenology, data are gathered from people who have experienced the phenomenon to create a composite description that captures the essence of each person's experience. The "what" and "how" of what they went through are described in this account. (13). The study was conducted at the Tikur Anbessa Specialized Hospital (TASH) Oncology Center, which is in Addis Ababa, the capital city of Ethiopia.

Participants

A total of 23 women were selected according to the inclusion criteria. The inclusion criteria included age under 50 years, at least one-year post-cancer diagnosis, and willingness to explore and describe their experiences. The final number of participants was determined by data saturation. Data saturation was assessed based on the informational redundancy of the data, which was deemed to have been attained at the point where no new categories or information were collected.

Data collection and analysis

In-depth interviews were conducted using an interview guide (Table 1). To provide privacy and an opportunity to deeply reflect on their experiences, each woman was interviewed alone. After interviews, thorough notes were assessed, and the recorded speech data were transcribed in a verbatim manner. The Amharic language was used to conduct the interviews. The data were translated into English-by-English fluent speaker after being transcribed. The translated data were imported into a qualitative data analysis software package called MAXQDA software (14) for coding. Quotations that describe participants' experiences with the phenomena are read repeatedly to build the data. These quotations then provide a cluster of meanings that develop into codes. The principal investigator and the assistant coder completed the majority of the coding; discrepancies in the codes that were found by the coders were addressed, and the investigator's coding was examined and discussed in order to make the research findings clearer. Based on their similarities and differences, all detected codes were then allocated to subthemes, and related sub-themes were grouped into main themes.

Table 1 Interview guide

Main Topic	Question
Introduction	How did you get diagnosed with cervical cancer?
Symptom recognition	Tell me about the symptoms you experienced.
Emotional reaction to Diagnosis result	Can you explain the emotional experience you had at the time of the of the cancer diagnosis? Tell me how the diagnosis result affects you as a person.
Treatment	Tell me about how you got treatment. Can you explain the burden you faced to get the treatment? What are the physical problems you have after cancer treatment?
Relationship	Can you tell me about your marital story? Tell me about the support you received from your partner. What are the challenges you faced after your cancer diagnosis? What do you think about your family, life, and surviving cervical cancer?
Sexual problems	What sexual problems do you have after cancer treatment? Tell me about your experience. How did you discuss the sexual issues with health care providers? How was your partner's
Psychosocial	What do you feel when you think about cancer treatment and follow-up? What did you experience when you told others about your case? Tell me about the support you have received from others, including health care providers.
Conclusions	Is there anything you want to add? Thank you

Trustworthiness

To ensure the trustworthiness of the data, of the data, the investigator used different approaches. Data was collected by the principal investigator, and the audio recordings were transcribed line by line in Amharic and then translated to English. The interviews were conducted with participants using audio recorders, and notes were collected during the interview and verbatim transcribed. This allows for cross-checking and confirmation of the consistency of the interpretations. Intertextual participant statements were quoted directly, and detailed definitions were developed between the studied context and the study itself. To minimize bias and errors, the interview guide was translated into the local language, and the questions were asked in the participant's language. The principal investigator tried to set aside preconceived assumptions and opinions, as well as prior knowledge, during the data collection, coding, and analysis in order to reduce researcher bias. The investigator used a thick description to clarify all the research processes from the time of data collection to the time of the final report.

Results

Participant Characteristics

A total of 23 cervical cancer patients participated in the study. The age range of the participants was 38–48 years. The majority were married, with a few women stating that they were divorced or widowed. The level of education ranged from the completion of elementary school to graduation from college, and very few lacked any formal education. The majority were government employees, housewives, private employees, or self-employed individuals.

The duration from cervical cancer diagnosis was one to four years. The duration of time since the start of treatment varied from six months to three years. The stage of disease ranged from FIGO IIB to IVA (Table 2).

Women with advanced-stage cervical cancer who were receiving follow-up care shared their experiences. Forty codes arose from the synthesis of the women's transcribed experiences, and these codes were subsequently grouped into themes and subthemes. Three main themes emerged and are presented as follows (Table 3).

Table 2 Sociodemographic characteristics of participants and clinical characteristics

Variable	Frequency
Age	
<45 years	14
45-50 years	9
Duration status	
Married	14
Divorced	5
Widowed	4
Number of children	
1-4	15
>4	8
Level of education	
No formal education	3
Elementary	5
High school	10
College	5
Occupation	
Government	8
Private	1
Self-employed	9
Duration since diagnosis	
1-3 years	14
3-6 years	9
Duration since treatment	
6 months -2 years	17
2-3 years	6
Type of treatment	
Radiotherapy	6
Chemoradiotherapy	15
Surgery + radiotherapy	2
Stage of cancer	
FIGO stage IIB	9
FIGO stage III	9
FIGO stage IV	5

THEME 1: THE JOURNEY OF DIAGNOSIS AND GETTING TREATMENT

Subtheme 1: Cervical cancer symptom recognition

Participants were asked about the symptoms they experienced before the diagnosis. Most of the participants said they had experienced vaginal bleeding. At first, they thought it could have been abnormal menstrual bleeding. As they mentioned, it took them longer to identify health problems. Some women frequently bled after having intercourse. Some women also said they had vaginal discharge, which they explained was embarrassing to them. This alerted them to the fact that something was wrong. Eventually, they realized there was a problem with their bodies. Upon identifying the symptoms, the majority of women expressed that they were hesitant to visit medical institutions and receive a diagnosis for various reasons. Some of the quotes are listed below.

"*There were blood clots most of the time, and I was bleeding excessively, more than I would have during a regular menstrual cycle." (P02).*

"After having intercourse, I started bleeding. In the beginning, it appeared accidental to me. However, it kept happening" (P 17).

"It took longer to go to the health facility. Bleeding occurred and then stopped. In addition, I didn't have enough money to visit a medical center. I believed that I had been cured when the condition vanished" (P05).

Subtheme 2: Emotional reactions during diagnosis

Women were mentioned about how they felt that they had cervical cancer. The majority of them were shocked, cried, feared the consequences, worried about their families, and were generally unaware of cervical cancer. A small number of participants were aware of cervical cancer and screening but had not been prepared for the possibility that they might have cancer.

"I did not know what cervical cancer was at first. However, I knew the word cancer, as it is a serious disease. I was shocked when I first heard the term cancer. It took me a while to ask for more clarification. I believed that once I left the hospital, I would die. Subsequently, the physician attempted to comprehend my confusion and provide an explanation of cervical cancer. When I thought of my kids, I started crying a lot" (P12).

"I shocked. I thought I would die soon. I cried. I was so sad that it happened to me. You know I am HIV-positive and already on ART. When cancer was also my problem, I was so hopeless" (P12).

Subtheme 3: Burden of waiting to receive treatment at Tikur Anbessa Specialized Hospital

Tikur Anbessa Hospital is the only oncology center in the country. Patients from all parts of the country are referred for radiotherapy. As a result, the oncology department is busy, and it is common to see the corridor full of patients and long queues at the nurses' station and at the radiotherapy gate. Women were asked about the burden of receiving their treatment. Most women reported that it was challenging. As they stated, receiving radiation treatment could take six months to a year.

"Oh, it was so tedious. There were many patients listed in the registration book. The doctor ordered radiation. However, it took 6 months to achieve radiotherapy." (P14).

"Oh, it was so annoying. There are many referred patients waiting for radiotherapy. During the first registration, they appointed me after 6 months. I could not come to the appointment for various reasons. Anyway, it took me a year to get radiotherapy" (P08).

"Here, it was so hard. Once the doctors ordered chemo- and radiotherapy, the nurse appointed me after 7 months. Because there were many patients registered. I asked my elder boy, who is a pharmacist, if I could get a solution. He was so sad when he heard that I could receive radiotherapy after 7 months. He contacted radiotherapy centers in Bangkok and Nairobi. The cost was high, but I went to Kenya and finished all the treatment cycles. Now, I am following up here." (P15).

THEME 2: SEXUAL EXPERIENCE

The participants shared that their sexual life was difficult. The majority of women stated that they had no desire to engage in sexual activity with the onset of their cancer symptoms or after cancer treatment. The majority of women said that their main experiences with sexual encounters were pain, bleeding, and a lack of interest.

"I had no desire for any kind of sexual intimacy. Most of the time, I had spotting or discharged after sex. I had discomfort as well" (P03).

"When I had coitus with my husband, I felt like my body was narrower and there was serious pain inside my womb." (P18).

"I hate it; that is it. I don't have any interest in having intercourse. Believe it or not, it has been 3 years since I stopped it." (P19).

Other women clarified that they were not interested in sex. They engage in sexual activity solely to satiate their partner's interest. Women reported that conflicts about sex were one of the main sources of disagreements with their husbands. A woman who was divorced said that financial difficulties and arguments on sexual issues were what led to the failure of her marriage

"We paused for a considerable amount of time because I was experiencing discomfort and bleeding. All of my symptoms have disappeared after finishing my cancer treatment. I am currently on follow-up. I still do not find it interesting. However, I think I was no longer able to say no. Since we are married, I have to fully satisfy my husband's interests.." (P08)..

"To tell the truth, my spouse was not interested in waiting for me. Of course, I had quit my job at the time, so he was solely responsible for my finances. It was quite difficult to have daily arguments about sexual concerns. He understood I was unfit for sex, and our marriage swiftly spiraled out of control" (P01).

Another woman explained that her husband was not concerned about sexual issues after he learned about the disease and the side effects of the treatment.

"Oh, how can anybody think about sex with all the symptoms of bleeding and pain? My husband is an educated person. In addition, we are free to talk about sex. The sexual issue was not our concern. He tried to be present here during my appointments and understood the condition. Even one day, he asked one young doctor whether he was permitted to have sex after radiotherapy was completed. I have already completed and am on follow-up, but still, I have pain around my womb. Therefore, I don't have any desire" (P10).

One of the main challenges raised by women was the dearth of information on sexual health. They worried that if they had intercourse, symptoms that had resolved with cancer treatment might return.

"Oh, to be honest, we are afraid that the symptoms may return. We don't want that moment to return. Furthermore, we are unsure if this is possible. How can you ask your doctor about this? They're busy, and I think we Ethiopians are too shy to ask such a thing" (P11).

Another woman shared her experience of how her condition made her feel ashamed.

“Unfortunately, my spouse lacked humility. I had a bad-smelling discharge for a while prior to bleeding. It went away occasionally and reappeared occasionally. Oh, I did not realize there was such a smell. Individuals shift their distance from me. I felt so ashamed. My spouse was against having sex with me. You have a bad odor, he said.” (P13).

THEME 3: PSYCHOSOCIAL CONCERNS

Subtheme 1: Partner relationship

Women were invited to share their personal stories of partner relationships. According to the majority of women, it took their partners some time to adjust to the new circumstances. Some women said that their partners were involved in the whole treatment process.

“When my husband heard about cervical cancer, he was so confused. Through process, both of us adapted with all things we have to do. I think we are closer more than before and passed the difficult time together.” (P18)

“We had the hardest time together. He understands me a lot. He is curious about all appointments. You know, for some months, I was so hopeless and discontinued all my follow-up. He was so stressed at that time that he begged and advised me a lot. I could not be here if he was not with me” (P19).

However, a few women shared that their partners changed after their cancer diagnosis. Their partners became irritated or irrationally upset about trivial matters. They would bemoan the expense of the medical procedures and the course of treatment. The women expressed how heartbreaking this was for them.

“Since I got sick, my house has been filled with stress. My spouse is responsible for covering all treatment costs. He stopped talking to me. My husband's behavior makes me feel alone and less valuable” (P14).

“He got a little irritable, to be honest. I am aware of his burden. I am, however, truly sadened by his recent complaints regarding my medical expense. It makes me feel worthless and hopeless” (P15).

Being a cancer patient may be one factor that affects spousal relationships, as mentioned by a few women. They claimed that their partners were not supportive and were unable to comprehend the emotional pain they were experiencing.

"Of course, we have argued in the past for a variety of reasons. However, he grew haughtier after learning that I had cancer. Furthermore, his relatives are bad. They began to advise him to stop with me since they knew I had cancer. Oh, it hurt so much. After a year of arguments, we recently got divorced" (P03).

"He blamed always. Our marriage ended after I began my treatment. I do not know where he is right now" (P02).

Subtheme 2: Psychosocial support from their partner

Women talked about the emotional support they received from their spouses during their hard times. Most women highlighted how important their partners' psychosocial assistance was to them during difficult times. The participants expressed gratitude to their spouses for their support.

"At the beginning, he was confused. He did not know what to do. In addition, I was a little bit hopeless. It hurts a lot to accept the condition. He was so worried about me. He advised me a lot, prayed for me every day and gave me a strength. I will not forget this" (P04).

"My husband was with me all the time. I thank my God for giving me such a caring guy" (P11).

It was stated that having partner support was crucial. It was important for the partners to have basic knowledge regarding the illness to provide this kind of help.

"In our society, cancer is a killer. My husband has the same thought. He said she would die because my family suffered from the treatment. My heart was broken when he said that to me. He is a farmer. He is not educated. He does not understand me at all" (P08).

Conversely, a few women reported feeling unsupported by their partner and being called ignorant. They were unhappy that their partner did not pay attention to their health. They expressed anger in response to their spouses' lack of attention throughout the process.

"He is not supportive. He never knows how my follow-up is going on. He is a farmer living there in the province. Now, I live with my relatives. He doesn't want to call me. As a husband, do not

you think he has to ask at least about the treatment and the cost of leaving? Nothing. He is so ignorant" (P07).

