

**LIVED EXPERIENCES OF ELDERLY GYNAECOLOGICAL ONCOLOGY
PATIENTS AND THEIR PRIMARY CAREGIVERS ATTENDING MBALE
REGIONAL REFERRAL HOSPITAL: A PHENOMENOLOGICAL STUDY.**

BY

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**A RESEARCH DISSERTATION SUBMITTED TO THE DEPARTMENT OF
NURSING FACULTY OF HEALTH SCIENCES IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE AWARD OF THE DEGREE OF BACHELOR OF
SCIENCE IN NURSING OF BUSITEMA UNIVERSITY.**

18 JUNE, 2026

DECLARATION

I Aporu Faith declare that this research dissertation on “Lived experiences of elderly gynaecological oncology patients and their caregivers attending Mbale Regional Referral hospital” is my original work and it has never been submitted to any university or institution of higher learning or any company for any purpose(s)

Signature

.....

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APPROVAL

This research dissertation, the title “Lived experiences of elderly gynaecological oncology patients and their caregivers attending Mbale Regional Referral hospital” was done under my supervision and is ready for submission to the Department of Nursing and Midwifery Faculty of Health Sciences, Busitema University.

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DEDICATION.

I dedicate this work to my family and friends who have continuously rendered me support and given me courage to work tirelessly throughout my academic journey. May God bless them abundantly for their exceptional support.

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OPERATIONAL DEFINITIONS.

Primary caregiver: An individual who helps individuals who need help with daily activities due to age, disability or illness. For this study, we will focus on the primary caregiver as one who had been doing so for the patient for at least 1 month.

Elderly: Defined as individuals equal to or above 65 years (Organization, 2023) but in this study we shall use the Uganda Ministry of health definition of individuals aged 60years and above(Nzabona)

Gynaecological oncology: A field in medicine that deals with cancers that originate from female reproductive organs.

Lived experiences: Firsthand knowledge, insights and understanding that people gain through their personal life circumstances.

Patient: An individual receiving medical care, treatment or consultation from health professionals for an illness or injury.

LIST OF ACRONYMS

CC- Cervical cancer

GC: Gynaecological cancer

FHS-Faculty of Health Sciences

OC-Ovarian cancer

MOH- Ministry of Health

MRRH-Mbale Regional Referral Hospital.

WHO- World Health Organization

VC-Vagina cancer

ABSTRACT

Background: Gynaecological cancers (GC) are the commonest cancers among females worldwide and constitute 14.4 to 18% of all cancers in the World. Relatedly, Uganda has a high burden of gynecological cancers due to the high incidence of cervical cancer which contributed to 43% of all cancers in 2019. Although gynaecological cancers are generally associated with untold morbidity and mortality, the elderly are disproportionately affected owing to their increased likelihood of physical fragility, comorbid states and socioeconomic challenges. Primary caregivers of these patients as well face physical, social and psychological burdens as they care for these patients. Although some studies have been done to explore the lived experiences of GC, little is known about this special age category.

Aim: This study therefore sought to explore the lived experiences of GC patients and their primary caregivers (PCG) at Mbale Regional referral hospital (MRRH).

Methods. A qualitative descriptive phenomenological study design was used. In total 11 patients and 11 primary caregivers were recruited purposively at Mbale Regional referral

hospital. Data was collected through in-depth one on one interviews. Clarke and Braun approach were used to conduct qualitative thematic analysis using Dedoose 10th version to code and generate themes. Themes and subthemes were then constructed using inductive thematic analysis.

Results. Six themes were constructed from patients' data (i) Journey to cancer diagnosis where patients experienced delayed diagnosis due to limited awareness and misinterpretation of early signs; (ii) pathway to caregiving role where primary caregiving role was assumed circumstantially or as a sense of obligation (iii) Response to cancer diagnosis where the diagnosis triggered emotional distress, fear of death and sleep disruption though acceptance gradually emerged through faith and resilience (iv) The physical burden, functional decline and dependence which manifested as disturbing bodily changes, pain, fatigue and functional decline which led to dependence on caregivers; (iv) Socioeconomic experiences and survival amidst living with cancer which was profound with loss of income, food insecurity, strained marriages and education leading to reliance on children and relatives for survival (v) coping mechanisms where coping was sustained through family and social support, faith in god and perseverance.

Conclusion. Elderly gynaecological cancer patients and their caregivers experience deep physical, emotional and social burdens but show resilience through coping strategies. This emphasizes the urgent need for strengthened nursing practice, culturally sensitive psychosocial support and policy interventions to improve oncology care.

Keywords: lived experiences, elderly, Gynaecological oncology, patient and primary caregiver

CHAPTER ONE: INTRODUCTION.

1.0. BACKGROUND.

Gynaecological cancers (GC) are cancers that originate in the woman's reproductive organs and include, uterine, cervical, vulvar, vaginal, fallopian tube, primary peritoneal and ovarian cancers (Ledford & Lockwood, 2019). Gynaecological cancers are the commonest cancers among females worldwide and constitute 14.4 to 18% of all cancers in the World (Gil-Ibanez et al., 2023). In 2022, about 1,473,427 were newly diagnosed with gynaecological cancers and 46.2%(680372) died from these cancers (Zhu et al., 2024). Among GC, cervical cancer (CC) has the highest incidence of 43.2% and is the fourth most common among all cancers whereas vaginal cancer has lowest incidence worldwide (Huang et al., 2022; Kataki et al., 2023; Sayed, 2021). Uganda has a high burden of gynecological cancers due to the high incidence of cervical cancer. In a study done by Okongo, cervical cancer contributed to 43% of all cancers in 2019 (Okongo et al., 2019).

Elderly gynaecological cancer patients experience many changes and new burdens in their physical, mental and social wellbeing (Li-Yun Tsai, 2020; Tsai et al., 2017). They experience physical symptoms like pain, bad bodily odour, vaginal bleeding and discharge, feeling exhausted most of the time, physical disability making it hard for them to do daily activities, pelvic symptoms like urinary incontinence, nausea and vomiting (Dzando et al., 2024; Kapya et al., 2024; Li-Yun Tsai, 2020; Nelson et al., 2018). They experienced psychological issues like feelings of hopelessness, hating themselves, anxiety, fear of what the public perceive of their symptoms (Li-Yun Tsai, 2020; Sekse et al., 2019; Wenzel et al., 2025). Socially, they experienced marriage break-up, isolation by family and community members, inability to attend and engage in social gatherings and activities (Herzog & Wright, 2007; Li-Yun Tsai, 2020; Shrestha et al., 2020), they also lose their working ability, lose jobs, they are also unable to afford the medical bills (Binka et al., 2017; Kissel et al., 2020).

The primary caregivers of gynaecological cancer patients who happen to be spouses, children, siblings (Andersen et al., 2023; Galica et al., 2022) also experience many challenges. These challenges are physical, social and psychological. The physical challenges include difficulty providing daily physical care, inability coping with patients' bad odour, vomiting (Alegbeleye & Amadi, 2024; Seven et al., 2014). The psychological challenges include stress, fear, confusion and anxiety, inability to provide psychological support to the patient (Ikharo et al., 2023; Seven et al., 2014). Socially, the caregivers have feelings of loneliness, limited time to

engage in social activities, shifts in social roles and responsibilities, loss of jobs (Alegbeleye & Amadi, 2024; Gosse et al., 2024)

The above experiences are largely influenced by physical, psychological and socioeconomic factors (Dumas et al., 2021; Zahediasl & Darveshifard, 2016) such as age of the patient, comorbidities, physical disabilities, stage at diagnosis and treatment (Dumas et al., 2021; Myrvold, 2023), social relationships and support, the economic status and economic support, and family involvement (Zahediasl & Darveshifard, 2016). Psychological factors include psychological support from family and community, ability to communicate (Kotkamp-Mothes et al., 2005).

Although there has been improvement in gynecological cancer patients' outcomes over decades with improved treatment modalities, the outcomes for elderly patients have been poor as compared to the younger ones (Quaglia et al., 2009). It is predicted that by 2030, nearly 70% of ovarian cancer deaths and 60% of endometrial cancer deaths will occur in those aged over 70 (Diaz et al., 2017). This is due to the inequalities in treatment status (Clark et al., 2016; Dumas et al., 2021; Sharma et al., 2012; Wright et al., 2005; Yunokawa et al., 2022), aggressive cancer types, increased comorbidity and deviance from adherent care delivery (Dumas et al., 2021), decreased physiologic reserve, limited capacity to respond to stressors, and a predisposition to adverse events (Fried et al., 2001). Relatedly, according to the Arbeit gemeinschaft Gynäkologische Onkologie (AGO) study group, 65% of the patients aged ≥ 75 received suboptimal surgery, while 50% were not given platinum-based chemotherapy (Hilpert et al., 2025). Moreover, there is general lack of access to guideline-concordant care for the elderly.

Although studies have been done about lived experiences of gynaecological cancers in Africa, to the best of our knowledge, there is a dearth of literature regarding lived experiences of the elderly gynaecological cancer patients and their primary caregivers in Uganda. This study, therefore, sought to explore the lived experiences of elderly gynaecological oncology patients and their primary caregivers attending Mbale Regional Referral hospital.

1.1 PROBLEM STATEMENT.

Gynaecological cancers remain a major health burden in Uganda. The risk of developing gynaecological cancer increases with age. Elderly women especially in the developing countries are bound to increase in numbers. In 2019, it was 1 billion globally, it is projected to increase to 1.4 billion by 2030 and 2.1 billion by 2050 (Organization, 2023). The elderly population is highly vulnerable to gynaecological cancers due to physical frailty, limited screening, comorbidities, poor access to oncology services and limited social support systems. Furthermore, aging affects patients' perception of illness, pain coping and adjustments to changes brought by the disease and this poorly affects the elderly gynaecological patients' experiences. Caregivers who are usually family members play an important role in supporting these elderly patients through their journey. However, caregiving brings its own psychosocial, physical and financial challenges. These together contribute to the undesirable consequences of cancer including poor quality of life, unmet needs and caregiver strain.

No published study has been done to explore the lived experiences of elderly gynaecological cancer (GC) patients at Mbale Regional Referral hospital and their caregivers limiting context appropriate interventions.

1.4 JUSTIFICATION.

Gynaecological cancers are a significant public health issue worldwide. The gynaecological cancer outcomes are usually worse in elderly patients and yet they are at higher risk of developing gynaecological cancer. Both gynaecological oncology patients and their caregivers encounter significant burden in their psychological, social and physical wellbeing. However, little is known about the lived experiences of elderly oncology patients and their caregivers despite the number of elderly and the burden of non-communicable diseases including but not limited to gynaecologic cancers rising.

This study therefore serves to address this gap by providing insight into the lived experiences of gynaecological oncology patients and their caregivers. By doing this study, we hope we will inform the health care system on the management of elderly patients to provide holistic care and reduce the burden to caregivers. We hope to inform the oncology nurses and midwives on tailored communication and symptom management; inform palliative care services design holistic packages; inform hospital management on resource allocation and caregiver support and to the teaching institutions to incorporate curriculum on oncology and caregiving.

1.2 RESEARCH OBJECTIVES

General objective

To explore the lived experiences of elderly gynaecological cancer patients and their primary caregivers attending Mbale Regional Referral Hospital.

