

Profiles, Needs and Survival of Women Diagnosed with Cervical Cancer on the Road to Care Programme of Hospice Africa Uganda

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Received: 18 Apr 2025; Accepted: 17 May 2025; Published: 27 Jun 2025

Citation: Róisín Sheehy, Janepher Nyakake, Nasur Buyinza. Profiles, Needs and Survival of Women Diagnosed with Cervical Cancer on the Road to Care Programme of Hospice Africa Uganda. *Nur Primary Care*. 2025; 9(2): 1-6.

ABSTRACT

Cervical cancer is one of the most prevalent cancers worldwide, particularly in low and middle-income countries such as Uganda, where it is the most frequently diagnosed cancer [1]. No recent review has been conducted to assess the profiles of these women, which provides treatment support for cervical cancer patients in Uganda, alleviating the financial burden of care. This study aimed to evaluate the profiles, needs, and survival outcomes of women enrolled in the Road to Care (RTC) programme of Hospice Africa Uganda (HAU).

This cross-sectional mixed-methods study utilised retrospective chart review of women diagnosed with cervical cancer between 2019 and 2023, supplemented by qualitative data from a focus group discussion. The study examined demographic, clinical, and socio-economic variables, with survival analysis conducted using Kaplan-Meier curves.

28% of study participants were aged 50-59 years and had low education levels, with 88% having primary-level education or less. Late-stage diagnosis of cervical cancer was prevalent, with 70% diagnosed either at Stage IIb or IIIb. Financial constraints were reported by 70% of participants as a major barrier to accessing treatment, while 59% experienced a lack of spousal support. Psycho-social support and counselling were provided to 91% of participants. The survival analysis indicated a sharp decline in survival probability from 96.7% in the first year to 0% by the fifth year.

The study findings underscore the impact of late-stage diagnosis and limited access to care, highlighting the need for accessible screening and awareness programmes, to enhance cervical cancer outcomes for women in Uganda.

Keywords

Cervical cancer, Uganda, Road to Care (RTC) programme, Hospice Africa Uganda, Patient profiles, Survival analysis, Socioeconomic barriers, Late-stage diagnosis, Palliative care, Health access inequality.

Background

Founded in 1993 by Nobel Peace Prize nominee, Dr. Anne Merriman, Hospice Africa Uganda (HAU) provides palliative care to patients, particularly those with cancer, aiming to bring peace to those suffering from painful and debilitating conditions. HAU offers holistic, affordable, and culturally appropriate care across Uganda, addressing physical, spiritual, psychological, and social suffering [2]. The primary palliative patient cohort HAU cares for

is cancer patients, with cervical cancer being the most frequently encountered malignancy.

Cervical cancer is one of the most prevalent cancers worldwide, particularly in low and middle-income countries (LMICs) like Uganda, due in part to poor health infrastructure, resources and screening and awareness campaigns. Uganda has approximately 13 million women at risk, and it is the most frequently diagnosed and the most common cancer in the country [1,3]. The primary risk factor for cervical cancer is sexual transmission via human papillomavirus (HPV), particularly serotypes 16 and 18. Other risk factors include HIV co-infection, high parity and low socioeconomic status [4].

Cervical cancer is preventable and curable if detected early and treated effectively. Early detection can lead to survival rates of 80 to 95% in women with early-stage disease [5,6]. Delayed diagnosis, however, has profound impacts on outcomes and survival and is a particular concern in LMICs.

The World Health Organization (WHO) advocates for the eradication of cervical cancer as a global public health concern, promoting screening programs, early interventions, and HPV vaccination uptake, especially in LMICs. Despite this, Uganda has one of the highest rates of cervical cancer globally, reporting 4607 deaths annually and a mortality rate of 35 per 100,000 women aged 15 or older, compared, for example, to 106 deaths per annum in Ireland [1].

Efforts to enhance cervical cancer care in Uganda include the introduction of an HPV vaccination program and the establishment of screening practices. However, due to limited vaccine availability, poor health education, and inadequate health infrastructure, uptake and impact have been poor [1,7].

Road to Care (RTC) is a charitable organization linked with HAU, empowering women diagnosed with curable cervical cancer by providing financial support for treatment at the Uganda Cancer Institute (UCI) in Kampala. Since 2009, RTC has provided access to life-saving cervical cancer treatment for over 1000 women, covering the costs of essential investigations, radiotherapy, transportation, welfare, and accommodation, ensuring that financial barriers do not prevent women from accessing the care they need to combat cervical cancer effectively [8].

