

## RESEARCH ARTICLE

# The economic burden of cervical cancer on women in Uganda: Findings from a cross-sectional study conducted at two public cervical cancer clinics

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**Data Availability Statement:** Data cannot be shared publicly due to ethical restrictions, as participants did not provide consent at the time of data collection for data to be shared publicly. Anonymized minimal data set will be made available by request for researchers who meet the criteria for access to confidential data and approval by the UBC Research Ethics Board (contact via [cwreb@bcchr.ubc.ca](mailto:cwreb@bcchr.ubc.ca)).

## Abstract

There is limited research on how a cervical cancer diagnosis financially impacts women and their families in Uganda. This analysis aimed to describe the economic impact of cervical cancer treatment, including how it differs by socio-economic status (SES) in Uganda. We conducted a cross-sectional study from September 19, 2022 to January 17, 2023. Women were recruited from the Uganda Cancer Institute and Jinja Regional Referral Hospital, and were eligible if they were  $\geq$  of 18 years and being treated for cervical cancer. Participants completed a survey that included questions about their out-of-pocket costs, unpaid labor, and family's economic situation. A wealth index was constructed to determine their SES. Descriptive statistics were reported. Of the 338 participants, 183 were from the lower SES. Women from the lower SES were significantly more likely to be older, have  $\leq$  primary school education, and have a more advanced stage of cervical cancer. Over 90% of participants in both groups reported paying out-of-pocket for cervical cancer. Only 15 participants stopped treatment because they could not afford it. Women of a lower SES were significantly more likely to report borrowing money (higher SES  $n = 47$ , 30.5%; lower SES  $n = 84$ , 46.4%;  $p$ -value = 0.004) and selling possessions (higher SES  $n = 47$ , 30.5%; lower SES  $n = 90$ , 49.7%;  $p$ -value = 0.006) to pay for care. Both SES groups reported a decrease in the amount of time that they spent caring for their children since their cervical cancer diagnosis (higher SES  $n = 34$ , 31.2%; lower SES  $n = 36$ , 29.8%). Regardless of their SES, women in Uganda incur out-of-pocket costs related to their cervical cancer treatment. However, there are inequities as women from the lower SES groups were more likely to borrow funds to afford treatment. Alternative payment models and further economic support could help alleviate the financial burden of cervical cancer care in Uganda.

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## Introduction

Cervical cancer is one of the leading causes of cancer among women globally, despite being a preventable disease [1]. The burden of cancer is rapidly growing in Africa. It is estimated that by 2040, the number of new cancer cases in Africa will increase by 37% and cancer deaths will increase by almost 40%. The burden of cervical cancer in Africa is expected to rise from 117,000 new cases in 2020 to 164,000 in 2030 [2]. This is significant because cervical cancer is an entirely preventable disease as a result of vaccination and screening tools. Currently, sub-Saharan African health systems are largely ill-equipped to handle the steadily increasing number of cancer cases. Much of the cancer care response to date has been reactive rather than proactive, with more investment in treatment than prevention [3]. Challenges in cancer care within the continent can be attributed to insufficient training of healthcare staff, absence of diagnostic facilities, weak coordination systems, and, most critically, insufficient funding [3]. This in turn has made it difficult for women to access high-quality cancer screening and treatment services.

Few countries in sub-Saharan Africa currently offer universal healthcare [4]. Given this, there is little research on how a cervical cancer diagnosis and subsequent treatment can financially impact individuals and their families in Africa. Economic impacts are defined as any change to an individual's financial status and can be direct (e.g., costs of medical treatment) or indirect (e.g., loss of work). Of the literature available, a large portion is qualitative in design [5–7]. In Uganda, user fees from national healthcare costs were eliminated in 2001, which resulted in an increase in seeking care at government-sponsored healthcare facilities [8]. However, it has widely been reported that individuals still often pay out-of-pocket for care at these facilities as not all costs are in fact universally covered [9–12]. In 2022, Germans et al. published a qualitative study on the socio-economic burden of cervical cancer on women in Uganda which largely focused on the financial burden. They found that a cervical cancer diagnosis leads to economic disruptions and can further exasperate a family's financial security. However, this sample was limited to rural participants seeking care at hospice centers and did not report on indirect financial outcomes such as reducing necessary household expenditures to pay for treatment costs and changes in unpaid labor (e.g., child minding) [13].

Dau et al reported in their 2022 systematic review that there are only two studies in low- and middle-income countries that quantify the direct and indirect costs of cervical cancer treatments [14–16]. However, as they are limited to two countries, they provide a limited understanding of the global burden. The first study by Hailu et al. in Ethiopia measured both direct costs such as consultation fees and indirect costs such as lost wages. The study team concluded that cervical cancer has a significant financial burden on women diagnosed as women often have to pay for direct costs such as treatments, transportation, and medication. Moreover, they report that women lost an average of 119 working days during the course of their treatment [14]. The second, Singh et al. from India, focuses primarily on direct costs such as treatment fees and reports similar findings [15].

It is important to understand the economic impact of a woman's cervical cancer treatment as it can have both far-reaching consequences. A 2021 study by Ngcamphalala et al. in Eswatini found that loss of productivity (i.e., loss of wages) due to premature death from cervical cancer is a significant burden of indirect costs [17]. Moreover, previous research has shown that a quarter of patients at the Uganda Cancer Institute (UCI) have lost their jobs as a result of their cancer diagnosis [18]. However, this research is limited in its applicability here as it does not specifically speak about cervical cancer. In Uganda, like many parts of the world, women spend one and a half more time on childcare when compared to men [19]. This means that when women are diagnosed with cervical cancer, unpaid labor such as child minding, needs to

also be considered along with traditional measures of impact such as lost wages and unemployment when speaking about the overall economic impact. Not only is it a tragedy that women and their families are experiencing economic hardship as a result of their cervical cancer treatment, but moreover this is stemming from a preventable disease. It is important to quantify the economic burden of cervical cancer because it can be used to provide evidence to invest in the expansion of preventative programs, such as cervical cancer screening, which can reduce the long-term incidence of cervical cancer and ultimately reduce the economic burden on women. As such, additional research is needed in more countries to highlight the economic burden of cervical cancer. The objective of this analysis is to describe the economic impact of cervical cancer treatment, including how this differs by socio-economic status in Uganda.

