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Barriers and facilitators of retention in care after cervical cancer screening: patients' and healthcare providers' perspectives

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Abstract

Background Cervical cancer continues to threaten women's health, especially in low-resource settings. Regular follow-up after screening and treatment is an effective strategy for monitoring treatment outcomes. Consequently, understanding the factors contributing to patient non-attendance of scheduled follow-up visits is vital to providing high-quality care, reducing morbidity and mortality, and unnecessary healthcare costs in low-resource settings.

Methods A descriptive qualitative study was done among healthcare providers and patients who attended the cervical cancer screening clinic at Mbarara Regional Referral Hospital in southwestern Uganda. In-depth interviews were conducted using a semi-structured interview guide. Interviews were audio-recorded, transcribed verbatim, and thematically analysed in line with the social-ecological model to identify barriers and facilitators.

Results We conducted 23 in-depth interviews with 5 healthcare providers and 18 patients. Health system barriers included long waiting time at the facility, long turnaround time for laboratory results, congestion and lack of privacy affecting counselling, and healthcare provider training gaps. The most important interpersonal barrier among married women was lacking support from male partners. Individual-level barriers were lack of money for transport, fear of painful procedures, emotional distress, and illiteracy. Inadequate and inaccurate information was a cross-cutting barrier across the individual, interpersonal, and community levels of the socio-ecological model. The facilitators were social support, positive self-perception, and patient counselling.

Conclusions Our study revealed barriers to retention in care after cervical cancer screening, including lack of partner support, financial and educational constraints, and inadequate information. It also found facilitators that included social support, positive self-perception, and effective counselling.

Keywords Cancer, Cervix, Screening, Loss to follow-up, Retention in care, Barriers, Facilitators

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Introduction

Cervical cancer (CC) continues to threaten women's health. Of the estimated 604,000 new cases that occurred worldwide in 2020 [1], low and middle-income countries contributed almost 90%. More than 341,000 cervical cancer deaths occurred during the same period, and mortality is expected to increase by 25% over the next 10 years if holistic measures are not considered [2]. About seven thousand Ugandan women (6959) are diagnosed with cervical cancer annually, and 4607 of all women living with cervical cancer die [3]. The age-standardized cervical cancer incidence rate is 56.2 per 100,000 women in Uganda compared with 40.1 in Eastern Africa, 6.6 in North America, and 13.3 globally [3]. The age-standardized mortality rate in Uganda is 41.1 per 100,000 women compared with 28.6 in Eastern Africa and 7.2 globally. High-income countries have seen a decline in cervical cancer mortality due to effective screening programs and early detection, which are often lacking in low- and middle-income countries (LMICs) [4, 5].

It is predicted that using a triple-intervention strategy of scaling up HPV vaccination, cervical cancer screening, and treatment of precancerous lesions and invasive cancer offers the best outcomes for population health [2]. In areas where HPV DNA testing is not yet available, the World Health Organization (WHO) recommends using visual inspection with acetic acid (VIA) or cytology (Pap smear) as the primary screening test among women 25 to 49 years and regular screening with the interval depending on the risk profile [6]. Women without suspicious cervical lesions are advised to do follow-up screening every three years. Women who have undergone treatment for cervical precancerous lesions should receive post-treatment follow-up testing and review within 12 months [6]. Screen-and-treat programs using VIA and cryotherapy are feasible for LMICs due to their simplicity, affordability, and sensitivity in identifying precancerous changes. HPV self-sampling method and alternative screening approaches have shown promise [7, 8]. However, HPV screening programs in LMICs face challenges, including high costs, low coverage rates, and significant health system limitations.

Uganda's cervical cancer screening program employs a "screen and treat" approach, in which the primary screening tests include Visual Inspection under Acetic acid and Pap smear cytology [9, 10]. Women aged 25 to 49 years undergo cervical cancer screening at intervals of 3 years if they are HIV negative and annually if they are HIV positive [9, 10]. The Uganda Ministry of Health is rolling out HPV-based cervical cancer screening for HIV-positive women, with a rescreening interval of three to five years as recommended by WHO [6, 11]. Treatment and follow-up of at least 90% of women with a positive screen test [12] is a significant component in providing

high-quality primary care to prevent unnecessary health-care costs [13] and reducing morbidity and mortality [2]. Uganda, like many countries in sub-Saharan Africa, still faces setbacks against organized cervical cancer screening and treatment. Inadequate infrastructure and insufficient number of trained personnel [9] affect not only the capacity to do initial cervical cancer screening but also the implementation of patient follow-up strategies.