Given the lack of recent evaluations of patient outcomes within the RTC programme, this study aims to address these knowledge gaps and contribute evidence to support improved service delivery and advocacy.

Study Objective and Aim

The study aimed to review the profiles of women benefiting from the RTC project to understand their needs, experiences, and expectations. These insights will help tailor support mechanisms, improve programme delivery, and enhance patient outcomes in Uganda's cervical cancer treatment context.

Methodology

Materials and Methods

This study employed a cross-sectional mixed methods approach, integrating quantitative and qualitative data to evaluate the RTC programme at HAU to provide an understanding of both numerical trends and personal experiences. Quantitative analysis involved retrospective data review of patients' charts and case notes from the three HAU sites: Kampala, Mbarara, and Hoima. Qualitative assessment included focus group discussion (FGD) with RTC recipients to understand their needs, barriers, and programme expectations.

Study Setting and Population

The study was conducted at HAU Kampala, Mbarara and Hoima sites. The target population was women diagnosed with cervical cancer, enrolled on the RTC programme from January 2019 to December 2023, aged 25 to 70. A total of 123 charts were reviewed. A focus group discussion was held at the RTC hostel in Kampala, with a sample of 9 participants selected by the RTC coordinator based on care duration and disease insight.

Data Collection Methods and Tools

The chart review used a data extraction tool developed by the research team, pilot-tested on non-road to care patients for completeness and reliability. Key variables included socioeconomic, clinical, and demographic profiles, psychosocial, spiritual, and other needs. The HAU data officer assisted in identifying charts meeting the inclusion criteria.

The focus group was conducted in the local language and recorded. An FGD guide focused on needs and barriers to treatment. The transcript was translated into English by an independent service provider.

Data Analysis

Quantitative data were recorded in Excel and analysed using descriptive statistics, including frequencies, percentages, and means. Survival analysis was performed using Kaplan-Meier curves. Qualitative data underwent thematic analysis to identify common themes.

Ethical Approval and Consent

Ethical approval was obtained from Hospice Africa Uganda REC and the University College Dublin Research Ethics Committee. Written consent for research use was obtained for each chart included in the study. Charts lacking explicit research consent were excluded. Informed consent was obtained from patients and programme managers before conducting the qualitative interview.

Results

Describe the profiles of women diagnosed with cervical cancer on the Road to Care programme of Hospice Africa Uganda

Age and Family Profiles

123 women diagnosed with cervical cancer on the RTC programme were reviewed. Ages ranged from 25 to 70 (mean age 48), with 28% aged 50-59. Of these, 17 participants had 10+ children, with 19% having five children, making it the most common category.

59% of participants lacked spousal or partner support due to being widowed, separated, or single, increasing their vulnerability to socioeconomic pressure and social isolation. In the words of one participant, *"I no longer work, we left families behind, children are out of school, the plantation I used to get food is gone. With cancer, I am a single mother"*.

Education, Occupation and Housing Profile

Over half (55%) of the women reported having an education up to

Primary 7, while 33% had no education. The majority of participants (63%) had partial to no understanding of their diagnosis, with the level of insight correlating with education status (Figure 2).

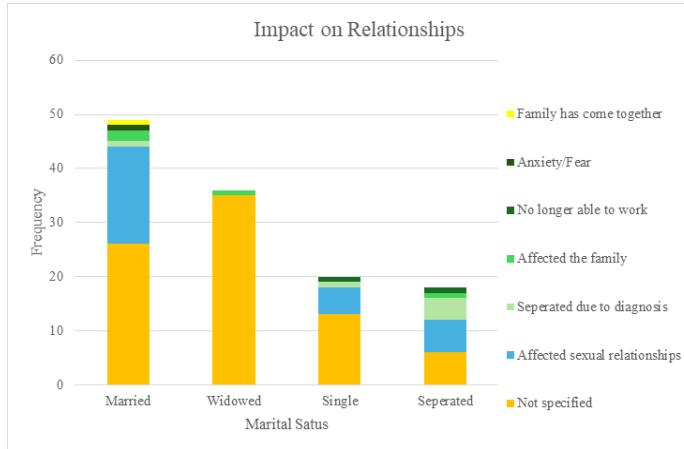


Figure 1

A common theme emerged from the focus group discussion, being the belief that cancer was an incurable diagnosis, with a second participant sharing: *"I was scared because of knowing that cancer is incurable, I thought the doctor was sending me to UCI* to die as this disease is incurable".*