## Methods

### Study population

This analysis is part of a larger exploratory cross-sectional study which aims to understand the social and economic impacts of cervical cancer on women and their children in Uganda. 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 in Kampala or JRRH cancer clinic for cervical cancer; and (iii) able to provide consent to participate in the study in English, Luganda, Lusoga, Luo, or Runyankole.

### Study site

We recruited women from September 19, 2022 to January 17, 2023 using convenience sampling at the gynecology-oncologic department at UCI in Kampala and the cancer unit at Jinja Regional Referral Hospital (JRRH). The UCI in Kampala is the only public center that offers comprehensive cervical cancer care. This includes radiation therapy, chemotherapy, surgery preventative care, and survivorship support. The clinic at JRRH is limited to pre-cancer screening and treatment, diagnosis, and palliative care.

### Data collection

Oncology nurses trained in data collection procedures and fluent in the five study languages recruited women and orally administered a 45-minute cross-sectional survey on electronic tablets using REDCap software [20]. As not everyone who participated in the study was literate, we chose to orally administer the survey for equity and to reduce bias.

### Survey tool

Out-of-pocket medical costs were informed by two existing surveys. The first was a cross-sectional study from Nepal by Khatiwoda et al. which measured the cost of cancer care [21]. The second was a cross-sectional study from Uganda on pediatric surgical expenditure by Yap et al. [9] Women in the study were asked to note what forms of medical care they had paid out-of-pocket for (e.g., chemotherapy, medication, bed, consult). It should be noted that while women were asked to report on what forms of care they paid out of pocket for, they were not asked to note all forms of care they received. Following, women were asked to provide the total amount that they had paid out-of-pocket since their cancer diagnosis. In addition to their cancer care, women were also asked how much they paid out-of-pocket for the indirect costs of transportation, housing, and food in the past month. Response options ranged from 0 UGX to 1,000,001+ UGX. These responses were recategorized to be a yes or no question in which women who indicated 0 UGX were classified as no and any monetary amount was classified as

yes. Women who did not provide a monetary amount because they refused to answer the question or did not know were not included in the denominator as they were considered missing.

Women were asked if anyone in their family received any type of support for their treatment or care. Check all options included cash support, waiver support (e.g., housing voucher), in-kind support, none, or do not know. Women were also asked if they needed any food, transportation, or accommodation support. Additionally, women were asked if they stopped or refused any cancer care because of the costs. If they answered yes, they were prompted to note which treatment(s).

The survey asked women if they had to reduce household expenditures to help pay for their cervical cancer treatment. Select all response options included borrowed money from family, asked for charity/begged, sold possessions (e.g., land, car, furniture), moved to more affordable housing, withdrew child from school, reduced food consumed, changed transportation type, cut down on other needs, no, and do not know.

The survey included questions on the woman's employment. The first question asked women if they took any time off work to attend the clinic today. If applicable, women were also asked if any of the adults in their family (excluding themselves) either left their employment, reduced the number of hours worked, increased the number of hours worked, or missed work because of their cervical cancer treatment. Answers included no, yes, not applicable, do not know, and refused. Only women who provided a yes or no answer were reported in this analysis. All other answers were recategorized to be missing.

In addition to the monetary impact that their cervical cancer treatment had on their family, women were also asked about unpaid labor. Women were asked how the amount of time had changed (increased, decreased, stayed the same not applicable, do not know) that they spent on certain household chores since their cervical cancer diagnosis. Questions included buying food, caring for children, cooking food, cleaning the house, retrieving water, assisting children with work, and washing clothes.

Demographic variables included in this analysis were as follows: participants age, marital status, education, economic status, number of children in their household, occupation, economic status, time since diagnosis, cancer stage, and cancer treatment received. Additional variables collected related to SES were informed by Rutstein [22] and were as follows: home floor type, cooking fuel type, toilet type, residence type, and electricity in the home were considered for the wealth index as well as ownership of a smartphone, basic phone, computer, sewing machine, bicycle, car, motorcycle, fridge, and sofa. Smartphone and basic phone were recategorized as "phone" and car and moto were recategorized as "vehicle".

## Analysis

Frequencies and proportions were used to construct all descriptive statistics. Bivariate data was analyzed using chi-square and fisher-exacts tests for categorical data and t-test for numeric. P-values  $\leq 0.05$  were considered significant. Surveys with more than 75% of missing data were removed from the analysis. All analyses were conducted using R 4.2.3 [23].

Principal component analysis was used to construct the wealth index to classify SES [24, 25]. All considered variables were first recoded to be binary. The variables floor material type [26], cooking fuel type [27], toilet type [28], drinking water source [28, 29], and residence type [22] were categorized as either improved (yes) or unimproved (no) based on global standards. The remaining variables were categorized as either own (yes) or do not own (no). Following, all of the asset variables were reviewed and those in which under 5% or over 95% of the sample indicated yes, were removed [30]. A complete case analysis was used as there was a small percentage (3.7%) of rows with missing data [25]. The R package "psych" was used to conduct the

principle component analysis [31–33]. The varimax rotation was used with one component for extraction was included in the final index [25, 32, 33]. In all, nine participants were excluded from the wealth index due to insufficient data for computation. The final index included the variables: improved floor, improved toilet, improved water source, electricity in the house, radio, television, refrigerator, sofa, phone, and vehicle. The index was split into two wealth quintiles which were labeled as higher socio-economic status (higher SES and lower SES). These grouping are based on the SES of the participants in the sample, not the study population.

## 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). Written consent was obtained from all participants. If a participant was unable to read or write, the consent form was read aloud to the participant and a thumbprint was accepted in lieu of a signature.