Specific objectives

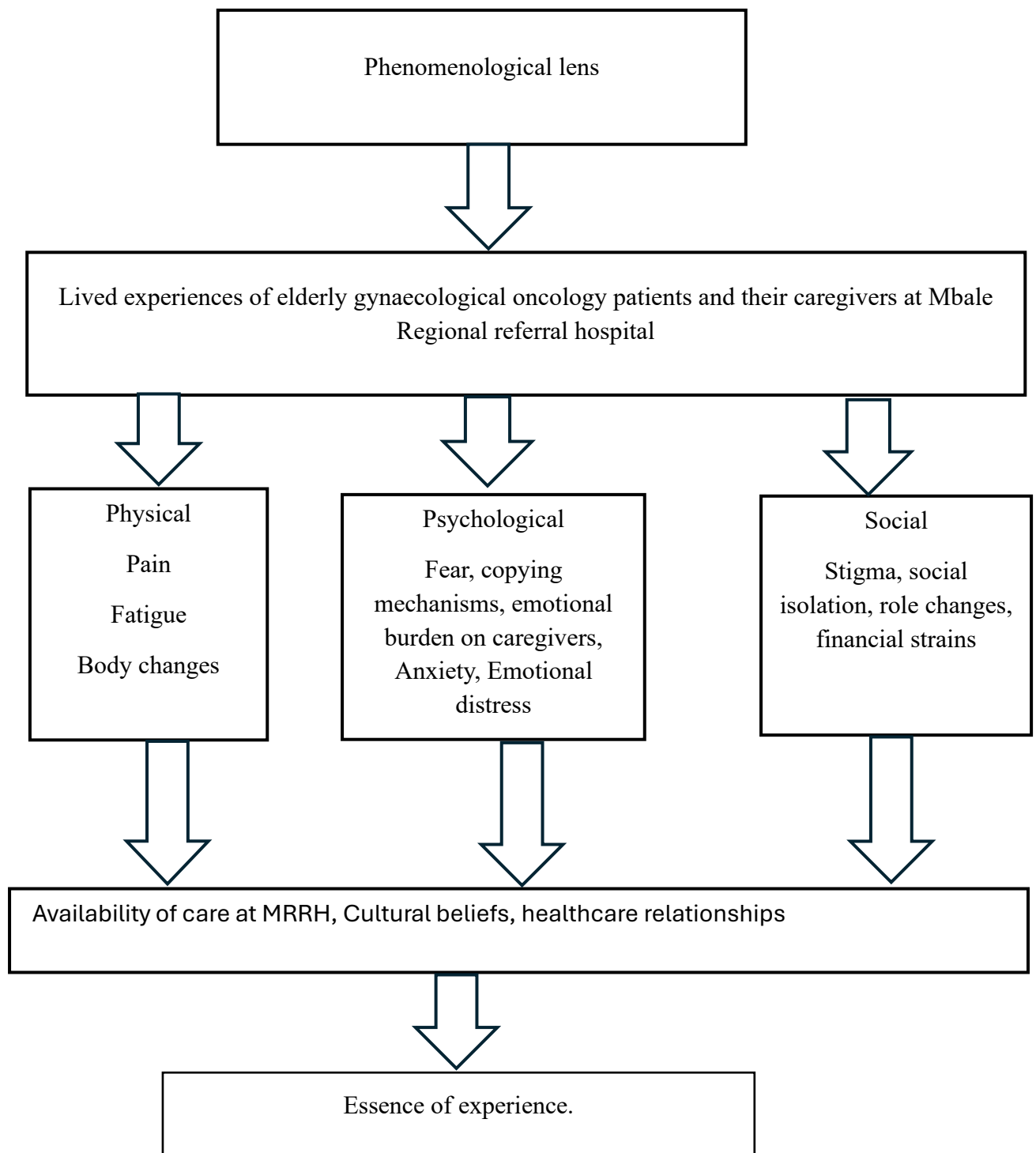
1. To explore the physical, psychological and social experiences of the elderly gynaecological cancer patients attending Mbale Regional Referral Hospital.
2. To explore the physical, psychological and social experiences of primary caregivers of elderly gynaecological cancer patients attending Mbale Regional Referral Hospital.

1.3 RESEARCH QUESTIONS.

1. What are the physical, psychological and social experiences of elderly gynaecological oncology patients attending Mbale Regional Referral Hospital?
2. What are the physical, psychological and social experiences of elderly gynaecological oncology patients' caregivers attending Mbale Regional Referral Hospital?

1.5 THEORETICAL FRAMEWORK

Phenomenological theory by Husserl Edmund 1859–1938.



Narration of the theoretical framework

The study will be grounded in phenomenology, a research paradigm that seeks to understand and describe the lived experience of individuals in a particular phenomenon. According to Husserl, phenomenology is the general study of what appears to conscious experience (Husserl & Moran, 2012). This theory assumes that reality is constructed through experience and interpretation.

This theory mainly entails how their lived experiences of a person are purely subjective and go through 3 major domains of life that is physical, social and psychological wellbeing. The disease influences these main domains of life and lived experience arises an interplay between the physical suffering, ability to adapt psychologically and interaction with the healthcare environment and community.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction.

This chapter will review existing literature and research on the lived experiences of Gynecological oncology patients and their caregivers. This chapter will critically examine and analyze the findings of different studies putting into consideration the different themes under each study. Much emphasis will be given to studies conducted in sub-Saharan Africa and Uganda. This will enable us to identify the realistic experiences of elderly gynecological oncology patients and identify gaps that future research must address to enhance holistic gynecological oncology care.

2.1 Physical experiences of elderly gynecological oncology patients and their caregivers.

In a systematic review study, gynaecological oncology patients experienced changes in their bodies permanently and substantially and them coming to terms with the altered body a core issue (Sekse et al., 2019). They entered excessive menopause in that those who were already in menopause got a new phase (Sekse et al., 2019). This was usually associated to symptoms like vaginal dryness and lack of elasticity which led to sexual dysfunction due (Sekse et al., 2019). In another related study, gynaecological oncology patients were also found to face significant sexual disfunction after surgery (Nelson et al., 2018). In Turkey, Women refrained from sexual intercourse because they believed it would implicit pain to them and they also believed their partners were no longer attracted to them (Yaman & Ayaz, 2016).

Elderly gynaecological patients with ovarian cancer reported to experience unusual and excessive body exhaustion that usually limited them from doing daily activities and was present most of the time of the day (Dumas et al., 2021). In other related studies, gynaecological oncology patients experienced cancer related exhaustion and weakness that was not usually related to doing any heavy activity (Nelson et al., 2018; Sekse et al., 2019). In a related study done in Zambia, patient reported tiredness and exhaustion that was perseverance and exhausting that disrupted their routine ability to engage in activities (Kapya et al., 2024).

Gynaecological oncology patients also experienced pelvic symptoms that originated from Bowels, the urinary tract, the lymphatic system and the genitals (Sekse et al., 2019). Cervical cancer survivors suffered from severe bladder symptoms including continuous leakage of urine, straining to initiate voiding, night-time micturition, failure to empty bladder completely and continuously had urge to void (Sekse et al., 2019). other patients had Lower Limb swelling especially those with high BMI (Sekse et al., 2019). Another study done in Zambia revealed

that these patients experienced unpredictable bowel habits like wanting to pass stool with little warning, leakage of stool and gas, having diarrhoea and constipation within the same period (Kapyra et al., 2024). Other women experienced bowel issues like blood in stool in Ghana (Agyeiwaa et al., 2024).

Gynaecological oncology patients also experienced pain that was overwhelming and mainly around the pelvic area that was associated to bladder and intestinal morbidity (Sekse et al., 2019). In another related study among the elderly by Dumas, many of the patients experienced joint pain which they described as being sore, aching most especially the knee joints, they also experienced pain in the muscles most especially muscles of arms, lower limbs, back and neck plus abdominal muscles that were very hard to tolerate. Peripheral neuropathy had a significant and long-term issue on physical activity of these patients because of its impact on body function (Dumas et al., 2021). In Ghana, cervical cancer patients experienced severe waist pain (Agyeiwaa et al., 2024). The patients also experienced pain in the back and referred cervical cancer as a painful and unbearable disease (Maree & Kaila, 2014).

In studies done in Ghana, Tanzania and Zambia, gynaecological oncology patients especially those diagnosed with cervical cancer experienced vaginal bleeding and watery discharge as the commonest physical characteristic (Agyeiwaa et al., 2024; Chona et al., 2023; Dzando et al., 2024; Maree & Kaila, 2014). Vaginal bleeding was reported to have existed prior the diagnosis (Agyeiwaa et al., 2024; Dzando et al., 2024). Patients experienced bad Odor due to the vagina bleeding and discharge and these made some people look at them like women who don't bathe (Maree & Holtslander, 2021). The vaginal bleeding led to development of complications of anaemia in some patients (Chona et al., 2023; Maree & Holtslander, 2021).

Gynaecological oncology patients undergoing chemotherapy in Zambia experienced significant loss of appetite (Kapyra et al., 2024). This was related to nausea and vomiting, emotional and physical exhaustion (Kapyra et al., 2024). They described how eating became a complex task because food was tasteless or metallic in taste (Kapyra et al., 2024). Another related study done in Tanzania revealed that these patients also experienced significant loss of appetite for several days right after they started their treatment due to treatment side effects like nausea, vomiting among others (Chona et al., 2023).

Caregivers had a burden copying with patients' signs and symptoms like vomiting, bad odour, taking the patient to the hospital and back, postoperative physical care to the patient and medication use (Seven et al., 2014). In another related study done in Nigeria, caregivers had a

high burden of care; some lost their jobs (Alegbeleye & Amadi, 2024). Caregivers also believed that the best they could do for their patients was being there for them, learn about good food and cook for them, massage their feet and arms and help them get around when it was needed (Han et al., 2016). They were also not able to balance the patients and their own responsibilities so they were not able to meet their own needs (Alegbeleye & Amadi, 2024) They also didn't have privacy as much as needed and most patients were entirely dependent on their caregivers (Alegbeleye & Amadi, 2024).

In Uganda, a study done on experiences of patients with Ovarian cancer patients, they all had abdominal symptoms like bloating, constipation, abdominal mass, abdominal distention, flatulence, vague abdominal pain (Katumba et al., 2013).

2.2 Psychological experience of gynaecological oncology patients and their caregivers.

At diagnosis, gynaecological oncology patients expressed suffering (Kapyra et al., 2024) and grief right after the diagnosis (Chona et al., 2025). They believed cervical cancer would cause them to die soon (Chona et al., 2023). In another related study in Turkey, patients perceived cancer as a death diagnosis, so they felt helpless causing frustration and despair (Yaman & Ayaz, 2016). In a study on elderly women with gynecological cancers, participants were overwhelmed and could not believe the diagnosis especially those who had had a relative lifestyle in their life (Dumas et al., 2021).

Gynecological patients also lacked emotional support from family and healthcare providers (Chona et al., 2023). Participants had feelings of hopelessness and anxiety due to altered social routines (Chona et al., 2023). Some family members isolated the patients and never interacted with them with belief that they would acquire the disease from the patients (Chona et al., 2023). Gynaecological oncology patients felt hopeless and worthless due to frustration and constant thoughts of death, change in body image, emerging effects of cancer, treatment side effects (Yaman & Ayaz, 2016). Though in another study among the elderly, friends and family provided emotional support to these patients (Dumas et al., 2021). Those with dependent spouses were concerned how their spouses would manage without them and thought they would burden their children with their death (Dumas et al., 2021).

In a study done in Tanzania, Gynaecological cancer patients reported stigma and discrimination that was due to negative attitudes and low knowledge about cancer (Chona et al., 2025). A study done in China revealed that patients get so worried about their family members including

children, parents and spouses (Ma et al., 2025). They also experienced extreme distress from treatment and their unpleasant side effects (Ma et al., 2025).

In Zambia, cervical cancer patients who were undergoing chemotherapy experienced various psychological issues. The patients reported various ways of going through these issues which included coping mechanisms, stress management, adaptation to uncertainty, emotional adjustments and dealing with treatment related fears. These were achieved by joining cancer support groups, seeking professional help from therapists, practicing gratitude amidst cancer difficulties, connecting with survivors were strategies to navigate psychological challenges (Kapyra et al., 2024).

For caregivers, the biggest challenge was with coping depressive symptoms, psychological problems of the patient (Seven et al., 2014). They also had a problems providing psychological support to the patient and feelings associated to the cancer diagnosis of their patient (Seven et al., 2014). Caregivers also experienced stress, fear, confusion and anxiety caused by emotional distress. Inability to control the pain of the patient and psychological aspect causes more emotional distress to the caregivers (Ikharo et al., 2023). Increased levels of stress among caregivers limited their words of encouragement to the patients (Ikharo et al., 2023).

2.3 Social experiences of gynecological oncology patients and their care givers.

In a study done in turkey, gynecological oncology patients lost their household roles to other family members who were either their partners, older family members especially mothers or elder sisters(Akyüz et al., 2008). A study done in Tanzania showed that cervical cancer patients faced issues like disruption of economic activities and these made them depend entirely on their family members(Chona et al., 2025). Many patients felt uncomfortable and anxious as they became dependent on others to do their duties, they easily took care of (Akyüz et al., 2008).

In Tanzania, Gynaecological oncology patients also faced a disruption in their family relationships and social life since they had to leave their home to attend cancer institute for treatment (Chona et al., 2025). Most family members believed going for cancer treatment was a waste of time, resources and money since cancer was believed to be incurable (Chona et al., 2023). In another study in Taiwan, patients mutually were supported by the healthcare professionals and colleagues (Tsai et al., 2017). The support from family and friends reduced patient's perceptions of helplessness. Some also believed in prayer for confidence and courage (Tsai et al., 2017).