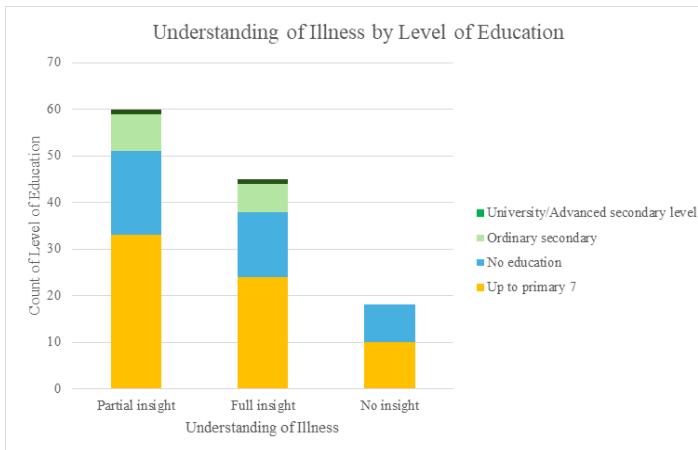


Figure 2

The predominant occupation was peasant work, small-scale farming, or trading (88%), reflecting lower education and socioeconomic status. The remaining occupations included small business owners (9%) and unemployed or destitute (3%).

79% of women who owned their own houses; however, it is important to note that these homes are typically traditional Ugandan village houses, often constructed from mud and thatch. This type of housing indicates a lower socioeconomic status despite the high rate of home ownership.

Clinical Profiles

The distribution of HIV among the participants was notable, with

45% presenting as HIV positive and 51% with a negative status. Five women reported their status as unknown.

The distribution of cervical cancer stage at diagnosis varied among the 123 women reviewed. However, late-stage diagnosis was common among study participants, with Stage IIb and IIIb being the most prevalent, accounting for 40% and 30% of cases, respectively. A significant proportion of women were diagnosed with an unknown stage.

As one patient describes, the main cause of this is late diagnosis is the fact that she was not able to arrange transport to Kampala. She is still worried about the costs.

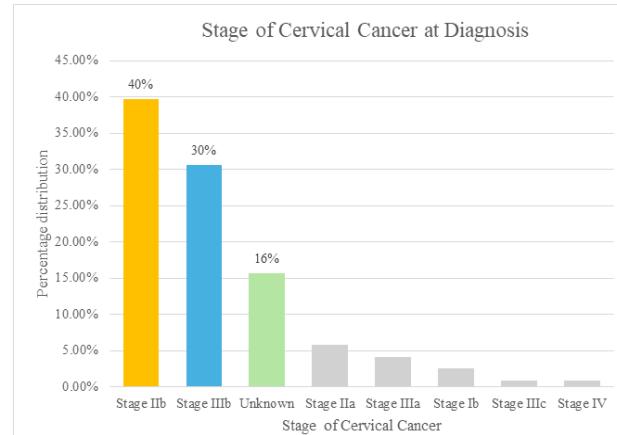


Figure 3

Examine the needs of patients on the Road to Care programme, aiming to identify barriers to access, socio-economic constraints, and clinical challenges

Psycho-social and Support Needs

29% of participants expressed psycho-social needs, with six participants separated due to their diagnosis. 39% of participants were married, with many reporting sexual relationship issues due to their diagnosis. One participant shared: *"The husbands no longer care, they stopped supporting us because they perceive us as dead now we are no longer sexually active - the bleeding scares sexual activity"* while another participant disclosed *"my husband says I have no use, since I stay in hospital."*

Psycho-social support and counselling were provided to 91%, and in the words of one of the participants, *"it's the Hospice counselling that gave me life again."*

The primary care goal was treatment support (32%), followed by symptom and pain control (28%). Chronic pain and vaginal bleeding are two of the main concerns (23% and 20%). As one patient described.

Additional unmet needs included boredom. Many participants residing at the RTC hostels for months expressed feeling bored and needed some entertainment to drive away their worries. There is a

need to fundraise to buy a TV for the hostel and solicit donations to secure monthly food deliveries for the two RTC hostels, with emphasis in particular on providing foods rich in iron to combat the persistent bleeding experienced by many of the women.