## Results

In total, 155 participants were classified in the higher SES category and 183 in lower SES category. Among the participants in the higher SES, the mean age was 50.4 (+/- 11.3) and among the lower SES it was 52.4 (+/- 11.7) ( $p < 0.001$ ). Most notably, while only 17.4% ( $n = 27$ ) of the higher SES women reported being widowed, 37.7% ( $n = 69$ ) of the lower SES reported being widowed ( $p$ -value  $< 0.001$ ). Additionally, 74.9% ( $n = 137$ ) of the lower SES women had a primary school of less education compared to 46.5% ( $n = 72$ ) of the higher SES ( $p$ -value  $< 0.001$ ). In terms of stage, 15.8% ( $n = 29$ ) of the lower SES women were diagnosed with stage I compared to 6.5% ( $n = 10$ ) of the higher SES women ( $p$ -value  $< 0.001$ ). [Table 1](#) provides further demographic information.

Among the women surveyed, 95.5% ( $n = 148$ ) of women from the higher SES and 92.3% ( $n = 169$ ) of women from the lower SES reported that they paid out-of-pocket for at least one item related to their medical care ( $p = 0.3354$ ). The most common items that women reported paying out-of-pocket for both SES groups were x-ray (higher SES  $n = 129$ , 83.2%; lower SES  $n = 157$ , 85.8%), scan (higher SES  $n = 127$ , 81.9%; lower SES  $n = 156$ , 85.2%), and radiation (higher SES  $n = 120$ , 77.4%; lower SES  $n = 137$ , 74.9%). When asked how much they had spent, in total, on their cervical cancer treatment, 76 women of the higher SES and 93 women of the lower SES were able to provide an amount. The majority of the women in both groups reported between 500,001 to 2,000,000 UGX (between \$130–530 CAD). [Table 2](#) reports on the indirect costs that women paid out-of-pocket for in the past month by SES. Over 90% of women from both SES groups reported paying for food and transportation costs related to their care.

Moreover, only nine (5.8%) women from the higher SES and six (3.3%) women from the lower SES reported that they stopped their cervical cancer treatment because they could not afford it. Among these 15 women, the most common treatments stopped due to cost were medications, biopsy, and radiation.

In all, only four (2.6%) women from the higher SES and six (3.3%) women from the lower SES reported that they received in-kind support. When asked about what kind of in-kind or financial support they needed while receiving treatment, 49 (31.6%) higher SES and 80 (43.7%) the lower SES said food, 50 (32.3%) higher SES and 73 (39.9%) lower SES said transportation, and 23 (14.8%) higher SES and 24 (13.1%) the lower SES said housing.

Table 1. Participant demographic information by socio-economic status.

Variable name	Overall	Higher SES	Lower SES	P-value
Sample size	338	155	183	
Site				0.629
Kampala	308 (91.1)	143 (92.3)	165 (90.2)	
Jinja	30 (8.9)	12 (7.7)	18 (9.8)	
Age				
Range	20–82	27–78	20–82	
Mean (SD <sup>a</sup> )	50.4 (11.3)	48.2 (10.4)	52.4 (11.7)	0.001
Missing	2 (0.6)	1 (0.6)	1 (0.5)	
Marital status				<0.001
Married/In a relationship	134 (39.6)	75 (48.4)	59 (32.2)	
Single	31 (9.2)	17 (11.0)	14 (7.7)	
Separated/Divorced	73 (21.6)	34 (21.9)	39 (21.3)	
Widowed	96 (28.4)	27 (17.4)	69 (37.7)	
Do not know	2 (0.6)	2 (1.3)	0 (0.0)	
Missing	2 (0.6)	0 (0.0)	2 (1.1)	
Religion				0.003
Anglican	108 (32.0)	44 (28.4)	64 (35.0)	
Catholic	121 (35.8)	47 (30.3)	74 (40.4)	
Other Christian	61 (18.0)	32 (20.6)	29 (15.8)	
Muslim	47 (13.9)	32 (20.6)	15 (8.2)	
Other	1 (0.3)	0 (0.0)	1 (0.5)	
Education				<0.001
≤ Primary school	209 (61.8)	72 (46.5)	137 (74.9)	
> Primary school	120 (35.5)	76 (49.0)	44 (24.0)	
Missing	9 (2.7)	7 (4.5)	2 (1.1)	
Number of children in household				0.337
None	54 (16.0)	25 (16.1)	29 (15.8)	
1	35 (10.4)	20 (12.9)	15 (8.2)	
2–3	119 (35.2)	58 (37.4)	61 (33.3)	
4+	120 (35.5)	49 (31.6)	71 (38.8)	
Missing	10 (3.0)	3 (1.9)	7 (3.8)	
Occupation				<0.001
Businessperson	74 (21.9)	60 (38.7)	14 (7.7)	
Farmer	97 (28.7)	23 (14.8)	74 (40.4)	
Housewife	28 (8.3)	17 (11.0)	11 (6.0)	
Other	45 (13.3)	20 (12.9)	25 (13.7)	
Not employed	91 (26.9)	34 (21.9)	57 (31.1)	
Missing	3 (0.9)	1 (0.6)	2 (1.1)	
Time since diagnosis				0.865
≤ 1 year	139 (41.1)	67 (43.2)	72 (39.3)	
> 1 year	159 (47.0)	74 (47.7)	85 (46.4)	
Missing	40 (11.8)	14 (9.0)	26 (14.2)	
Cancer stage				<0.001
I	58 (17.2)	41 (26.5)	17 (9.3)	
II	111 (32.8)	52 (33.5)	59 (32.2)	
III	125 (37.0)	48 (31.0)	77 (42.1)	
IV	39 (11.5)	10 (6.5)	29 (15.8)	

(Continued)

Table 1. (Continued)

Variable name	Overall	Higher SES	Lower SES	P-value
Missing	5 (1.5)	4 (2.6)	1 (0.5)	
Treatment received <sup>b</sup>				
None	2 (0.6)	1 (0.6)	1 (0.5)	-
Chemotherapy	269 (79.6)	124 (80.0)	145 (79.2)	0.969
Radiation	277 (82.0)	126 (81.3)	151 (82.5)	0.881
Surgery	44 (13.0)	32 (20.6)	12 (6.6)	<0.001
Palliative Care	40 (11.8)	13 (8.4)	27 (14.8)	0.102