Gynecological oncology patients also experienced being left to themselves and felt lonely in their cancer experiences after discharge (Breistig et al., 2024). In Zambia, Cervical cancer patients who were undergoing chemotherapy reported experiencing significant community support, which extended beyond their immediate social circles. The support was not only verbal but tangible too with friends and neighbors offering practical assistance, comforting meals and heartfelt encouragement (Kapyra et al., 2024).

In Zambia, patients highlighted the financial burden of cancer treatment, the costs for chemotherapy drugs were so expensive and forced difficult decisions beyond health care (Kapyra et al., 2024). The increase and accumulation of medical bills became a very huge burden and caused a sense thinking more about debts rather than having attention on health and recovery (Kapyra et al., 2024). Though churches organized fundraising events, local businesses offered discounts, and organizations provided transportation assistance bringing about financial support and deep compassion (Kapyra et al., 2024)

Many participants explained the difficulty of talking about sexual relations with the physician or nurse and yet they didn't provide adequate information from healthcare staff (Akyüz et al., 2008). Another study revealed that sex was an intimate and private issue and was very difficult for them to talk about throughout the treatment period. Women usually bled at the point of penetration and it was a turn off to both parties and the act and would not proceed any further from that point (Oldertrøen Solli et al., 2019).

The care takers reported issues like having limited time for family, work and lack of support from family members, difficulty with medication use, dosage and timing (Seven et al., 2014). In another related study, caregivers experienced social life changes including feelings of loneliness, limited time to engage in social activities, shifts in social roles and responsibilities. They also had lifestyle changes and low involvement in recreational activities and limited time to hang out with friends and family (Gosse et al., 2024).

Limited studies have been done on lived experiences of elderly gynecological oncology patients in Africa, and none has been done in Uganda among the elderly patients and yet the lived experiences of elderly patients are not known. There are some studies done in Uganda though they were not concentrating on this population (Natuhwera et al., 2021). Therefore, this study serves to provide detailed literature about the lived experiences of elderly gynaecological patients and their caregivers at Mbale regional referral hospital.

Summary of key gaps in the literature above.

In Africa and East Africa, existing studies have primarily focused on adult populations in general and specific gynaecological cancers like cervical cancer. They have not provided clear information about the experiences of elderly gynaecological oncology patients. Most studies provide hints on lived experiences of gynecological cancer patients of all ages without emphasis on the elderly population mainly concentrating on one cancer type. We believe that there are more gaps in the lived experiences of elderly gynaecological oncology patients and their caregivers. And very few studies have been done globally on lived experiences of primary caregivers. There is a very big gap in the work (Natuhwera et al., 2021) in western Uganda about lived experiences of advanced stage cervical cancer patients as it did not include other gynaecological cancers and also didn't put emphasis on the elderly population or the caregivers.

CHAPTER THREE: MATERIALS AND METHODS.

Introduction

This chapter of the study included the study design, study setting and site, study population, sampling size and sampling procedure, data collection methods, ethical considerations, data analysis, study limitations and data quality and control in relation to the research study and its aim.

3.0 Study design.

A phenomenological descriptive qualitative research design was used. This method was preferred because it enables in depth exploration of experiences of participants as proposed by Doyle(Doyle et al., 2009).

3.1 Study setting

This study was carried out at Mbale regional referral hospital (MRRH) located in Mbale district, Eastern Uganda and it is 224.2km from Kampala the Capital city of Uganda(Jimmy & Geresom). Mbale is bordered by Sironko district to the North, Manafwa and Bududa Districts to the East, Tororo and Butaleja Districts to the Southwest, Budaka and Pallisa to the west. It lies latitudes 0057' North and longitude 34020' east and has a total area of 518.4sqkm.

It is a tertiary and teaching hospital with a capacity of 450-beds tertiary with 5specialities which include obstetric and gynaecological, surgery, paediatrics and child health, internal medicine, Nursing and midwifery(Jimmy & Geresom; Kennedy et al., 2023).

It has gynaecology department under which a specialised Gynaecologic Oncology clinic that was established in 2023 to provide health services to gynaecological oncology patients. This department has three major wards that is postnatal ward, High dependency unit and gynaecological ward. These wards admit post-partum mothers and gynaecological patients.

The study was conducted in the Gynaecologic ward and gynaecological clinics. The gynaecological clinic ran four times a month and received about ten patients on each clinic day though few were gynaecological oncology patients and of which one or two or even none was an elderly gynaecological patient. The gynaecological ward on the other side admitted about 100 patients every week of which less than ten were gynaecological oncology patients. The gynaecological clinic offered services like cervical cancer screening, follow ups for gynaecological patients and the gynaecological ward admitted patients with abortions, cysts, gynaecological oncology in poor health conditions for further management.

3.2. Study population.

- i) All elderly gynaecological oncology patients of 60 years and above who were receiving care at Mbale Regional Referral hospital (MRRH).
- ii) Primary caregivers of elderly gynaecological oncology patients. Attendants of those who passed on were also included in the study

3.3. Eligibility criteria

Inclusion criteria.

- i) Gynaecological oncology patients who were at least 60 years of age and were available and willing to take part.
- ii) Primary caregivers of gynaecological oncology patients for at least 1 month, had attended clinic with the patient, and or attended to them while admitted on ward.

Exclusion criteria.

- i) Elderly gynaecological cancer patients who were too frail or not of a sound mind to give IDI or were unavailable
- ii) Primary caregivers who hadn't stayed with patients for at least 1 month

3.4 Sample size and sampling strategy

Sampling size

The original sample size was not calculated but saturation was used as the basis of halting further recruitment. Thematic saturation was reached when no new themes were emerging after the last interviews.

11 patients and 11 caregivers were recruited, giving us a total of twenty-two participants.

Sample Strategy.

In this study, participants were selected using purposive sampling.

With the aid of respective unit Nurse in-charges identified elderly gynaecological patients, who had come for follow up in gynaecological clinic and those who were admitted on gynaecological ward. The primary caregivers who mostly accompanied these patients were also identified and interviewed.

Patients' files were checked and those who were diagnosed from the year 2023 and met the inclusion criteria were called upon to participate if they were not scheduled for the clinic during the study period. Primary caregivers of those who had passed away were contacted to come and participate if possible.

3.5 Data collection methods.

3.5.1 Data collection tools.

Qualitative data was collected using in-depth interviews for both categories of participants using different interview guides. The interview guides for elderly gynaecological oncology patients and their caregivers were both structured into two sections of questions including; the sociodemographic data and lived experiences having gynaecological cancer or caring for a patient with gynaecological cancer. The tools were pretested on elderly non gynaecological cancer patients and their primary caregivers in a separate chronic care clinic. The tools used were developed for the study and are attached to the appendix 2A and 2B.

3.5.2 Data collection methods

Data was collected between March 2026 and 1st June 2026.

41 possible participants were identified, 11 physically and 30 via phone call. 11 patients and their PCG were interviewed. We stopped at 11 on either population because we reached saturation.

During the in-depth interviews, the patients and caregivers were interviewed separately to avoid bias. The physicians and nurses directly taking care of the patients did not participate in the interview process. Each interview lasted between 30minutes to 45minutesminutes for patients and 30 to 1hour minutes for the caregivers. -This entire process was carried out during the day in a comfortable and private place like private rooms in the ward and at their home to obtain their in-depth experiences. Audios were recorded and notes for biodata, emotions and gestures were taken during the process. The in-depth interviews were conducted in English, Luganda, Lugwere and Ateso. The audios were then transcribed into verbatim. Forward and back translation was used for the audios in the local languages to ensure the verbatim stays accurate.

3.6 Data quality and control.

In this study, consecutive sampling of participants was used to select participants with relevant and rich experiences which ensured transferability. Researchers spent enough time in interviews with participants to build trust and obtained in-depth information about the experiences to promote credibility of the study. All interviews were recorded and transcribed into written work that was stored securely in password protected files accessible to only supervisors and researchers to promote confidentiality. The tools were pretested on elderly non gynaecological cancer patients and their primary caregivers in a separate chronic care clinic. The tools used were developed for the study and are attached to the appendix 2A and 2B.

3.7 Data analysis.

In this study the Clarke and Braun approach was used to conduct qualitative thematic analysis using Dedoose 10th version to code and generate themes from the data that was collected by in-depth interviews. The following steps for manual thematic analysis were used; familiarization with data, generating initial codes, searching for initial themes, reviewing the themes, Defining and naming themes and writing the report.

Inductive led analysis was used while analyzing data and this enabled the researcher to gather information from each participant before generalizing it. Thematic analysis provided an orderly procedure for generating codes and themes from the qualitative data. Dedoose software, the 10th version was used to code the qualitative data. After coding the initial codes for each participant, the initial codes were exported to excel, and similar codes were arranged and grouped together to form a meaningful subtheme according to the research question. After generating the subthemes, similar subthemes were grouped to form one major theme. This was done independently for both the patients and the caregivers.

Six main themes were constructed for the elderly gynaecological cancer (GC) patients and their caregivers; (i) Journey to cancer diagnosis, (ii) pathway to caregiving role (iii) Response to cancer diagnosis, (iv) The physical burden functional decline and dependence (v) Socioeconomic experiences and survival amidst living with cancer (vi) coping mechanisms

3.8 Ethical considerations

The work was initially presented to the Nursing department. The study was then submitted to the Research and Ethics Committee (REC) of Faculty of Health Sciences,

Busitema University and approved under the Reference number BUFHS 2026-655. Administrative clearance was thereafter sought from MRRH leadership.

The study adhered to ethical principles and patients' rights for instance Informed consent. Participants were informed of the study purpose, potential risks and benefits and it's only those who consented were interviewed. For confidentiality, the study participants were interviewed in private rooms identified within the ward and clinic and their names were not disclosed on the interview guides. If a participant became distressed, the interview was paused/stopped, and psychosocial support or referral was offered.

3.9 Dissemination of results.

The dissemination plan for the study on Lived experiences of Elderly gynaecological oncology patients and their caregivers attending Mbale Regional Referral hospital involved a systematic and comprehensive approach to share the findings with various stakeholders. These stakeholders include Department of Nursing, Faculty of Health Sciences, Busitema University-the awarding institution, Mbale Regional Referral Hospital, and the Gynaecologic cancer community including the patients, caregivers and their families and the Science world. Results will also be disseminated in Academic journals, conferences, online platforms and collaborative partnerships. By utilizing diverse dissemination strategies, the study aims to maximize the impact of its findings on Gynaecologic oncology care practices and policies in Mbale, Uganda and the rest of the Globe.

CHAPTER FOUR: RESULTS

INTRODUCTION OF RESULTS

This chapter presents the findings of the study with a summary of sociodemographic characteristics of patients and the disease profile plus their primary caregivers. In total, 36 patients and their primary caregivers met the criteria from physical contact and reviewed the records from October 2023 and May 2025.

Of the 30 GC patients' records reviewed, 9 (30%) patients had passed on, 11 (36.7 %) could never be reached out to despite several attempts(all registered phone numbers were off); 5(16.7%) declined to participate; 1(3.3%) the caregiver reported was too ill and they did not want any interference, the other 4 patients(13.3%) were undergoing care at Uganda cancer Institute(UCI) Kampala (about 245km away from Mbale hence were constrained by distance. All the primary caregivers of the deceased declined to participate; and the major reason for the decline was stress. They said they didn't want to go through that painful story again. We offered contacts from the counsellor for follow-up.

Therefore, in total, 22 participants were interviewed; 11 patients who were aged between 60-87 years, and 11 primary caregivers aged between 20-62 years. 5 patients and their caregivers were interviewed on gynaecological clinic days, 3 on gynaecological ward and 3 from their homes. The 11 caregivers interviewed were primary caregivers of the 11 elderly gynaecological patients. All these were active patients at Mbale Regional Referral hospital.

Of the 11 patients, 8 were elderly patients with cervical cancer, 2 were having ovarian cancer and 1 had vaginal cancer. Majority of the patients were widows and peasants with no direct source of income while 2 were retired social workers (Table 1).

Of the 11 primary caregivers, 9 primary caregivers were female while 2 were male. 7 of them were daughters of these patients, 2 were sons, 1 was a daughter in-law and one a granddaughter as below (Table 2)

Table 1: Sociodemographic, clinical characteristics 11 patients.