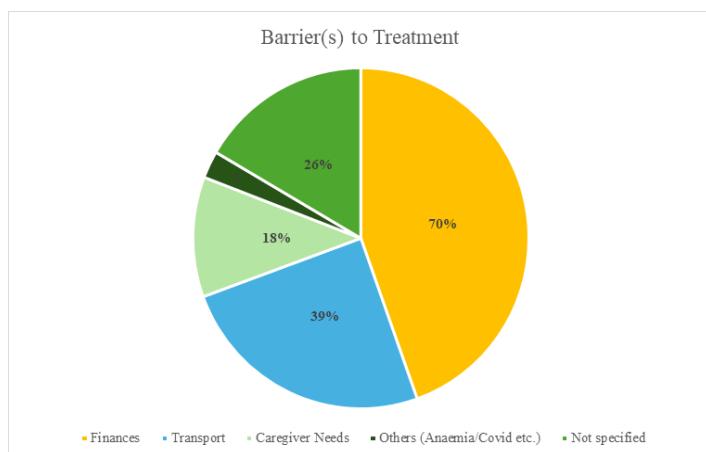
Table 1: Main Concerns Following Diagnosis among Participants.

Main Concerns	Frequency (n=123)	Percentage
Chronic pain	28	23%
Cancer diagnosis	25	20%
Vaginal bleeding/discharge	24	20%
Financial constraints	12	10%
Care for the family	10	8%
Other	24	19%

Socio-economic Constraints

70% of participants reported financial constraints as a major barrier to treatment, with 100% receiving monetary support through RTC and an additional 85% receiving further assistance through HAU.

Following her cancer diagnosis, one patient shared, while a second patient noted Transport was a barrier for 39% of participants, with only 3 of 123 women reporting access to a vehicle. Transport was also the most frequently reported need. As one participant stated.



Clinical Challenges

Analysis of the 123 charts revealed pain as the most distressing symptom, reported by 89% of the participants, followed by foul-smelling vaginal bleeding/discharge, (83%). Additional symptoms included anxiety, anaemia and loss of appetite.

Table 2: Main Distressing Physical and/or Psychological Symptoms Reported by Participants.

Distressing Physical/Psychological Symptoms	Frequency (n=123)	Percentage
Pain	109	89%
Vaginal bleeding/discharge	102	83%
Other (Anaemia, constipation, anxiety, etc.)	12	10%

Chemo and radiotherapy side effects included loss of appetite and bleeding. One participant said, “*the treatment can be distressing;*

you can't eat or drink... yet the treatment is every day.”

Patients frequently reported delays in appointments and treatment. One shared, “*there is a lot of overstaying... you have to wait for others to finish until you get a space.. all the while the disease keeps progressing.*” A second participant said, “*we come when we are so sick, but we stay long before being treated.*”

The communal aspect of the RTC Hostels positively impacted patients’ treatment journeys. The participants also discussed their wish to have follow-up reviews by professionals from regional hospitals, such as Mbarara, which are nearer to them than Kampala. Participants reported, however, that expert oncological care is based in the Uganda Cancer Institute (UCI) in Kampala, and it is only there that the follow-up reviews can be undertaken.

Another participant reported that support from RTC is not sufficient to cover the costs of reviews post-treatment, and 37 of the 123 participants were lost to follow-up; this could be a factor in the poor prognosis of many of the women included in this study.

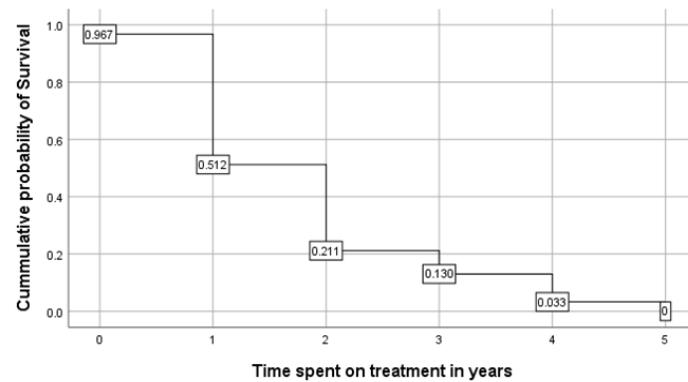
Explore the survival of cancer patients on the RTC programme through retrospective chart review

Among the 123 charts, 28 participants were deceased, and 37 had unknown status, suggesting a higher mortality rate than reported. Notably, 9 out of 13 patients diagnosed in 2019 are deceased, indicating it as the highest mortality year in this study.

Table 3: Participant Status by Year of Diagnosis.

