


## RESEARCH ARTICLE

# The burden of travelling for cervical cancer treatment in Uganda: A mixed-method study

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## Abstract

**Background:** Uganda has one of the highest rates of cervical cancer in the world. Many women are diagnosed and treated with advanced stages of the disease. With only one facility offering comprehensive cervical cancer care in Uganda, many women are required to travel significant distances and spend time away from their homes to receive cervical cancer care. It is important to understand the burden of time away from home while attending treatment because it can inform the expansion of cervical cancer treatment programmes. The aim of this mixed-methods paper is to describe how the distance to cervical cancer treatment locations impacts women in Uganda.

**Methods:** Women were recruited from 19 September, 2022, to 17 January, 2023, at the Uganda Cancer Institute (UCI) and the cancer clinic at Jinja Regional Referral Hospital (JRRF). Women were eligible for the study if they were (i) aged  $\geq 18$  years with a histopathologic diagnosis of cervical cancer; (ii) being treated at the UCI or JRRF for cervical cancer; and (iii) able to provide consent to participate in the study in English, Luganda, Lusoga, Luo, or Runyankole. All participants completed a quantitative survey and a selected group was sampled for semi-structured interviews. Data were analysed using the convergent parallel mixed-methods approach. Descriptive statistics were reported for the quantitative data and qualitative data using an inductive-deductive thematic analysis approach.

**Results:** In all, 351 women participated in the quantitative section of the study and 24 in the qualitative. The quantitative and qualitative findings largely aligned and supported one another. Women reported travelling up to 14 h to receive treatment and 20% noted that they would spend three or more nights away from home during their current visit. Major themes of the qualitative include means of transportation, spending the night away from home, and financial factors.

**Conclusion:** Our findings show that travelling to obtain cervical cancer care can be a significant burden for women in Uganda. Approaches should be considered to reduce this burden such as additional satellite cervical cancer clinics or subsidised transportation options.

## KEYWORDS

cervical cancer, mixed-methodology, travel, treatment, Uganda

**Sustainable Development Goal:** Good Health and Wellbeing

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## INTRODUCTION

Cervical cancer is a largely preventable disease and is considered the most preventable type of cancer if detected in the pre-cancerous stage [1, 2]. However, cervical cancer is the second most common type of cancer in low- and middle-income countries (LMIC). The high rates of cervical cancer in LMICs can largely be attributed to a lack of comprehensive and accessible screening programmes. More specifically, women in LMICs are often not screened due to the cost [3–5], lack of trained personnel [6], unavailable programmes [3–6], and a lack of information [4]. Globally, Uganda has one of the highest rates of cervical cancer. It accounts for 40% of all female cancer cases in the country [7]. Furthermore, it ranks number one in both incidence and mortality among female cancers [8]. In all, 80% of Ugandan women are diagnosed with advanced stages of the disease [7]. Many women delay seeking treatment because of a lack of knowledge about symptoms, limited access to healthcare, and stigmatisation [9].

The Uganda Cancer Institute (UCI) was established in 1967 and is the primary treatment facility for all types of cancer in Uganda. It is the only public facility available for comprehensive cancer treatment in the country and treats over 4000 individuals annually [9, 10]. The mission of the UCI is, 'provision of state of the art cancer care and prevention by advancing knowledge, fostering the use of research as a resource in training and professional development' [11]. The Institute provides cancer care to over 200 individuals each day and is a leading cancer research centre in Eastern Africa [12]. The UCI is located in Kampala, the largest city in Uganda, and offers prevention services, chemotherapy, radiation therapy, surgery, palliative care, and survivorship support. The UCI also operates several smaller satellite clinics for cervical cancer care which include facilities in the less urban settings of Jinja, Gulu, and Arua. However, these facilities largely offer only pre-cancer screening and treatment, diagnosis, and palliative care.

Given that UCI in Kampala is the only centre offering comprehensive cervical cancer treatment, there is a need to consider the impact of travel for women diagnosed with cervical cancer throughout the country. Currently this understanding is fixed to either all cancer types or purely qualitative methodology [9, 13]. In 2021, Nakaganda et al. reported that individuals diagnosed with cancer travel an average of 132 km roundtrip from UCI and over one-third spent more than a week from home during their treatment session [9]. However, this study was limited in that it did not stratify these findings by cancer type. Rather it included all cancers and sexes. Furthermore, while Germans et al. published a qualitative study in 2022 on the socio-economic impact of a cervical cancer diagnosis on women in rural Uganda, their results primarily focused on the cost of transportation [13]. It is important to specifically understand how cervical cancer treatment impacts women in Uganda because women have a breadth of roles which include caregiving, income earning, and homemaking [14–16]. With

that, women travelling to the clinic often have families and young children at home. Women are essential providers for the family, and a cancer diagnosis can have profound impacts on a family's overall well-being. Globally, they spend two and a half more time on unpaid or domestic work than men [17]. This means that when women are attending cervical cancer treatment, their normal duties, including childcare or income earning, either have to be filled in by someone else or they will go unfulfilled.