Patient	01	02	03	04	05	06	07	08	09	10	11
Variable											
Age (yrs)	60	75	64	61	87	76	68	60	73	87	78
Residence	Rural	Rural	Urban	Rural	urban	urban	urban	rural	Urban	rural	Rural
Type of GC and stage	CC Stage IIB	CC stage IIIB	CC Stage IIIB	CC Stage IB	CC Stage IIA2	VC stage II	OC stage IC3	CC Stage IIIA	CC Stage IIA2	CC Stage IIIB	OC Stage III
Comorbidities	PUD	HTN	HIV and HTN	HIV	PUD	HTN	HTN	None	HTN	None	HTN
Former occupation	Police officer	Peasant	Peasant	Peasant	Peasant	Peasant	Nurse	Peasant	Peasant	Peasant	Peasant
Relation of primary caregiver	son	Daughter	Daughter	Grand daughter	Daughter	Daughter-in-law	Daughter	son	Daughter	Daughter	Daughter

Key: CC-Cervical cancer, GC-Gynaecological cancer, HIV-Human immune virus, HTN-Hypertension, PUD-peptic ulcer diseases, OC-Ovarian cancer, VC-Vagina cancer

Table 2: Caregivers sociodemographic

Primary caregiver (PCG)	Sex	Age (years)	R/ship with patient	Occupation	Marital status	Duration of stay with patient
001	Male	21	mother	Student	single	21years
002	Female	55	mother	Peasant	Widow	3 months
003	Female	20	mother	Student	Single	6 months
004	Female	27	grandmother	Peasant	Single	27years
005	Female	47	mother	Teacher	Married	7 months
006	Female	29	Mother-in-law	Plumber	Married	3 years
007	Female	38	mother	Nurse	Married	6months
008	Male	33	mother	Peasant	Married	3months
009	Female	45	mother	Peasant	Married	2months
010	Female	62	mother	Peasant	Widow	4 months
011	Female	49	mother	Peasant	Divorced	2months

Key: PCG-primary caregiver, R/ship-relationship

THEMES AND SUBTHEMES

The chapter includes the qualitative results, highlighting the themes and patterns that emerged from interviews and observations. Direct quotations from participant's transcripts were included to give a voice to and illustrate richness of their contributions.

Six themes were constructed from patients' data i.e.(i) Journey to cancer diagnosis, (ii) pathway to caregiving role (iii)Response to cancer diagnosis, (iv) The physical burden functional decline and dependence (v) Socioeconomic experiences and survival amidst living with cancer (vi) coping mechanisms

Theme	Subtheme
A) Journey to cancer diagnosis	1. Limited awareness about gynaecological cancer early warning signs. 2. Health seeking habit 3. Worsening of illness 4. Delayed and misdiagnosis of cancer.
B) Pathway into primary caregiving role	1. Circumstantial role 2. Sense of obligation
C) Response to cancer diagnosis	1. Emotional distress after cancer diagnosis 2. Fear of death 3. Sleep disruption 4. Acceptance
D)The physical burden, functional decline and dependence.	1. Disturbing bodily changes 2. Cancer related pain, weakness and fatigue. 3. Daily activity functional decline 4. Dependence on caregivers
E) Socioeconomic experiences and survival amidst living with cancer	1. Social interactions and support 2. Economic burden and disruption 3. Financial dependence 4. Financial and social needs.
F) Coping methods	1. Self and symptom management 2. . Family and social support 3. Perseverance

DESCRIPTION OF THE THEMES FOR PARTICIPANTS (ELDERLY GYNAECOLOGICAL ONCOLOGY PATIENTS AND THEIR CAREGIVERS)

THEME A: JOURNEY TO CANCER DIAGNOSIS

This theme entails the patients' care pathway right from index experience of cancer symptoms and signs to the time of diagnosis. Most of the patients frequently reported limited awareness of signs and symptoms of cancer symptoms which contributed to poor health seeking practices. Many initially started using alternative treatments including herbs to manage signs and symptoms instead of seeking conventional medical facilities. Both patients and the primary care givers appreciated that there was significant delays from the onset of signs and symptoms to the actual diagnosis which was not necessary caused by financial constraints but confusion of where right care should have been sought from. They attributed disease progression, misdiagnosis and delayed diagnosis to this phenomenon.

Subtheme 1: Limited awareness about gynaecological oncology early warning signs

This subtheme captures the knowledge gap and misinterpretation of early warning signs of gynaecological oncology patients and their families. Many women experienced abnormal vaginal bleeding, watery discharge, lower abdominal pain and backache. They didn't recognize and appreciate that could be early warning signs of a serious disease like gynaecological cancer. Most patients often thought the symptoms were related to other common health conditions such as Urinary tract Infections (UTI), candida, sexually transmitted infections (STIs) whereas others even attributed these symptoms to long term sequelae of childbirth and every day's strain.

Ahaa(sigh)..... "watery discharge, bleeding which was on and off, and I was thinking it is UTI" (Patient 001 60years, CC, rural)

'My daughter, what can I say? 'She pauses a question. (pause) "I was wondering what was happening.... I only poured water when I was giving birth, so I kept thinking me who is no longer giving birth wat is happening!" (patient 010, 87yrs, CC, rural)

..... "I have experienced watery vaginal discharge, bleeding and pus pouring that smell quite abnormally that started in July last year accompanied with tense lower abdominal pain. At first, I thought maybe the work I was doing was too much and was the cause"
(Patient 002, 75years, rural, cervical cancer)

Subtheme 2: Health seeking habit

The journey to cancer diagnosis among elderly gynaecological oncology patients was characterized by complex health seeking behaviors. The health seeking habits were influenced by an interplay between cultural beliefs, family and social involvement, Ability to disclose the signs and symptoms they were experiencing. Most patients took long to seek medical care from health facilities or even open to tell their children. Most of them went to nearby clinics, pharmacies where they first got drugs for management of symptoms and some of them were given herbal medicine to control the signs and symptoms mainly vaginal bleeding. The health-seeking habits of the patients revealed a pattern of movement between multiple health facilities, using both conventional and complementary medicines to manage symptoms. This often delayed patients from acquiring formal health care until symptoms worsened. These are noted in quotes below

“ohoo’ It had taken long almost a full year before my children came to know about symptoms and that I was sick. We then discussed taking me to the hospital”’(patient 005, 87years, Ca cervix, urban)

.....“Even then my children initially took me to the small private clinics around; they (health workers) gave me some medicine that I was taking, my children also brought me the African herbal medication to use”’ (patient 010, 87 years, CC, rural)

Subtheme 3: Worsening of illness

The final decision to seek formal medical attention was marked by gradual worsening of symptoms. In most patients, what began as a mild watery vaginal discharge, vaginal bleeding, abdominal pain often progressed into severe pain, debilitating weakness mainly caused by dizziness, palpitations and easy fatigability. This marked deterioration in health not only caused fear in patients but also forced patients to disclose their condition to their close family members and subsequently seek care at health facilities.

The worsening of illness and inability to perform daily chores became the turning point that shifted most patients from silence, self-medication and use of herbal remedies to formal medical attention at higher health facilities such as Health center IVs, District hospitals and Mbale Regional Referral hospital. For the patients who already had other comorbidities, they also became worse than the cancer itself.

..... *“the watery discharge worsened further, the back there was just not paining but it was ehhehh.... like someone was using a hoe to dig on my back, and I was not passing stool at a moment so i decided to go to Mufudu health center”*.....(patient 009, 73years, urban, CC)

..... *“blood pressure was high and he said he was not giving me any medication and I came back..... the following day I became worse I went to this nearest health Centre, they checked me and the blood pressure was high, so they gave me amlodipine and other treatment”*.....(patient 007, 68years, ovarian cancer, urban)

Subtheme 4: Delayed and misdiagnosis of cancer.

The unique feature about diagnosis of most gynaecological oncology patients was that most of them had a prolonged period of misdiagnosis and delayed recognition of cancer. But still there were some who sought medical attention early enough from the conventional modern medical facilities but were largely misdiagnosed and spent most of the time receiving wrong treatment or one targeting only signs and symptoms. Many patients were being treated for UTIs, STIs, and kidney diseases. This misdiagnosis led to repeated visits to clinics, pharmacies and hospitals, use of inappropriate medications and a sense of frustration since their illness just worsened more. The delay in reaching accurate diagnosis prolonged suffering among these elderly patients.

“my husband and his sister advised me to try an herbalist around our village there who really, we believed could cure. He found out that I had a Kidney disorder and he managed to put me on some medicine to treat my kidneys”.....(Patient 008, 60years,cervical cancer, rural)

..... *“they were treating candida, Urinary tract Infections”*.....(patient 001, 60years, cervical cancer, rural)

THEME B: PATHWAY TO CAREGIVING ROLE

Primary caregivers of elderly gynaecological oncology patients often described how they became primary caregivers. For some, caregiving role emerged as a circumstantial role shaped by family situations, and absence of alternatives. To some, the caregiving role emerged as a sense of obligation. This theme has two subthemes as follows

Subtheme 1: circumstantial role

Most caregivers assumed the primary caregiving role not by choice but rather because of the circumstances that positioned them as the most available option. Staying nearest to the patient was a major factor as several primary caregivers lived near or within the same households as the patient making them by default the natural choice for daily care. Work and lifestyle also shaped caregiving roles; so those with flexible schedules or no formal employment were the best choice for primary caregiving role.

..... “mummy used to stay alone in her home just next to my own home.....so, when she got sick, I brought her to stay with me in the same home”.....(caregiver 010 female 62 years)

..... “Other relatives who would have helped have got businesses they operate and for me I got no work I stay at home so it’s better for me to be there other than another person closing her business to come and care for her and yet we shall still need money to take care of her”.....(caregiver 009, female 45years, daughter taking care of CC patient)

Subtheme 2: Sense of obligation

Many other caregivers assumed the primary caregiving role was not only circumstantial but also deeply rooted in a sense of duty, love and moral responsibility. Some emphasized the irreplaceable bond with their mothers whereas others the obligation extended beyond biological bonds where daughters-in-law explained caregiving as part of marital commitment. Even when faced with various challenges like distance, they were still compelled to travel and come and support.

..... “if they call me, I come and take care of her because now I stay very far but I still must travel, come and take care of her. Am the only daughter she has so I can’t also abandon her”..... (caregiver 011, female, 49years)

..... “she is my mother-in-law she is just like a mother to me, and I love my marriage so much so that is the least of what I can do for her”.....(caregiver 006, 29years, daughter in-law taking care of 76yr old vagina cancer patient)

THEME C: RESPONSE TO DIAGNOSIS

This theme describes the emotional and psychological response to cancer diagnosis. Elderly patients as well as their primary caregivers reacted differently to the diagnosis of cancer. Most of them had initial shock and fear and expressed themselves while others kept it inside themselves and didn't want their family members to know. With time most patients and their primary caregivers accepted the truth and learnt to live with the illness. This theme contains four themes as stated below;

Subtheme 1: Emotional distress after cancer diagnosis

Receiving gynaecological cancer diagnosis triggered deep emotional distress among elderly patients and their primary caregivers. Most Patients and primary caregivers reported feelings of fear, sadness, worry, helplessness. The emotional distress was caused by various factors among which were, fear of the unknown, worry about responsibilities, worry about the anticipated suffering. Distress was intensified by memories of other cancer patients suffering, social realities of financial constraints, loneliness, and lack of social support.

..... ‘I felt bad because I looked at a poor old woman like me getting such a serious disease, this scared me because I anticipated and it has even come to pass that am suffering a lot. I used to cry and see my lifeless body there, have no children who are financially stable just know I got scared and so worried’ (patient 011, 78years, ovarian cancer, rural)

..... ‘I felt worried and scared because first I knew she was going to bother me all times taking care of her while sick, yet I have a family to care for too’(caregiver 011, 49years, daughter taking care of Ovarian cancer patient)

However, some few patients for some reason were not emotionally distressed after receiving the diagnosis. These patients accepted the reality and modified living in the new normal without feeling scared of the diagnosis.

..... ‘I didn’t get scared because even when I fear the illness is on the body.....[laughs]... its God himself who will heal me. Me I do things in the name of God’ (patient 010, 87years, Cancer of the cervix, rural).