Loss to follow-up in cervical cancer care is a critical challenge affecting cervical cancer screening program goals. In southwestern Uganda, the month-12 loss-to-follow-up rate of 76.2% was reported at Mbarara Regional Referral Hospital [14]. A similarly high rate of loss-to-follow-up was found in a community-based HPV self-sampling study—only one out of three women with abnormal HPV screening results turned up for care in the hospital [7]. Moreover, coverage of national cervical cancer programs in high-burden and low-income countries is poor [9, 15, 16]. Studies have shown a significant risk of recurrence of high-grade cervical dysplasia post-treatment of preinvasive cervical lesions [17-20], underscoring the importance of addressing loss to follow-up. These data suggest that women with precancerous lesions who miss their follow-up appointments may report for care when their condition is beyond remedy. For cost-effective programming, countries with a high burden of cervical cancer must pay more attention to the follow-up of women with baseline high-risk HPV or VIA screen-positive results.

Studies of disease screening and retention in care for chronic conditions suggest that a complex array of factors, including cognitive, psychosocial, structural and healthcare system deficiencies, affect patient retention [13, 21–23]. Cervical cancer is a pressing public health issue that affects women at their productive life prime with social and economic impacts on their families and communities. Exploring factors that drive loss to follow-up of patients is critical to devising strategies for retention in care to improve health outcomes. This study aimed to explore the barriers and facilitators to retention in care after cervical cancer screening.

Methods

Study design and setting

We conducted a qualitative exploratory study using indepth interviews to describe individual perspectives of patients and healthcare providers on barriers and facilitators to attending scheduled follow-up visits post cervical cancer screening and treatment. Study participants were patients who attended screening and treatment for premalignant cervical lesions at Mbarara Regional Referral Hospital (MRRH) and healthcare providers involved in screening and treating the lesions. MRRH is a public referral health facility (https://www.health.go.ug/sites/

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default/files/Mbarara_RRH.pdf) and a teaching hospital of the Medical School of Mbarara University of Science and Technology (MUST). The hospital, located in southwestern Uganda, 270 km from the capital city of Kampala, serves over four million people.

Study participants

Our study participants were patients who had been screened and treated for cervical lesions (both those in active care as well as those lost to follow-up) and health-care providers at the cervical cancer clinic. A patient was considered lost from the clinic if she missed a scheduled visit for three months or more. All the health workers who provide care at the cervical cancer clinic at MRRH were eligible for study participation. These included five nurses/midwives and one gynaecologist. The gynaecologist was unavailable for an interview due to a busy work schedule.

Participant recruitment

Participants were recruited between 5th and 26th June 2023. Potential participants were identified in the cervical cancer screening clinic register. Patients active in care were recruited in person during their follow-up clinic visits. Patients who were not active in care were contacted by phone based on information in the registry and invited to the clinic for an interview. Phone call attempts were made to 39 patients not active in care, of whom 19 verbally expressed acceptance of the invitation to participate in the study. Only eight of the inactive patients who were contacted came to the hospital for the interview. All participants received a refund for transportation expenses after the interview. Participants were recruited until the saturation point [24] when no more new information was being obtained.

Data collection

JO and PM collected data; both were graduate nurses trained in conducting in-depth interviews for qualitative research and had no history of working in cervical cancer care or MRRH. Both data collectors were fluent in English and the local dialect, Runyankore, in which interviews were conducted. A semi-structured interview guide, developed based on the social-ecological framework, was used to identify facilitators and barriers to retention in cervical cancer care (CCC). Guiding questions were developed by the study team based on the study's aims and the previous literature on this topic. Face-to-face interviews took place at the cervical cancer clinic office; only the interviewer and participant were present. Each interview lasted between 30 and 45 min. All study participants who reported their status as married or living with a male partner as husband and wife were regarded as married. All patients enrolled in the study had been screened using the VIA method and treated for precancerous lesions. HIV status data was not available in the clinic register used for participant recruitment, and the study team did not ask patients to self-report their HIV status. Interviews with patients were conducted in the Runyankore-Rukiga dialect, and healthcare providers were interviewed in English. All interviews were audio recorded, and none were repeated. All patient and healthcare provider participants signed a written informed consent before the interview.

Data management and analysis

ET transcribed five initial interviews, and JO reviewed the transcripts to identify and fix unexpected gaps in the interview guides. A research assistant transcribed the full set of data verbatim. We did a thematic analysis [25] and used the social-ecological framework [26] to identify barriers to and facilitators of retention in cervical cancer screening and care at five levels: policy, organisational, community, interpersonal and individual. The socialecological framework provides a structured approach to identifying factors that influence health behaviours and the interaction of those factors within the patients' immediate and broader environment [26]. The policy level includes national regulations and funding for the healthcare system. The organisational level refers to structural and human resource constraints and enablers at health facilities where patients are screened for cervical cancer lesions and treated. The community level is the socio-cultural environment where patients experience and share social relationships, cultural values, beliefs, and norms. The interpersonal level refers to a person's family and related network, and the individual level encompasses knowledge, attitudes and skills, personal characteristics and behaviour [26]. All transcripts were checked against the audio for correctness of information and read several times to identify text that contained expressions of barriers and facilitators. JO, ET, and PM manually coded the data and reached a consensus through an iterative process. The quotes representative of the patterns in the data related to barriers and facilitators were selected.