<sup>a</sup> Standard deviation

<sup>b</sup> Multiple response question

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When asked how the women paid for their cancer care 154 women from the higher SES and 181 from the lower SES responded. Women of a lower SES were significantly more likely to report borrowing money (higher SES  $n = 47$ , 30.5%; lower SES  $n = 84$ , 46.4%;  $p$ -value = 0.004) and selling possessions (higher SES  $n = 47$ , 30.5%; lower SES  $n = 90$ , 49.7%;  $p$ -value = 0.006). On the other hand, women of a higher SES were statistically more likely to report not needing to seek out money to pay for their cervical cancer treatment (higher SES  $n = 65$ , 42.2%; lower SES  $n = 44$ , 24.3%;  $p$ -value = 0.001).

When asked if they took time off work to attend the clinic today, 44.3% of women in the higher SES (58/131) and 11.7% of women from the lower SES (14/120) indicated yes ( $p < 0.001$ ). There was no statistically significant difference between the two groups when asked if someone in their family either left their employment (higher SES  $n = 66/140$ , 47.1%; lower SES  $n = 62/147$ , 42.2%), reduced the number of hours worked (higher SES  $n = 69/139$ , 49.6%; lower SES  $n = 71/147$ , 48.3%), or missed employment (higher SES  $n = 70/139$ , 50.4%; lower SES  $n = 74/153$ , 48.4%). However, women from the higher SES were more likely to report that someone in their household took time off of work to care for them (higher SES  $n = 58/131$ , 44.3%; lower SES  $n = 14/117$ , 14.0%;  $p$ -value < 0.001).

Fig 1 highlights the change in time that women spent on unpaid labor since their cervical cancer diagnosis. Among the 109 higher SES women and 121 lower SES women who had a child under the age of 18, 31.2% of the higher SES group ( $n = 34$ ) and 29.8% ( $n = 36$ ) of the lower SES group reported that the amount of time they spent caring for their children decreased after their diagnosis. Furthermore, 31.5% of the higher SES group ( $n = 34$ ) and 26.4% ( $n = 32$ ) of the lower SES group reported that they decreased the amount of time that they helped their children with schoolwork.

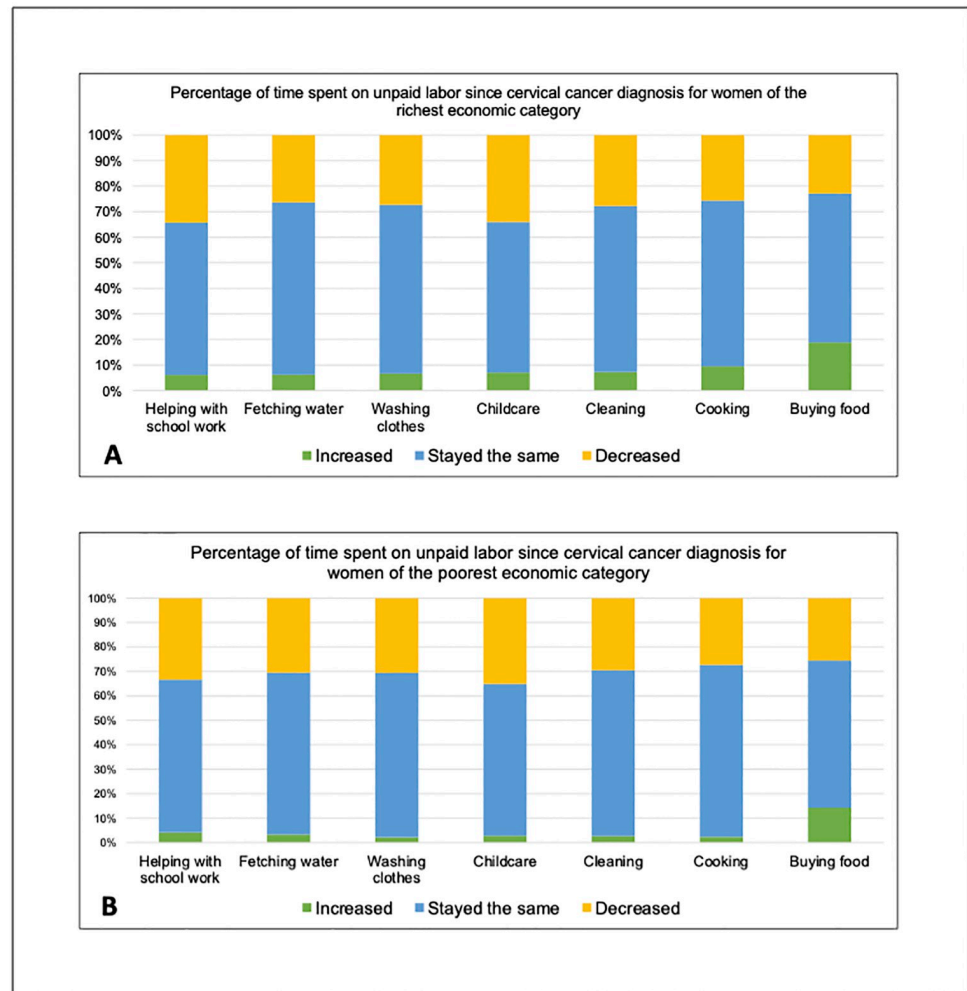
## Discussion

The results from the study show that women, regardless of their SES, incur out-of-pocket costs related to their cervical cancer treatment. The majority of women reported paying for

Table 2. Indirect costs that women paid out-of-pocket for in the past month by SES.