Many Ugandan women are required to travel and spend time away from their homes to receive cervical cancer care. It is important to understand the burden of time away from home while attending treatment because it can inform the expansion of cervical cancer treatment programmes. The aim of this mixed-methods paper is to describe how the distance to cervical cancer treatment locations impacts women in Uganda.

## METHODS

### Data collection

This mixed-methods cross-sectional study is part of a larger study, ASPIRE GENERATIONS, which aims to understand the social and economic impacts of cervical cancer on women and children in Uganda. The study consisted of a structured survey, chart review, and qualitative interviews among selected participants. Women were recruited from 19 September 2022, to 17 January 2023. We recruited women from both the UCI in Kampala as well as a satellite clinic at Jinja Regional Referral Hospital (JRRH). Women participating in the quantitative section were recruited from the gynaecology-oncologic department at UCI in Kampala and the cancer unit at JRRH. Women participating in the qualitative section were recruited only from the gynaecology-oncology department at UCI in Kampala. Women were eligible for the study if they were (i) aged  $\geq 18$  years with a histopathologic diagnosis of cervical cancer; (ii) being treated at the UCI or JRRH for cervical cancer; and (iii) able to provide consent to participate in the study in English, Luganda, Lusoga, Luo, or Runyankole.

Trained research nurses collected data in all five included study languages for both the quantitative and qualitative sections. For the quantitative section, women were recruited using convenience sampling. All eligible women were identified and approached from the clinic waiting room. The quantitative survey was orally administered on electronic tablets using REDCap software [18] to consented women in a private room. We chose to orally administer the survey as there were varying literacy levels in the population and as such, we determined this to be the best way to distribute the survey. A select number of participants who completed the quantitative section were recruited for a qualitative interview. We sampled women based on information power [19] in order to recruit a demographically diverse sample that includes women with different stages of cancer, geographic location, and ages.

## Quantitative survey tool

The included survey questions are part of a larger 161-question survey tool. Each participant completed a survey which took approximately 45 min. The survey included questions on a participant's demographics, cancer care, economic situation, social situation, and children.

Several variables were included in this analysis to understand the amount of time women spend away from home to attend cervical cancer treatment. Questions in this section of the survey were informed by Yap et al., a 2018 study that measured the out-of-pocket and catastrophic health expenditure of families of children receiving surgery in Uganda [20]. First women were asked how many hours they travelled to attend the clinic that day. Women were then asked what type of transportation method they used to travel to the clinic. Choices included taxi-bus, boda boda (i.e., motorcycle), personal car, plane, boat, by foot, bicycle, other, or do not know. Women were also asked how many nights they planned to spend away from home with the option of selecting zero, one, two, or three or more nights. If a woman indicated that she was spending one or more nights away, they were asked where they planned to spend the night. Response options were clinic, hotel, hostel, family, friend, other, or do not know.

Additionally, several participants and cancer demographics were included in this analysis. They included the participant's age, marital status, whether or not they were in a polyamorous relationship, education, number of children in their household, occupation, time since diagnosis, most recent cancer stage, and cancer treatment received.

## Qualitative interview

Semi-structured interviews were conducted by nurses, in a private room to explore the social impacts of participants' cervical cancer diagnosis and treatment. Questions were developed to be part of the larger study on the socio-economic impacts of cervical cancer on women and children and, as such, women were asked three open-ended questions on how their cervical cancer diagnosis has impacted their children, family, and social relationships. Interviews were conducted and audio recorded in the participant's preferred language. Following completion, they were translated into English by a Ugandan transcriptionist. All translated transcripts were then checked for accuracy.

## Analysis

The quantitative analyses were conducted using R 4.2.3 [21]. All descriptive statistics were calculated using counts and frequencies. The values were provided for all variables that contained missing data. Chi-square and Fisher-exact tests were used to analyse the bivariate data. A choropleth map was developed using the R package ggplot2 [22]. The district

map was retrieved from the United Nations High Committee for Refugees [23].