Results

Participant demographics

A total of 23 participants were interviewed, of whom five were healthcare providers offering cervical cancer screening care, and 18 were patients receiving or had received cervical cancer care services at the facility. Most patients in this study were married or living with a male partner as husband and wife. Sixteen [16] of the 18 patients were aged 25–49, and one was under 25 years. Most healthcare providers had spent over five years in healthcare service (Table 1).

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Table 1 Demographics of patient participants and healthcare providers

Characteristics	Patients(n = 18)
Patients	
Age	
20–29 years	3
30–39 years	6
40–49 years	8
50 years or older	1
Marital Status	
Single	3
Married	11
Divorced	3
Widowed	1
Retention status	
Active in care	10
Lost to follow-up	8
	Healthcare Providers ($n = 5$)
Health care providers	
Cadre	
Midwife	2
Nurse	3
Total years in cervical cancer care	
1–4 years	3
5 or more	2

Barriers

Barriers to attending scheduled follow-up visits post cervical cancer screening were multi-faceted, including transportation, lack of support from family, psychosocial factors, inadequate and inaccurate information, patient crowding and long waiting time, long turnaround time for laboratory results, understaffing, healthcare provider training gaps, and lack of integration of cervical cancer screening and treatment services into the mainstream primary healthcare (Table 2).

Individual level

Lack of money for transport

The lack of money for transportation was reported to be the most common barrier affecting patients' attendance of scheduled follow-up visits after screening and treatment for cervical lesions. Healthcare providers and patients noted that most women do not have incomegenerating activities and thus depend on support from their husbands and other family members, which may not be readily available. Patients and healthcare providers emphasized that without transport funds, there was nothing women could do to honour scheduled follow-up appointments.

"Most of the time, women don't work and therefore don't have money for transport. You find that when time is due for review, she won't have transport, forc-

Table 2 Barriers and facilitators to follow up after cervical cancer screening

Themes	Sub-themes		
	Barriers	Facilitators	
Intrapersonal factors	Lack of money for transport Fear of painful procedures Absence of pain Lack of adequate and ac- curate information Illiteracy Mistrust in screening results Patients' negligence or carelessness	Fear of pain or death Desire to moni- tor progress after treatment. Positive perceptions of self-worth	
Social/Interper- sonal factors	Lack of support from spouses or other family members Non-disclosure of screening results to family members/ spouses Misconceptions and misinformation Use of herbal medicine and spiritual interventions	Social support	
Community/Fa- cility factors	Long waiting time at the facility Overwhelming patient numbers Congestion and lack of privacy Understaffing Lack of training for health-care providers Long turnaround time for results Lack of screening reagents Scheduling appointments on working days only	Provider communica- tion behavior Counselling Trust in the health facility Communication plat- forms like WhatsApp	
Policy factors	Lack of integration of cervical cancer screening and treatment services in mainstream healthcare services		

ing her to turn down the review appointment". (Married woman, 44 years)

Transport costs were reported to be much higher for patients from rural communities, farther away from the health facility, where the distance was too long to walk.

"And remember, we are dealing with housewives who can't afford [transport]. So, the husband must give her transport. If he doesn't, that person automatically cannot come! So, we keep waiting." (Nurse, 30–39 years).

Lack of adequate and accurate information

This study showed that some patients did not return to health facilities for follow-up due to lack of adequate and accurate information. Some patients thought that having precancerous lesions signified the end of their life. Such patients became worried, fearful, and hopeless; anticipating death, they did not want to waste resources on futile follow-up visits.

"What hinders them, I think, is fear! After [a woman] has been diagnosed and they tell her that she's either cancerous or something like that, then she immediately loses hope and thinks, 'Why should I even go back yet I already have this disease?". (Single woman, 27 years)

"Some of them, you find they are not so aware of the issue. You teach them, but I think they just don't understand well. So, you find they act reluctant about coming...they know they have to come back, they know their return date, they even have the transport, but they are like 'ah ah I will go there any time'." (Midwife, 20–29 years).

Participants highlighted variations in access to information about cervical cancer, emphasising that the patients' level of formal education was associated with understanding of information. It was reported that illiterate patients barely comprehended information provided in a healthcare setting and did not appreciate the purpose of follow-up visits in the absence of pain.

"With this illiteracy, somebody will think that when I am operated on, and the pain is gone [it means] I am well, not knowing that since cancer had shown up, it can still show up again, and she stays at home." (Widowed woman, 73 years).