Variable	Higher SES % (n)	Lower SES % (n)	P-value
Food	94.1% (95/101)	95% (95/100)	1.000
Transportation	96.2% (101/119)	100% (97/97)	0.123
Accommodation	7.1% (9/127)	9.9% (14/142)	0.553

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**Fig 1. Changes in time spent on unpaid labor since the woman's cervical cancer diagnosis stratified by higher SES (A) and lower SES (B).**

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common procedures such as a scan or radiation- costs which are not covered by the government. However, women in the lower SES group were more likely to report having to seek out funds to pay for treatment costs such as biopsy, chemotherapy, and laboratory tests. While these care costs are covered by the government, it is known that women are sometimes required to pay out of pocket for them. This means that while required costs are largely equal across socio-economic groups, there are incidences of inequity within the healthcare system. Moreover, we found that women from the higher SES group were more likely to have someone take time off of work to care for them. This can most likely be attributed to financial stability as families for a higher SES may have the economic support to allow for a member of their family to forgo wages to support them during their treatment.

An important finding from this analysis is that women from the lower SES group were more likely to be diagnosed with higher stage of cervical cancer. These findings are aligned with Mwaka et al. who reported in their 2016 study from Northern Uganda that women who reported that financial difficulties were more likely to be diagnosed with an advanced stage of cancer than those who did not [34]. Most likely this is because they do not have regular,



reliable access to screening. Common barriers to cervical cancer screening in Uganda include lack of access to affordable, reliable transportation [35–37], accessible, wide-spread, screening services and infrastructure [37, 38], and available time to screen [36]. All of which can be exacerbated by financial poverty. With that, it is not uncommon for women in Uganda to seek cervical cancer treatment not as a result of screening results, but because they are experiencing symptoms [18]. As such, these results highlight the urgent need to expand and improve the cervical cancer screening program in Uganda. One of the most demonstrated practical, efficient, and effective ways to achieve this is through a human papillomavirus (HPV)-based self-sampling program [39]. Although the HPV vaccine has a high uptake rate in Uganda (75% for the first dose) [40] and will reduce mortality in the long-term, there is still a need to screen immediately women for cervical cancer to prevent women from dying of this disease today. HPV-based self-sampling allows women to self-screen for cervical cancer on their own or under the care of a trained health worker [41]. Research in Uganda has shown that HPV-based self-sampling is an effective and acceptable way to screen women for cervical cancer [42–44]. Moreover, HPV-based self-sampling methods have shown to be the most cost-effective method, particularly when focused on increasing population coverage [45, 46]. Providing wide-spread, accessible HPV-based self-sampling would eliminate the economic burden of cervical cancer treatment on women and their families as it would prevent women from developing the disease in the first place.

We found in our analysis that although women are required to pay out-of-pocket for cervical cancer treatment, it does not lead them to stop care once they have started. In all, only 15 women from the study stopped a treatment because they could not afford it. Rather women cut costs or borrowed money to fund their cervical cancer care. However, we found, unsurprisingly, that women of the lower SES group were more likely to borrow money when compared to those of the higher SES group. This finding is aligned with a multitude of research in various healthcare fields on how individuals from the poorest economic status face the greatest financial strain when faced with healthcare costs [47–50]. This is important to highlight because it demonstrates that a cervical cancer diagnosis can have reverberating financial effects for those most vulnerable. These findings are further aligned with several other studies in Uganda which reported out-of-pocket healthcare expenditure at government funded hospitals [9, 10, 51]. For example, Anderson et al. reported in 2017 on surgical patients in southwestern Uganda and found that 12.5% to 33% of surgical patients were pushed into poverty from their medical costs [10]. With that, our findings demonstrate a clear need for additional economic support for financially vulnerable women in Uganda.

This analysis highlights that when women with children are diagnosed with cervical cancer and undergo treatment, they spend less time fulfilling childcare roles. In fact, we found that approximately one in three women from both SES groups with children under the age of 18 reported spending less time caring for their children and one in three from the higher SES group and one in four from the lower SES group spend less time helping their children with schoolwork since their diagnosis. This finding aligns with qualitative research. For example, Molefe et al. reported that in Botswana women relied on family support to care for their children when they were unable to [52]. The findings from this research are important because globally, women are still expected to be the primary caregivers to children and, without them, children would be left without replacement support. While more research is needed, it cannot be assumed that this caregiving role is picked up by other family members such as husbands, mothers, or siblings. In fact, several research studies, including those in Ghana, Zambia, and Ethiopia, have reported in some incidences that male partners have abandoned their wives after their cervical cancer diagnosis [6, 53, 54]. With that, there needs to be a greater

consideration as to how a woman's cervical cancer diagnosis impacts the future generation as research has shown that children without mothers have poorer outcomes [55–59].

There are several strengths and limitations of this study. An important limitation of this study is that it only surveyed women who began treatment. This means that it excluded women who were diagnosed with cervical cancer but were unable to begin treatment due to financial barriers. This is important to highlight as it means these findings can only be taken in the context of those who were able to start treatment. Secondly, as this is a cross-sectional survey, we are unable to measure the direct change in a woman's financial situation over time, which limits our understanding of the impact. These findings are also limited to individuals who attended government sponsored hospitals in Uganda. This means that they are limited in scope to patients who attend the UCI in Kampala or JRRH and cannot be applied to the entire population as they exclude individuals who attend private hospitals or seek care outside of the country. This study did not ask women where they received their in-kind support from. Collecting this information would allow policymakers to better understand how to direct resources to support women. The wealth index was only split into two categories due to the sample size. This prevented us from fully understanding the policy needs of individuals in the middle socio-economic status. A strength of this analysis is that it provides new and unique data on the individual financial burden of cervical cancer in Uganda. These novel findings can be used to make policy and care recommendations about cervical cancer in the country. Additionally, as we asked women questions pertaining to the wealth index and how much money they earned per month, this enabled us to validate the wealth index against the woman's reported earnings.