Subtheme 2: Fear of death

The diagnosis of gynaecological cancer caused immediate thoughts of death among most of the elderly gynaecological oncology patients and primary caregivers. Most patients and primary caregivers often equated cancer with an inevitable end of life. This fear was expressed in different forms such as immediate fear for death that patients thought was just ahead of them, concern for family members they would leave behind, acceptance and spiritual questioning. The caregivers became so overwhelmed and were always in grief in anticipation of death of their loved ones.

..... ‘I also got worried because I thought I was going to die soon and leave my children and yet am their mother and at the same time their father’(patient 001, 60years, cervical cancer, rural)

..... ‘you just be there knowing someone is going to die and right now looking at her health state, there is little hope of her living longer and she may not return to a normal health status. Just know every time I look at my mother deep inside I be seeing her like a dead person’(caregiver 003, 20years, daughter to cervical cancer 64years patient 003)

Subtheme 3: Sleep disruption.

Sleep disruption was a common experience among elderly gynaecological oncology patients and primary caregivers. This was associated with psychological burden of cancer and the physical discomfort associated with the illness. While a few patients and primary caregivers reported sleeping well, most of the patients described persistent difficulties such as insomnia, nightmares and relentless nights. Emotional distress played a big role in sleep disruption with patients and primary caregivers recounting nights they spent crying or lying awake with disturbing thoughts. These accounts show that cancer affects not only daytime functioning but also the restoration process of sleep leaving patients and their primary caregivers exhausted and emotionally vulnerable.

..... ‘ever since I got this illness I have never slept. Even when I try to sleep, I wake up suddenly and get nightmares’(patient 003, 64years CC patient, urban)

..... ‘I was not so scared, and I didn’t think much about it at first but right now I don’t know if its fear, but am so worried, I keep thinking the whole night, I feel sadness inside my heart’(caregiver 009, 45years, daughter to CC patient 009, 73years)

Subtheme 4: Acceptance

Elderly patients and primary caregivers shifted from a sense of fear and distress towards resilience, faith, and readiness to undergo treatment. Most patients and caregivers manifested their acceptance in spirituality, expressing trust in God's healing power and surrendering their situation to divine will. Others described acceptance through practical readiness, acknowledging that fear could not change their condition and instead chose to pursue treatment. Encouragement from health workers also played a very crucial role. Some reflected and attended clinic with those that had returned for follow up having completed treatment at Uganda cancer Institute in Kampala and were apparently doing well.

..... *“even if I fear it's on my body, its God himself who will heal me. Me I do things in the name of God.”* (patient 010, 87years, CC, rural)

..... *“the disease already attacked our mother, even if I continue worrying, I can't reverse it, I can't cure so I just handed everything to God himself”* (caregiver 010, 62years, daughter to 83yr old CC patient 010)

THEME D: THE PHYSICAL BURDEN, FUNCTIONAL DECLINE AND DEPENDENCE.

Gynaecological cancers imposed a heavy physical burden on elderly patients and their primary caregivers. These were manifested through bodily changes, persistent pain, weakness and fatigue and inability take care of self. This theme had four themes as below

Subtheme 1: Disturbing bodily changes.

Patients experienced what they described as disturbing bodily changes that accompanied gynaecological cancers. These signs and symptoms were often discomforting, severely distressing and above all embarrassing to them as elderly women with even in-laws and grandchildren. The most common experiences were persistent watery vaginal discharge, bleeding and foul-smelling discharge which disrupted daily life. Others reported swelling in the abdomen, loss of appetite, tasteless food, difficulties passing stool describing how cancer altered daily functions. Some patients also described pus discharge, itching veins, paralysis of legs and continuous farting (pelvic floor disorder) which increased their suffering, sense of abnormality and embarrassment. On the other hand, these distressing bodily changes greatly

disturbed the primary caregivers too. They described them as disgusting, especially the smelly discharge, smell of urine and stool for those who were bedridden and paralyzed. The disturbing bodily changes were among the most distressing aspects of cancer, undermining dignity and reinforcing the perception of illness as overwhelming and uncontrollable.

..... *“I have experienced watery vaginal discharge, bleeding and pus pouring that smell quite abnormally” You cannot sit among people, you don’t even want them around you”.....But... again you cannot clean yourself, you need somebody to help you!”.....(patient 002, 75years, CC, rural)*

..... *“At least my abdomen is fair now, it no longer pains, back then it used to become so bloated but now it no longer bloats so much except the too much passing of flatus”.....(patient 011, 78years, OC, rural)*

..... *“She smells but at least not as much ever since we started using some medicine Doctor encouraged us to use. Back then before we came here, she used to bleed and have a terrible watery discharge that was very smelling and would interrupt the whole house. Sometimes I could even fail to eat”..... (caregiver 006, 29years, daughter in-law taking care of the 76-yr old VC patient 006)*

Subtheme 2: Cancer related pain, weakness and fatigue.

Cancer-related pain, weakness and fatigue were among the most overwhelming physical burdens described by patients often dominating their daily experiences and shaping their perception of illness. Severe back pain, abdominal pain and pelvic discomfort were common to most of the elderly gynaecological oncology patients. Others reported generalized body aches, numbness and paralysis leaving them unable to walk, sit or even eat. Fatigue was a constant to most patients, they felt too weak to move sometimes accompanied by tremors and dizziness. Primary caregivers too reported their patients being weak and expressing pain. Fatigue, pain and body weakness increased suffering, reducing patient’s ability to pray, perform tasks and this perpetuated more intense suffering.

..... *‘With this disease I can’t even walk, I cannot sit or even eat food. To make matters worse the pain is too intense that I sometimes think it’s better to die’.....(patient 003, 64years, CC, rural)*

..... *‘Ever since she came to my place, I don’t allow her to do any work and besides, she is very weak and her back pains so much’...* (caregiver 010, 62years daughter to CC patient 87years)

Subtheme 3: Daily activity functional decline

Gynaecological oncology progressively reduced patients’ ability to carry out daily activities forcing them to abandon activities they once performed. Most of the patients were unable to walk long distances, cook, fetch water or do household chores. Some patients reported limited ability to do small tasks like washing inner garments while leaving heavier tasks to others. Functional decline wasn’t only in terms of physical burden but also took an emotional toll on many patients. They expressed frustration over inability to do what originally was a routine. This was supported by the primary caregivers. This diminished functional autonomy turned them into dependents; a cause of more frustration.

..... *‘I don’t do any housework, I don’t cook, I don’t clean clothes, even plates. I used to bathe all by myself, but I can no longer bathe myself because of the pain in my legs. I cannot even stand on my own. my daughter in-law and my daughter help me to do everything’....*

‘(patient 006, 76years, VC urban)

..... *‘you know she is not like strong the way she used to be before she became sick so she can only do few simple house activities’*.....(caregiver 001, 21years old son of a 60yr old mother with CC)

Subtheme 4: Dependence on caregivers

As illness progressed, patients increasingly relied on caregivers to meet their daily activities. Most of the patients were helped by their children, daughters in law to cook, wash clothes, fetch water and provide personal care. Dependence was often perceived as expected and a necessity with some of the patients acknowledging that it was time for their children to take care of them and take on the responsibility. The care extended to individual care including bathing them, feeding them, toileting them. This shows that dependence on caregivers for daily needs is not just a necessity but a defining feature of lived experience of elderly gynaecological oncology patients reshaping family roles. The primary caregivers believed it was an obligation to do everything for their patients since they could not do the work by themselves.

..... *“I cannot feed myself; I cannot bathe, I cannot ease myself outside bed, I pass urine and stool while on the bed and the people taking care of me do literally everything for me all the time”*..... (patient 003, 64years, CC, urban).

..... *“I cook for her, I bathe her, I literally do all housework for her though sometimes her daughter also helps to do some house chores”*.....(caregiver 006, 29years, daughter in law to a 76yrs old VC patient,)

THEME E: SOCIOECONOMIC EXPERIENCES AND SURVIVAL AMIDST LIVING WITH CANCER

Beyond the physical and emotional burden, cancer profoundly reshaped patients’ social and economic realities and that of their primary caregivers. The illness disrupted the normal social interactions and economic opportunities. The economic burden emerged as a central struggle with treatment costs, loss of income and inability to work. Social and financial needs became pressing as patients and their primary caregivers sought assistance not only with medical care but also for daily survival. This theme has three subthemes as below.

Subtheme 1: Social interactions and support.

Most of these patients who were mostly widows were staying alone in their homes before the illness. Upon getting ill, most of them started staying with their children (daughters, sons), in-laws and grandchildren who became their primary caregivers. Social connections and support systems played a vital role in patients’ experiences living with gynaecological oncology and this provided emotional support. Most of the patients and primary caregivers reported the importance of religious gatherings, visits by relatives and friends in providing emotional support. However social participation was limited by illness as most patients could not attend functions like weddings, burials, introductions and expressed sadness about missing community life. Some patients expressed moments of isolation and neglect when family members failed to provide care or when family members left them alone.

..... *“my friends and relatives come around and visit me in fact they always come around as they go to fetch water, church”*.....(patient 008, 60years, CC, rural)

..... *“Me who does not sit or stand, how can I even. I always have the urge to go to church, social gatherings but I can’t.....”(patient 003, 64years, CC, urban)*

On the other hand, caregiving role greatly affected the social lives of the caregivers. Many abandoned their primary families, friends and community because caregiving took most of their time. Many caregiver's marriages and family relations were disrupted. Young caregivers who were still studying experienced disruption of their studies due to not only time but also by economic and physical constraints.

..... *‘My daughter who was schooling in senior three got married when I left my home to take care of my mother. By the time I went back home, she had already married. It hurt me so much. My husband also left me, over time he got another woman so from that time he only comes home for a couple of nights only and leaves... so you can see, my daughter lost studies, I lost marriage and mummy is not yet well’*(caregiver 011, 49years daughter of OC patient 78years).

‘It has greatly affected my academics because at times,.....This is my first time in eLearning and at times you need to program yourself to make sure you have fetched the water and everything is done, you have online lectures, course work so I just try my level best to balance that work’(caregiver 001, 21years son to a 60 yr old mother with CC)

Subtheme 2: Economic burden and disruption

Living with the physical and emotional burden of gynaecological oncology and caregiving significantly disrupted the patient's and caregiver's economic stability creating persistent financial strain. Most patients and primary caregivers reported inability to farm, dig or run businesses as they once did, and this led to loss of income and food insecurity. The inability to work forced families to sell livestock, poultry or household items to cover house responsibilities like school fees and medical costs. Treatment alone was financially draining as most drugs were bought from pharmacies due to stock shortages in Government facilities. Food insecurity was another problem with patients and primary reporting inability to have at least three meals a day, others eating monotonous diets. Patients and primary caregivers also had a burden acquiring basic needs for daily survival like soap for bathing and washing and smearing oil. The financial burden was also caused by family responsibilities as patients and primary caregivers were at times the sole providers for their children and household needs despite their illness. However, some few patients did not have any financial burdens as their children continuously provided and they also had other sources of income

..... ‘Don’t even talk about feeding... someone boils rice and gives you to eat, and you got to force yourself to eat and drink water, sometimes posho and salt and there are days when we completely don’t get anything to eat and I sleep hungry. The situation has become so tough on me so i just keep quiet and think because I have a lot of challenges that i even curse

God’’.....(patient 011, 78years, OC, rural)

..... ’I cannot do my garden work like the way I used to; I used to go to the garden early in the morning like at 6am but now I can’t because I must be home, I must cook for her food and stay with her. I always try but there are days when I really fail even to get food to feed my mother and the entire family’’.....(caregiver 010, 55year, daughter of 87yr old with cervical CC)

Subtheme 3: Financial dependence

All patients revealed that gynaecological, oncological financial burden and disruption left them dependent on children, relatives and friends for survival. Many relied on small contributions from family members and friends. Others emphasized that their treatment and needs were only possible when children provided support. This dependence often carried emotional weight, with patients worrying about their children getting tired of providing food and money. Friends and relatives often stepped in and contributed but the burden largely fell onto children who themselves faced financial challenges. This dependence increased feelings of helplessness and hopelessness.

..... ‘If my children don’t have money, I don’t get treatment’’.....(patient 010, 87years, CC, rural)

..... ‘Ever since she became sick, I have been the one providing money for hospital bills, money to buy drugs, money to feed her and cover other needs’’.....(caregiver 008, 33years son of a 60yr old patient of CC,)

Subtheme 4: Financial and social needs.