One woman told her story that she hurts a lot since no body wanted to support her.
"No body supported me. I beg my neighbors and relatives; they were ignorant. What person is there? It is chaos in the province as you know; it is chaos… it is chaos. What will support me? It hurts. People became bad or I don't know. sometimes I asked myself we Ethiopians used to help each other? Where is those our values? nobody doesn't want to hear your problem" (P19).

The majority of women stated that receiving emotional or financial support is crucial to accepting oneself in all circumstances and regaining hope.

"My children, particularly older ones, are my sole source of support. My kids were with me throughout the entire period. Additionally, there is excellent social interaction in the province. After learning about my condition, my friends raised funds from all of their neighbors to pay for my treatment. I am lucky that people around me are supportive, emotionally or financially. I just regained my hope. I want to live more. I want to live for my children" (P09).

"When people around you understand you and are supportive, you want to live more" (P16).

Subtheme 3: Psychosocial support from their children, relatives, neighbors or any social group
Women were asked about the emotional or financial support they received from their children, relatives, neighbors, or any social groups. The following quotes are among the most common.
"Next to my husband, my kids were with me all the time. We in Ethiopia have good support for each other by different social groups. The so-called 'idir' "እድር" in our living area financially supports its members. I was a member of more than 20 years. The "idir" social group gave me financial support. My 'idir' group members were with me, and I believe it has a good relief." (P11).

"After I divorced my husband, only my sister and her husband gave me a lot of emotional and financial support" (P01).

"My relatives are my source of support" (P07).

"Only from my son, I do not have any support" (P17).

Subtheme 4: Psychosocial support from health care providers

Finally, women were asked to describe how they had benefited from the psychosocial support offered by medical professionals in the oncology department. They stated that while some of them were negligent, others provided psychosocial support. The most common quotations are enumerated here.

"It is good. They told me to drink fluids and to take care of myself" (P16).

"Two doctors were so good for me. They treat me very well, and I like them very much. Therefore, when a person treats you and supports you emotionally, you will be happy." (P12).

"Thank you for asking me this. I am so wondering why doctors don't want to talk with us, at least to reassure us. In my understanding, cancer patients are hopeless. We need some reassurance. Nurses will call your name, then you will get in and be asked to sit down. They just ask a few questions. They may not even see your face. Then, all words will sit down, stand up, come, and go. Oh, Anyway, I just conclude that it may be enough if they give the treatment. After all, Allah will help us" (P23).

A few doctors told me and instructed me more during my follow-up, but some did not seem to care. They call you by name, ask if you have any problems, write down a prescription, and then appoint you. Sometimes you might leave for home without knowing what is going on. Maybe they are busy. I hope they run out of time to talk because there are so many patients here" (P01).

Table 3 Summary of findings by themes, sub-themes and main quotes

Themes	Sub-themes	Main quotes
Theme 1: The Journey of Diagnosis and Getting Treatment	Subtheme 1: Cervical cancer symptom recognition	“There were blood clots most of the time, and I was bleeding excessively, more than I would have during a regular menstrual cycle.” (P02).
	Subtheme 2: Emotional reactions during diagnosis	“I shocked. I thought I would die soon. I cried.” (P12)
	Subtheme 3: Burden of waiting to receive treatment at TASH	“Oh, it was so tedious. There were many patients listed in the registration book. The doctor ordered radiation. However, it took 6 months to achieve radiotherapy.” (P14).
Theme 2: Sexual Experience		“I had no desire for any kind of sexual intimacy. Most of the time, I had spotting or discharged after sex. I had discomfort as well” (P03).
Theme 3: Psychosocial Concerns	Subtheme 1: Partner relationship	“When my husband heard about cervical cancer, he was so confused. Through process, both of us adapted with all things we have to do. I think we are closer more than before and passed the difficult time together.” (P18)
	Subtheme 2: Psychosocial support from their partner	“My husband was with me all the time. I thank my God for giving me such a caring guy” (P11).
	Subtheme 3: Psychosocial support from their children, relatives, neighbors or any social group	“After I divorced my husband, only my sister and her husband gave me a lot of emotional and financial support” (P01).
	Subtheme 4: Psychosocial support from health care providers	A few doctors told me and instructed me more during my follow-up, but some did not seem to care. They call you by name, ask if you have any problems, write down a prescription, and then appoint you. Sometimes you might leave for home without knowing what is going on..” (P01)

Discussion

The main objective of this study was to explore the sexual and psychosocial experiences of women with advanced-stage cervical cancer.

This study describes the sexual problems that women with cervical cancer suffer after the onset of their symptoms and during and after their cancer treatment. The most commonly reported problems in this study were pain during sexual intercourse, bleeding, spotting or vaginal discharge after sexual intercourse and diminished sexual desire. These findings are supported by the literature (15–21). Pain during intercourse leads to avoidance of sexual activity or feeling inhibited during intercourse. Vaginal changes that cause pain or bleeding during intercourse may limit sexual pleasure (22,23). For most of the women in this study, treatment consisted of radiotherapy or radiotherapy combined with chemotherapy. Evidence shows that women treated with radiation experience greater sexual dysfunction than women treated with surgery and chemotherapy (19,24). The primary effects of radiation on the vagina include fibrosis, stenosis, reduced flexibility and depth, and mucosal atrophy (24). These vaginal effects lead to dyspareunia, lack of arousal, low libido, loss of lubrication, and frigidity, all of which contribute to sexual dysfunction (16,17). Additionally, the side effects of chemotherapy and foul-smelling discharge can lead to reduced libido (22).

Women reported that it can be challenging for them to start these conversations and that medical providers do not always provide them with information on sexual issues. This might be because there is a high patient load to take time and discuss sexual issues. This might also be due to cultural influences, as patients may not want to express sexual problems since, in most Ethiopians, talking about sex is taboo. Although sexuality is an important psychosocial issue, it is not openly discussed in Ethiopia, likely due to cultural and religious barriers. A study in the Netherlands mentioned that a few participants claimed they had never received any information about sexual repercussions. Half of the participants reported that during treatment and recovery, they were not particularly focused on their sexual functioning (25). Women may better handle the challenges related to sexual activity if their sexual and psychological needs are given greater consideration (26). Prior to and following treatment, women should have conversations about and clarification of sexual harms (24). Prior to treatment, it is crucial to analyze the patient's sexual history so that her expectations and worries are recognized. This should also apply to unmarried women, as being honest about their circumstances may boost their self-assurance and enable them to start new connections (27).

In our study, even if some husbands were helpful, some partners were ignorant, callous, and unaware of the circumstances. In addition to their spouses, the women mentioned children, relatives, and medical professionals as sources of emotional and financial support. Women stated that having supportive and caring people in their lives made them feel much more alive. On the other hand, women who did not receive emotional or financial support expressed feeling less confident, less valuable, hopeless, less attractive, worried about their spouse's attitude, and feared how the family would handle illness and treatments. Similar findings were reported in other studies (9,26–29). In our study, some women mentioned that being a cancer survivor contributed to their divorce. Similarly, approximately half of the participants in a study from the Netherlands said that their previous or present sexual relationships had been negatively impacted by their cancer treatment or sexual dysfunction (25).

This study also examined the common symptoms of cervical cancer, the patients' emotional responses to the diagnosis, and the difficulties they experienced while receiving cancer treatment at Tikur Anbessa Hospital. Vaginal bleeding, postcoital bleeding, lower abdominal pain, dyspareunia, and foul-smelling vaginal discharge were the most often reported symptoms, and these symptoms have been reported in other studies (11,30–33). Women's typical emotional responses to their diagnosis included shock, anxiety, tension, crying, and denial, which have also been reported in previous research (11,34–36).

Limitations of the study

In this study, it was challenging to enroll participants because they did not want to share their sexual experience. Women who participated in the study also mentioned that they were reluctant to ask about and discuss their sexual problems with their doctors. It would be beneficial to provide more useful and reassuring information regarding the implications of cervical cancer for relationships and sexuality. Integrating sexual counseling is needed. By helping healthcare practitioners develop their capacity for sexual counseling, stakeholders can support oncology care. Because the principal investigator who performed the in-depth interviews was an Amharic speaker, the scope of this study was limited. As a result, women who were not proficient in Amharic were unable to be recruited. Thus, this study was not able to capture the experience of non-Amharic speaking women with cervical cancer in Ethiopia. Furthermore, to have a full picture of sexual and psychosocial experience, more insight into the partner or spousal perspective is needed.

Conclusions

In conclusion, the physiological changes that cervical cancer patients face after cancer treatment may have an immediate impact on their sexual functioning. These physiological changes pertaining to sexual functioning, in turn, have greater negative impacts on the psychological well-being of survivors. Psychosocial support plays a critical role in mitigating adverse psychological reactions in patients with cancer. Patients with cancer will benefit from psychosocial support from their partners, families, and doctors to feel hopeful again.

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Ethical statement

After ethical clearance, the data were collected by the ethical board of review of the Addis Ababa University College of Health Science IRB (057/21/Nursing). Permission was obtained after contacting the department head of the oncology center. Their names and other personal identifiers were kept anonymous during the study to preserve confidentiality. The purpose of the study was explained to the participants, and those who volunteered to participate in this study provided written consent.

Conflicting interest statement

The authors declare that there are no conflicts of interest.

Data availability statement Data are available upon reasonable request.

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CHAPTER FIVE: PAPER 4

Sexual, psychosocial and lived experiences of male partners who live with cervical cancer survivor

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Abstract

Cancer impacts the couple collectively, rather than individually, to differing degrees. For cancer patients, the spouse typically serves as the primary caregiver. The experiences of male partner are not well understood, and more research is needed. Therefore, this study was aimed to explore the sexual, psychosocial and lived experiences of male partners of women who live with cervical cancer at Tikur Anbessa Specialized Hospital Ethiopia. A phenomenological study design was employed. A total of 15 male partners were recruited purposively. An in-depth interview using an interview guide was conducted. Data was recorded. The recorded data was transcribed using verbatim approach, translated into English and coded. The identified codes were categorized into themes and sub-themes.

The majority of participants stated that prior to their spouses' diagnosis, they were unaware about cervical cancer. Most participants described how it influenced their family income, how it affected their daily activities, how their sexual life was disrupted since the cervical cancer diagnosis. and how their social interactions were influenced. Cervical cancer is very challenging for male partners. Most male partners had supported their female partners in diverse ways during the treatment and follow-up process.

Key words: Male partners; Experience; Qualitative; TASH; Ethiopia

Introduction

Cancer patients' and their partners' lives are profoundly affected by the diagnosis and course of treatment. Cancer patients experience psychological and social impacts in addition to physical changes. Psychosocial concerns may include such as anxieties about the illness, ability to plan, and life quality (1). A significant side effect of treatment is sexual dysfunction; research indicates that 23 to 70% of women who have survived cervical cancer report having issues with their ability to have sexual relations. (2). Furthermore, reduced quality of life in the area of sexual functioning among long-term cancer survivors suggests that special attention should be paid to problems in this area to counteract treatment-related impairments that negatively affect quality of life, emotional well-being, and relationships (3)

Being the partner of a person diagnosed with cancer means facing new challenges and responsibilities emotional, social and practical (4). The majority of cervical cancer sufferers are unable to work, which costs the society economically. Women's daily lives are also significantly impacted by cervical cancer. The physical and mental well-being of cancer patients and their spouses can be adversely affected by sexual issues (3).

Men have a critical role in the prevention of cervical cancer, and it is anticipated that increased awareness of the disease will change men's health-related behaviours and attitudes. Men are less interested in preventing cervical cancer and are less knowledgeable of the disease. Men must play a vital role in lowering the incidence of cervical cancer. (5). Men participate in their partners' reproductive health experiences in a variety of ways, from financial support and transportation for medical services to joint decision-making or granting consent for specific procedures (6).

According to studies, the majority of men are unaware about cervical cancer, and some even think that males are not responsible for women's cervical cancer (6,7). Males can significantly lower the incidence and mortality of cervical cancer. This might be accomplished through providing education that would provide people the necessary understanding of the illness, which would help to remove barriers to screening and treatment (8).

Quantitative research has shown that a far higher proportion of gynaecological cancer survivors (including cervical cancer) report needing psychosexual healthcare than actually seeking treatment (8). Psychosexual healthcare requirements are common among patients and partners, but information and treatment are typically scarce. Psychosexual support should go beyond physical sexual functioning and should take aspects such as sexual distress (2). The experiences and demands of informal caregiving regarding a partner with cancer are not well understood, and more research is needed. Moreover, little is known about lived experience of husbands of women with cervical cancer. Therefore, this study is aimed to explore lived experiences of male partners who live with cervical cancer patients.

Methods

Design

A phenomenological study design was employed. Individuals' lived experiences with a phenomenon are described by participants in a phenomenological design. The essence of the experiences shared by multiple individuals who have all witnessed the event is captured in this account (9).

Study Setting

The study was conducted at Tikur Anbessa Specialized Hospital Oncology Center which is in Addis Ababa, the capital city of Ethiopia. Tikur Anbessa Specialized Hospital (TASH) is the biggest referral hospital in Ethiopia and offers diagnosis and treatment for approximately 400,000 inpatients and outpatients a year. The oncology center of TASH provides chemotherapy, radiation therapy and other supportive and palliative care.