The qualitative analysis was completed using NVivo 12 software [24]. Data were analysed using an inductive-deductive thematic analysis approach [25]. Initial coding was informed by the research objective and from this, emerging key themes were identified.

The convergent parallel mixed-methods approach was used in which the qualitative data was used to further the interpretation of the quantitative data to inform findings [26]. In this analysis, the quantitative data was weighted more heavily. The two datasets were interpreted to understand how the quantitative and qualitative data compared and diverged [27].

## Ethics

Ethics for this study was approved by the University of British Columbia (H17-02435), UCI (UCI-2022-39), and the Uganda National Council of Science and Technology (HS2420ES).

## RESULTS

### Quantitative

In all, 351 women participated in the quantitative section. Participants' demographics and cancer characteristics in Table 1. The majority of the women were recruited from the Kampala clinic (90.6%,  $n = 318$ ). Most women were between the ages of 36–65, were married or in a relationship, and had an education level of primary school or less. Furthermore, 80.6% ( $n = 283$ ) of women reported having children ( $\leq 17$  years) in their household. With regards to their cervical cancer diagnosis, the majority of women were most recently staged with stage II or III cervical cancer. Additionally, the most common treatments reported by participants were chemotherapy (78.5%,  $n = 274$ ) and radiation (80.8%,  $n = 282$ ).

Figure 1 is a map of Uganda which includes each district in the country. The map depicts the number of women in the study from each district in Uganda. The majority of women in the study were from either the districts of Kampala or Wakiso. In all, women spent an average of 3.6 h (standard deviation 2.7, range 0–14 h) travelling to Kampala and 1.4 h (standard deviation 1.2, range 0–5 h) travelling to Jinja. The most common ways women travelled to the clinic were a bus/taxi ( $n = 296$ , 84.3%) and boda boda ( $n = 86$ , 24.5%).

Among the 351 women who participated in the study, 313 (89.2%) indicated that this was not their first visit to the clinic. Of these 313 women who had made multiple visits to the clinic since their diagnosis, 75 (24.0%) indicated that they had made 10 or less visits to the clinic, 33 (10.5%) indicated that they had made 11–20 visits, and 73 (23.3%)

**TABLE 1** Demographic information of the quantitative participants.

Variable name	n (%)
Sample size	351
Site	
Kampala	318 (90.6)
Jinja	33 (9.4)
Age	
18–25	1 (0.3)
26–35	31 (8.8)
36–45	82 (23.4)
46–55	117 (33.3)
56–65	81 (23.1)
66+	37 (10.5)
Missing	2 (0.6)
Marital status	
Married/In a relationship	137 (39.0)
Single	31 (8.8)
Separated/Divorced	75 (21.4)
Widowed	102 (29.1)
Do not know	2 (0.6)
Missing	4 (1.1)
Religion	
Anglican	110 (31.3)
Catholic	125 (35.6)
Other Christian	63 (17.9)
Muslim	50 (14.2)
Other	1 (0.3)
Missing	2 (0.6)
Education	
≤ Primary school	218 (62.1)
> Primary school	122 (34.8)
Missing	11 (3.1)
Number of children in household	
None	56 (16.0)
1	36 (10.3)
2–3	124 (35.3)
4+	123 (35.0)
Missing	12 (3.4)
Occupation	
Businessperson	75 (21.4)
Farmer	99 (28.2)
Housewife	28 (8.0)
Other	48 (13.7)
Not employed	96 (27.4)
Missing	5 (1.4)
Time since diagnosis	
< 6 months	78 (22.2)
6 months–1 year	66 (18.8)
1–2 years	103 (29.3)

(Continues)

**TABLE 1** (Continued)

Variable name	n (%)
3+ years	60 (17.1)
Do not know	4 (1.1)
Missing	40 (11.4)
Cancer stage	
I	61 (17.4)
II	112 (31.9)
III	133 (37.9)
IV	40 (11.4)
Missing	5 (1.4)
Self-reported treatment <sup>a</sup>	
None	3 (0.9)
Chemotherapy	274 (78.5)
Radiation	282 (80.8)
Surgery	48 (13.8)
Palliative care	40 (11.5)

<sup>a</sup>Multiple response option.

indicated that they had made 21 or more visits to the clinic. The remaining 132 women indicated that they did not know how many visits they had made to the clinic (42.2%). The majority of women (53.6%,  $n = 188$ ) noted that they would not spend the night away from home on this visit. However, 20.5% ( $n = 72$ ) women said that they would spend at least three nights away from home to receive treatment. Notably, no woman said that they would spend 1–2 nights away from home; however, 74 (21.1%) said that they did not know if they would spend the night away from home. Among the 72 women who said that they would spend the night away from home, 65.3% ( $n = 47$ ) had a child under the age of 18. Finally, when asked where they would spend the night, most of the 72 women reported a hostel (59.7%,  $n = 43$ ), or with family (16.7%,  $n = 12$ ).