Year of Diagnosis	Stable	RIP	Unknown	Treatment ongoing/In pain	Total
2019	1	9	3	0	13
2020	6	3	7	0	16
2021	5	2	3	3	13
2022	7	7	16	14	44
2023	16	7	8	6	37

The cumulative survival probability (Figure 5) for women diagnosed with cervical cancer in the RTC program starts high at 96.7% but drops sharply to 51.2% in the first year. Survival probability decreases to 0% by the fifth year, indicating a poor long-term prognosis for the cohort.



Discussion

This study analysed the profiles of 123 women diagnosed with cervical cancer on the RTC programme, and included the input of 9 participants from a focus group discussion. The study examined the profiles of these women, including age, marital status, housing, education, occupation and clinical profiles. In addition, the needs of the participants were examined to identify barriers to access, socio-economic constraints, and clinical challenges encountered during treatment and the survival of the patient cohort was also investigated.

Most participants were between 50-59 years old, with a mean age of 48, and had low education levels, with a significant 88% of the participants having either education up to Primary 7 level or no education. The majority of patients in the study were diagnosed either Stage IIb or Stage IIIb, aligning with existing literature regarding cervical cancer diagnosis [9,10]. Lower education levels are associated with reduced health literacy and delayed healthcare seeking behaviour, and are a likely contributor to the late-stage diagnosis of the majority of study participants.

Socio-economic constraints and transport difficulties were recurrently mentioned as barriers in both the chart review and the focus group. Concerns regarding the cost of treatment and diagnosis dissuaded women from seeking care. One patient reported and, for most, it is when symptoms such as vaginal bleeding are at their worst that they finally seek care, with one focus group participant delaying her treatment journey by nine months due to difficulties accessing care.

Psycho-social issues also emerged as a significant concern, with 59% of participants lacking spousal or partner support, exacerbating their vulnerability to social isolation and economic hardship. The fear of death and its impact on family dynamics was commonly expressed, with one participant reporting, These barriers indicate that while RTC provides essential services, there is a need for more extensive support mechanisms, especially in early screening and diagnosis and suggest a potential need for RTC to invest in social workers, counselling services, and community support programs to help address these issues.

The survival analysis indicates a poor prognosis for women on the RTC programme, with survival probabilities dropping significantly after the first year post-diagnosis. By the fifth year, survival drops to 0%, reflecting the severe impact of late-stage diagnosis and inadequate access to timely care, emphasising the need for improved early detection and accessible follow-up to enhance survival rates.

Overall, this study highlights a critical need for improved and attainable cervical screening and detection programmes. One participant expressed, with another sharing, These statements underscore the importance of incorporating robust screening and awareness programmes to enhance early diagnosis and treatment. While RTC provides essential treatment services, it could also consider rolling out local screening or detection campaigns in the

villages or regional hospitals to facilitate earlier-stage diagnosis, enhancing early detection and potentially improving survival rates for cervical cancer patients.

Limitations

Limitations included the lack of sufficient data in the patients' charts on their needs and specifics of the cancer treatment they received. Information regarding the frequency and duration of both chemo and radiotherapy received was housed in the hospital charts and not shared with the RTC. This limited our ability to accurately assess treatment and survival outcomes.

Additionally, the study's retrospective design relies on existing records accuracy and completeness. Some data, such as socioeconomic status and needs, were underreported. The study's findings are based on a specific cohort of patients enrolled in the RTC programme, which may not be generalisable to all women with cervical cancer in Uganda.

The selection of qualifying participants of the focus group discussion was done by the programme coordinator. This could have brought in an element of bias since only those whom the coordinator thinks are friendly but not with the desired characteristics could have been selected.

To address these limitations, future research should consider a prospective design involving a more diverse sample and structured data collection tools. Additionally, future studies could assess the impact of introducing community-based education, screening, and follow-up services to improve early diagnosis and patient retention.

Conclusion

This study highlights the critical need for comprehensive, accessible, and patient-centred cervical cancer care in Uganda. The findings reveal that most women on the RTC programme present with late-stage disease, face significant socio-economic and psychosocial barriers, and have poor long-term survival outcomes. These challenges are compounded by limited education, financial hardship, inadequate follow-up care, and a lack of early screening opportunities.

By addressing these systemic issues, particularly through improved awareness, decentralised screening, and strengthened psychosocial support, the RTC programme has the potential to significantly enhance its impact. Implementing targeted, community-focused interventions can improve early detection, treatment adherence, and ultimately the quality of life and survival of women diagnosed with cervical cancer.

This study contributes valuable insights to the existing literature on cancer care in low-resource settings and underscores the importance of integrating prevention, treatment, and support services into national cancer strategies.

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