Study Participants and sample

The participants were husbands of cervical cancer women. A total of 15 male partners who came at hospital with their partner were recruited purposively. The participants were selected with inclusion criteria of being male partners of cervical cancer, willingness to describe their experiences, male partners of cervical cancer patient who started any cancer treatment, at least 1 year since cancer diagnosis, and below the age of 50.

Data Collection

An ***in-depth interview*** using an interview guide was conducted (Table-1). Data was collected from May 10-25/2023. At outpatient department of oncology center women who came on their appointments were checked. Women who came with their male partners were contacted. Data was collected until saturation was achieved. Data saturation was assessed using informational redundancy, which means that it was considered to have been reached when no new categories or information emerged from the data.

Table 1 Interview guide

Main topic	Questions
Introduction	1. Can you tell me what you knew about cervical cancer before your wife's diagnosis?
Emotional/fear/anxiety	**2.** Would you share the emotions you experienced when you heard that she has cervical cancer?
Daily activity burden	**3.** Would you share if you have fear when you think about her cancer treatment?
Relationship	**4.** What did you feel when your wife started cancer treatment
	5. How would you describe and compare your level of confidence doing your daily activities
Social support	6. How would you describe the relationship with your wife since her diagnosis?
Financial burden	7. Tell me about your relationship with your friends, neighbours and relatives
Sexual problems	8. Can you tell me about any social support from friends and relatives since your wife started cancer treatment?
	9. Can you describe the financial strain associated with the cost of living?"
	10. Can you tell me about your sexual relationship with your wife?
	11. Can you share your and your wife's sexual complaints?
	12. Can you describe any sexual issues you have experienced after cancer treatment?
	Is there anything you want to add?
	Thank you
Conclusion	

Trustworthiness

During in-depth interview, it was ensured that the data is completely collected. To maintain reflexivity and avoid investigators' own opinions from affecting the study data by precisely reviewing interview transcripts, comparing codes with the raw data, and checking the findings with the participants' views several times. Sufficient samples were considered and the data collection finalized when data was saturated.

Data Analysis

The audio record was transcribed using verbatim approach, and the researcher read through all the qualitative data (transcripts and notes) several times to get an overall feeling for them. The transcribed interview was translated into English. The Then returning to each transcript, significant statements that pertained directly to the male partners' psychological, social and sexual experience of contracting was identified and extracted. Subsequently, the texts were divided into meaningful units made up of important words from the transcripts. Codes that were created inductively as they emerged from the data and deductively from the interview guide. The identified codes were sorted into different categories/subthemes. Finally, the subthemes were organised into themes. The data was analysed with the assistance of MAXQDA software (10).

RESULT

Participants characteristics

A total of 15 male partners participated in this study. The ages of the male partners ranged from 41-49 years. The duration of their marriage ranged from 10 to 29 years. Level of education ranged from no formal education to college completion. The duration of cancer diagnosis was ranged 1-6 years. The cancer stage was at FIGO stage IIB to IVB (table 2).

After reading repeatedly, the translated transcription was coded using deductive and inductive method and 50 codes were created. Then, codes were organized into themes (table 3).

Table 2 Table 2 Sociodemographic characteristics of participants and clinical characteristics of their spouse

Variable	Frequency
Age	
<45 years	3
45-50 years	12
Duration since married	
<10 years	1
>10 years	14
Number of children	
1-4	9
>4	6
Level of education	
No formal education	3
Elementary	3
High school	9
College	
Occupation	
Government	5
Private	1
Self-employed	9
Duration since diagnosis	
1-3 years	10
3-6 years	5
Duration since treatment	
6 months -2 years	11
2-3 years	4
Type of treatment	
Radiotherapy	6
Chemoradiotherapy	8
Surgery + radiotherapy	1
Stage of cancer	
FIGO stage IIB	7
FIGO stage III	8

THEME 1: Awareness and emotional reaction

Sub-theme 1: Awareness about cervical cancer

Participants were asked whether they had heard about cervical cancer before the diagnosis of their partners. Some participants said that they didn't hear about cervical cancer before the diagnosis of their wives.

"I didn't know anything about cervical cancer before" (P02).
" I don't know any think about it… we don't know about it. I was not aware of it" (P04).

"I haven't heard. I didn't aware of it." (P09).

"I don't know. This is not known in our village. We don't have education. Nothing was there in our village such kind of disease." (P13).

Other participants indicated they were unaware of cervical cancer specifically, but had heard about cancer in the media. They claimed they were unaware that cervical cancer existed till their spouse had the illness.
"I heard just about cancer. But I didn't know about cervical cancer?" (P12).
"Before she diagnosed for cervical cancer, I knew a little about cancer. But it is not much" (P07).
"I don't have any information about cervical cancer. But I knew and heard about cancer." (P15).

A few participants reported learning about cervical cancer from television. They also stated that they had seen the Ministry of Health Screening statement on television. However, they were unable to focus on it.
"I heard from media but I didn't give it focus." (P01).

"It is mentioned in the media a lot. I heard about that from the radio" (P10).

"I heard about it. And, she was screened at the health centre. We heard on the media that women after the age of 30 should be screened." (P14).

Participants who reported having heard about the disease, were asked about risk factors. They were asked about the risk of having multiple sexual partners, HPV infection, or any other risk factors they were aware of. Only one male partner explained what he had heard about a "sexually transmitted virus" causing cancer of the cervix. Others, however, were not aware of any risk factors.
"I have never heard that honestly. I didn't know the cause. Even now, I am not well oriented about that" (P01).

"I don' know. I think there are risks that may cause cancer. Frankly speaking I am not sure what causes cancer of cervix." (P06).

"I heard there is virus which is transmitted sexually. I don't know exact name. I heard repeated infection of this virus may cause a cancer on the cervix. After we knew she has the cancer I was curious to read these things. So having many partners may also has a risk". (P14).

Table 3 Summary of findings by themes, sub-themes and main quotes

Themes/sub-themes	**Quotes**
Awareness & emotional reaction	"I heard just about cancer. But I didn't know cervical cancer?" "You know what, I feel as I am the sick one. It affects me a lot. Al l financial burden is on my shoulder"
Burden of the disease • Hard time for males • Financial burden • Impact on social interaction	"When I heard that she has a cancer, I was shocked." "I worried a lot. I thought she may die soon, I asked myself as why happened to me? I fear a lot. I pray day and night. I worried about my children. I couldn't sleep. "Oh, for 3 years our life is just home, work and hospital."
Spousal relationship • Impact on relationship • Sexual problems	"When she diagnosed and knew it was a cancer, she became another woman. She became irritative with silly things, she was so hope less. Most of the time she wants to be quiet. "I can notice that she changed a lot." She doesn't want to have sex at all. It is so painfully for her. We stopped to have sex for two years

Sub-theme 2: Emotional reaction during the diagnosis

All participants were asked to describe their feelings when they first learned their partners had cervical cancer. Most participants mentioned that they were shocked when they heard the diagnosis of cancer.

"I was shocked. Before that she had repeated STIs symptoms. And then, I asked how this can be changed to cancer." (P02).

"I think it is very known that anybody will be shocked when this kind of news heard. Anyhow, when she and I heard that she got cancer I was shocked. I just want to say that I had bad feeling" (P03).

"At that time, I though she will die soon. I worried a lot. We were hopeless" (P04).
"I was shocked and asked her how this happen to her. "(P06)

"When I heard that she has a cancer, I was shocked. By the way our daughter was the one who advised to be checked. Because she knew that her symptoms and she always insist her to be seen. Surprisingly my wife even tried to hide that she had symptoms. At night I saw her when changes

pads and asked what is this thing. And one day my wife told me that not to tell to our daughter. And I said why you say like that there shouldn't be anything hidden from our daughter. Then, one day three of us discussed and came for diagnoses. At that time, she also shocked when she heard that she has a cancer." (P07)

On the other hand, other participants responded differently and had a less challenging time accepting the news.

"Before that she was diagnosed for mass of uterus. And I think it is natural. And I can accept easily such thing. I just believe I have to care her. But it was bad for her. She just shocked and worried. So, I have to care and treat her. But for me I didn't feel bad things because it happened as it can happen on the others. Rather, it was it difficult to advise her" (P01).

"I was a little bit worried. But I accept it. I am not that much worry person. My worry was how she can start the medicine" (P05).

Theme 2: Understanding the burden of the disease

Sub-them 1: Hard time for male partners

Participants talked about how they felt about their wives' cancer treatments and follow-up appointments. They discussed the state of their wives' health, the financial strain, the hardship, and the negative effects of radiation treatment. They talked about how they deal with difficult situations by worrying about the well-being of their partners. They talked about how difficult it was for them *to get their partner treated with radiation.*

"Ahh. for me, I worried a lot. Every time I worry a lot, I thought she may die soon, I asked myself as why happened to me? I fear a lot. I pray day and night. I worried about my children. I couldn't sleep. Here, when the person told to go there and here, I can't focus. I don't have any support. I don't have person beside me. When I came here, I don't have a place to rest. I have to pay for hotel. I finished all my money at each appointment. I feel sad and say sometimes what I shall do. I feel hopeless and say I don't have any choice. I was just lonely and hopeless for most of days. Then, through time I regain my strengthen thanks to GOD (P04).

"Ahh the feeling I had it was so hard. You know what, she was a hard worker. She got more income than me. She covers for most of activities in our family. So yes, it was so hard to me to live in such

case. How I can tell you how much I am hurt. Even though we have a daughter to do home activities, she cannot replace her. Anyways I pray for her. I hope she will be cured. You know women are stronger and hard worker than men in all aspects (P07).

"I was in fear thinking that she may die soon. I was not sure how the treatment will help her. When we referred here from Menilik Hospital, I assumed she will get the treatment soon. Oh. but the thing was the opposite. It was so annoying. There were a lot of repeated appointment, investigations which were mandatory. First, she had a surgery which was so stressful and difficult time for me. After 7 months she took chemo and radiotherapy. With the help of God, she is fine" (P10).

"So hard, to get the treatment. Almost every week we came here to wait admission. The doctors I think they prioritize after they evaluate the patients. Almost for two months we came and tried for our chance. As couple it was the hardest time for us" (P12).

"Oh, so hard. Oh, we live far from here. They appointed us repeatedly for different reasons. I don't know why. So, it was hard to left my farm and come here." (P13).

Sub-theme 2: Financial burden

Participants were asked to talk about financial burden they faced. After their spouse was sick with cervical cancer, male partners were left to face the financial burden. They described the difficulties they overcame. Below is a list of some quotes.

"You know what, she is not sick. I feel as I am the sick one. It affects me a lot. All financial burden was on my shoulder" (P06).

"As she became sick, I couldn't work. I am the only one caregiver for her. I can't do my farming. Previously she was a merchant and was working. We had good income. After she is sick, she stopped to work, I can't do my farming properly. I sold my oxen. I am losing what I have. For example, today when we come for the appointment, I had only 2000 birr. I finished it. Even I don't have a person to take care of my home. I beg one of my relative. I called to him if he can help till, we go back. He told me he will have a business to do" (P04).

"I worry about it. It is a bad time. I ask myself. Will she survive? When I think about the family, children you cannot imagine how it can influence. Now, she returned to work. It is not the issue

that she brings an income but as human you will be worried. Oh, it hurts. How I can express that…. when you look at it is very difficult. Now we are trying to cope with that" (P03).

Sub-them 3 Impact on social interaction

Participants described their social interaction with friends, neighbours, relatives and or staff as having changed because since their wives became cervical cancer patients. Participant reported quitting social interactions and spending more time with their spouse after work.

"It is very difficult to have social interaction. She needs me a lot. I don't care about that now. Of course, it affects a lot." (P03).

"Yeah, it is hard. I can't do that now. I can only interact with phone. I don't have time" (P02).
"But I don't have time to chill and join them after she is ill. All my activities are work… home and home." (P10).

"Oh, for 3 years our life is just home, work and hospital. No time for friends or social life at all. Some of them understand. The said "yeah his wife is cancer patient". My neighbours and relatives understand us if we are absent from any social affair" (P11).

"Well, no social life. Are you kidding me? how do you think about spending with friends while she is suffering from cancer? No friend no social life. And I am okay with that" (P12).

THEME 3: SPOUSAL RELATIONSHIP

Sub-theme 1 Impact on relationship

Participants were questioned about the impact of the disease on their relationship with their spouse. The majority of individuals stated how their wife's behaviour changed as a result of their cancer, which affected their relationships.

"We had enjoyable life before that. There was no as such a problem before the cancer. ahh, I think as a human you may face a challenge. My wife is not good in discussion. She didn't tell me even she was so suffering with bleeding. "(P01)

"Before that there was no problem with our relationship. After the radiotherapy, we stopped to have sex. She has pain. It is okey for me. I didn't complain. But I think she worried a lot about it. Sometimes she hesitates because I didn't complain. And, I think it create some gap in our relationship." (P02)

“Well, when somebody is weak, or as anybody is becoming sick, any smooth relationship will be affected” (P03).

“When she diagnosed and knew it was a cancer, she became another woman. She became irritative with silly things, she was so hopeless. Most of the time she wants to be quiet. I can say that a little bit we had stressful, and hopeless moment until she gets fine.” (P10).

Sub-theme 2 Understanding of sexual problems

The participants talked about their sexual experiences after receiving a cervical cancer diagnosis. The majority of interviewees said that they had stopped having sex for long period of time.

“Since she had bleeding, we stopped to have sex. It is almost four years (Participant 7)

“Believe me or not for 4 years we didn't have sexual activity.” (P10).