This analysis highlights the economic burden that a cervical cancer diagnosis can have not only on women, but also their families. Although Uganda eliminated national healthcare costs in 2001, findings from this study demonstrate that women often have to pay out-of-pocket for direct treatment costs. Moreover, many women, particularly those of lower SES backgrounds, must source funds to pay for their care. This puts a financial stress on women while they are undergoing treatment and also likely creates a prohibitive treatment barrier. With that, the Ugandan Ministry of Health should reflect on how healthcare costs can be financed more equitably. The Ministry of Health could consider universal health financing models such as a national health insurance program with tiered premium levels according to income. Revenues from a national health insurance program could help specifically fund the healthcare system, while ensuring that citizens continue to have access to care.

Given the findings from the study, we have several recommendations in turns of health policy. More funding for cancer treatment programs through revenue such as a health insurance program would help offset the necessary costs for individuals undergoing treatment. In addition to this, our study supports the expansion of satellite clinics into more communities to help alleviate transportation, housing, and food costs for women travelling to the clinic, as this was a major source of out-of-pocket costs. This in turn would help prevent families from experiencing financial catastrophe and reduce the stress of seeking care. Additional education to destigmatize cervical cancer and traditional gender roles would help support mother's undergoing treatment. Most importantly though, the Ugandan Ministry of Health should consider expanding the screening and vaccination program for cervical cancer in order to prevent women from being diagnosed and dying of this preventable disease.

In conclusion, the results from our study demonstrate that cervical cancer has an economic impact on women in Uganda. Moreover, women from a lower SES experience a larger financial strain when undergoing treatment. Given the novelty of this data, future research, such as how a woman's marital status or number of children impact her economic stability, is needed

to better explore this issue. With this, we can better understand the widespread consequences of a cervical cancer diagnosis.

## Supporting information

### S1 Checklist. Inclusivity in global research checklist.

(DOCX)

### S2 Checklist. STROBE statement—Checklist of items that should be included in reports of cross-sectional studies.

(PDF)

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## References

1. Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, et al. Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: a cancer journal for clinicians*. 2021; 71(3):209–49. <https://doi.org/10.3322/caac.21660> PMID: 33538338
2. International Agency for Research on Cancer. Estimated number of new cases from 2020 to 2040, Both sexes, age [0–85+] Lyon, France: World Health Organization; 2023 [cited 2023 June 21]. <https://gco.iarc.fr/tomorrow/en/dataviz/bubbles>.
3. Ngwa W, Addai BW, Adewole I, Ainsworth V, Alaro J, Alatise OI, et al. Cancer in sub-Saharan Africa: a Lancet Oncology Commission. *The Lancet Oncology*. 2022; 23(6):e251–e312. [https://doi.org/10.1016/S1470-2045\(21\)00720-8](https://doi.org/10.1016/S1470-2045(21)00720-8) PMID: 35550267
4. Edwine B, Jacob K, Peter N, Nirmala R. Examining the level and inequality in health insurance coverage in 36 sub-Saharan African countries. *BMJ Global Health*. 2021; 6(4):e004712. <https://doi.org/10.1136/bmjgh-2020-004712> PMID: 33903176
5. Binka C, Doku DT, Awusabo-Asare K. Experiences of cervical cancer patients in rural Ghana: An exploratory study. *PloS one*. 2017; 12(10):e0185829–e. <https://doi.org/10.1371/journal.pone.0185829> PMID: 29020099

6. Kebede W, Kebede K. Psychosocial experiences and needs of women diagnosed with cervical cancer in Ethiopia. *International Social Work*. 2017; 60(6):1632–46. <https://doi.org/10.1177/0020872815617993>
7. Tadesse SK. Socio-economic and cultural vulnerabilities to cervical cancer and challenges faced by patients attending care at Tikur Anbessa Hospital: a cross sectional and qualitative study. *BMC women's health*. 2015; 15:75-. <https://doi.org/10.1186/s12905-015-0231-0> PMID: 26376638
8. Mugisha F, Kirunga C, MacQ J, Criel B. Abolition of user fees: the Uganda paradox. *Health Policy and Planning*. 2011; 26:ii41–51. <https://doi.org/10.1093/heapol/czr065> PMID: 22027918
9. Yap A, Cheung M, Kakembo N, Kisa P, Muzira A, Sekabira J, et al. From procedure to poverty: out-of-pocket and catastrophic expenditure for pediatric surgery in Uganda. *Journal of Surgical Research*. 2018; 232:484–91.
10. Anderson GA, Ilcisin L, Kayima P, Abesiga L, Portal Benitez N, Ngonzi J, et al. Out-of-pocket payment for surgery in Uganda: the rate of impoverishing and catastrophic expenditure at a government hospital. *PloS one*. 2017; 12(10):e0187293. <https://doi.org/10.1371/journal.pone.0187293> PMID: 29088302
11. Kwesiga B, Zikusooka CM, Ataguba JE. Assessing catastrophic and impoverishing effects of health care payments in Uganda. *BMC Health Services Research*. 2015; 15(1):30. <https://doi.org/10.1186/s12913-015-0682-x> PMID: 25608482
12. Nabyonga Orem J, Mugisha F, Okui AP, Musango L, Kirigia JM. Health care seeking patterns and determinants of out-of-pocket expenditure for Malaria for the children under-five in Uganda. *Malaria Journal*. 2013; 12(1):175. <https://doi.org/10.1186/1475-2875-12-175> PMID: 23721217
13. Germans N, Ellis P, Wilson S, Merriman A, Rabwoni M. The socioeconomic burden of a diagnosis of cervical cancer in women in rural Uganda: findings from a descriptive qualitative study. *International Journal of Palliative Nursing*. 2022; 28(7):322–32. <https://doi.org/10.12968/ijpn.2022.28.7.322> PMID: 35861442
14. Hailu A, Mariam DH. Patient side cost and its predictors for cervical cancer in Ethiopia: a cross sectional hospital based study. *BMC cancer*. 2013; 13:69-. <https://doi.org/10.1186/1471-2407-13-69> PMID: 23391288
15. Singh MP, Chauhan AS, Rai B, Ghoshal S, Prinja S. Cost of treatment for cervical cancer in India. *Asian Pacific Journal of Cancer Prevention (APJCP)*. 2020; 21(9):2639–46. <https://doi.org/10.31557/APJCP.2020.21.9.2639> PMID: 32986363
16. Dau H, Trawin J, Nakisige C, Payne BA, Vidler M, Singer J, et al. The social and economic impacts of cervical cancer on women and children in low- and middle-income countries: A systematic review. *International Journal of Gynecology & Obstetrics*. 2022; n/a(n/a). <https://doi.org/10.1002/ijgo.14395> PMID: 35962711
17. Ngcamphalala C, Östensson E, Ginindza TG. The economic burden of cervical cancer in Eswatini: Societal perspective. *Plos one*. 2021; 16(4):e0250113. <https://doi.org/10.1371/journal.pone.0250113> PMID: 33857233
18. Nakaganda A, Solt K, Kwagonza L, Driscoll D, Kampi R, Orem J. Challenges faced by cancer patients in Uganda: Implications for health systems strengthening in resource limited settings. *Journal of Cancer Policy*. 2021; 27:100263. <https://doi.org/10.1016/j.jcpo.2020.100263> PMID: 35559936
19. Addati L, Cattaneo U, Esquivel V, Valarino I. Care work and care jobs for the future of decent work: International Labour Organisation (ILO); 2018.
20. Harris PA, Taylor R, Minor BL, Elliott V, Fernandez M, O'Neal L, et al. The REDCap consortium: Building an international community of software platform partners. *Journal of biomedical informatics*. 2019; 95:103208. <https://doi.org/10.1016/j.jbi.2019.103208> PMID: 31078660
21. Khatiwoda SR, Dhungana RR, Sapkota VP, Singh S. Estimating the Direct Cost of Cancer in Nepal: A Cross-Sectional Study in a Tertiary Cancer Hospital. *Front Public Health*. 2019; 7:160. Epub 2019/07/12. <https://doi.org/10.3389/fpubh.2019.00160> PMID: 31294011
22. Rutstein SO. Steps to constructing the new DHS Wealth Index. Rockville, MD: ICF International. 2015.
23. R Core Team. R: A language and environment for statistical computing. Vienna, Austria: R Foundation for Statistical Computing; 2021.
24. Filmer D, Pritchett LH. Estimating wealth effects without expenditure data—or tears: an application to educational enrollments in states of India. *Demography*. 2001; 38(1):115–32. <https://doi.org/10.1353/dem.2001.0003> PMID: 11227840
25. Vyas S, Kumaranayake L. Constructing socio-economic status indices: how to use principal components analysis. *Health Policy Plan*. 2006; 21(6):459–68. Epub 2006/10/13. <https://doi.org/10.1093/heapol/czl029> PMID: 17030551.
26. Florey L, Taylor CA. Using household survey data to explore the effects of improved housing conditions on malaria infection in children in sub-Saharan Africa: ICF International; 2016.