## Qualitative

In all, 24 women were interviewed. Among the women who participated in the qualitative section, their ages ranged between 29 and 68 years, with a mean age of 49.5 years. The majority of the women were married ( $n = 9$ ) or widowed ( $n = 8$ ). Over half had a primary school or less education ( $n = 13$ ) and one-third were a farmer for their occupation ( $n = 8$ ). The three major themes that were identified are as follows.

## Means of transportation

As the UCI in Kampala is the central cancer treatment centre and the vast majority of participants were not from Kampala, many had to travel, sometimes great distances, to

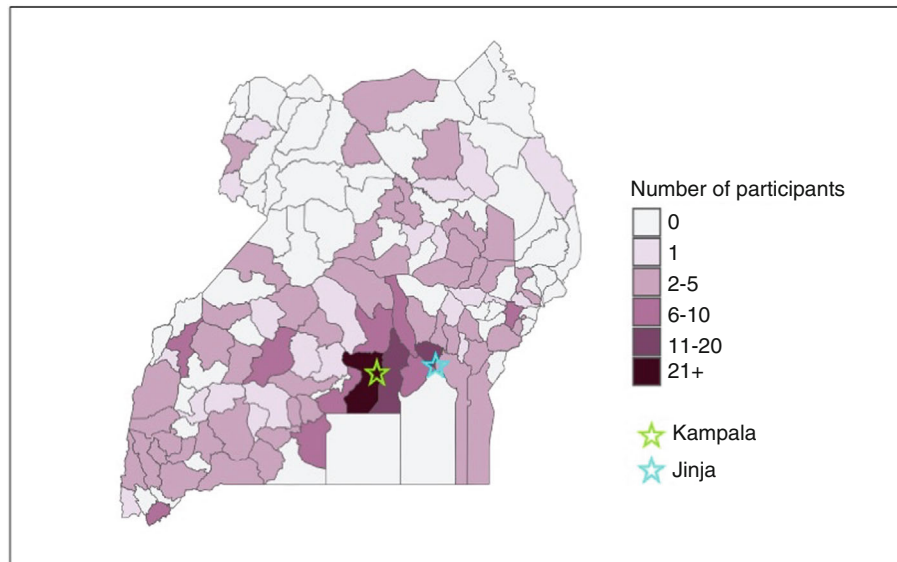


FIGURE 1 Participants home district.

receive care. Participants spoke about the various methods of transportation that they used to arrive at the clinic which included boda bodas, motorbikes, and taxi buses. One participant noted that travelling by taxi bus or boda boda was not a viable option and that they resorted to travelling by foot.

But remember there was no means of transport. There were no taxis, no buses, apart from motor bikes. And I told her that, musawo I have no money. I had only 40,000 Ugs in the house in my life. Now the health worker told me to go, she wrote me a referral letter and I went to Kawempe. When I asked the motor cyclists to take me, they told me 70,000Ugs which was more than what I had. What I did, musawo I woke up in the morning at 5am and walked up to Kawempe from Munyonyo.

(Unemployed, age 39)

### Spending the night away from home

As participants were often required to travel significant distances for care, many reported spending one or more nights away from home. One woman recalled that she had to travel to receive initial care and then spent the night at the hospital because there was no overnight transportation available to take her to a healthcare facility that provided a greater level of care.

They took me to the hospital but it was small hospital as you know village ones...And said we can't manage this individual, take her to city. The daughter in-law said that where will I go, it is 1am, where will I start from?...The

health worker told me that okay; sleep over then you go in the morning. Now when we slept there, in the morning at 6 am we boarded a taxi and arrived in the city (in the city at the big hospital), and they put me on a drip.

(Farmer, age 63)

### Financial factors

Participants spoke about the financial burden of travel. Some women reported that the high cost of transport prevented them from accessing needed care.

