



## Research Report

## Views on cervical cancer screening among female caregivers at the Uganda cancer Institute

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## ABSTRACT

Patients admitted to Uganda Cancer Institute (UCI) have their non-medical needs provided by caregivers called “attendants” who are predominantly female family members. This provides a unique opportunity to provide free screening among attendants during their free time at the hospital. The objective of this qualitative focus group study was to understand knowledge of and facilitators and barriers to cervical cancer screening among attendants at the UCI. The goal is to use these data to inform a future opportunistic intervention. Female attendants 25 years of age or older were included in this focus group study. The focus group discussions explored knowledge of cervical cancer and screening modalities, health information sources, barriers and facilitators for cervical cancer screening, and potential use of mobile phone technology to share cervical cancer screening information among one's social community. Data were analyzed using an inductive approach and thematic analysis. Results showed moderate understanding of risk factors for cervical cancer, supplemented by misinformation. Knowledge of symptoms of advanced cervical cancer was high. Most participants were aware that cervical cancer screening exists but knew little about screening modalities. Responses were mixed regarding preferred information sources, and included healthcare workers and facilities, radio and family members. Participants were enthusiastic about mobile phone messaging to provide information about screening but emphasized a need to catch their attention and incentivize screening with promise of good such as sugar, demonstrating prioritization of immediate needs over future cancer risk. These results will inform an intervention which aims to connect female caregivers with free screening available at the adjacent cancer prevention clinic.

## 1. Introduction

Cervical cancer is the most common cancer and cause of cancer-related death in Uganda. In 2020, 6,959 Ugandan individuals were diagnosed with cervical cancer, and 4,607 died of the disease (World Health Organization. Cervical Cancer Uganda, 2021). Cervical cancer is a potentially preventable disease, but lifetime screening prevalence among eligible persons in Uganda is only 4.8–30 % (Ndejjo et al., 2016; Isabirye et al., 2020). Among individuals with access to screening, common reasons for not screening include lack of knowledge, fear of

pain during the procedure, fear of test outcomes, and false perceptions of negative effects of screening (Ndejjo et al., 2016; Ndejjo et al., 2017). Facilitators include knowledge about cervical cancer and screening, recommendation by a healthcare worker, knowledge of screening locations, and knowing someone who has been screened (Ndejjo et al., 2016; Ndejjo et al., 2017).

The Uganda Cancer Institute (UCI) is located in Kampala. UCI registers 4,000 new patients annually from a large and heterogeneous catchment area comprising the various tribes and polities of the country (Nakaganda et al., 2021). Approximately 80 % of newly diagnosed

**Abbreviations:** CCCP, Comprehensive Community Cancer and Prevention clinic; FGD, focus group discussion; HPV, human papillomavirus; LC1, Local Council; UCI, Uganda Cancer institute; VHT, Village Health Team; VIA, Visual Inspection with Acetic Acid.

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cancers are advanced, metastatic and incurable and require hospitalization for management (Menon et al., 2018). Patients hospitalized for cancer care receive their non-medical care by family member caregivers, referred to as “attendants.” Attendants are predominantly female per Ugandan cultural norms. Attendants are required to leave the hospital wards for 3–4 h per day during medical rounds. Attendants generally spend this time in the public areas of the UCI campus. While not generally utilized by attendants, UCI campus has a Comprehensive Community Cancer and Prevention (CCCP) clinic which provides health education and screening for cancers of the breast, cervix and prostate free-of-cost. A scheduled appointment is not required. Cervical cancer screening is provided by a trained nurse via Visual Inspection with Acetic Acid (VIA). If VIA shows changes concerning for a pre-cancerous lesion or cancer, the patient is referred for a same-day appointment in the gynecologic oncology clinic, located 100 m from the CCCP clinic, for additional evaluation and treatment.

Proximity of the CCCP clinic to the main hospital provides an opportunity to increase cervical cancer screening uptake among eligible attendants.

The overarching goal of this UCI-based study is to provide an educational and cervical cancer screening opportunity for UCI attendants while they are freed from caretaking duties. CCCP nurses routinely provide education to patients presenting to CCCP. However, attendants may have unique barriers or facilitators to screening since they are not presenting to the institution with the intention of receiving cervical cancer screening. There is also the potential that they may be more open to screening since they are currently caring for a family member who has a diagnosis of cancer. This study adopts a qualitative approach to provide an in-depth understanding to cervical cancer screening beliefs among UCI attendants, with the goal of informing a future opportunistic educational and cervical cancer screening intervention among this population.

## 2. Methods

### 2.1. Study design

This study used a descriptive qualitative design employing focus group discussion (FGD) and adapting a phenomenological approach.