27. World Health Organization. WHO guidelines for indoor air quality: household fuel combustion. Geneva: World Health Organization; 2014 2014.
28. WHO/UNICEF Joint Water Supply Sanitation Monitoring Programme. Progress on sanitation and drinking water: 2015 update and MDG assessment: World Health Organization; 2015.
29. World Health Organization. Safely managed drinking water: thematic report on drinking water 2017. 2017.
30. Hjelm L, Mathiassen A, Miller D, Wadhwa A. VAM Guidance Paper. Creation of an Asset Index. World Food Program, 2017.
31. Revelle W. psych: Procedures for psychological, psychometric, and personality research. version 2.2.9 ed: Evanston, IL; 2022.
32. Nyoro S. Constructing a wealth index: R Pubs by RStudio; 2019 [cited 2023 March 2]. <https://rpubs.com/Sternonyos/526030>.
33. Christine W. Wealth Index Across Provinces in Kenya: R Pubs by RStudio; 2020 [cited 2023 March 2]. <https://rpubs.com/ChristineWaita/658990>.
34. Mwaka AD, Garimoi CO, Were EM, Roland M, Wabinga H, Lyratzopoulos G. Social, demographic and healthcare factors associated with stage at diagnosis of cervical cancer: cross-sectional study in a tertiary hospital in Northern Uganda. *BMJ Open*. 2016; 6(1):e007690. Epub 2016/01/24. <https://doi.org/10.1136/bmjopen-2015-007690> PMID: 26801459
35. Rawlance N, Trasiyas M, Juliet K, David M. Knowledge, facilitators and barriers to cervical cancer screening among women in Uganda: a qualitative study. *BMJ Open*. 2017; 7(6):e016282. <https://doi.org/10.1136/bmjopen-2017-016282> PMID: 28606908
36. Li M, Nyabigambo A, Navvuga P, Nuwamanya E, Nuwasiima A, Kaganda P, et al. Acceptability of cervical cancer screening using visual inspection among women attending a childhood immunization clinic in Uganda. *Papillomavirus Research*. 2017; 4:17–21. <https://doi.org/10.1016/j.pvr.2017.06.004> PMID: 29179864
37. Twinomujuni C, Nuwaha F, Babirye JN. Understanding the Low Level of Cervical Cancer Screening in Masaka Uganda Using the ASE Model: A Community-Based Survey. *PLOS ONE*. 2015; 10(6):e0128498. <https://doi.org/10.1371/journal.pone.0128498> PMID: 26030869
38. Mutyaba T, Mmiro FA, Weiderpass E. Knowledge, attitudes and practices on cervical cancer screening among the medical workers of Mulago Hospital, Uganda. *BMC Medical Education*. 2006; 6(1):13. <https://doi.org/10.1186/1472-6920-6-13> PMID: 16509979
39. Holly N, Ping Teresa Y, Habibat O, Caitlin EK, Manjulaa N. HPV self-sampling for cervical cancer screening: a systematic review of values and preferences. *BMJ Global Health*. 2021; 6(5):e003743. <https://doi.org/10.1136/bmjgh-2020-003743> PMID: 34011537
40. Bruni L AG, Serrano B, Mena M, Collado JJ, Gómez D, Muñoz J, et al. Human Papillomavirus and Related Diseases in Uganda. Summary Report. ICO/IARC Information Centre on HPV and Cancer (HPV Information Centre), 2023.
41. World Health Organization. Regional Office for South-East A. Cervical cancer screening and management of cervical pre-cancers: training of community health workers. New Delhi: World Health Organization. Regional Office for South-East Asia; 2017 2017.
42. Gottschlich A, Payne BA, Trawin J, Albert A, Jeronimo J, Mitchell-Foster S, et al. Community-integrated self-collected HPV-based cervix screening in a low-resource rural setting: a pragmatic, cluster-randomized trial. *Nature Medicine*. 2023; 29(4):927–35. <https://doi.org/10.1038/s41591-023-02288-6> PMID: 37037880
43. Bansil P, Wittet S, Lim JL, Winkler JL, Paul P, Jeronimo J. Acceptability of self-collection sampling for HPV-DNA testing in low-resource settings: a mixed methods approach. *BMC Public Health*. 2014; 14(1):596. <https://doi.org/10.1186/1471-2458-14-596> PMID: 24927941
44. Ogilvie GS, Mitchell S, Sekikubo M, Biryabarema C, Byamugisha J, Jeronimo J, et al. Results of a community-based cervical cancer screening pilot project using human papillomavirus self-sampling in Kampala, Uganda. *International Journal of Gynecology & Obstetrics*. 2013; 122(2):118–23. <https://doi.org/10.1016/j.ijgo.2013.03.019> PMID: 23731506
45. Mezei AK, Armstrong HL, Pedersen HN, Campos NG, Mitchell SM, Sekikubo M, et al. Cost-effectiveness of cervical cancer screening methods in low- and middle-income countries: A systematic review. *International Journal of Cancer*. 2017; 141(3):437–46. <https://doi.org/10.1002/ijc.30695> PMID: 28297074
46. Mezei AK, Pedersen HN, Sy S, Regan C, Mitchell-Foster SM, Byamugisha J, et al. Community-based HPV self-collection versus visual inspection with acetic acid in Uganda: a cost-effectiveness analysis of the ASPIRE trial. *BMJ open*. 2018; 8(6):e020484. <https://doi.org/10.1136/bmjopen-2017-020484> PMID: 29895648