Patients had pressing financial and social needs that went on beyond medical treatment showing the broader struggles of survival amidst cancer. Many experienced high-cost treatment and lack of free treatment, transport burdens to the hospital and food insecurity. For these reasons patients thought of support to ease the cost of travel for follow-ups, and provision of nutritious food. Caregivers shared that beyond their daily struggles, they also have unmet financial and social needs for instance many lacked money for basic items and

drugs for their patients. Socially patients and primary caregivers wished for visits, encouragement and emotional support from the community. They also wished for decentralization of cancer services to lower facilities to reduce costs.

..... *“the first thing is to bring free treatment to us especially now like me I come from very far and the medicine is expensive so that we just come and get that free treatment. Even transport if they could give me some transport every time am to come here”*.....(patient 001, 60years, CC, rural)

..... *“as long as they come and check on me both at home and in the hospital, that can make me feel better and they give me those encouraging words like ‘please stay strong Allah will heal you’ that’s the hope i would like to get from the community people”*.....(patient 009, CC, 73years, urban)

..... *“they could help and solicit for us some food now like this moment when we are in the hospital and we need to eat”*.....(caregiver 009, 62years, daughter to CC 87yrs).

THEME F: COPYING MECHANISMS

In the face of overwhelming physical, emotional and socioeconomic challenges, patients lived through different copying methods that helped them to endure the realities of living with cancer. Primary caregivers of these patients on the other hand described different ways of coping with the stress and burden of caring for elderly relatives with gynaecological cancer. Copying was expressed through strategies like self-symptom management and perseverance. This theme has three subthemes as below;

Subtheme 1: self and symptom management

Patients used various strategies to manage symptoms and maintain a sense of control amidst overwhelming symptoms of living with gynaecological cancer. Many relied on herbal medicines, painkillers to relieve bleeding discharge and pain. Pain management was a central focus with most of the patients frequently using capsules for pain bought over the counter, oral morphine from government facilities. Others used physical practical methods like padding with multiple pieces of clothing to prevent leaking of blood and or fluids par vaginum while others adopted some form of exercises to prevent massive muscle weakness. All these enabled patients to endure the illness with dignity and ease.

..... *“For the pain sometimes, I swallow some painkillers to help and relieve the pain”*.....(patient 007, 68years, OC, urban)

..... *“Doctor wrote for me some medicine to put down there called, I think pessary, I bought some and used and at least there is some improvement right it is not so much and it does not smell so much like it used to smell back then”*(patient 001, 60years, CC, rural)

Theme 2: Family and social support

Elderly gynaecological cancer patients and their primary caregivers explained that support from family members, relatives and community was very essential in coping. Many said their children, siblings, relatives and friends contributed money for hospital bills, food and other needs. Others described how grandchildren, daughters-in-law or neighbors helped with chores like cooking, washing, farming when they were absent. Some mentioned that their brothers, fathers or community members provided financial help even if in small amounts to buy food, drugs.

..... *“each time I bring her to the hospital, the rest of my siblings be knowing that am with our mother the hospital so the ones who stay nearby bring us food at the hospital and when something is needed in the hospital they collect though we don’t have much money but we always try to solicit the little we got because our father died”*(caregiver 009, female, 45years, daughter of 73yr CC patient 009)

..... *“I have my children who give me money, I can’t deny because they give”*(patient 010, 87years, cervical cancer, rural)

..... *“Some community members.....uhmmmm that my mother knows come around sometimes and give her some money that we use to buy some stuff, drugs for he like that as we continue gambling”* (caregiver 011, 49years daughter to 78 Ovarian cancer patient 011)

Subtheme 3: Faith in God and perseverance

Caregivers explained that their faith in God and determination to endure gave them strength to continue caring for the loved ones. Many accepted that worry could not change the situation at hand. Many endured difficult tasks, smells and sleepless nights because they felt it was their duty. Caregivers also sacrificed their wellbeing sometimes going without food so that the patient could eat. Over time most got used to the challenges and had nothing to do but to just continue.

..... *‘I just must endure because I cannot leave her there because am the only person to be there always’*..... (caregiver 003, 20years, student and daughter to 64yr CC patient)

..... *‘I can stay the whole day without eating food as long as the patient has eaten now like today, I have not eaten’*.....(caregiver 008, 33years, son to 60yrs old CC patient)

Subtheme 2: Perseverance

Most patients were determined to endure suffering and continue despite the challenges of gynaecological cancer. Many endured pain, austerity measures, and waited patiently for their children to provide support and accepted limitations without giving up. Even amidst persistent overwhelming physical burden, they chose endurance over despair, and this showed the resilience of these patients. Caregivers explained that their faith in God and determination to endure gave them strength to continue caring for the loved ones. Many accepted that worry could not change the situation at hand. Many endured difficult tasks, smells and sleepless nights because they felt it was their duty. Perseverance in the case of these patients and their caregivers was not passive suffering but rather an active choice to withstand hardship, sustain hope and continue the journey of survival amidst living with gynaecological oncology.

..... *‘when I feel so much worried and for a longer time, ...I just reach a time and stop worrying you know when you are a person who sometimes talks to God’*.....(patient 009, 73years, CC).

..... *‘I just endure the pain in my limbs nothing to do, always try to economize the money and use very little money at a time.’*.....(patient 008, 60years, CC, rural)

..... *‘I just must endure because I cannot leave her because am the only person to be there always’*..... (caregiver 003, 20years, daughter to 64year old CC patient 003)

CHAPTER FIVE: DISCUSSION OF RESULTS

Discussion of findings among elderly gynaecological oncology patients and their caregivers

Journey to cancer diagnosis

The study revealed that elderly gynaecological oncology patients experienced prolonged and a complex care pathway to cancer diagnosis characterised by limited awareness of early signs and symptoms of gynaecological cancers. This leads to delays in seeking care, delay in seeking care from the right facilities and personnel and thus worsening of illness and repeated misdiagnoses. Many participants interpreted symptoms such as abnormal vaginal bleeding and discharge as urinary tract infections, sexually transmitted infections, or even normal aging changes accentuated by childbirth and daily life burdens.

This knowledge gap is well documented in African contexts. A study in Ghana similarly reported that women attributed vaginal bleeding as normal female conditions until symptoms worsened (Agyeiwaa et al., 2024). Another study showed that women struggled to interpret bodily changes as cancer related, often normalizing them (Breistig et al., 2024). In Uganda, ovarian cancer patients misinterpreted bloating and abdominal pain as digestive issues (Katumba et al., 2013). These results are consistent with evidence showing that low awareness of gynaecological cancer symptoms contributes significantly to delayed diagnosis in low- and middle-income countries (Singh et al., 2023). In sub-Saharan Africa, late presentation remains common due to limited screening and low health literacy (Sung et al., 2021).

Most of the patients delayed disclosing to their family members and relied on herbal remedies and local pharmacies and clinics. This is consistent with the pattern in the study done in Tanzania where women alternated between biomedical and traditional care, delaying diagnosis (Chona et al., 2025). Similarly in Zambia, participants relied on herbal remedies due to cultural trust and accessibility (Kapyra et al., 2024). The use of herbal medicine and multiple pathways shows a mixed care seeking behaviour widely reported in African contexts. This has been reported by Agwau et al (Agwu et al., 2025). And finally, according to Kleinman's model of illness, patients often move between traditional and biomedical systems based on cultural beliefs and perceived effectiveness of the treatment. Globally, it is noted that even in high-income countries, patients sometimes delay seeking care due to

embarrassment or misinterpretation, but in Uganda, delays are longer due to systemic barriers such as poverty, transport costs, and weak referral systems (Nelson et al., 2018).

Most patients sought formal care when signs and symptoms such as severe pain, severe offensive watery discharge and bleeding or inability to pass stool became unbearable. This is consistent with the results in a study done in Zambia where worsening of symptoms was the turning point for patients (Kapyia et al., 2024). Another study in Ghana revealed that patients' health status deterioration forced patient's disclosure to the family (Maree & Kaila, 2014). This comparison highlights that worsening illness acts as a trigger for care seeking across contexts so therefore delays in seeking care means patients often present at advanced stages reducing survival chances or even leading to poor lived experiences.

Elderly gynaecological oncology patients were often treated and managed for UTIs, STIs or kidney disease before cancer was diagnosed. Patients' account of misdiagnosis reflects system gaps in diagnostic capacity. This is consistent with results in the studies done in Ghana and Tanzania where both reported cervical cancer patients being misdiagnosed as having infections such as STIs and Reproductive tract Infections (RTI) way before cancer diagnosis was made (Chona et al., 2023; Maree & Kaila, 2014). Delayed diagnosis observed in this study is also consistent with the findings in another study which showed that cervical cancer is often diagnosed at advanced stages in Low- and Middle-income countries (LMIC) due to weak referral systems and diagnostic delays (Bhatla et al., 2019; Kajabwangu et al., 2024; Nakisige et al., 2017; Ronald Mayanja & Joseph, 2016).

Pathway to caregiving role

Caregivers of elderly gynaecological oncology patients describe how they assumed their role either circumstantially or through sense of obligation. Many caregivers became primary caregivers because they lived closest or had flexible schedules. Others emphasized duty, love and moral responsibility. This is consistent with findings from studies that reported that caregiving fell to those most available, unemployed, and to the patient nearest (Alegbeleye & Amadi, 2024; Seven et al., 2014). Primary caregivers viewing the role as an expression of love, duty and moral responsibility has been reported before (Dumas et al., 2021; Han et al., 2016).

Response to cancer diagnosis.

Elderly gynaecological, cancer patients and their primary caregivers experienced intense emotional distress following gynaecological cancer diagnosis, including expressions shock,

fear, sadness, insomnia and eventual acceptance. Cancer was often equated with death and suffering.

Patients and their caregivers reported feelings of fear, sadness, worry helplessness and hopelessness. This distress expressed verses resilience is central to lived experience. In Tanzania, women experienced similar distress, they expressed grief and hopelessness after the diagnosis (Chona et al., 2025). (Ikharo et al., 2023). Researchers in Turkey reported that caregivers had the most problem with coping with the depressive symptoms (Yaman & Ayaz, 2016) and in Uganda advanced cervical cancer patients felt hopeless due to stigma and lack of support (Natuhwera et al., 2021) The shock and fear expressed by caregivers is consistent with findings in a study where caregiver distress limited their ability to encourage patients and others struggled with depressive symptoms (Ikharo et al., 2023; Seven et al., 2014). The comparison shows that while emotional distress is universal, its intensity is magnified in Low- and middle-income countries by poverty, loneliness and limited social support.

Elderly gynaecological patients and their caregivers equated cancer to death. Most of them perceived cancer as a very dangerous disease that had no cure and would cause someone to die very soon. This reflects the cultural framing of cancer as incurable. This is consistent with what was found in a study done in Tanzania (Chona et al., 2023), Taiwan (Li-Yun Tsai, 2020) and France (Dumas et al., 2021) where patients feared imminent death and often became socially withdrawn.

Elderly gynaecological oncology patients and their caregivers experienced insomnia, nightmares and restless nights. Most of them could not sleep peacefully after the diagnosis as they were distressed, the overwhelming bodily symptoms like pain, and the burden of caregiving. This is consistent with the findings in another study in China, patients reported extreme distress from treatment side effects leading to poor sleep (Agwu et al., 2025). In another study, sleep disruption of elderly gynaecological patients was due to pain and anxiety. Sleep disruption is thus both psychological and physical burden, reducing resilience (Dumas et al., 2021). The inability of patients and their caregivers leaves patients and caregivers physically and emotionally exhausted there by leaving them less functional.

Despite the emotional distress after diagnosis, elderly gynaecological oncology patients and their primary caregivers eventually reached acceptance often through faith, encouragement from children and health workers. This is consistent with results in a study done in Taiwan where prayer and social support helped reduce helplessness and hopelessness among patients

(Tsai et al., 2017). In Zambia patients used gratitude and therapy to adopt (Kapya et al., 2024). In Uganda faith-based coping is particularly strong, reflecting cultural reliance on spirituality. This collectively indicates that acceptance is a coping mechanism that blends faith, resilience, and trust in medical care to gain emotional stability and confront their diagnosis with strength.

Physical burden, functional decline and dependence

Patients experienced bodily changes that they described as overwhelming including pain, fatigue, vaginal bleeding, foul smelling watery discharge, bloating and constant passing of flatus. In another study, gynaecological oncology patients experienced pelvic symptoms from bowels, urinary tract and lymphatic system including leakage of urine and unpredictable bowels (Breistig et al., 2024). In another similar study in Ghana, women experienced severe waist pain, blood in stool (Agyeiwaa et al., 2024). Primary caregivers too described exhaustion from lifting, bathing and feeding the elderly oncology patients which was consistent with another study where physical strain of caregiving was a burden (Seven et al., 2014). This comparison shows that bodily changes are universal and cause distress in both to the patients and their caregivers.