“After she became sick. We didn't even think about that. You know how could you think about that just observing how she is sick and suffering with cancer?” (P11).

“. She didn't show any interest. I think it maybe she was suffering with cancer symptoms” (P12).

“After she has a cancer and surgery, we can't do that. She has a pain.” (P04).

Participants shared the main sexual complaints expressed by their partners.

She complains burning after sex. And pain during sex. Sometimes she feels hopeless. She has no a desire to have sex. (P01).

She doesn’t want to have sex at all. It is so painful for her. We stopped to have sex for two years. (P02).

She said I have bleeding, lower abdominal pain, burning and the like. (P04)

And last, a question about their present sexual relationship was posed to those whose partner's health was stable.

“Now, she is fine and on follow up. We have tried. But we were not comfortable. I worry if she is in pain again.” (P13).

“Since she is okay. I had it. But we fear most of the time. I think she may be in pain” (14).

Discussion

In this study, nearly half of the participants said they had never heard of cervical cancer. Of course, everyone in the group had heard of cancer, but only a few participants were aware of cervical cancer, risk factors and prevention. Our findings are supported by other studies reporting lack of awareness of cervical cancer among men in Korea (5), South Africa (11), Kenya (12), and Ghana (6). Men play a critical role in preventing cervical cancer, and it is anticipated that knowledge of the disease will influence men's health-related behaviors and attitudes (11).

Cervical cancer is a major contributor to cancer-related mortality in developing countries including Ethiopia, even though it is preventable with early screening and treatment (12). Within middle- and low-income nations, the World Health Organization has advocated involving men in the prevention of cervical cancer. They should be empowered to participate in the decision-making, and in informed of medical decisions, including changes in caregivers and treatment, and should be guided in best practices of palliative care too (13). Studies in Malawi and Kenya among women attending cervical cancer screening programs have shown that male engagement and support are essential determinants for women to participate in screening programs and adhere to treatment and follow-up advice. Women who disregarded the aforementioned follow-up advice did not tell their male partners that they had tested positive for HPV and did not receive any financial or emotional support from them (14,15). Studies have also indicated that a potential unnoticed barrier to cervical cancer screening could be a man's lack of involvement (16,17).

According to our study's findings, male partners of women who have cervical cancer often go through a difficult time. Male partners' accounts of their experiences with the treatment, appointments, and overall follow-up procedures at the oncology unit suggest that the condition places a strain on husbands. The stories in this study teach us much about the financial burden, diminished social interaction, and hard times experienced by male partners of women with cervical cancer. Most respondents described how it influenced their family income, how it affected their daily activities and how their social interactions were influenced. The disease comes with a triple financial burden. First, patients are not able to work due to physical weakness. Second, family resources drain, and finally, other members of the family are interrupted from regular productive work while helping the sick. This three-fold financial impact is supported by previous research

(2,18–22). Being the spouse of someone with cancer entails taking on additional duties and responsibilities on an emotional, social, and practical level (23,24).

In our study participants described how their sexual life was disrupted since the cervical cancer diagnosis. The stories reveal that cervical cancer is a major problem that influences the sexual relationship between husband and wives. The main sexual complaints stated were pain, spotting or bleeding and lack of sexual interest. It is recognized that shifts in body image can have an impact on how women experience sexuality. This may influence the cervical cancer patient's lack of sexual interest. Many articles support that women experience these sexual problems due to the cancer and treatment effects (25–31). It is crucial to learn from this research that psychosexual assistance should address issues including sexual distress, relationship satisfaction, and the partner's point of view in addition to physical sexual functioning.

Implications

The impact of cervical cancer extends beyond the woman with the disease to partners and family members. It follows, therefore, that social workers must address the spiritual, psychological, social, and economic needs of not only cancer patients, but also their family members. The findings from this study suggest that male partners are an important target of emotional and social support interventions.

Two major areas of need for male partners of cervical cancer patients identified by our study are 1) the emotional, financial and social burden of the disease; and 2) the impact of the disease on the marital relationship. In order to assist couples in regaining their sexual closeness, healthcare providers should be aware of the complexity of this problem and recommend them to psychosexual counseling. Patients and their male partners should receive timely, understandable information regarding the illness, treatment side effects, and sexual issues. In order to establish policies and initiatives for cancer care, and treatment, social workers should work together. The emotional and sexual concerns of patients with cervical cancer should be taken into account by all relevant stakeholders, including governmental and non-governmental organizations, in their strategic plans for cervical cancer care and treatment. The most commonly acknowledged psychosexual support requirements of participants and partners were getting information and helpful guidance on sexual issues (2). Furthermore, community-based awareness campaigns on prevention and screening of cervical cancer should involve men.

Conclusions

In conclusion, cervical cancer is very challenging for male partners' psychosocial and sexual life. Most male partners had supported their female partners in diverse ways during the treatment and follow-up process. Male partners were reported to have played the role of financiers during the treatment and follow-up. In Ethiopia, the medical service cervical cancer treatment is very limited and it is beyond its capacity. There is no or very limited medical, financial or other means of support from non-governmental organization or societies for cervical cancer patients and their family.

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Conflicting interests' statement

The authors declared that there is no conflict of interest**.**

Data availability statement Data are available upon reasonable request

Ethical statement

Data was collected after getting approval from the Addis Ababa University College of Health Science IRB (IRB (057/21/Nursing). Participants were informed about the objective of the study and written informed consent was obtained.

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CHAPTER SIX: SYNTHESIS

SYNTHESIS

This study employed a mixed method approach, employing a cohort design to quantify the survival status and pre-post treatment QoL, with a qualitative method to investigate the sexual and psychosocial experiences of women with cervical cancer and their partners. To gain a comprehensive understanding of sexual problems and psychosocial experiences among cervical cancer patients and their male partners, the qualitative data were a valuable complement to the quantitative findings.

Survival status and quality of life

According to this study, 77% of women with cancer survived the first year following treatment. Other one year survival findings are 74% (91), 78.5% (92), and 58% (93). Cancer survival is often influenced by a wide range of characteristics, such as the type of cancer, the time of diagnosis, disease stage, and treatment. Additionally, different populations have different levels of access to diagnostic and treatment services. This could account for the variation in survival rates observed in various population (79). Our research confirms what has been identified in other studies, namely that survival status is significantly influenced by age (10,44,45,48,50,95–98), cancer stage (44,50,96,99, 100), longer treatment waiting time (80–82), and presence of anemia (31,34,82,83).

The concept of HRQoL encompasses multiple dimensions of well-being, including an individual's physical, emotional, mental, and social functioning. It can be linked to the effectiveness of treatment and the kind of care used to manage the patient (84). Gaining insight into the QoL experienced by women receiving treatment for cervical cancer can facilitate the introduction of treatments aimed at improving their care and results (41).

The QoL of patients with advanced cervical cancer was investigated in this study both before and after treatment. In our study global health QoL and the functional domain of QoL greatly improved after undergoing six months of cancer therapy. Age, marital status, length of time since diagnosis, cancer stage, and the presence of comorbidities were factors that affected the improvement in QoL following therapy. Patients with cervical cancer have been reported to have lower QoL scores than both the general population and other survivors of gynecological cancers (85). Once the acute symptoms of the disease and its treatment have subsided, it seems sensible to start using survivorship measures to improve QoL both during and shortly after treatment completion (86). While some research considers HRQoL to be a significant endpoint, others look at the relationship between HRQoL and cancer survival. Research considering HRQoL as a benchmark for assessing QoL after cancer survivorship report significant findings. Such studies yield valuable data for improving psychosocial and symptom management (87). While QoL has been typically studied as an outcome, it has also been thought to be a predictor of survival (88–90).

We synthesized the relationship of survival status and QoL as displayed below. Participants who had cancer treatment were included to evaluate the association between survival status and pre-treatment QoL. To assess this relationship, age, stage of cancer and presence of comorbidities were controlled. Of the 128 survivors, the majority (n=57) reported a moderate global health status. The analysis revealed a significant relationship between the QoL global health and symptom scales and survival status, whereas no significant relationship was observed with the QoL functional scale. Of the 38 individuals who died, the majority (n=22) had low global health status scores. Prior to starting therapy, patients with a low global health status had a 2.79 times higher chance of dying than those with a high global health status (P=0.027) (Table 3).

To assess the relationship between post-treatment QoL and survival status, patients who were interviewed at 6 months were included. Of the 113 survivors, 66 patients had good global health at six months of life, making up the majority of the survivors. Women with poor QoL scores in terms of global health had a 4.01 times higher chance of dying than those with a higher QoL scores (P=0.015) (Table 4). In our study the QoL global health and symptom domain subscale scores were significantly associated with survival status which is similar with other findings (91). Pre-treatment QoL global health and symptom domains were significantly associated with survival for the women with advanced cervical cancer in this study, and this has been similarly reported in another study (92).

Table 3: Association between survival status and pre-treatment quality of life (n=166)

Pre-treatment QoL	Survival status		AHR (95% CI)	P-value
	Event (n)	Censored (n)		
Global Health status				
Good	7	47	1	
Moderate	9	57	1.42 (0.5,3.9)	0.501
Poor	22	24	**2.79 (1.1,6.9)**	**0.027**
Functional scale				
Good	12	36	1	
Moderate	11	75	1.08 (0.4,2.4)	0.846
Poor	15	17	0.51 (0.2,1.9)	0.122
Symptom scale				
Less symptomatic	7	55	1	
Moderate	21	53	1.8 (0.6,5.1)	0.232
Sever symptomatic	10	20	**2.49 (1.3,6.0)**	**0.040**
Age				
Below 60 years	18	98	1	
Above 60 Years	20	30	1.18 (0.6,2.4)	0.631
Stage of cancer				
FIGO IIB & III	7	101	1	
FIGO IVA	18	23	6.49 (2.6,15.9)	0.001
FIGO IVB	12	5	15.4 (5.5,42.2)	0.001
Comorbidities				
No	15	75	1	
Yes	23	53	1.13(0.8,2.2)	0.714

Table 4: Association between survival status and post-treatment quality of life (n=134)

Post-treatment QoL	Survival status		AHR (95% CI)	P-value
	Event (n)	Censored (n)		
Global Health status				
Good	6	66	1	
Moderate	6	38	1.4 (0.4,4.8)	0.606
Poor	9	9	**4.01 (1.3, 14.6)**	**0.015**
Functional scale				
Good	6	54	1	
Moderate	8	51	0.83 (0.3,2.3)	0.788
Poor	7	8	1.94 (0.2,14.9)	0.521
Symptom scale				
Less symptomatic	52	5	1	
Moderate	39	13	1.26 (0.3,5.3)	0.777
Sever symptomatic	21	98	**3.86 (1.7,13.1)**	**0.038**
Age				
Below 60 years	18	98	**1**	
Above 60 Years	20	30	1.28 (0.5,3.3)	0.610
Stage of cancer				
FIGO IIB & III	7	101	**1**	
FIGO IVA	18	23	**5.2 (1.8,15.6)**	**0.003**
FIGO IVB	12	5	**24.1 (6.3,19.2)**	**0.001**
Comorbidities				
No	15	75	1	
Yes	23	53	1.1 (0.3,5.3)	0.977

After examining the factors associated with survival (See Paper 1 Table 6) and QoL (See Paper 2 Table 5 & 6), the following conceptual framework was developed. These factors have also been reported in other studies (27,29,30,32,33,93,94). Additionally, the relationship between survival status and QoL is displayed.

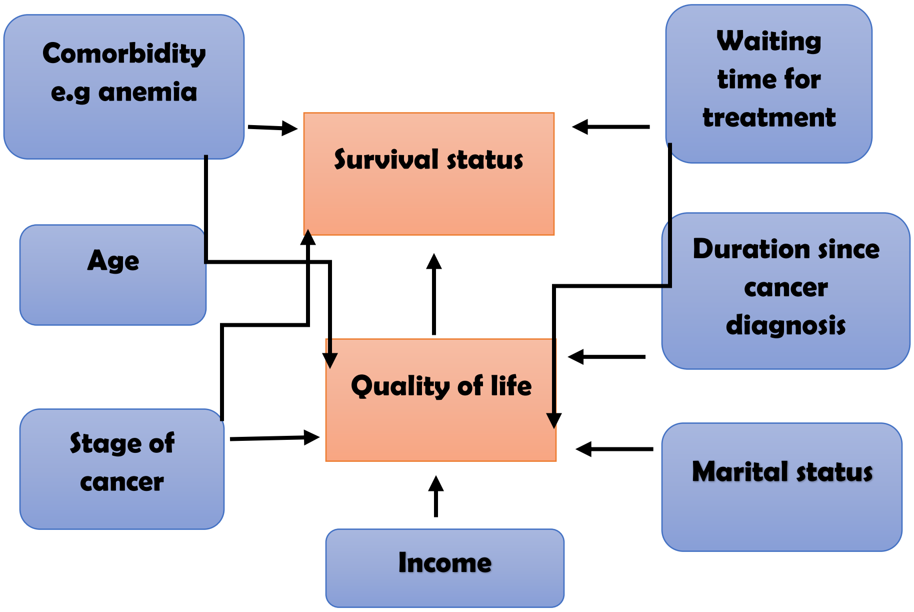

Figure 3: Conceptual framework - The relationship of survival status, quality of life and associated factor

Sexual functioning and women/male partners' sexual experience (QUANT + QUAL)

Women who have survived cervical cancer often experience severe discomfort due to sexual dysfunction, such as feeling unable to meet their partner's needs or noticing changes in their partner's sexual interest (67,112). Radiation therapy may have intermediate- to long-term effects on sexual functioning in survivors of cervical cancer (104).