### 2.2. Eligibility and recruitment

FGD participants were female attendants of patients with cancer hospitalized at UCI. Participants were recruited from the UCI through posters displayed in public areas commonly used by attendants, and postcards distributed by study staff to potentially eligible attendants congregating in common areas. Inclusion criteria were female attendants at UCI age 25 years or older who were able to converse in English or Luganda. The age criterion was based on the Ugandan cervical cancer screening recommendations, which initiate screening at age 25 years. Individuals with a personal history of pre-invasive disease of the cervix (e.g. cervical dysplasia, carcinoma in-situ, high-grade squamous intra-epithelial lesion, adenocarcinoma in situ, or treatment of a suspicious lesion without diagnostic confirmation) were eligible to participate, but individuals with a personal history of invasive cervical cancer per self-report were ineligible. Ability to provide consent was required. For participants unable to read in either English or Luganda the consent was read to them by a study staff in their preferred language, and consent was provided by signature or thumbprint. Goal enrollment was 32 participants (4 focus groups of 8 participants each; minimum number 16, maximum number 48), with the ability to add additional FGDs until saturation was reached. The sample size was chosen based on qualitative methodology research showing code saturation is reached at 4 focus groups, with an optimal number of participants of 8–12 per group (Krueger and Casey, 2009). Focus groups were conducted the same day or within 24 h of recruitment due to the frequent influx and efflux of

patients and their attendants.

### 2.3. Focus group

Participants completed a questionnaire to provide demographic data including ethnicity, primary language, city of residence, number of people living in the home, primary mode of transportation for medical care, as well as personal cervical cancer screening history. The questionnaire was provided as a paper form in English or Luganda per participant preference; for participants unable to read or write in either English or Luganda the questions were read to the study participant and responses were recorded by a study staff member.

The FGD guide was developed by the study investigators based on prevalent barriers to cervical cancer screening in Uganda cited in the literature (Black et al., 2019; Isabirye et al., 2020; Mukama et al., 2017) as well as from the experience of the medical providers at UCI. FGDs were conducted by a trained moderator and co-moderator from the UCI CCCP who were not part of the study team. The FGDs were held in a private room at UCI adjacent to the inpatient wards to ensure participant privacy. Attendant participation time was 60–90 min, inclusive of completion of the questionnaire. Refreshments were provided to participants during the FGDs.

The team collected field notes, audio recordings, and memos during the interview. FGDs conducted in English were transcribed verbatim. FGDs conducted in Luganda were transcribed verbatim and back-translated into English before data analysis. Unique study identifiers were assigned to each focus group participant and focus group responses and questionnaire data were linked by the unique study identifier.

### 2.4. Ethical Considerations

The Uganda Cancer Institute Research and Ethics Committee approved the study (UCI-2022–65) and the UCI administration provided permission to conduct the study. All participants provided written informed consent prior to enrollment in the study. All participants were fully informed about how their data and information would be used within the study and were fully aware of their right to not participate. All privacy rights for participants were observed. All paper documents stored in a locked drawer in a private locked office, and all electronic documents are stored in password-protected files. Data are stored using the unique study identifier to further protect the privacy of the participants.

### 2.5. Analysis

Data coding was done manually using the inductive approach and data were analyzed using thematic analysis. Data were organized around key themes which were continuously reviewed, defined and named. This involved the following steps: transcripts were checked for accuracy and repeatedly read to familiarize the analyst with the data as line-by-line coding was done, identifying emerging ideas and themes within each transcript. Through this process, broader themes were developed to envelop the views and experiences of the attendants and create a picture of the data as a whole. A codebook was developed by the qualitative research team who coded the transcripts using line by line coding. These team members met regularly to compare similarities and differences and to agree on the emerging patterns and anomalies across transcripts, ensuring consistency and reflexivity in the interpretation of the data. With the codebook in place, the coding began. Regular meetings were conducted with continuous discussions until consensus was reached about points of saturation, and data were collected until there were no new emerging ideas. Analytic rigor was enhanced throughout theme development by searching for and resolving any contradicting cases. Analysis was performed by a contracted qualitative data analyst (S.I.K) and their team who were not part of the study team. A detailed record of sampling and recruitment, focus group audio recordings, field

notes and transcripts, and records of the coding process have been maintained in a secure file.

### 3. Results

#### 3.1. Demographics and clinical information

Five FGDs were conducted from March to April 2024, comprising 40 participants. Saturation was reached at five FGDs. Two FGDs were conducted in English, and three in Luganda. Median age was 39 years, and participants came from different districts of the country (Table 1). Almost one-third ( $n = 13$ ) reported having had at least one cervical cancer screening test.

#### 3.2. Overview of themes

Five themes encapsulated the views on cervical cancer and cervical cancer screening among female attendants at the UCI: 1) Awareness and knowledge of cervical cancer; 2) information about cervical cancer screening methods; 3) information sources and acceptability of cancer

**Table 1**  
Demographics and cervical cancer screening history (N = 40).

Variable	Median	(range)
Age (in years)	39	(25–64)
Number of people in household	7	(2–15)
Ethnic Identity	N	(%)
Lango	2	(5.0)
Muganda	18	(45.0)
Mukiga	2	(5.0)
Munyakole	2	(5.0)
Musoga	5	(12.5)
Mutooro	2	(5.0)
Other <sup>1</sup>	9	(22.5)
Primary Language		
Lango	2	(5.0)
Luganda	23	(57.5)
Lunyakole	2	(5.0)
Lusoga	6	(15.0)
Rukiga	2	(5.0)
Other <sup>2</sup>	5	(12.5)
City of Residence		
Entebbe	3	(7.5)
Fortportal	2	(5.0)
Kampala	3	(7.5)
Masaka	2	(5.0)
Matugga	2	(5.0)
Mukono	5	(12.5)
Other <sup>3</sup>	23	(57.5)
Primary mode of transport for healthcare		
Boda boda	27	(67.5)
Car (personal/friend)	3	(7.5)
Taxi	9	(22.5)
Walking or biking	1	(2.5)
Ever had cervical cancer screening		
Yes	13	(32.5)
No	25	(62.5)
Unsure	2	(5.0)

<sup>1</sup> Other ethnic identities include Alur, Banyole, Itesot, Mugada, Mugwere, Mulugbara, Munyakole, Munyalwanda, Musamya.