Sometimes I fail to get the money to bring me from home to come here and I decide to miss, and I don't come here to save my life yes.

(Farmer, age 39)

To obtain the money they required for transport, women reported selling their belongings and receiving financial support from family members. The financial burden associated with the transportation required to access cervical cancer care was not limited to the patient themselves, but often-times impacted other household members such as their husbands.

He [husband] said that I brought him poverty, every money he gets he must give it to me to come to the hospital...He used to bring me... He said that my work is getting spoilt, all the time Mulago, Mulago has become Mulago. It takes money, I have to escort you, sometimes you don't have strength.

(Farmer, age 39)

Some women reported redirecting household funds towards their treatment travel costs, which sometimes meant pulling their children out of school.

The children have been affected so much. Those who were studying, they did not study because of school fees and there was no money, because it was taking care of me in transport to come to the hospital.

(Unemployed, age 60)

## DISCUSSION

This mixed-methods analysis recruited 351 participants for the quantitative section and 24 for the qualitative section. Overall, our findings show that travelling to obtain cervical cancer care can be a significant burden for women in Uganda. The quantitative and qualitative findings largely align and support one another. However, as a whole, the qualitative findings provide a more robust understanding of how a woman's financial situation can increase the stress of care with regard to transportation. For example, we found in the quantitative findings that women most often travelled to the clinic by bus/taxi or boda boda, which are considered a form of public transportation in Uganda. However, this may be because they are the most affordable option. A bus/taxi costs approximately 500–2000 UGX (\$0.20–0.60 USD) within Kampala [28]. For women experiencing financial strain, public transportation or walking may be the only viable option for reaching the cancer clinic. This highlights the increased burden that the need for transportation puts on women who do not live within walking distance of the clinic. These findings are further supported by Germans et al. who reported in their qualitative study that women walked to the clinic due to financial difficulties [13]. Similarly, one woman in the qualitative section of this study noted that she skips her appointments when she does not have the funds to travel to the clinic. Further research is needed to better understand how many women forgo care because they cannot obtain transportation to receive cervical cancer treatment.

The results of this study highlight the burden that centralised cervical cancer care can have on women in Uganda. Our quantitative findings showed that over one in four women in Uganda are required to travel significant distances to receive treatment and one in five spend the night away from their home communities. The qualitative theme 'spending the night away from home' further supported this burden. This is an important finding because it highlights the added strain that a cervical cancer diagnosis has on women in Uganda. Not only are women being removed from their communities and support systems to undergo cervical cancer treatment, but many of them are required to travel significant distances, while in poor health, in order to receive treatment. Notably approximately half of the women in the quantitative analysis had advanced stages of cervical cancer. Symptoms of advanced cervical cancer include incontinence, leg swelling, tiredness, severe back

pain, blood in the urine, and vaginal bleeding [29, 30]. This means that many of these women are likely travelling, on poor road conditions using public transportation, while they are severely ill. Travelling significant distances for cancer care with no provided support strips away the dignity of women in Uganda. The primary focus of these women should be getting healthy, not wondering where they will spend the night.

This study has several strengths and limitations. First, this study is strengthened by the study team's experience conducting collaborative cervical cancer research in Uganda. Secondly, the use of tablets to collect the quantitative data is a strength as it reduces the chance of data entry errors. Furthermore, the study is strengthened by its novelty. To our knowledge, this is the first mixed-methods study to examine the amount of time women spend away from home to receive cervical cancer treatment in sub-Saharan Africa. The study has several limitations. First, the study is limited by its sampling type. Convenience sampling was used to recruit women into the study which could lead to selection bias [31]. Similarly, while the quantitative sample included participants from Jinja, they were not included in the qualitative sample due to study resource constraints. Finally, interviews did not probe about transportation specifically; nevertheless, the challenges associated with clinic location and transportation frequently came up. We believe this reflects the woman's lived experience and highlights this as a significant issue for Ugandan women with cervical cancer.

This mixed-methods study demonstrates that the location of cervical cancer care facilities has a significant burden on women in Uganda. The Ugandan Ministry of Health should consider approaches to reduce this strain. For example, opening regional centres that offer comprehensive treatment such as chemotherapy and surgery would allow women to stay closer to their communities and support systems. Additionally, offering funded or subsidised transportation options may increase the number of women who are able to seek care. Providing safe, reliable, transportation options for women seeking cervical cancer care is essential for reducing global cervical cancer mortality.

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## CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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