The majority of subjects in our quantitative analysis did not engage in sexual activity before or after treatment. There was no change in sexual or vaginal functioning between the pre- and post-treatment periods. These results are consistent with a number of prior research (13, 14, 24, 62, 94, 95, 106, 107). Very few individuals in the current study had sexual activity, which is comparable to what was shown in other studies (108, 56). Numerous studies have indicated that dyspareunia, orgasmic difficulties, dry vagina, and vaginal atrophy are related to the adverse effects of cancer treatments (105,109–111).

According to our qualitative analysis, the most often reported complaints by women were pain during or after a sexual encounter, bleeding, spotting or vaginal discharge, and decreased desire for sexual activity. Male partners also described the main sexual complaints of their wives as being pain, spotting or bleeding during or after sex and lack of sexual interest. The literature (112–118) corroborates these sexual problems. Avoiding sexual activity or feeling inhibited during intercourse are the result of experiencing pain during intercourse. Vaginal abnormalities that result in pain or bleeding during sexual activity may reduce the enjoyment of sex (119, 120).

Our study included advanced cancer patients who were treated with either radiotherapy or chemoradiotherapy. Research indicates that women who receive radiation therapy have more sexual dysfunction than those who receive surgery and chemotherapy (116,121). Radiation therapy mostly causes fibrosis, stenosis, decreased depth and flexibility, and mucosal atrophy in the vagina (121). Sexual dysfunction is exacerbated by these vaginal side effects, which also cause dyspareunia, low libido, lack of excitement, loss of lubrication, and frigidity (113,114).

Sexual dysfunction is more prevalent than is indicated in the literature because patients are reluctant to talk about it, clinicians don't have enough time, and there aren't enough resources to treat the psychological, social, and sexual elements of patients' sickness experiences (95). Women in our study reported that it can be difficult for them to initiate these discussions and that they don't always receive information on sexual matters from medical professionals. This could be the result of finding it challenging to find time to talk about sexual difficulties due to heavy patient loads. Since discussing sex is frowned upon for the majority of Ethiopians, patients may be reluctant to disclose sexual issues. This could also be the result of cultural factors.

Emotional functioning, social functioning and women/male partners psychosocial experiences (QUANT + QUAL)

Psychosocial adjustment to sickness is impacted by all illness and treatment-related difficulties. It entails handling a variety of adjustments brought on by a cancer diagnosis and treatment options. Positive or negative psychosocial adjustments to sickness can impact the course of cervical cancer.

Emotional, physical, interpersonal, and practical domains have all been identified as areas of psychosocial adjustment during the early post-cancer treatment phase (96).

Pre-treatment emotional and social functioning scored lower in our quantitative study than other functional domains. Nonetheless, there was a post-treatment improvement in emotional and social functioning. In our qualitative study, according to male partners' stories of their interactions with the oncology unit's treatment, appointments, and general follow-up procedures, the illness put a strain on spouses too. This study's narratives revealed the decreased social engagement, and difficult times that male partners of women with cervical cancer experiences pre- and post-treatment. The majority of respondents discussed how it changed their daily routines, their social relationships, and their family income. According to women, they felt considerably more alive when they were surrounded by kind and supportive people. Conversely, women who did not receive financial or emotional support reported feeling less attractive, less hopeful, less useful, less confident, and fearing their spouse's attitude. The majority of women emphasized how crucial their partners' psychosocial support was for them during difficult times.

CONCLUSIONS

Due to inadequate access to effective management, particularly in low- and middle-income countries, advanced cervical cancer is one of the leading causes of cancer-related mortality among women (40, 52). To ensure that patients receive high-quality treatment at every step of the cancer continuum, survivorship care is just as important as early diagnosis and conventional therapies (9). The one-year cumulative survival rate among advanced stage cervical cancer patients was 77%. The overall mean time of survival after 12 months was 10.392 months. Patients who received cancer therapy had a survival rate of 70–80%, compared to 21% for those who did not. Major factors associated with survival were age, cancer stage, the presence of anemia, and longer treatment waiting time.

Global health and QoL significantly improved after six months of cancer treatment. Additionally, there were enhancements in social and emotional, role-fuctioning, and physical functioning. Fatigue improved, but pain and nausea/vomiting symptoms remained unchanged. Furthermore, no discernible variations were observed in sexual function, sexual activity, or sexual enjoyment between the pre- and post-treatment phases. Age, marital status, length of time from diagnosis, stage of the cancer, and the presence of comorbidities were the variables associated with post-treatment QoL.

Patients with cervical cancer may have acute alterations in their sexual performance as a result of the physiological changes they experience following cancer therapy. The psychological well-being of survivors is more adversely affected by these physiological alterations related to sexual functioning. In order to reduce unfavorable psychological reactions in cancer patients, psychosocial support is essential. Doctors, Nurses, partners, and families can provide psychosocial support to cancer patients so they can regain hope. The emotional and sexual lives of male partners are severely impacted by cervical cancer. The majority of male partners provided their female companions with various forms of assistance during the course of treatment and follow-up care. It was stated that male partners served as financiers for both the course of treatment and the follow-up.

Recommendations

To Ministry of Health

- Tikur Anbessa Hospital is the only public hospital in the country offering comprehensive cancer treatment. In this study and other evidence show that patients die while waiting for their appointment, particularly for radiation therapy (97). The oncology health care services available for Ethiopia need to be improved through a focused effort that includes the national expansion of comprehensive cancer care services and nationwide access to affordable diagnostic and treatment modalities. Beyond the Tikur Anbessa Specialized Hospital Oncology Center, focus should be placed on expanding radiotherapy centers throughout the country.
- Community engagement, health education, and counseling on cervical cancer, as well as the major cervical cancer preventive strategy of immunizing girls between the ages of 9 and 14 against HPV before they begin sexual activity, should all be strengthened.
- Women and male partners in the community ought to get education regarding the prevention, screening, and treatment of cervical cancer.
- Health care providers must possess the skills and resources required to counsel cervical cancer patients on psychosocial issues and sexual problems.
- Community education should encourage women to be screened every 3-5 years.
- Community education should be ongoing, emphasizing that women should see a health care professional if they experience any of the following symptoms: increased or foul-smelling vaginal discharge; unusual bleeding between periods, after menopause, or after sexual activity; persistent pain in the back, legs, or pelvis; fatigue and lack of appetite; or vaginal discomfort.
- Women, their spouses, their families, and the community at large should all be made aware of the preventable nature of cervical cancer through community health education.

To health professionals

- Healthcare professionals, including physicians, nurses, health educators and community health workers, should offer information on cervical cancer both inside and outside of the health facility.

- Healthcare professionals should be trained to treat concerns about human papillomavirus (HPV) and cervical cancer in a nonjudgmental manner, all the while maintaining patient confidentiality and privacy.
- When determining and planning a cancer patient's course of therapy, QoL should be taken into account in addition to clinical factors.
- Sexual counselling must be taken into account in every facet of cervical cancer treatment.

Future Research

- Research recommendations that include a prospective cohort and/or clinical trials are encouraged to reduce biases resulting from retrospective studies
- It is necessary to further investigate factors related to survival in the context of Ethiopia and to prospectively determine accurate survival rates.
- An observational method was used to conduct the current investigation. Additional study methodologies beyond observational design should be encouraged to evaluate pre- and post-treatment impacts involving control groups.

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Appendix A: English version data collection tools

Study Information sheet I (Quantitative study)

Good morning /good afternoon my name is _______________. I am working with Roza Teshome who is conducting a research study for the partial fulfillment of her PhD in Nursing at AAU-Emory University. Her research project is entitled **Survival Status, and pre- post-treatment quality of life, sexual.** The supervisors are Dr. Jessica Wells, Dr. Yang Irene, Prof. Higgins Melinda, Dr. Eshetu Girma & Dr. Edom Seife.

Objective of the study: the aim of this study is to assess survival status, and pre and post treatment quality of life

Duration of the study: The duration of the study will take one year. During this period, interview will be conducted at the beginning, at 6 month and at one year. At the beginning and at 6 month a face-to-face interview will be conducted. At one year a telephone interview on survival status will be conducted.

The benefits of this study are to generate information about survival status, and quality of life. There will be no cost for participation and it will not affect your medical treatment at TASH. There will be no direct benefit to you for your participation in this study However, we believe this research will have important implications for future interventions aimed at improving the quality-of-life women post-cervical cancer treatment.

There are no expected risks to you for participating in this study. The study will be conducted by face-to-face interview and reviewing your medical cards. The study will take one year follow up. During this time interview will be done at the beginning of the study and after six months of the first interview. After one year, a follow up status will be gathered through face to face on your cancer follow-up appointment or through telephone. The interview will take 20-30 minutes.

Confidentiality: Your responses will be completely confidential. The information gathered during this study will remain confidential. Research records will be kept in a locked file, and all electronic information will be coded and secured using a password protected file; only the researcher will have access to the records. In any sort of report, we make public we will not include any information that will make it possible to identify you.

Right: Your participation is entirely voluntary. If you do not wish to participate or withdraw at any time during the study, you are free to withdraw at any time, without giving a reason and without cost.

To effectively attain the objectives of this research project, we kindly requesting your participation.

Contact Information You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, data collector by telephone at phone number.

If you have any other concerns about your rights as a research participant that has not been answered by the data collector, you may contact

The principal investigator Roza Teshome by

Email rozateshome2007@gmail.com

telephone 251911028610.

If you have any further problems or concerns that occur as a result of your participation, you can report them to the IRB at Addis Ababa University, college of health sciences

IRB address Email: chs.irb@aau.edu.et

Telephone 2511118961396

Consent

I have read and I understand the provided information. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without cost. I do also understand that there is no risk in participating in the study, so I voluntarily agree to take part in this study.

Participant's signature ________________________________Date ______________

Data collector’s Name and signature _______________________________Date ______________

Appendix A1: Data abstraction for survival status

Baseline information

Part I Sociodemographic and socio-economic Characteristics	
Serial Number	**Check list**
01.	Age (in years) ___________________________
02.	Residence a. Urban b. Rural
03.	Region ________________________
04.	Occupation a. House wife b. Government employee c. Self-employed d. Merchant e. Other (specify) ___________________
05.	Level of Education a. No formal education b. Elementary c. Secondary d. College/University
06.	Marital status a. Single b. Married c. Divorced d. Separated e. Widowed
07.	Level of income a. Less than 2500 birr b. 2500-5000 birr c. Greater than 5000 birr
08.	History of smoking a. Smoker b. Ex-smoking c. Never smoke
Part II Reproductive History	
09.	Age at first marriage ________________
10.	Age at first sexual intercourse ____________________________
11.	Parity a. Nulliparous b. Less than 4 c. More than 4
12.	Age at first pregnancy
13.	No of children

14.	Age at menopause (years)____________________
15.	Use of oral contraception a. Yes b. No
16.	Performance status at presentation a. Active b. Bedridden
Part II Clinical and histopathological characteristics of cervical cancer patients	
17.	Date at first cancer diagnosis (dd/mm/yy)
18.	Age at diagnosis (years) __________________
19.	Figo staging a. IA b. IB c. IIA d. IIB e. III f. IV
20	Histopathology a. Squamous b. Adenocarcinoma
21.	Anemia a. Yes b. No
Part III Comorbidities	
22.	Present comorbidity (Pls write all diagnosed Comorbidities
Part IV Treatment related characteristics of cervical cancer patients	
23.	Treatment initiated a. Surgery and chemotherapy b. Chemotherapy only c. Radiotherapy only d. Chemoradiotherapy only e. Surgery + chemotherapy + radiotherapy
24.	Date of cancer treatment initiated_________________________________
25.	Chemotherapy cycles a. No chemo b. First cycle c. Second cycle d. Third cycle e. Fourth cycle f. Other (specify)_____________
26.	Aim of radiation therapy a. Radical b. No radiation c. Palliative

Part V Observational Prospective follow up for survival status
Telephone number 1 __________________
Telephone Number 2_____________________

27.	Date of enrollment for observational Prospective follow up (dd/mm/yy)
28.	Next appointment at oncology center (dd/mm/yy)
29.	Final date for survival follow-up (dd/mm/yy)
30.	Survival status a. Died b. Alive c. Lost to follow-up
31.	Known Cause of Death a. Cervical cancer b. Other (pls specific) ______________________________

Participant Identifier Information (Separate Sheet)

Fill the following Information to identify participants in Prospective Follow up

1. Given Code

   ____

2. Full name

   ____

3. Card/registration number

   ____

4. Address

   Region _______________

   Town ________________

   Kebele ________________

   Mobile Number _________________________, ______________________________

   Home (P hone no)____

5. Partner/Relative/ Friend/any who can provide information Name:________

   Mobile number: ____________________________

Appendix A2: EORTC QLQ CX30

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential

During the past week		Not at all	A little	A quite bit	Very much
1.	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	**1**	**2**	**3**	**4**
2.	Do you have any trouble taking a long walk?				
3.	Do you have any trouble taking a short walk outside of the house?				
4.	Do you need to stay in bed or a chair during the day?				
5.	Do you need help with eating, dressing, washing yourself or using the toilet?				
During the past week:					
6.	Were you limited in doing either your work or other daily activities?				
7.	Were you limited in pursuing your hobbies or other leisure time activities?				
8.	Were you short of breath?				
9.	Have you had pain?				
10.	Did you need to rest?				
11.	Have you had trouble sleeping?				
12.	Have you felt weak?				
13.	Have you lacked appetite?				
14.	Have you felt nauseated?				
15.	Have you vomited?				
16.	Have you been constipated?				
During the past week:					
17.	Have you had diarrhea?				