<sup>2</sup> Other languages include Alur, Lunyole, Lusamya, Lutooro, Rutooro.

<sup>3</sup> Other cities include Boleda, Bugiri, Busega, Busomba, Gayaza, Gomba, Jinja, Kamuli, Karimbira sanga, Kasangati, Kawanda, Kira, Kitintale, Kivubuka, Kyazanga katovu, Lukaya, Mayuge, Mukono seta, Nabiteete, Nakaloke, Nakifuma, Nebbi, Wakiso.

screening; 4) barriers to cervical cancer screening; 5) interest in mobile phone messaging to share healthcare recommendations. Each of these themes and their sub-themes are discussed below.

In almost all FGDs the participants had some knowledge about cervical cancer. The factual knowledge was often supplemented by incorrect information or confusion between causes of cancer and cancer symptoms.

#### 3.3. Risk factors

One-quarter of the participants made a connection between sexual relations and cervical cancer, and more than three-quarters of participants were aware that multiple sexual partners are a risk factor for cervical cancer. In almost all FGDs the use of family planning methods was incorrectly reported as a common cause of cervical cancer. In almost half of the FGDs having too many children with improper birth spacing was cited as a risk factor, while others thought having abortions caused cancer.

Participants confused symptoms of cervical cancer with causation. For example, many thought that heavy bleeding, especially during menstruation, can cause cervical cancer.

A few of the participants were aware that cervical cancer is caused by cells mutating. None were aware of human papillomavirus (HPV) as the viral cause of cervical cancer, but a few participants attributed cervical cancer to other disease such as syphilis.

Other common misconceptions about the cause of cervical cancer included genetic risk and behaviors such as wearing wet undergarments. Some respondents admitted to not knowing the cause of cervical cancer, and many expressed interest in learning the true causes of the disease.

#### 3.4. Signs and symptoms of cervical cancer

Knowledge of signs and symptoms of cervical cancer was high among participants. A majority reported symptoms of cervical cancer included heavy vaginal bleeding associated with very foul-smelling watery discharge, lower abdominal and waist pain accompanied by dizziness. Infertility was also known to be a sign of cervical cancer. Friends were the primary source of information regarding signs and symptoms of cancer.

A majority of participants knew that it would take a long time for the disease to show symptoms. Some participants recognized that a person could be unaware of asymptomatic disease. Participants also shared personal knowledge of individuals with missed diagnoses, or multiple medical visits to get a final diagnosis of cancer.

*Theme 1: Awareness and knowledge of cervical cancer (Table 2)*

#### 3.5. Perception of cervical cancer prevalence in the community

Cervical cancer was not openly discussed in the participants' communities. Sharing of this diagnosis was reported to be limited to close relatives and friends due to the stigma associated with being a "cancer patient."

*Theme 2: Information about cervical cancer screening (Table 3)*

#### 3.6. Importance of engaging in cervical cancer prevention activities

Almost all of the FGD participants thought it was very important to engage in cervical cancer screening activities. It was acknowledged to be a way to save lives. Overcoming myths related to cervical cancer was thought to be a way to restore family relationships. Despite this, there was a lot of fear associated with screening.

#### 3.7. Knowledge of screening modalities

Knowledge about cervical cancer screening methods was poor, with many participants stating they had never heard of any method. Those

**Table 2**  
Theme 1 quotes: Awareness & knowledge of cervical cancer.

Subtheme	Quotes
Risk factors	<u>Sexual Relations</u> 'My opinion is that; in the past, cervical cancer was not rampant. But because of women using different men where some can use 5 different men, they end up getting cervical cancer' (FGD 2)
	'I was still in high school because I was in a girls' school, so they would tell us, now you're finishing, you're going out to do the world, don't have multiple sexual partners. It will make you get cervical cancer' (FGD 2)
	<u>Family planning methods</u> 'According to rumors, some people say that it is caused by some family planning methods'. (FGD 3) 'What crosses my mind is that; may be cervical cancer is caused by the family planning which we use. That is my thinking.' (FGD 1)
	<u>Improper birth spacing</u> 'To me, I think unspaced child birth causes cervical cancer.' (FGD 3)
	<u>Abortions</u> 'My sister has cervical cancer and I am taking care of her; but what caused cervical cancer to her was because of the too many frequent abortions she performed.' (FGD 1)
	<u>Cells mutating</u> 'About cancers, including cervical cancer, I've heard that each one of us has cancer cells and depending on whichever environmental factors then some cells will mutate and then you develop cancer.' (FGD 4)
	<u>Other diseases</u> 'My opinion is that even these diseases we are infected with like syphilis can also cause cervical cancer.' (FGD 2)
	<u>Heavy menstruation</u> 'in my case when I had just finished my periods, I experienced a heavy period flow and when I came here, they told me to screen for cancer. They checked for it 3 times and finally declared that I was negative to cancer. Such heavy bleeding can cause cervical cancer.' (FGD 2)
	<u>Wet undergarments</u> 'Another thing that causes cervical cancer is putting on wet knickers' (FGD 3)
	<u>Genetic disease</u> 'Then also some people, it runs in the family'. (FGD 3)
Signs and symptoms	<u>Unknown</u> 'To me, I feel cervical cancer attacks our cervix as women. But I've never got a true understanding of exactly what brings cervical cancer. I've read so much about it, yet still, want to get more information about that cervical cancer, and what brings it'. (FGD 4)
	<u>Bleeding, discharge, pain</u> 'I hear that when you have cervical cancer, you get bleeding, non-stop bleeding. And another thing, I hear people who have cervical cancer, have headache, pain all the time, and dizziness'. (FGD 4)
	'And when you have that cancer, you go through a lot of pain'. (FGD 2)
	<u>Infertility</u> 'What I know is that cervical cancer affects the uterus.