47. Njagi P, Arsenijevic J, Groot W. Understanding variations in catastrophic health expenditure, its underlying determinants and impoverishment in Sub-Saharan African countries: a scoping review. *Systematic Reviews*. 2018; 7(1):136. <https://doi.org/10.1186/s13643-018-0799-1> PMID: 30205846
48. Adrianna M, Catherine M, Martin M, Marc S, Kara H. Coping with healthcare costs for chronic illness in low-income and middle-income countries: a systematic literature review. *BMJ Global Health*. 2019; 4(4):e001475. <https://doi.org/10.1136/bmjgh-2019-001475> PMID: 31543984
49. Kankeu HT, Saksena P, Xu K, Evans DB. The financial burden from non-communicable diseases in low- and middle-income countries: a literature review. *Health Research Policy and Systems*. 2013; 11(1):31. <https://doi.org/10.1186/1478-4505-11-31> PMID: 23947294
50. Wagner AK, Graves AJ, Reiss SK, LeCates R, Zhang F, Ross-Degnan D. Access to care and medicines, burden of health care expenditures, and risk protection: Results from the World Health Survey. *Health Policy*. 2011; 100(2):151–8. <https://doi.org/10.1016/j.healthpol.2010.08.004> PMID: 20828854
51. MacKinnon N, St-Louis E, Yousef Y, Situma M, Poenaru D. Out-of-Pocket and Catastrophic Expenses Incurred by Seeking Pediatric and Adult Surgical Care at a Public, Tertiary Care Centre in Uganda. *World J Surg*. 2018; 42(11):3520–7. Epub 2018/06/03. <https://doi.org/10.1007/s00268-018-4691-x> PMID: 29858920.
52. Molefe T, Se D. Experiences of Batswana women diagnosed with both HIV/AIDS and cervical cancer. *Curationis*. 2009; 32(4):29–39. <https://doi.org/10.4102/curationis.v32i4.982>
53. Binka C, Doku DT, Nyarko SH, Awusabo-Asare K. Male support for cervical cancer screening and treatment in rural Ghana. *PLOS ONE*. 2019; 14(11):e0224692. <https://doi.org/10.1371/journal.pone.0224692> PMID: 31738796
54. Maree JE, Kaila I. Zambian women's experiences and understanding of cervical cancer: a qualitative study. *International journal of gynecological cancer: official journal of the International Gynecological Cancer Society*. 2014; 24(6):1065–71. <https://doi.org/10.1097/IGC.000000000000144> PMID: 24905615
55. Ainsworth M, Semali I. The impact of adult deaths on children's health in northwestern Tanzania: World Bank Publications; 2000.
56. Asare H, Rosi A, Scazzina F, Faber M, Smuts CM, Ricci C. Maternal postpartum depression in relation to child undernutrition in low-and middle-income countries: a systematic review and meta-analysis. *European Journal of Pediatrics*. 2021:1–11. <https://doi.org/10.1007/s00431-021-04289-4> PMID: 34652508
57. Omoni AO, Ntozini R, Evans C, Prendergast AJ, Moulton LH, Christian PS, et al. Child Growth According to Maternal and Child HIV Status in Zimbabwe. *The Pediatric Infectious Disease Journal*. 2017; 36(9). <https://doi.org/10.1097/INF.0000000000001574> PMID: 28198792
58. Anderson FW, Morton SU, Naik S, Gebrian B. Maternal mortality and the consequences on infant and child survival in rural Haiti. *Maternal and child health journal*. 2007; 11(4):395–401. <https://doi.org/10.1007/s10995-006-0173-0> PMID: 17265193
59. Knight L, Yamin AE. "Without a mother": caregivers and community members' views about the impacts of maternal mortality on families in KwaZulu-Natal, South Africa. *Reproductive Health*. 2015; 12(1):S5. <https://doi.org/10.1186/1742-4755-12-S1-S5> PMID: 26001160