18.	Were you tired?				
19.	Did pain interfere with your daily activities?				
20.	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?				
21.	Did you feel tense?				
22.	Did you worry?				
23.	Did you feel irritable?				
24.	Did you feel depressed?				
25.	Have you had difficulty remembering things?				
26.	Has your physical condition or medical treatment interfered with your family life?				
27.	Has your physical condition or medical treatment interfered with your social activities?				
28.	Has your physical condition or medical treatment caused you financial difficulties?				
For the following questions please circle the number between 1 and 7 that best applies to you					
29.	How would you rate your overall health during the past week?	**1 2 3 4 5 6 7** Very poor Excellent			
30.	How would you rate your overall quality of life during the past week?	**1 2 3 4 5 6 7** Very poor Excellent			

Appendix A3: EORTC QLQ-CX24

The European Organization for Research and Treatment of Cancer (EORTC) Quality-of-Life questionnaire cervical cancer module

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems. Please answer by circling the number that best applies to you.

During the past week		Not at all	A little	A quite bit	Very much
31.	**Have you had cramps in your abdomen?**	**1**	**2**	**3**	**4**
32.	Have you had difficulty in controlling your bowels?	1	2	3	4
33.	Have you had blood in your stools (motions)?	1	2	3	4
34.	Did you pass water/urine frequently?	1	2	3	4
35.	Have you had pain or a burning feeling when passing water/urinating?	1	2	3	4
36.	Have you had leaking of urine?	1	2	3	4
37.	Have you had difficulty emptying your bladder?	1	2	3	4
38.	Have you had swelling in one or both legs?	1	2	3	4
39.	Have you had pain in your lower back?	1	2	3	4
40.	Have you had tingling or numbness in your hands or feet?	1	2	3	4
41.	Have you had irritation or soreness in your vagina or vulva?	1	2	3	4
42.	Have you had discharge from your vagina?	1	2	3	4
43.	Have you had abnormal bleeding from your vagina?	1	2	3	4
44.	Have you had hot flushes and/or sweats?	1	2	3	4
45.	Have you felt physically less attractive as a	1	2	3	4

	result of your disease or treatment?				
46.	Have you felt less feminine as a				
	result of your disease or treatment?	1	2	3	4
47.	Have you felt dissatisfied with your body?	1	2	3	4
During the past week		Not at all	A little	A quite bit	Very much
31.	**Have you had cramps in your abdomen?**	**1**	**2**	**3**	**4**
32.	Have you had difficulty in controlling your bowels?	1	2	3	4
33.	Have you had blood in your stools (motions)?	1	2	3	4
34.	Did you pass water/urine frequently?	1	2	3	4
35.	Have you had pain or a burning feeling when passing water/urinating?	1	2	3	4
36.	Have you had leaking of urine?	1	2	3	4
37.	Have you had difficulty emptying your bladder?	1	2	3	4
38.	Have you had swelling in one or both legs?	1	2	3	4
39.	Have you had pain in your lower back?	1	2	3	4
40.	Have you had tingling or numbness in your hands or feet?	1	2	3	4
41.	Have you had irritation or soreness in your vagina or vulva?	1	2	3	4
42.	Have you had discharge from your vagina?	1	2	3	4
43.	Have you had abnormal bleeding from your vagina?	1	2	3	4
44.	Have you had hot flushes and/or sweats?	1	2	3	4
45.	Have you felt physically less attractive as a result of your disease or treatment?	1	2	3	4
46.	Have you felt less feminine as a				

	result of your disease or treatment?	1	2	3	4
47.	Have you felt dissatisfied with your body?	1	2	3	4
During the past 4 weeks					
48.	Have you worried that sex would be painful?				
49.	Have you been sexually active?				
Answer these questions only if you have been sexually active during the past 4 weeks:					
50.	Has your vagina felt dry during sexual activity?				
51.	Has your vagina felt short?				
52.	Has your vagina felt tight?				
53.	Have you had pain during sexual intercourse or other sexual activity?				
54.	Was sexual activity enjoyable for you?				

Study Information sheet II (Qualitative Study)

Good morning /good afternoon my name is ________________. I am working with Roza Teshome who is conducting a research study for the partial fulfillment of her PhD in Nursing at Emory University. Her research project is entitled "**Sexual and psychosocial experience among cervical cancer patients and their partners"**. The supervisors are Dr. Jessica Wells, Dr. Yang Irene, . Higgins Melinda, Dr. Eshetu Girma & Dr. Edom Seife.

Objective of the study: the aim of this study is to psychosocial experience among cervical cancer patients and their partners

Benefit: The benefits of this study are to generate information about the psychosocial experience among cervical cancer patients and their partners. There will be no cost for participation and it will not affect your medical treatment at TASH. There will be no direct benefit to you for your participation in this study However, we believe this research will have important implications for future interventions aimed at improving the quality-of-life women post-cervical cancer treatment.

Risks: There are no expected risks to you for participating in this study. The study will be conducted by face-to-face interview. The interview will take 40-60 minutes. The interview will be recorded.

Confidentiality: Your responses will be completely confidential. The information gathered during this study will remain confidential. Research records will be kept in a locked file, and all electronic information will be coded and secured using a password protected file; only the researcher will have access to the records. In any sort of report, we make public we will not include any information that will make it possible to identify you.

Right: Your participation is entirely voluntary. If you do not wish to participate or withdraw at any time during the study, you are free to withdraw at any time, without giving a reason and without cost.

To effectively attain the objectives of this research project, we kindly requesting your participation.

Contact Information You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, data collector by telephone at phone number.

If you have any other concerns about your rights as a research participant that has not been answered by the data collector, you may contact

The principal investigator Roza Teshome by

Email rozateshome2007@gmail.com

telephone 251911028610.

If you have any further problems or concerns that occur as a result of your participation, you can report them to the IRB at Addis Ababa University, college of health sciences

IRB address Email: chs.irb@aau.edu.et

Telephone 2511118961396

Consent

I have read and I understand the provided information. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without cost. I do also understand that there is no risk in participating in the study, so I voluntarily agree to take part in this study.

Participant's signature ________________________________Date _______________

Data collector's Name and signature ________________________________Date _______________

Appendix A4: Guiding for in-depth interview *1*

Part I Background characteristics of respondents

Code participant number___________

Stage of cancer

Type of cancer treatment given

Date treatment started

Part II Illness experience since onset of cancer symptom

1. Can you tell me about body pains you had at the onset/ diagnosis of cancer?

2. Can you explain emotional experience you had at the time cancer diagnosis?

Part III lived experience with late effects of cervical cancer treatment

Body pain

3. What are physical problems you have after cancer treatment?

Sexual disruptions

4. What are sexual problems you have after cancer treatment

Sleep disturbance

5. Can you tell me about your sleep pattern since you start treatment?

Economic disruption

6. What do you work currently for living?

7. Are still working since cancer treatment

8. Tell me if you have any inability to work?

9. Do you face income reduction?

Psychological disruption

10. Do you think about your cancer treatment?

11 Do you have any fear when you remember treatment?

Relationship to family

12. How do explain the relationship with your husband after cancer treatment?

13. What do you think about your family, life & surviving with cervical cancer

Social relationship

14. Can you tell me about your relationship with friends after cancer treatment?

15. Can you tell me about your relationship with neighbors?

16. Can you explain to me about your social participation since your cancer treatment

Appendix A5: Guiding question for in-depth interview *2*

Code : _______________

Part I Socio Demography Characteristics

1. Age: (Years) Age your wife
2. Duration since your wife started cancer diagnosis
3. Duration since your wife started cancer treatment
4. Stage of cancer
5. Type of cancer treatment she is taking
6. Marriage duration
7. No of children
8. Educational level Your Wife's educational level
9. Occupation Your Wife's occupation

Part II Psycho social related Experiences

Awareness about cervical cancer

10. Can you tell me what did you know about cervical cancer before your wife's diagnosis? (probe: cause, risk screening and treatment information)

Emotional, anxiety/fear

11. Would you share the emotions you and your wife experienced when she was diagnosed with cervical cancer?
12. What did you feel when your wife started cancer treatment (Probe; any trial for religious and traditional options)
13. Would you share if you have fear when you think about her cancer treatment?
14. How would you describe and compare your level of confidence doing your daily activities before and after she started cancer treatment

Social interaction, social support

15. How would you describe the relationship with your wife since she started cancer treatment?

16. Can you describe your relationship with friends since your wife started cancer treatment?
17. Can you tell about your relationship with your neighbours and relatives after cancer treatment?
18. Can you tell me about your social support from friends and relatives since your wife started cancer treatment?
19. How would you describe cost burden on living since your wife started cancer treatment (Probe Still working,)
20. Can you describe psychological supports from health care providers that follow your wife?
21. How you say about medical supports or cervical cancer treatment service?

Part III Sexual Relationship related Experiences

22. Can you tell me about your sexual relationship with your wife?
23. Can you describe any sexual issues you have experienced after cancer treatment?
24. What are the impact of cervical cancer (treatment) on the relationship and the perception of your wife?
25. Can you share your and your wife sexual complaints after cancer treatment? (Probe: desire, pain)

Appendix B: የአማርኛ ትርጉም መረጃ መሰብሰቢያ መጠይቆች

የመረጃና የፈቃደኝነት ማረጋገጫ ***(Quantitative study)***

ቀን___________ወር ___________ አመት___________

እንደምን አደሩ /እንደምን ዋሉ ስሜ ________________________________ይባላል።

በኢሞሪ ዩኒቨርሲቲ በነርሲንግ ሶስተኛ ዲግሪዋን ለመስራት ጥናት ከሚያካሂዱት ከሮዛ ተሾመ ጋር መረጃ ሰብሳቢ ሆኜ እየሰራሁ ነው ። የምርምር ሥራዋ በጥቁር አንበሳ ስፔሻላይዝድ ሆስፒታል የማኅጸን በር ካንሰር ሕክምና ከተደረገ በኋላ በሕይወት የመቆየት ሁኔታ፣ ከካንሰር ህክምና በፊትና የድህረ ሕክምና አኗኗር ሁኔታ የሚል ነው ። የጥናቱ ሱፐርቫይዘሮች ዶ/ር ጄሲካ ዌልስ ፣ ዶ/ር ያንግ አይሪን ፣ ዶ/ር ሂጊንስ መሊንዳ ፣ ዶ/ር እሸቱ ግርማ እና ዶ/ር ኤዶም ሰይፈ ናቸው።

የጥናቱ ቆይታ - የጥናቱ ቆይታ አንድ ዓመት ይወስዳል። በዚህ ጊዜ ውስጥ ቃለ መጠይቅ በጥናቱ መጀመሪያ ፣ በ ***6*** ወር እና በአንድ ዓመት ውስጥ ይካሄዳል። በመጀመሪያ እና በ 6 ወር ፊት ለፊት ቃለ- መጠይቅ ይደረጋል። አንድ ዓመት ሲሞላ (በጥናቱ ማብቂያ) የስልክ ቃለ -መጠይቅ ይካሄዳል።

ዓላማ፡ ሕክምና ከተደረገ በኋላ በሕይወት የመቆየት መጠን፣ የኑሮ ሁኔታ መገምገም ነው።

ጥቅሞች የማህጸን በር ካንሰር ህክምና ክትትል ፤ የካንሰር ህክማ መውሰድ በታካሚዎች የኑሮ ሁኔታ ያለው አስተዋጽኦ ፡ እንዲሁም የማህጸን በር ካንሰር በማህበራዊ ፤በስነልቦናዊ እና ስነተዋልዶ ጤና መረጃ በማግኘት ለዘርፉ ከፍተኛ ሚና ይሰጣል።

በጥናቱ በመሳተፍዎ ከካንሰር ማእከሉ በሚያገኙት ህክምናዎ ላይ ተጽዕኖ አይኖረውም። በዚህ ጥናት ውስጥ ለመሳተፍ ለእርስዎ ምንም ቀጥተኛ ጥቅም ባይኖርም ነገር ግን ፣ ይህ ጥናት የዘርፉን ህክምና ለማሻሻል ትልቅ አስተዋጸኦ ይኖረዋል የሚል እምነት አለን ። በዚህ ጥናት ውስጥ ለመሳተፍ ለእርስዎ ምንም የሚኖሩ አደጋዎች የሉም ። ጥናቱ የሚካሄደው ፊት-ለፊት ቃለ-መጠይቅ በማድረግ እና የሕክምና
ካርዶችዎን በማየት ነው ። ጥናቱ የአንድ ዓመት ክትትል ይወስዳል። በዚህ ጊዜ ቃለ-መጠይቅ የሚደረገው በጥናቱ መጀመሪያ ፤ ስድሰት ወር ላይ እና አንድ አመት ሲሞላ ይሆናል። ቃለመጠይቁ ከ20-30 ደቂቃዎችን ይወስዳል።

ሚስጥራዊነት፡ የእርስዎ ምላሾች ሙሉ በሙሉ ሚስጥራዊ ይሆናሉ ። በዚህ ጥናት ወቅት የተሰበሰበው መረጃ ሚስጥራዊ ሆኖ ይቀጥላል። የምርምር መዝገቦች በተቆለፈ ፋይል ውስጥ ይቀመጣሉ ፣ እና ሁሉም የኤሌክትሮኒክስ መረጃዎች በይለፍ ቃል በመጠቀም ኮድ ተደርጎባቸው ደህንነታቸው የተጠበቀ ይሆናል።በማናቸውም ዓይነት ዘገባዎች የእርሶን ማንነት ለመለየት የሚያስችል ማንኛውንም መረጃ አናካትትም።

የእርስዎ ተሳትፎ ሙሉ በሙሉ በፈቃደኝነት የሚደረግ ነው። በጥናቱ ወቅት በማንኛውም ጊዜ መሳተፍም ሆነ መውጣት የሚፈልጉ ከሆነ በማንኛውም ጊዜ መውጣት ይችላሉ። የዚህን የምርምር ፕሮጀክት ዓላማዎች በብቃት ለማሳካት እንዲሳተፉ በትህትና እንጠይቃለን። ስለዚህ የምርምር ጥናት ጥያቄዎችን የመጠየቅ እና እነዚያን ጥያቄዎች ከጥናቱ በፊት ፣ በጥናቱ ወቅት ወይም በኋላ መተው መብት አለዎት ። ስለጥናቱ ተጨማሪ ጥያቄዎች ካሉዎት በማንኛውም ጊዜ እኔን ለማግኘት ነፃነት ይሰማዎ ፣ በመረጃ ሰብሳቢ ያልተመለሰ ጥያቄ ካሉዎት ዋና ተመራማሪዋን ማነጋገር ይችላሉ

ዋና ተመርማሪው ሮዛ ተሾመ

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ስልክ 251911028610.