**Table 2 (continued)**

Subtheme	Quotes
	When you have it, it is difficult to get pregnant because when you get it, the uterus gets out, so what I was asking, is it true or not?' (FGD 5)
	<u>Late symptoms &amp; misdiagnosis</u> 'One thing I learned was that cancer of the cervix takes long to be felt. You as a person, you can take long to feel the symptoms of cancer of the cervix. And in most cases, it results into getting late diagnosis, which has affected many women in the community' (FGD 1)
	'I have a sister who went late; she kept going to the hospital and they would tell her she had an infection. At the end of it all, by the time she came to Mulago Cancer Institute to be diagnosed of cancer of the cervix, it was too late.' (FGD 2)
	'I hear some of the signs for cancer of the cervix are related to those of fibroids. So it is hard for you as a person to detect, maybe, do I have cancer of the cervix or I have fibroids?' (FGD 2)
	<u>Asymptomatic disease</u> 'It's still very low because few people who happen to move to the health facilities for screening, they go when they have already seen signs, they are very sick, but majority move with the disease. They don't know that they have it. So if it was made mandatory for every woman to screen, you would find the number is high' (FGD 3)
Perception of cervical cancer in the community	'They don't talk about it. It is always between that person, the doctor and maybe she can inform her relatives and her next of kin' (FGD 2)
	'According to me and where I stay, it's not common, I can say, because it's not revealed. People will not reveal that they have cancers, unless it's a family member or a friend who will be honest and tell you, I have this cancer'. (FGD 5)

who had been tested were unaware of the screening method used, and they consistently reported the healthcare provider did not inform them of the screening test being performed. Across all five FGDs participants did not have any knowledge about cervical cytology (Pap testing), and limited knowledge about VIA. Participants were not familiar with the term “HPV test.” Irrespective of screening modality, multiple participants emphasized that cervical cancer screening involves a painful test based on vague information from female friends or family who may or may not have had screening themselves. Fear of pain resulted in some of them changing their mind about the desire to engage in screening if available.

Theme 3: Information sources and acceptability of screening (Table 4)

3.8. Channels for healthcare information

Sources of information included health facilities, media, and family. Health facilities and media were thought to provide factual information, but family members were viewed as trusted sources. Politicians can also play a role in providing this information. Specifically, former State Minister for Primary Education in the Ugandan Cabinet member Rosemary Nansubuga Sseninde’s cervical cancer screening campaign was thought to be especially influential.

3.9. Preferred sources of cervical cancer screening information

The preferred sources of cervical cancer screening information were the health workers and government health facilities. Trainings in the health facilities at the district and sub-county levels and in the



**Table 3**  
Theme 2 quotes: Cervical cancer screening.

Subtheme	Quotes
Importance of engaging in cervical cancer prevention	<p><i>'It is very important to engage in cervical cancer prevention activities to save the lives of so many adult women. For example, many women still have that fear of going to test to know if at all they already have the disease or they don't have. Even they go ahead to scare their friends not to test, and by so doing, they hinder the fight against cancer of the cervix'. (FGD 2)</i></p> <p><i>'So it is very vital if any program comes, either from government or from NGOs, to educate women to know that it is okay for you to move to a health unit and test even before feeling any symptom, any sign on your body. I think very many souls would be saved in our communities' (FGD 1)</i></p> <p><i>'it will break myths. There are many myths around what causes it, like someone said, drinking many herbs. Or if you share, for example, maybe public toilets. I think it will also save families because someone would accuse the other that it is you who brought it to me and yet it might not be the case, therefore, family's relationships will be saved.' (FGD 4)</i></p>
Knowledge of screening modalities	<p><u>Unaware of methods</u> <i>'Because they never informed me; I do not know what they did; after several visits, they just informed me that I don't have cervical cancer.' (FGD 4)</i></p> <p><u>Pap testing or VIA</u> <i>'No, I have never heard about it because I have not been going to the hospitals to make checks. It is my first time to hear about it'. (FGD 5)</i></p> <p><u>HPV testing</u> <i>'I have been asking some ladies down that side about it but they have told me that the procedure is painful'. (FGD 5)</i></p> <p><i>'they even showed me the place and I had vowed not to leave this place without checking; but when they told me that the procedure is painful, I changed my mind' (FGD 2)</i></p>

HPV, human papillomavirus; VIA, visual inspection with acetic acid.

communities themselves were suggested as good information delivery systems. Others preferred getting the information from the Village Health Teams (VHTs) or from leaders such as the Local Councils (LC1) since it does not require them to attend a health facility to receive information. Others suggested the radio as a good delivery method since not many people have access to televisions, but many have access to radio stations, even on their mobile phones. However, participants acknowledged this would require referral to another center for screening, and thus may limit uptake of screening despite generating interest.