Elderly gynaecological cancer patients experienced severe back pain, paralysis, dizziness and generalised weakness. This aligns with results in a study done on elderly women, they experienced muscle aches, neuropathy that limited physical activity (Dumas et al., 2021). Other patients reported cancer related exhaustion unrelated to heavy activity and others described cancer as painful and unbearable in other studies (Kapya et al., 2024; Maree & Kaila, 2014; Nelson et al., 2018).

Elderly gynaecological patients reported inability to cook, fetch water, bathe or perform house chores. Some of the participants could only do light work like washing inner wears. This is consistent with findings in another study done in Turkey where women lost household roles to partners or older family members (Akyüz et al., 2008). Consistent findings in a study done in Uganda where Ovarian cancer patients experienced abdominal symptoms that disrupted daily functioning (Katumba et al., 2013). Primary caregivers reported extensive responsibilities, house chores physical assistance. Caregivers cooked, washed, fetched water and bathed patients. This is consistent in a study carried out Nigeria where caregivers lost

jobs to carry out daily house chores for the patient (Alegbeleye & Amadi, 2024). Globally functional decline is a marker of disease progression; it carries emotional burden because women traditionally hold central household roles which they must leave to their caregivers entirely.

Elderly gynaecological oncology patients relied on their children, daughters in law for cooking, washing, bathing and toileting. This is consistent in findings in a study done in Nigeria, where caregivers bore the heavy burdens, often losing jobs and privacy (Alegbeleye & Amadi, 2024). Consistent findings were found in a study where caregivers struggled with postoperative care and medication management (Seven et al., 2014). Globally, dependence is expected in advanced cancer, but in Uganda, it reshapes family roles, reinforcing caregiving as both circumstantial duty and moral obligation.

Socio-economic experiences and survival

The study found out that gynaecological cancer severely disrupted patients' and their caregivers' economic and social lives, leading to loss of income, food insecurity and dependence on family members. These findings are consistent with another study that described cancer as a major catastrophic health experience globally (Sullivan et al., 2018). In Uganda and similar setting, out of pocket payments for cancer care contribute to financial hardships (Atuhairwe et al., 2018). Patients often sell properties or rely on relatives.

Elderly gynaecological oncology patients and their primary caregivers valued visits from relatives, friends and church members which provided emotional strength. Regardless some other patients didn't receive social support from the community except the primary caregivers. This is consistent with findings in a study done in Zambia where patients reported strong community support including providing meals, fundraising (Kapyra et al., 2024). This shows that social support is uneven, while some patients and caregivers benefit from community solidarity, others face neglect and isolation.

Elderly gynaecological oncology patients reported inability to farm, dig or run businesses leading to loss of income and food insecurity. These findings are consistent with findings from another study on Zambian women where patients sold livestock and household items to cover the medical costs (Kapyra et al., 2024). In Tanzania, noted economic disruption forced dependence on family (Chona et al., 2025). Globally, cancer patients in high income countries also faced financial strain but social insurance systems mitigated the impact

(Nelson et al., 2018). In Uganda, lack of insurance magnifies the burden, making cancer care financially catastrophic.

Elderly gynaecological oncology patients relied heavily on children and relatives for financial support since most of them could no longer carry out any income generating activity. This is consistent with findings in another study in Ghana where patients relied on children for survival (Maree & Kaila, 2014). Other consistent findings among Advanced cervical cancer patients who depended on family contributions (Natuhwera et al., 2021). Globally, elderly women worried about burdening spouses and children showing dependence carries emotional weight across contexts (Dumas et al., 2021).

Patients expressed needs for free treatment, transport support, nutritional support and community engagement. Those who lived far from the Hospital expressed needs for decentralised cancer services to reduce costs. This is consistent with findings in a study done in Uganda where patients highlighted the need for decentralization of cancer services (Natuhwera et al., 2021).

Primary caregivers of elderly gynaecological oncology patients faced interrupted social life, economic disruption and unmet needs. Caregivers reported loneliness and reduced recreational activity consistent with findings in a study where caregivers experienced social isolation (Gosse et al., 2024). Many lost jobs and their sources of income consistent as in a study done in Nigeria where Caregivers lost their jobs (Alegbeleye & Amadi, 2024). Caregivers wished for support with transport, food and encouragement and as in a study done in Zambia where caregivers wished the community would support them with food, encouraging words (Kapyra et al., 2024). This highlights that caregiving disrupts both social participation and economic stability, conforming to regional evidence of financial toxicity.

Copying mechanisms

Elderly gynaecological oncology patients described strategies like use of vagina pessaries, and painkillers to manage symptoms and maintain dignity. Others padded themselves to control bleeding and abnormal watery discharge per vaginum. Others adopted some form of exercise to alleviate complications evolving from pelvic floor disorders such as loss of anal sphincter control (LASC) marked by uncontrolled farting. These findings are consistent with

those in a study in Zambia where patients used painkillers and herbal remedies to cope with the symptoms (Kapyra et al., 2024). These findings are collaborated by those in Tanzania where patients with loss of appetite and nausea relied on dietary adjustments and herbal teas (Chona et al., 2025). Globally, symptom management often involves both medical and self-directed strategies, in LMICs, limited access to palliative care forces patients to rely more heavily on improvised methods.

Elderly gynaecological oncology patients and their primary caregivers relied on family and social support. Elderly gynaecological patients and their caregivers valued encouragement and financial support from family and relatives and this consistent with findings in a study where social support reduced helplessness (Gosse et al., 2024). Some coped by engaging in leisure activities consistent with findings in another study where social support reduced helplessness (Gosse et al., 2024). This therefore implies that social and family support is universally important for the resilience and journey for the patients and caregivers.

Beyond symptom management and relying on family and social support, elderly gynaecological oncology patients and their caregivers emphasized endurance and resilience. Perseverance was not passive suffering but an active choice to withstand hardship. Some stopped worrying by talking to God while others took austerity measures given the shrinking scarce at their disposal. This is consistent with findings in a study where prayer gave patients confidence and courage (Tsai et al., 2017). In Uganda, consistent findings where advanced stage cervical cancer patients relied on faith and family solidarity to persevere (Natuhwera et al., 2021). Endurance and resilience through spirituality is therefore a global coping mechanism and is more eminent in the Ugandan context.

5.1 STRENGTHS AND LIMITATIONS

The study strengths

It was a prospective study that employed a phenomenological approach that enabled collection of firsthand information on experiences of elderly gynaecological oncology patients and the caregivers. The study involved both patients and caregiver voices that provides a holistic view of cancer's impact, strengthening credibility.

The study also had an elderly focus including patients aged between 60-87 years filling a gap in African Oncology research where elderly populations are often overlooked.

Limitations

The results in this study should be interrupted in view of the following limitations.

The researcher only collected data at Mbale Regional Referral Hospital, findings may not fully represent experiences in other regions in Uganda.

Elderly patients may struggle to recall the symptom onset, health seeking pathways.

6.0 CHAPTER SIX: CONCLUSION

The findings demonstrate that elderly gynaecological oncology patients and their caregivers experience multidimensional challenges including physical suffering, emotional distress, social disruption and economic hardship.

These experiences are worsened by the webbed trajectory of care with late diagnosis and delay getting the right care leading to profound physical dependency and economic strain while caregivers' shoulder intense emotional and practical burdens in often fragile resource context.

Additionally, there are poor support systems at the tertiary centers with drugs and supplies largely unavailable at the tertiary hospitals especially for those patients who present with advanced gynaecologic cancers.

Worse still, the economic toll is not helped by lack of food for those patients and their caregivers that are admitted, loss of income.

However, resilience, spirituality and social support play a crucial role in coping and adaptation for both patients and their caregivers. There is therefore need to strengthen support and coping mechanisms and harness opportunities to address bottlenecks to care.

6.1 Recommendations

Health care system should employ community sensitization campaigns on early warning signs of gynaecological cancers especially targeting elderly women who often misinterpret symptoms to reduce delays in diagnosis.

Training village health teams and primary health workers to recognize and refer suspected cases promptly.

Integrating counselling peer support groups and faith-based interventions into oncology care to reduce emotional distress and fear of death..

Caregiving training in oncology clinics to provide structured training for caregivers on symptom management, nutrition, hygiene and emotional support to reduce burn outs.

Decentralization of gynaecological cancer care services by Ministry of Health (MOH) to reduce transport costs and improve access to rural patients

Implications for care

Clinical practice: nurses and all health workers must adopt holistic care approaches that address physical, emotional, social and spiritual needs for both patients and caregivers.

Policy: findings call for inclusion of caregiver support in Uganda's national cancer control strategies, recognizing caregivers as an integral to patients' outcomes.

Education: Training curricula for nurses and other medical students should emphasize cancer patient and caregiver experience, psychosocial support and culturally sensitive care.

Research: future should explore interventions that strengthen caregiver resilience, evaluate the impact of social support systems and assess long term outcomes of elderly cancer patients in low- and middle-income countries.

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APPENDICES.

APPENDIX 1: CONSENT FORMS.

PROTOCOL TITLE: LIVED EXPERIENCES OF ELDERLY GYNAECOLOGICAL ONCOLOGY PATIENTS AND THEIR CAREGIVERS AT MBALE REGIONAL REFERRAL HOSPITAL. A PHENOMENOLOGICAL STUDY.

Principal investigator: Aporu Faith

Purpose: This study aims at exploring the experiences of elderly women with gynaecological oncology and their primary caregivers at Mbale Regional Referral Hospital, Eastern Uganda.

Investigators: The principal investigator in this study is Aporu Faith, a fourth-year bachelor's degree nursing student at Busitema University, faculty of health sciences. Other investigators in the study include Dr. Nteziyaremye Julius. (0706614213/0775300892)

Population: participants in this study will be selected purposefully with all women 60years and above diagnosed with gynaecological cancer and receiving the management at Mbale Regional Referral Hospital since 2023. All the primary caregivers of these patients will be included in the study even when their patients died. Women less than 60years will be excluded from the study and caregivers who are or were not directly involved in care of patient will be excluded. The results will be determined by saturation point.

Period: Data will be collected within a period of 2 months, and one will only participate once during this period. The interview session will last for about 20-30minutes

Procedures: Participants will be selected consecutively by the Researcher and the health care team in Gynaecological ward and gynaecological clinic as assistant researchers. The study will involve interviews with participants using interview guide as guided by the researcher. Recording and documentation of the participants' responses will be done for better representation of their opinions. The questions in the interview guide will be structured according to experiences of gynaecological oncology patients and their caregivers, and the study will take 20-30 minutes

Risks: in this study, there will be no risks associated with patients' participation. And hence there will be no harm to your participation.

Benefits: this study may not have direct benefits to you the participant. On the other hand, information collected will contribute to knowledge in regards of experiences of elderly gynaecological oncology patients and their caregivers. This could help policy makers to develop appropriate interventions to address the needs of elderly gynaecological patients and their caregivers at Mbale Regional Referral Hospital and other settings.

Costs: there are no costs required for you to participate in this study and no payment will be given to you for participation.

Participants' rights: your participation in this study is voluntary and refusal to take part in this will not affect your care at this facility. Your voluntary participation in this study will be beneficial if you provide required information regarding your experiences.

Privacy and confidentiality: The study interviews will be conducted from a private place in gynecological ward and gynaecological clinic. The information shared will be treated with maximum respect and confidentiality. Data will be coded and sorted and all papers and books used will be destroyed.

Contacts: Aporu faith, Nursing student, Busitema University faculty of health sciences

Tel: 0771315790/ 0709497362, Email: faithaporu@gmail.com

Documentation and Authorization of informed consent.

The information given above was accurately explained and understood by participants as required and informed consent voluntarily given

Name of participant.....signature..... date.....

Name of witness.....signature.....date.....

Investigators name..... signature..... date.....

APPENDIX 2 A: INTERVIEW GUIDE.

For elderly gynaecological cancer patients

Demographic questions.

serial number.....

what is your age.....

Tribe.....

Religion:

Anglican ☐ catholic ☐ Muslim ☐ other ☐

Place of residence

Rural ☐ urban ☐

Level of education

Only informal Primary ☐ Secondary ☐ tertiary ☐

Marital status

Single ☐ married ☐ divorced ☐ other ☐

Occupation.....

retired...