በተሳትፎዎ ምክንያት የሚከሰቱ ተጨማሪ ችግሮች ወይም ስጋቶች ካሉዎት በአዲስ አበባ ዩኒቨርሲቲ ፣ በጤና ሳይንስ ኮሌጅ ለ IRB ሪፖርት ማድረግ ይችላሉ ።

የ IRB አድራሻ ኢሜይል chs.irb@aau.edu.et

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በቃለ መጠይቅ ለመሳተፍ የፈቃድኝነት ቃል መቀበያ ቅጽ

የቀረበውን መረጃ አንብቤ ተረድቻለሁ ። የእኔ ተሳትፎ በፈቃደኝነት እንደሆነ እና ምክኒያታዊ በሆነ ወይም ባልሆነ መልኩ ከጥናቱ መውጣት ብፈልግ በማንኛውም ጊዜ መልቀቅ እንደምችልም ተረድቻለሁ። በተጨማሪም በጥናቱ ውስጥ መሳተፍ አደጋ እንደሌለ ስለተረዳሁ በዚህ ጥናት ውስጥ ለመሳተፍ ፈቃደኛ መሆኔን አረጋግጣለሁ።

የተሳታፊ ፊርማ ________________________________

ቀን ______________

የመረጃ ሰብሳቢው ስም ________________________________

የመረጃው ሰብሳቢ ስልክ ቁጥር ________________________________

ፊርማ ________________________________

ቀን ______________

Appendix B1: በህይወት የመቆየት መጠን መከታተያ መጠይቅ

ሀ. ማህበራዊ እና ኢኮኖሚያዊ መረጃዎች

1. የተሰጠው ኮድ
2. የካርድ ቁጥር __________________
3. የሥራ ሁኔታ
4. እድሜ __________________

   ሀ. የቤት እመቤት ለ. የመንግስት ሰራተኛ ሐ. በግል ተዳዳሪ

መ. ነጋዴ ሠ. ሌላ (ይግለጹ)_______________

5. የትምህርት ደረጃ

ሀ. መደበኛ ትምህርት ያልወሰዱ ለ. እስከ አንደኛ ደረጃ የወሰዱ ሐ. እስከ ሁለተኛ ደረጃ

የወሰዱ መ. ኮሌጅ / ዩኒቨርሲቲ ያጠናቀቁ

6. የጋብቻ ሁኔታ

ሀ. ያላገባች ለ. ያገባች ሐ. የተፋታች   መ. ተለያይተው/በሩቅ የሚኖሩ ሠ. ባለቤቷ የሞተባት

7. ከማን ጋር ይኖራሉ

ሀ. ብቻዬን ለ. ከቤተሰቤ ጋር ሐ. ከዘመድ ጋር

8. የሚከተሉት ሀይማኖት

ሀ. ኦርቶዶክስ ክርስቲያን ለ. ፕሮቴስታነት ሐ. ሙስሊም መ. ሌላ ________

9. አማካይ የወር ገቢ (ብር) ___________________

10. ሲጋራ ያጨሳሉ;

ሀ. በፍጹም አጭሼ አላውቅም

ለ. ከዚህ በፊት አጭሼ አውቃሉ፤ ነገር ግን አሁን ማጨስ

አቁሜያለሁ ሐ. አዎ አጨሳለሁ

11. አልኮሆል ይጠጣሉ

ሀ. አዎ በየቀኑ እወስዳለሁ ለ. አዎ በሳምንት አንድ-ሁለት ቀን እወስዳሉ ሐ. አዎ አልፎ አልፎ እወስዳለሁ መ.

በፍጹም አልወስድም

12. የአካል ብቃት እንቅስቃሴ ያደርጋሉ

ሀ. በፍጹም   ለ. በሳምንት አንድ ቀን ሐ. አልፎ አልፎ መ.

በየቀኑ **ለ.** የስነ-ተዋልዶ ጤና እና ተያያዥ መረጃዎች

13. የመጀመርያ ጋብቻ ሲፈጽሙ እድሜዎት ስንት ነበር ________ (በአመት ይገለጽ)

14. ለመጀመርያ ጊዜ የግብረ ስጋ ግኑኝነት የፈጸሙበትን እድሜ ቢነግሩኝ _________

15. ልጆች ወልደዋል

ሀ. አዎ ለ. አይደለም

16. መልሶት አዎ ከሆነ ስንት ልጂች ወልደዋል ____________________

17. የመጀመርያ እርግዝናዎት ወቅት እድሜዎት ስንት ነበር________

18. የወር አበባ ማየት አቁመዋል (አርጠዋል) ሀ. አዎ ለ. አይደለም

19. ሶት አዎ ከሆነ በስንት እድሜዎ ተከሰተ ____

20. በአፍ የሚወሰድ የወሊድ መከላከያ

ይወስዱ ነበር ሀ. አዎ   ለ አልወስድም

21. መልሶት አዎ ከሆነ ለምን ያክል ጊዜ ወስደዋል ____________(ጊዜው ይገለጽ ምሳሌ ለ____ወር/አመት)

ሐ. የማህጸን በር ካንሰር ምርመራ፤ ህክምና እና ተጓዳኝ በሽታዎች ጋር የተያያዘ መረጃ (ከታከሚው

ማህደር ያረጋግጡ)

22. የማህጸን በር ካንሰር በምርመራ የተረጋገጠበት (ከታከሚው

ማህደር ያረጋግጡ) ቀን   ወር ___ አመት___________

23. ወደ ጥቁር አንበሳ ካንሰር ማእከል በሪፈራል ነው የተላኩ
ሀ. አዎ ለ. አይደለም ሌላ ___________

24. ወደ ጥቁር አንበሳ ካንሰር ማእከል በሪፈራል የተፃፈበት
ቀን __________ወር __________አመት __________

25. የካንሰሩ መነሻ አይነት (ሂስቶፓቶሎጂ) (ከታከሚው
ማህደር ያረጋግጡ) ሀ. ስኩአመስ ለ. አዲኖካርሲኖማ

26. በምርመራ ወቅት የተረጋገጠው የካንሰር ደረጃ (ከታከሚው ማህደር
ያረጋግጡ) ሀ. IA ለ. IB ሐ. IIA መ. IIA ሠ. IIB ረ. IIIC1 ሸ.IIIC2 ቀ.
IVA በ.IVB

27. የካንሰር ህክምና የሚጀመርበት (ከታከሚው ማህደር
ያረጋግጡ) ቀን_ ወር _________ አመት_________

28. የሚጀመርለት የካንሰር ህክምና አይነት (ከታከሚው ማህደር ያረጋግጡ)
ሀ. የቀዶ ጥገና ለ. የኬሞቴራፒ ብቻ ሐ. የቀዶ ጥገና እና ኪሞቴራፒ መ. ራዲዮቴራፒ
ብቻ ሠ. ኬሞቴራፒ እና ራዲዮቴራፒ ረ. ቀዶ ጥገና + ኬሞቴራፒ + ራዲየሽን

29. ህክምና በሚጀመርለት ወቅት የካንሰር ደለጃ (ከታከሚው ማህደር
ያረጋግጡ) ሀ. IIA ለ. IIB ሐ. IIIC1 መ.IIIC2 ሠ. IVA ረ.IVB

30. በህክምና የታወቁ ተጓዳኝ/ተያያዥ ህመሞች ካሉ ያክብቡ (ከታከሚው ማህደር ያረጋግጡ)
ሀ. የደም ማነስ ለ. ከልብና የደም ስር ጋር የተያያዘ በሽታ ሐ. የስኳር በሽታ መ. የኩላሊት
በሽታ ሠ. የኤችአይዠቪ ኤድስ በሽታ ረ. የጉበት በሽታ ሸ. ሌላ ካለ _____________

31. ለካንሰር ህክምና እና ክትትል የተሰጠው ቀጣይ ቀጠሮ (ከታከሚው
ማህደር ያረጋግጡ) ቀን ወር ___ አመት

Appendix B2: የ EORTC QLQ-CX30 አማርኛ ትርጉም መጠይቅ

አንዳንዴ ታካሚዎቻችን የተለያዩ ምልክቶችና ስሜቶች እንደሚሰማቸው፡፡ እባክዎን ከስር የተጠቀሱትን

ስሜቶች በምን ያህልሁኔታ እንደተሰማዎት ይግለፁልኝ፡፡

ባለፉት ሳምንታት

1. የካርድ ቁጥር __________

		በጭራሽ 1	በትንሹ 2	በመጠኑ 3	በጣምበብዛት 4
1.	አንድ ከባድ ዘንቢል ወይም ሻነጣ መሸከም የመሳሰሉት ጉልበት የሚጠይቁ እንቅስቃሴዎችን ለማድረግ ችግር አለብዎ	1	2	3	4
2.	ረጅም የእግር ጉዞ ለማድረግ ችግር አለብዎ	1	2	3	4
3.	ከቤትዎ ውጪአጭር የእግር ጉዞ ለማድረግ ችግር አለብዎ	1	2	3	4
4.	በህመምዎ የተነሳ በቀን አልጋ ላይ ሆነው ረጅም ሰአት ያሳልፋሉ	1	2	3	4
5.	ሲመገቡ፡ ሲለብሱ ፡ ሲታጠቡ ወይም ሽንጽ ቤት ሲጠቀሙ እገዛ ያስፈልጎታል	1	2	3	4
ባለፈውሳምንት ውስጥ		በጭራሽ	በትንሹ	በመጠኑ	በጣም በብዛት
6.	ስራዎትን ወይም የእለት ተእለትእንቅስቃሴዎችን ለማከናወን ተገድበው ነበር	1	2	3	4
7.	በትርፍ ጊዜ የሚከናወኑ ስራዎችን ወይም ሌሎች የመዝናኛ ጊዜዎችን ለማሳለፍ ገድቦት ያውቃል	1	2	3	4
8.	ሲተነፍሱ የትንፋሽ ማጠር አጋጥሞት ነበር	1	2	3	4
9.	የህመም ስሜት ነበርዎ	1	2	3	4
10.	ከወትሮ የተለየ እረፍት አስፈልጎት ነበር		2	3	4
11.	የእንቅልፍ ችግር ነበረብዎ	1	2	3	4
12.	አቅም ያንስዎት ነበር	1	2	3	4
13.	የምግብ ፍላጎትዎ ቀንሶ ነበር	1	2	3	4
14.	የማቅለሽለሽ ስሜት ነበርዎ	1	2	3	4
15.	አስመልሶት ነበር	1	2	3	4
16.	የሰገራ ድርቀት ነበርዎ	1	2	3	4
17.	ተቅማጥ ነበርዎ	1	2	3	4

18.	የድካም ስሜት ነበርዎ	1	2	3	4
19.	ህመሙ የእለት ተእልት እንቅስቃሶዎትን ያውክብዎ ነበር	1	2	3	4
20.	አንድ አንድ ነገሮችን ትኩረት ሰጥተው ለመስራት ያውክዎት ነበር (ለምሳሌ ጋዜጣ ለማንበብ፡ ሬድዮ ለማዳመጥ)	1	2	3	4

21.	የውጥረት ስሜት ነበርዎ	1	2	3	4
22.	የመጨነቅ ስሜት ነበርዎ	1	2	3	4

23.	የመነጫነጭ ስሜት ነበርዎ	1	2	3	4
24.	የመደበር ስሜት ነበርዎ	1	2	3	4
25.	ነገሮችን ለማስታወስ ችግር ነበርዎ	1	2	3	4
26.	አካልዊ ሁኔታዎ ወይም ህመምዎ በቤተሰባዊ ህይወትዎ ላይ ያሳደረው ተፅእኖ ነበር	1	2	3	4
27.	የጤናዎ ሁኔታ በማህበራዊ ህይወትዎ በሚደረጉት እንቅስቃሴዎች ላይ ያሳደረው ተፅእኖ ነበር	1	2	3	4
28.	የጤናዎ ሁኔታ ገንዘብ እንዲያጥርዎ/እንዲቸግርዎ አድርጎ ነበር	1	2	3	4
29.	በአጠቃላይ ባለፈው ሳምንት የነበረዎን የጤንነት ሁኔታ እንዴት ይመዝኑታል (1 ዝቅተኛ፤ 7 ከፍተኛ) 1 2 3 4 5 6 7				
30.	በአጠቃላይ ባለፈው ሳምንት የነበረን የኑሮ ጥራት እንዴት ይመዝኑታል (1 ዝቅተኛ፤ 7 ከፍተኛ) 1 2 3 4 5 6 7				