Some of the participants thought woman-to-woman healthcare recommendations were Bbetter than formal healthcare provider recommendations because it does not involve spending money. It is notable thatwhile services at government health facilities are formally free-of-charge, informal charges and even bribery are not uncommon, resulting in a financial barrier to seeking formal medical recommendations. Others disagreed with getting healthcare recommendations from fellow women, citing fear of getting false information, or fear of being talked about. Although most agreed they would receive factual information from healthcare workers, they were also worried that health professionals provide information primarily to get money from them.

Theme 4: Barriers and facilitators for cervical cancer screening (Table 5)

**Table 4**  
Theme 3 quotes: Healthcare information sources & acceptability of screening.

Subtheme	Quotes
Channels for information	<p><u>Health facilities</u> <i>'These things of cervical cancer are normally taught in hospitals; when we have gone there to get treatment.' (FGD 1)</i></p> <p><u>Media</u> <i>'...also on TV. They normally run programs which encourage women to go and screen themselves.' (FGD 2)</i></p> <p><u>Family</u> <i>'The information about cervical cancer; I learnt it from my sister. There is one of my sisters who suffered from it; though it was discovered when it was still at its early stages; she was treated and healed well' (FGD 5)</i></p> <p><i>'For me, I learnt it from my grandmother because she would always say that since these modern life styles came like family planning; the scale of diseases is just escalating.' (FGD 2)</i></p> <p><u>Politicians</u> <i>'For me, to learn about cervical cancer, mainly I got to know about it during that time when Mrs. Sseninde Rosemary was still a member of parliament. She encouraged people in the community to screen and sometimes she brought doctors. She was very active in the communities where she was representing to screen for cancer' (FGD 2)</i></p>
Preferred sources	<p><u>Health workers &amp; government health facilities</u> <i>'There are other places where someone would get the information but to me it would be the doctor because he is the one, I have gone to see about my disease and he qualifies to check me'. (FGD 3)</i></p> <p><i>My opinion is that it would be government hospitals to handle all the issues of cervical cancer. That is my thinking' (FGD 1)</i></p> <p><i>'What I suggest trainings should be organized at the hospitals such that when someone goes there, they can explain to him' (FGD 4)</i></p> <p><u>VHTs</u> <i>'In my view, if I want to inquire about cervical cancer; in my community we have many VHTs whom we can approach and ask if I want to screen for cervical cancer. Sometimes they refer us to referral hospitals' (FGD 3)</i></p> <p><u>LC1s</u> <i>'What I would like, is to have this taken to our community Local councils such that even the last local person in the village who doesn't move can benefit from that information or even via our local public address systems which can alert people that the gathering will take place from the church or from such and such a place just as they used to inform us about COVID vaccination. (FGD 3)</i></p> <p><u>Radio</u> <i>'I would say that maybe on the radio because if I talk of a TV; not everybody has it and also on their mobile phones' (FGD 3)</i></p> <p><u>"Woman-to-woman" communication</u> <i>'It might be easier; because there are some persons who can listen to me better than hearing from a doctor thinking that the doctor is intending to distort money from her. However, from experience she will do it because she has heard that so and so did it so let me also go and do it. (FGD 2)</i></p> <p><i>'For me it is supposed to be qualified medical doctor. I wouldn't consider something from friend as much; I have to trust a word from the doctor because it him who can tell me everything in depth. It is a qualified doctor that I would need. (FGD 4)</i></p> <p><i>'You may talk to your friend about it and she ends up gossiping about you to the whole community yet when I visit the doctor; everything remains there'.</i></p>

LC1, Local Councils; VHT, Village Health Team.