Primary source of money for her care and relationship

Who do you live with

family members ☐ hired caretaker ☐

Relationship with primary caretaker Duration of illness

Date of diagnosis

Type of cancer

Stage of cancer

Performance status at presentation

Comorbidities

Treatment history

Surgery ☐ chemotherapy ☐ radiation therapy ☐ palliative ☐

Hospital admissions related to cancer

Question guide

- 1) I understand you are not well and am sorry for your condition, may I know how long have you been feeling unwell because of this illness?
- 2) Paint a picture of your journey for care and how long it took you to get here? If you got treatment from lower facilities, we are happy to know what you were being treated for and the challenges encountered.
- 3) The first you were diagnosed with this cancer; in your own words could you describe how you felt?
- 4) Has there been any change of mood from the first time you got to know that you had cancer?
- 5) What common challenges do you experience while doing your day-to-day activities including ability to do home chores, personal care, feeding, self-care.
- 6) How has this illness affected your socio-economic activities including interactions with family and friends, income, social gatherings like prayers, burials.
- 7) I know and understand this disease may be different from others you have been diagnosed with before, could you explain to me those differences.
- 8) I know you have discussed with me enormous challenges you could be facing, may I know how you are trying to cope?
- 9) Finally, how do you think the community/ government can do to help people diagnosed with cancer.

Closing.

Thank you for your active participation, time and contribution to this study. The information you have shared will be used well. Feedback will be sent to you through the implementation of the key issues by the stakeholders responsible. Thank you and have a blessed day.

Appendix 2B: Interview guide for caregivers

Demographic questions.

serial number.....

what is your age.....

Tribe.....

Religion:

Anglican ☐ catholic ☐ Muslim ☐ other ☐

Place of residence.....

Level of education

Only informal ☐ Primary ☐ Secondary ☐ tertiary ☐

Marital status

Single ☐ married ☐ divorced ☐ other ☐

Occupation..... retired...

Relationship with patient

Time of stay with patient

Interview guide

- 1) How did you become the primary caregiver of your patient and what kind of support do you provide
- 2) How did you feel when you first learned about the patient's diagnosis and how do you feel about your caregiving role?
- 3) What challenges have you encountered as a primary caregiver and how has it affected your daily activities and social relationships and interactions?

- 4) What kind of support do you wish was available for you and the patient from the community, health care system or the government.

Closing.

Thank you for your active participation, time and contribution to this study. The information you have shared will be used well. Feedback will be sent to you through the implementation of the key issues by the stakeholders responsible.

Thank you and have a blessed day.

APPENDIX 3: WORK PLAN.

S/NO	ACTIVITY	2025			2026				
		October	November	December	January	February	March	April	May
1	Topic selection								
2	Topic approval								
4	Proposal writing								
5	Proposal submission								
6	Data collection								
7	Data analysis								
8	Report writing								
9	Report Submission								

APPENDIX 4: BUDGET

Item	Quantity	Unit cost (Ug. shs)	Total cost
Ream of paper	2	20,000	40,000
Book and pens	1 box of pens and 1book	15,000	15,000
Travel		500,000	500,000
Research assistants	2	300,000	600,000
IRB fee		100,000	300,000
Internet		300,000	200,000
Printing and binding		50,000	50,000
Total			1,705,000

CONSENT FORMS.

PROTOCOL TITLE: LIVED EXPERIENCES OF ELDERLY GYNAECOLOGICAL ONCOLOGY PATIENTS AND THEIR CAREGIVERS AT MBALE REGIONAL REFERRAL HOSPITAL. A PHENOMENOLOGICAL STUDY.

Principal investigator: Aporu Faith

Purpose: This study aims at exploring the experiences of elderly women with gynaecological oncology and their primary caregivers at Mbale Regional Referral Hospital, Eastern Uganda.

Investigators: The principal investigator in this study is Aporu Faith, a fourth-year bachelor's degree nursing student at Busitema University, faculty of health sciences. Other investigators in the study include Dr Nteziyaremye Julius.

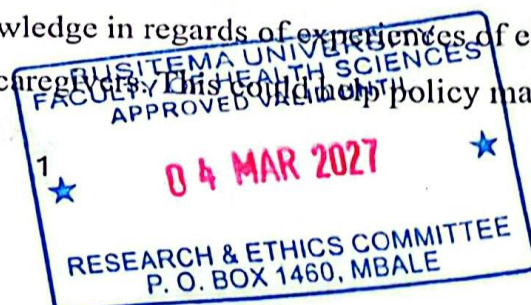
Population: participants in this study will be selected purposefully with all women 60 years and above histologically diagnosed with gynaecological cancer and receiving the management at Mbale Regional Referral Hospital since 2023. All the primary caregivers of these patients will be included in the study even when their patients died. Women less than 60 years will be excluded from the study and caregivers who are or were not directly involved in care of patient will be excluded. The results will be determined by saturation point.

Period: Data will be collected within a period of 2 months, and one will only participate once during this period. The interview session will last for about 20-30 minutes

Procedures: Participants will be selected purposively by the Researcher and the health care team in Gynaecological ward and gynaecological clinic as assistant researchers. The study will involve interviews with participants using interview guide as guided by the researcher. Recording and documentation of the participants' responses will be done for better representation of their opinions. The questions in the interview guide will be structured according to experiences of gynaecological oncology patients and their caregivers, and the study will take 20-30 minutes

Risks: in this study, there will be no risks associated with patients' participation. And hence there will be no harm to your participation.

Benefits: this study may not have direct benefits to you the participant. On the other hand, information collected will contribute to knowledge in regards of experiences of elderly gynaecological oncology patients and their caregivers. This could help policy makers to



develop appropriate interventions to address the needs of elderly gynaecological patients and their caregivers at Mbale Regional Referral Hospital and other settings.

Costs: there are no costs required for you to participate in this study and no payment will be given to you for participation.

Participants' rights: your participation in this study is voluntary and refusal to take part in this will not affect your care at this facility. Your voluntary participation in this study will be beneficial if you provide required information regarding your experiences.

Privacy and confidentiality: The study interviews will be conducted from a private place in gynecological ward and gynaecological clinic. The information shared will be treated with maximum respect and confidentiality. Data will be coded and sorted and all papers and books used will be destroyed.

Contacts: Aporu faith, Nursing student, Busitema University faculty of health sciences

Tel: 0771315790/ 0709497362, Email: faithaporu@gmail.com

Documentation and Authorization of informed consent.

The information given above was accurately explained and understood by participants as required and informed consent voluntarily given

Name of participant.....signature..... date.....

Name of witness.....signature.....date.....

Investigators name..... signature..... date.....



INTERVIEW GUIDE.

For elderly gynaecological cancer patients

Demographic questions.

serial number.....

what is your age.....

Tribes.....

Religion:

Anglican ☐ catholic ☐ Muslim ☐ other ☐

Place of residence

Rural ☐ urban ☐

Level of education

Only informal ☐ Primary ☐ Secondary ☐ tertiary ☐

Marital status

Single ☐ married ☐ divorced ☐ other ☐

Occupation.....

Retired civil servant active civil servant business farming no direct source of income

Primary source of resources including money for care relationship with the primary source

Who have you primarily been living with for the past 6 months

family members ☐ hired caretaker ☐

Relationship with primary caretaker Duration of illness.....

Date of diagnosis.....

Type of cancer.....

Stage of cancer.....



Performance status at presentation

Comorbidities if any?

.....

.....

.....

Primary complications at diagnosis

Anemia fistula neuropathy encephalopathy electrolyte
imbalance others

Treatment history

Surgery ☐ chemotherapy ☐ radiation therapy ☐ palliative ☐

supportive treatment for symptoms prior to definitive treatment for cancer stage

anemia severe vomiting severe constipation

Referred to Cancer institute

Hospital admissions related to cancer in the past 6 months



Question guide

- 1) I understand you are not well and am sorry for your condition, may I know how long have you been feeling unwell because of this illness?
- 2) Paint a picture of your journey for care and how long it took you to get here? If you got treatment from lower facilities, we are happy to know what you were being treated for and the challenges encountered.
- 3) The first time you were diagnosed with this cancer; in your own words could you describe how you felt? Did you get so scared, how did it affect your thoughts, what came into your mind at that moment, how did it affect your sleep pattern and moods?
- 4) Has there been any change of mood from the first time you got to know that you had cancer? Are you having hope now, is your sleep better, has your mood improved?

- 5) What common challenges do you experience in your body and how do they affect your day-to-day activities including ability to do home chores, personal care, feeding, self-care.
- 6) How has this illness affected your socio-economic activities including interactions with family and friends, income, social gatherings like prayers, burials among others?
- 7) I know and understand this disease may be different from others you have been diagnosed with before, could you explain to me those differences.
- 8) I know you have discussed with me enormous challenges you could be facing, may I know how you are trying to cope physically, socially and psychologically?
- 9) Finally, how do you think the community/ government can do to help people diagnosed with cancer.

Closing.

Thank you for your active participation, time and contribution to this study. The information you have shared will be used well. Feedback will be sent to you through the implementation of the key issues by the stakeholders responsible. Thank you and have a blessed day.

Interview guide for caregivers

Demographic questions.

serial number.....

what is your age.....

Tribe.....

Religion:

Anglican ☐ catholic ☐ Muslim ☐ other ☐

Place of residence.....

Level of education

Only informal ☐ Primary ☐ Secondary ☐ tertiary ☐

Marital status

☐


Single married ☐ divorced ☐ other ☐

Occupation..... retired...

Relationship with patient

Time of stay with patient

Interview guide

- 1) How did you become the primary caregiver of your patient and what kind of support do you provide to the patient?
- 2) How did you feel when you first learned about the patient's diagnosis? Did you feel scared, how did it affect your sleep pattern and mood
- 3) How do you feel about your caregiving role? Do you find it tiresome?
- 4) What challenges have you encountered as a primary caregiver and how has it affected your daily activities and social relationships and interactions?
- 5) It's evident from your conversations you face challenges in your caregiving role, how are you able to cope physically, socially and economically?
- 6) What kind of support do you wish was available for you and the patient from the community, health care system or the government.

Closing.

Thank you for your active participation, time and contribution to this study. The information you have shared will be used well. Feedback will be sent to you through the implementation of the key issues by the stakeholders responsible.

Thank you and have a blessed day.





FACULTY OF HEALTH SCIENCES' REC

04/03/2026

To: FAITH APORU
BusitemaUniversity

Review Type: Initial Review



Re:BUFHS-2026-655: LIVED EXPERIENCES OF ELDERLY GYNECOLOGIC ONCOLOGY PATIENTS AND THEIR CAREGIVERS ATTENDING MBALE REGIONAL REFFERAL HOSPITAL: A PHENOMENOLOGICAL STUDY.

I am pleased to inform you that the Busitema University Faculty of Health Sciences REC, through expedited review held on **12/02/2026** approved the above referenced study.

Approval of the research is for the period of **04/03/2026** to **04/03/2027**.

As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the protocol or the consent form must be submitted to the REC for re-review and approval **prior** to the activation of the changes.
3. Reports of unanticipated problems involving risks to participants or any new information which could change the risk benefit: ratio must be submitted to the REC.
4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by participants and/or witnesses should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.
5. Continuing review application must be submitted to the REC **eight weeks** prior to the expiration date of **04/03/2027** in order to continue the study beyond the approved period. Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study.
6. The REC application number assigned to the research should be cited in any correspondence with the REC of record.
7. You are required to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.

The following is the list of all documents approved in this application by Busitema University Faculty of Health Sciences REC:

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No.	Document Title	Language	Version Number	Version Date
1	Letter to the REC/IACUC Chairperson	English	1.0	2026-03-02
2	Main Consent forms	English	1.1	2026-03-02
3	Data collection tools	English	1.1	2026-03-02
4	Translated consent	LUGISHU	1.1	2026-03-02
5	Protocol	English	1.1	2026-03-01
6	Data collection tools	LUGISHU	1.0	2026-03-02
7	Main Consent forms	english	1.0	2026-02-05
8	Data collection tools	english	1.0	2026-02-05
9	Protocol	English	1.0	2026-02-04
10	Informed consent form for the recruitment of research participants	english	1.0	2026-01-31

Yours sincerely,




Richard Katuramu

For: Busitema University Faculty of Health Sciences REC