Appendix B3: የ EORTC QLQ-CX30 አማርኛ ትርጉም መጠይቅ

ባለፉትሳምንታት					
31.	ከቤትዎ ውጭ አጭር ጉዞ ለማድረግ ችግር አለብዎ	1	2	3	4
31.	የሆድ ቁርጠት ስሜት ተሰምቶታል	1	2	3	4
32.	የአንጀት እንቅስቃሴ መቆጣጠር ችግር አለ	1	2	3	4
33.	ሰገራዎ ላይ ደም አይተው ያውቃሉ	1	2	3	4
34.	ቶሎ ቶሎ ይሸናሉ	1	2	3	4
35.	በሚሸኑ ጊዜ የህመም ስሜት አለው	1	2	3	4
36.	የሽንት ውሃ አምልጥዎት ያውቃል	1	2	3	4
37.	ሙለ በሙሉ ከፍኛ የሽንት ውሃን ማስወገድ ያስቸግሮታል	1	2	3	4
38.	አንደኛው ወይም ሁለቱ እግር ላይ እብጠት አይተዋል	1	2	3	4
39.	የወገብ ህመም ተሰምቶት የውቃል	1	2	3	4
40.	.እግርዎ ላይ የመቆጥቆጥ ወይም የስሜት ማጣት ነገር አይተው ያውቃሉ	1	2	3	4
41.	በማህፀንዎ አካባቢ የማቃጠል ስሜት ተሰምቶት ያውቃል		2	3	4
42.	ከማህፀንዎ ፈሳሽ ነገር ይዋጣ ነበር	1	2	3	4
43.	ከማህፀንዎ ያልተለመደ ደም መድማት አጋጥሞታል	1	2	3	4
44.	የሰውነት ሙቀት መጨመር ወይም ስብ ያጋጥሞታል	1	2	3	4
45.	በህመም ምክንያት ስለሰውነት አካላትዎ ውበት የቀነሰ ስሜት ይሰማዎታል	1	2	3	4
46.	በህመም ምክንያት የሴትነት ስሜትዎ ቀንሷል	1	2	3	4
47.	ስለ አካላዊ ሁኔታዎ ያለ መርካት ስሜት ያጋጥሞታል	1	2	3	4
ባለፉት **4** ሳምነታት					

48.	የግብረ ስጋ ግንኙነት የህመም ስሜት ያመጣብኛል ብለው አስበው ያውቃሉ	1	2	3	4

49.	የግብረስጋ ግንኙነት አርገው ያውቃሉ	1	2	3	4
የሚከተሉትን ጥያቄዎች የሚመልሱት ላለፉት **4** ሳምንታት የግብረስጋግንኙነት ካደረጉ ብቻ ነው።					
50.	በግንኙነት ጊዜ ማህፀንዎ የመድረቅ ስሜት ነበረው	1	2	3	4
51.	ማህፀንዎ ያጠረ መስሎ ተሰምቶታል	1	2	3	4
52.	ማህፀንዎ የጠበበ መስልዎታል	1	2	3	4
53.	በግንኙነት ጊዜ ወይም ካለ ግብረ ስጋ ግንኙነት)በግንኙነተ ሁኔታ ላይ ህመም ተሰምቶታል	1	2	3	4
54.	ይህ ግንኙነት አዝናንቶታል	1	2	3	4

የጥናት መረጃ መጠይቅ (Qualitative study)

እንደምን አደሩ እኔ ሮዛ ተሾመ ፣ በኤሚሪ-አአዩ የጋራ የዶክትሬት ፕሮግራም ፒኤችዲ ተማሪ ነኝ ፡፡

በአሁኑ ወቅት ከማህፀን ካንሰር ሴቶች እና አብረው የሚኖሩት የወንድ አጋሮች የቀጥታ ስነ-ልቦናዊ እና ወሲባዊ የልምድ ተሞክሮ በሚል ርዕስ የጥራት ጥናት እሰራለሁ ፡፡ በጥቁር አንበሳ ስፔሻላይዝድ ሆስፒታል ኦንኮሎጂ ማዕከል ፣ 2021

የዚህ ጥናት ዓላማ ከማህጸን ጫፍ ካንሰር ህመምተኞች ጋር አብሮ የሚኖር የወንድ አጋሮች የስነ-ልቦና እና የወሲብ ሙከራዎችን ማሰስ ነው ፡፡ የዚህ ጥናት ጥቅሞች ከማህፀን ካንሰር ሴት ጋር አብሮ የሚኖር የወንዶች አጋር መረጃን የቀጥታ ተሞክሮ ማመንጨት ነው ፡፡ የዚህን የምርምር ፕሮጀክት ዓላማዎች በብቃት ለማሳካት የእናንተን ተሳትፎ በትህትና እጠይቃለሁ ፡፡

የእርስዎ ተሳትፎ ሙሉ በሙሉ በፈቃደኝነት ነው። ከመጀመሪያው ላለመሳተፍ ወይም ተሳትፎ ከጀመሩ በኋላ በማንኛውም ጊዜ የማቆም መብት አለዎት ፡፡ ለማያውቁት መረጃ ምላሽ እንዲሰጡ አይገደዱም። የእርስዎ ምላሾች ሙሉ በሙሉ ሚስጥራዊ ይሆናሉ።

ለመሳተፍ ፈቃድዎን ይሰጣሉ?

አዎ ፣ አደርጋለሁ ☐ አይ ፣ አላደርግም

APPENDIX B4: የቃለ መጠይቅ መመርያ 1

ተ. ቁጥር	ዝርዝር

ክፍል I የመልስ ሰጪዎች መረጃ

የኮድ ተሳታፊ ቁጥር ___________

የካንሰር ደረጃ

የተሰጠው የካንሰር ሕክምና ዓይነት

ህክምና የተጀመረበት ቀን

የክፍል II የሕመም ተሞክሮ የካንሰር ምልክት ከተከሰተበት ጊዜ ጀምሮ

1. በካንሰር መጀመሪያ / ምርመራ ወቅት ስለደረሰብዎ የሰውነት ህመም መንገር ይችላሉ?
2. በወቅቱ በካንሰር ምርመራ ወቅት ያጋጠመዎትን ስሜታዊ ተሞክሮ ማስረዳት
ይችላሉ? ክፍል ሶስት ከማህፀን በር ካንሰር ህክምና ጋር የኖረ ልምድ የነበረው
አካላዊ ህመም
3. ከካንሰር ህክምና በኋላ ምን አይነት የአካል ችግሮች አሉዎት?

የወሲብ ሁኔታ

4. ከካንሰር ህክምና በኋላ ምን አይነት ወሲባዊ ችግሮች አሉዎት

የእንቅልፍ መዛባት

5. ህክምና ከጀመሩ ጀምሮ ስለ እንቅልፍ ሁኔታዎ ሊነግሩኝ ይችላሉ?

የኢኮኖሚ ሁኔታ

6. በአሁኑ ጊዜ ለመኖር ምን ይሰራሉ?
7. ከካንሰር ህክምና ጀምሮ አሁንም እየሰሩ ነው
8. መሥራት የማይችሉት ነገር ካለ ይንገሩኝ?
9. የቤተሰብ ገቢዎ የተያያዘ ጉዳት እባኮን ያስረዱኝ;

የስነ-ልቦና ሁኔታ

10. ስለ ካንሰር ህክምናዎ ያስባሉ/ይጨነቃሉ?

11 ህክምናዎን በሚያስታውሱበት ጊዜ የፍርሃት፤ የመረበሽ ይሰማዎታል?

የቤተሰብ ግንኙነት

12. ከካንሰር ህክምና በኋላ ከባለቤትዎ ጋር ያለውን ግንኙነት እንዴት ማስረዳት ይቻላል?

13. ከማህፀን በር ካንሰር ጋር ስለ ቤተሰብዎ፣ ስለ ህይወትዎ እና ስለ ከህመሙ ጋር አብሮ በህይወት ስለመቆት ምን ይላሉ?

ማህበራዊ ግንኙነት

14. ከካንሰር ህክምና በኋላ ከጓደኞችዎ ጋር ስላለው ግንኙነት ሊነግሩኝ ይችላሉ?

15. ከጎረቤቶች ጋር ስላለው ግንኙነት መናገር ይችላሉ?
ከካንሰር ህክምናዎ ጀምሮ ስለ ማህበራዊ ተሳትፎዎ ሊያስረዱኝ ይችላሉ

APPENDIX B 5: የቃለ መጠይቅ መመርያ 2

ኮድ _______________

ክፍል **I** ሶሺዮ የስነ-ህዝብ ባህሪዎች

1. ዕድሜ (ዓመት)   ሚስትህ እድሜ

2. ሚስትዎ የካንሰር ምርመራ ከጀመረበት ጊዜ?

3. ሚስትዎ የካንሰር ህክምና ከጀመረበት ጊዜ?

4. የካንሰር ደረጃ

5. የምትወስደው የካንሰር ህክምና ዓይነት

6. የጋብቻ ቆይታ ጊዜ?

7. የልጆች ብዛት

8. የትምህርት ደረጃ   ሚስትዎ የትምህርት ደረጃ

9. ሥራ   የባለቤትዎ ሥራ

ክፍል **II** ሥነ ልቦና–ማህበራዊ ነክ ልምዶች

ስለ የማህጸን ጫፍ ካንሰር ግንዛቤ

10. ከባለቤትዎ ምርመራ በፊት ስለ የማህጸን ጫፍ ካንሰር ምን ያውቁ እንደነበር ሊነግሩኝ ይችላሉ? (***probe/***ምርመራ; መንስኤ,ተጋላጭ, ቅድመ ካንሰር/ምርመራ; ሕክምና)

ስሜታዊ ምላሽ

11. እርስዎ እና ባለቤትዎ የማሕፀን በር ካንሰር እንዳለባት በምርመራ ወቅት ያጋጠሟቸውን ስሜቶች ሊነግሩኝ ይችላሉ??

12. ባለቤትዎ የካንሰር ህክምና ስትጀምር ምን ተሰማህ? (***probe/***ምርመራ; ለሃይማኖታዊ እና በህላዊ አማራጮች ማንኛውም ሙከራ)

13. ስለ ካንሰር ህክምናዋ ሲያስቡ ጭንቀት / ፍርሃት ካለዎት ያካፍሉን?

14. የካንሰር ህክምና ከጀመረች በኋላ የእለት ተእለት እንቅስቃሴዎን በመፈፀም ላይ የሚያሳድረው ተጽዕኖ ሊነግሩኝ ይችላሉ?

ማህበራዊ መስተጋብር ፣ ማህበራዊ ድጋፍ

15. ባለቤትዎ የካንሰር ህክምና ከጀመረችበት ጊዜ አንስቶ ስለ ግንኙነቱ መንገር ይችላሉ?

16. ባለቤትዎ የካንሰር ህክምና ከጀመረችበት ጊዜ አንስቶ ከጓደኞችህ ጋር ያለህን ግንኙነት መግለፅ መንገር ይችላሉ?

17. ከካንሰር ህክምና በኋላ ከጎረቤቶችዎ እና ከዘመዶችዎ ጋር ስላለው ግንኙነት መንገር ይችላሉ?

18. ሚስትዎ የካንሰር ህክምና ከጀመረችበት ጊዜ አንስቶ ከጓደኞች እና ከዘመዶች ስለ ማህበራዊ ድጋፍዎ ሊነግሩኝ ይችላሉ?

19. ሚስትህ የካንሰር ህክምና ከጀመረችበት ጊዜ ጀምሮ በመኖር ላይ የሚኖረውን የወጪ ሸክም እንዴት ትገልጸዋለህ (Probe;/ አሁንም እየሰራ ነው)

20. ሚስትዎን ከሚከተሉት የጤና እንክብካቤ አቅራቢዎች የስነልቦና ድጋፎችን መግለፅ ይችላሉ?

21. ስለ ህክምና ድጋፎች ወይም ስለ የማህጸን ጫፍ ካንሰር ህክምና አገልግሎት ምን ይላሉ?

ክፍል **III** ከወሲባዊ ግንኙነት ጋር የተዛመዱ ልምዶች

22. ከሚስትዎ ጋር ስላለው የግብረ ሥጋ ግንኙነት ሊነግሩኝ ይችላሉ?

23. ከካንሰር ህክምና በኋላ ያጋጠሙዎትን ማንኛውንም ወሲባዊ ጉዳዮች መግለፅ ይችላሉ?

24. የማህፀን በር ካንሰር (ህክምና) በባለቤትዎ ግንኙነት እና ግንዛቤ ላይ የሚያሳድረው ተጽዕኖ ምንድነው?

25. ከካንሰር ህክምና በኋላ የርስዎን እና የባለቤትዎን የወሲብ ቅሬታ ሊነግሩኝ ይችላሉ? (ምርመራ: ፍላጎት ፣ ህመም)