**Table 5**  
Theme 4 quotes: Barriers & facilitators of cervical cancer screening.

Subtheme	Quotes
Barriers	<u>Violation of privacy</u> <i>'I think just the phobia of having to open up to a stranger; your most private parts, is a hindrance.'</i> (FGD 1)
	<u>Husbands</u> <i>'Cervical cancer screening is about private parts, so for the men in the home, most times when you tell them that you are going to be tested and they hear that they are going to be inserted with machines they ask, what is that all about? We struggle with our husbands'</i> (FGD 1)
	<i>'These days you have to pray a lot for God to give you a caring husband; but out of 100 % you can find like 30 % who can take care of you. You might inform him that you have cervical cancer and he drops out of the relationship. So in the end, you have to look after yourself.'</i> (FGD 2)
	<i>'whenever the children are sick, he has never fixed time to escort me or even me when I am sick; he just leaves me neglected. So, I don't know what he would do; if I told him that I have cervical cancer. I think he can even chase me away.'</i> (FGD 1)
	<u>Lack of local screening centers</u> <i>'Accessibility to the services is not as easy. For example, not every health center can carry out cervical cancer screening, because I myself, first went to a health center IV, and they told me they were not screening. They sent me to a regional referral hospital.'</i>
	<i>'About the men's issue, so, many of them want to support their wives; however, sometimes you find that he has no money despite the fact that he would want to support.'</i> (FGD 3)
	<u>Fear of pain</u> <i>'Many people fear to be screened because we get information from our friends, that when you test for cervical cancer, it is painful. Others say the uterus will become wide, the instruments can tear you, they will make you sick, and yet you are not yet sick. Many things scare us not to go and test, so the wrong information from friends creates fear.'</i> (FGD 1)
	<i>'It is fear, many people fear the machine because the way how our colleagues tell us how cervical cancer screening is performed it is scarcely. It is what scares us most; but in my case as a person who visited the doctor down there would just encourage that person to go and screen for breast cancer, cervical cancer or even leukemia because the machine is not painful the doctor told me how it operates; he just puts something on you and it starts observing you from the computer.'</i> (FGD 5)
	<u>Religious doctrine</u> <i>'In some doctrines they say when you speak something, you have created it. So speaking the word that somebody has cancer or might have cancer, they believe that you are the one who is giving it life, giving that word life, and so it will manifest...So religious beliefs also have been a barrier to people actually engaging in life-saving, screening'</i> (FGD 5)
	<u>Stigma &amp; witchcraft</u> <i>'For me personally, I have fear to screen, like in our community if you come out to screen yourself, everyone will say that you are infected'</i> (FGD 3)
	<i>'I saw an experience of one mother who died recently who gave birth and had cancer of the cervix, they never mentioned, they didn't even want to mention it, because they believed people will fear their family, that their family has cancer'</i> (FGD 2)
	<i>'Some people fear, they fear to open up because some of them, think that cancer is a curse. Or others think that when you have cancer, you have been bewitched'</i> (FGD 4)
	<u>Facilitators</u> <u>Trainings &amp; informatin from healthcare providers</u> <i>'There must be massive trainings to sensitize the community because when I am well trained, I can go back and inform the rest that, "I have a new topic to unveil for you so, lets gather somewhere and share".'</i> (FGD 3)
	<i>'For me the experience I had from the doctor who told me that it is safe and that it is not painful is the reason that drove away my fear. It was a doctor from here at Mulago on the side where they admit patients for spine problems. That is what he told and I was encouraged to screen for cervical</i>

**Table 5 (continued)**

Subtheme	Quotes
	<i>cancer'</i> (FGD 4)
	<u>Husband support</u> <i>'how would the man know; that I have cervical cancer if I don't go with him for testing? For example, like how we do it these days when we go for antenatal, if you don't go with your husband, you will not be allowed. So, the same would be done for cervical cancer that if you want to test for cervical cancer, a man and a woman should come together. When the woman is checked in the presence of the husband, in case she is positive, it would be easier for him to be concerned'</i> (FGD 5)

3.10. Barriers to cervical cancer screening

Most FGD participants reported that cervical cancer screening would violate their privacy. Husbands were also cited as a barrier to cervical cancer screening due to the intimate nature of the exam and perceptions about the way their wives would be assessed. Fear of their husbands leaving them if they were diagnosed with cervical cancer was another deterrent to screening.

Even when there was interest in screening, absence of local cancer screening services was a barrier for many. Lack of transportation or financial resources to travel to a larger facility could result in the motivated individual abandoning their screening goal.

Another barrier reported by half of the respondents was fear of pain. This fear was primarily due to reports from friends who may or may not have personally undergone screening. Religious beliefs and doctrine also came up as a barrier for cervical cancer screening. Some believed that thinking or speaking of a condition could manifest the disease; therefore, seeking screening would result in a diagnosis of cancer.

Stigma of being known as a “cancer patient” is another barrier. Participants feared the assumption that would be made by others if they were seen to seek screening, regardless of the screening test result. Many believed that cancer is a curse associated with witchcraft.

3.11. Facilitators for cervical cancer screening

Some of the facilitators for cervical cancer screening identified by participants were trainings about cervical cancer screening and correct information shared by healthcare providers. Attending screening with their husband was also seen as a solution to increase support, especially

**Table 6**  
Theme 5 quotes: Mobile technology & social networks to motivate cervical cancer screening.

Subtheme	Quotes
Alternative advertising to entice reading	<i>'This message can come starting with the word; "Mobile money". By the time one finishes reading it; it will be about cervical cancer. I think this can work because they have ever tested it on me and I really got it attention.'</i> (FGD 1)
	<i>'Another thing that I have just thought about is that people like musicians a lot; so, in these text messages you can say that in this and that area there shall be musicians and you can attract people that way.'</i> (FGD 1)
Incentives	<i>'The message should be spiced for example; "If you don't screen, you will miss a kilogram of sugar".'</i> (FGD 4)
	<i>'Just as the other respondent has said; if the message comes to my phone with some incentives like sugar, I will definitely inform my colleague to come because there are some gifts please go and screen your selves. No one would wish to waste her time for nothing; there should be a gift.'</i> (FGD 2)

if a cancer diagnosis is made.

Theme 5: Use of mobile technology and social networks (Table 6)

We explored the use of mobile text messages to encourage screening and to increase sharing of factual information among one's social network. A common theme that emerged was a need to advertise for something other than screening to catch their attention. Participants stated they would be unlikely to read a message that led with "cervical cancer screening" but would read a message that promised money or even musical entertainment. Promise of another more immediate incentive, such as sugar or soap, was thought to be attractive.

#### 4. Discussion

This qualitative study was conducted to further understand the baseline knowledge of, barriers and facilitators to cervical cancer screening among female hospital caregivers ("attendants") for patients with cancer hospitalized at UCI. Similar studies have been conducted in Ugandan populations, but often focus on a specific population, for example a rural population or specific community (Dau et al., 2024; Isabirye et al., 2020; Mezei et al., 2024; Mukama et al., 2017; Nakisige et al., 2024). UCI is the only comprehensive public cancer center in Uganda, and has a large catchment area comprising both urban and rural populations, multiple ethnicities, and a mix of educational and financial levels. Due to the absence of organized cancer screening programs in Uganda, most patients present to UCI due to symptoms related to advanced cancer (Nakaganda et al., 2021). The family member attendants who provide care for patients admitted to UCI for cancer care are the population of interest for our intervention study. Potential participants are located in a healthcare setting but unlike most other studies performed in a healthcare setting, did not present with the intention of receiving healthcare for themselves. This setting, along with the heterogeneous background of the potential participants, warranted a study to better understand the population we aim to serve in our interventional study. The intention of this study was to understand prevalent cultural barriers and facilitators for cervical cancer screening that can be applied to an intervention at the UCI CCCP clinic rather than to compare and contrast findings by participant background.

We presented our findings as five themes which emerged from the focus group discussions, but for application to an intervention these themes can be more broadly grouped as 1) barriers and facilitators; and 2) information sources.

##### 4.1. Barriers and facilitators

Results from this study show that attendants at UCI had some knowledge about cervical cancer and its causes, but that this knowledge was often misinterpreted or supplemented with misinformation. Participants were aware that cervical cancer screening is available and even important, but there was a general lack of knowledge about how screening is performed and this resulted in a lot of fear of pain related to screening. These findings are similar to the findings of multiple other studies. A systematic review of studies conducted in Uganda showed fear of pain associated with the procedure, change in sexual organs due to screening procedures, and infection or even cancer being caused by the procedure to be barriers to screening (Black et al., 2019). One study which included nurse and midwife focus group participants showed they may also have inaccurate information about causes of cervical cancer and the role of cervical cancer screening which further contributes to misinformation (Mutuyaba et al., 2007). Participants in our study were generally interested in learning more about screening procedures, emphasizing that a successful intervention will need to include information about how the screening will be performed.

Among participants who were interested in screening, lack of local and affordable screening facilities was cited as a major barrier to screening uptake, and unsurprisingly this is a common theme in other studies (Black et al., 2019; Mutuyaba et al., 2007) unless the wealth index

is high (Isabirye et al., 2020). While medical care in government facilities is free, informal charges and bribery are common (Mutuyaba et al., 2007; Dau et al., 2024). Additionally, even when the screening is free, indirect costs for transportation and food for individuals living a distance from a screening facility can be cost-prohibitive (Dau et al., 2024; Ndejjo et al., 2016). Therefore, opportunistic and truly free screening is needed to increase lifetime screening. Screening at the UCI CCCP clinic is truly free of cost for the person seeking screening, even outside of our planned intervention. The planned intervention seeks to connect female attendants at UCI with screening while they are located at UCI, eliminating travel and accommodation costs. For populations with low screening coverage (generally defined as coverage of 30 % or less) each 10 % increase in once-lifetime screening in the population is associated with an increase in the population life expectancy by 0.039 years (Campos et al., 2017). The CCCP will remain an option for participants to receive future screening to achieve the recommended 2–3 lifetime screenings, but additional outreach interventions will be needed to reach most of the population since most patients travel a great distance to receive care at UCI (Nakaganda et al., 2021).

Participants were able to identify common symptoms of advanced cervical cancer, and some awareness that the disease can be asymptomatic and thus undetected without screening. Many participants in our study as well as those in previously published studies have shown a fatalistic view of cervical cancer since advanced-stage disease is not curable, and the benefits of screening and early diagnosis can only be realized if access to curative treatment is also provided (Mukama et al., 2017). The advantage of providing opportunistic screening for attendants at UCI is that treatment for pre-invasive disease or even cancer is available within walking distance of the screening clinic and hospital. Education around screening in our intervention will need to emphasize how early intervention can result in curative treatment of early-stage cancer or, ideally, prevention of cancer altogether to overcome this fatalistic view (Mukama et al., 2017).

The stigma of being diagnosed with cervical cancer, or even the perception that one is seeking screening because they are at risk for cervical cancer, is a cultural barrier to screening that is more difficult to overcome. Many worried about the loss of their husband and community (Mutuyaba et al., 2007), and this fear is substantiated by data from other African nations which have shown an increased risk of men leaving their wives after a cervical cancer diagnosis (Dau et al., 2024). Therefore, another theme which emerged was the role of men in cervical cancer screening. A lack of understanding of the potential positive impact on cancer prevention or cancer cure leads to de-prioritization of screening. This may manifest in lack of permission for screening, or more often lack of prioritization of limited funds for screening (Black et al., 2019; Nakisige et al., 2024; Mutuyaba et al., 2007). One participant in our study emphasized the importance of a spouse attending the screening appointment with the wife, and other studies have suggested more male-focused messaging about HPV and cervical cancer since 60 % of healthcare decisions are made by men or as shared decision-making with a male partner (Nakisige et al., 2024). These findings highlight an important factor for screening uptake in our opportunistic study since the spouse or senior male family member is unlikely to be present unless they are the patient admitted for cancer care.

##### 4.2. Information sources

We explored current and preferred information sources for future plans to increase the reach of cervical cancer screening through the UCI CCCP clinic. Friends were a primary source of information primarily because there was no cost involved. Although participants were aware the information they receive from friends and family may be incorrect, they were also suspicious of healthcare workers trying to get money from them. Another published study showed that education alone is not enough, and that behavior may only change if the health educator is already known to and trusted by the community (Nakisige et al., 2024).

Radio messages or messages freely shared within healthcare facilities or by local healthcare workers was thought to be a good solution to providing factual information free of charge, and this is supported by findings from other studies (Black et al., 2019; Isabirye et al., 2020). While public messaging is a good way to raise awareness, it is unclear if this will truly increase cervical cancer screening uptake, especially if screening services are not immediately and locally available.

We explored the idea of using community networks to increase screening information via mobile phone text messaging due to widespread use of mobile phones even in rural areas (Campos et al., 2017) and the results of other studies in low-income countries showing increased cervical cancer screening uptake following various mobile phone messaging interventions (Mwandacha et al., 2024; Bhochhibhoya et al., 2021; Zhang et al., 2020). Interestingly the theme that emerged focused on the need to attract the user to read the message by promising something else, reflecting the focus on more immediate needs rather than screening for an asymptomatic cancer the person “may” have. While participants were enthusiastic overall about screening provided it could be done painlessly and safely, cervical cancer screening cannot be a priority unless basic needs such as food and hygiene are met. An earlier study showed that cervical cancer screening was not even a prominent reproductive health concern among women or men, overshadowed by concerns related to infertility, childbirth complications, sexually transmitted infections, and menstrual problems (Mutyaba et al., 2007).

For both our current intervention study as well as future outreach studies these findings highlight a need to provide a more basic and immediate need at the same time as providing cervical cancer screening and management.

## 5. Conclusions

The results from this study provided additional support for our planned intervention that aims to connect female attendants at UCI with free cervical cancer screening services available at the adjacent CCCP clinic. The ability to conduct these FGDs for UCI attendants during ward rounds provides support to utilize this free time to provide education and other health services to the attendants. Written questionnaires were almost entirely completed verbally with the assistance of the study staff, supporting use of verbal instruction and pictures rather than written communication for interventions aimed at increasing screening uptake. Scripted CCCP nurse education will be revised to specifically address misinformation, including details on how screening is performed at CCCP, follow-up procedures if the screening test is positive, causes of cervical cancer, and the benefits of early detection and treatment. We will further explore the role of male spouses/family members in uptake of free and immediately available screening where the male may not be physically present or able to provide permission for screening. We will also provide a small but basic incentive for screening which meets some of the participants’ more pressing and basic needs.

The strength of our study was the ability to provide a comprehensive understanding of barriers and potential solutions to increase cervical cancer screening among female attendants who are currently located on the UCI campus and who have screening freely available at the adjacent CCCP clinic. Limitations of this opportunistic study include the inability to enhance sampling from underrepresented groups, which may limit generalizability of the findings. Even so, among the 40 participants 15 ethnicities were represented. All of the demographic and clinical data were collected through self-report, and we are unable to verify the cervical cancer screening status of participants. We also acknowledge that perspectives among screened versus unscreened individuals and especially among those with a history of abnormal screening results may be different. Due to the small sample size and need to conduct the focus group discussions within 24 h of recruitment we were unable to stratify the groups by screening status. However, only 13 participants had any history of screening, and the number with an abnormal screening result would be even smaller. Further, the goal of this study was to identify

prevalent barriers and facilitators to screening which could be applied broadly in a screening intervention study, rather than to compare findings by participant characteristics or clinical history.

The results of this qualitative study reinforce many of the cultural and logistical barriers to cervical cancer screening in Uganda. Our opportunistic intervention which aims to connect individuals located on the UCI campus with free screening services available at the CCCP clinic, with treatment of abnormal findings available the same day at the adjacent gynecologic oncology clinic overcomes many of the logistical barriers.

Findings of this qualitative study informed the pre-screening education, including details on screening procedures and the benefits to screening to decrease morbidity and mortality, to overcome some of the fear and stigma associated with screening. Other cultural barriers, such as support from a spouse or other senior male family member will be explored in the current intervention, but will likely require additional studies and interventions that formally incorporate males in the discussion and decision-making. The findings from this qualitative study as well as the results of our opportunistic intervention study will inform future efforts to increase reach and lifetime screening among eligible individuals in Uganda.

## Data statement

Due to the nature of the research, data are available only on reasonable request to the corresponding author (MO). The data are not publicly available due to the sample size and nature of the information which could compromise the privacy of research participants.

## CRediT authorship contribution statement

**Martin Origa:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Funding acquisition, Conceptualization. **Anthony Kayiira:** Writing – review & editing, Resources, Methodology, Conceptualization. **Rahel Ghebre:** Writing – review & editing, Methodology, Conceptualization. **Lauren Bollinger:** Writing – review & editing, Funding acquisition. **Sheila Irene Kisakye:** Writing – review & editing, Validation, Investigation, Formal analysis, Data curation. **Deanna Teoh:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Funding acquisition, Conceptualization.

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## Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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