No pain, no need for a checkup

For some patients, the motivation to return to the hospital for follow-up was dependent on the level of pain they were experiencing. They interpreted the absence of pain as a sign of being healthy. Such patients concluded there was no need to return to the health facility for follow-up despite the revisit schedules advised by healthcare providers.

"I think that what makes someone keep visiting the hospital depends on the level of the pain she has: as long as she does not feel the pain, then she cannot take care at all." (Married woman, 45 years).

"When you ask them, 'But I told you to come back after six weeks...so that we can check and see, what happened? ... [the patient] says 'Now, what brings me is because I have pain!' ... Because there is pain. But when there is no pain, priority is less." (Nurse, 40–49 years).

Fear of painful procedures and instruments

Patients were concerned about the pain they felt when healthcare providers used the vaginal speculum during cervical cancer screening. They feared going through the same painful procedure during follow-up.

"I have realized that most people fear this treatment thing; others are scared of the machine. That is why you hear them complaining that it is so painful. They are always asking questions like 'how does it feel?' " (Woman, Married, 30 years).

"...some women don't want to be examined; they say the procedure is very painful. Yeah, they say the procedure is very painful. Like the women we usually stage would say, 'If you're putting back those instruments, I will not go on the bed.' They fear the instrument, the speculum itself. Some are just worried about the pain they go through." (Midwife, 30–39 years).

Relatedly, misconceptions about the screening and treatment process were reported. For example, there was a perception that examination involves 'removing the uterus and putting it on the plate' and that a woman could 'get cancer from screening'.

Interpersonal barriers

Lack of support and cooperation from spouse/family members

Some patients lacked social support from family members. This was mainly attributed to pre-existing tensions between spouses and non-disclosure of screening results after cervical cancer screening. It was reported that an individual patient's access to financial support from her male partner could be challenged further by her lack of confidence to negotiate for necessary resourses to attend scheduled follow-ups. Moreover, women without known illnesses or symptoms were perceived as not needing healthcare and, therefore, financial support.

"Other [patients] have family issues; they don't have support from their husbands. [Patients] who don't have husbands don't have support from their relatives." (Nurse, 30–39 years).

"Some people do not have a good relationship with their families; they receive the medicines and hide them...when your husband is at home, you fail to get your way out! Because you lack self-confidence and don't figure out what to do next, you end up not showing up for review." (Married woman, 42 years).

"When you are not feeling pain, people won't recognize you as someone who is a patient!" (Married woman, 44 years).

Some patients indicated they disclosed partial information concerning their screening visit to male partners and other family or community members to protect their identity and to avoid stigma related to the perceived causes of cervical cancer. Most patients in the study perceived sexual immorality as the cause of cervical cancer. This view may reflect community perceptions and partly explain families' and communities' negative attitudes towards women with a diagnosis of precancerous lesions or cervical cancer.

Misunderstanding of medical procedures, non-disclosure and pre-existing tensions within the family influenced some husbands to deny women permission to go for follow-up visits.

"I think like that which concerns husbands, you can tell him, and he stops you from honouring your return date arguing that 'were you not checked; do they have to check you all the time without stopping? Should they check you all the time?' So, he ends up also stopping her from honouring her return date." (Divorced woman, 37 years).

"Sometimes you find that the families are not cooperative or even with the husband who will refuse her from coming back for her review. She looks for any possible way to come out of that place, and she fails." (Divorced woman, 32 years).

In addition, the perception that cervical cancer has a poor prognosis resulted in family members withholding financial support and women themselves being discouraged, which affected the capacity to honour follow-up appointments. Family members were hesitant to 'waste' scarce resources on women with a cancer-related diagnosis because they did not hope for recovery— they thought that the woman was soon going to die of cancer.

"Most of them have lost hope, so when they reach home, they tell themselves 'I am not going back; why should I waste transport?' And even the relatives don't support them because they know I am going to put in [resources] and someone is dying tomorrow." (Nurse, 30–39 years).

Organisational level barriers Few staff and lack of training

Understaffing, amidst overwhelming patient numbers, reduced patient-provider contact time. Healthcare providers felt they did not always give patients sufficient information regarding the treatment plan or the importance of adherence to the follow-up schedule. They also noted that the few staff available had not been

comprehensively trained to offer cervical cancer screening and treatment monitoring services.

"Sometimes we're overwhelmed, and we don't give [patients] enough time to get the information about the disease and management...we are few and overwhelmed with numbers. Understaffing is a big problem; staff are too few." (Nurse, 40–49 years).

"even the healthcare providers we have are not

"...even the healthcare providers we have are not trained, ...and we don't have enough gadgets for treatment." (Nurse, 40–49 years).

Long waiting time at the facility

Patient participants narrated how they feared the long queues in the regional referral hospital and that obtaining follow-up services after cervical cancer screening required a lot of patience. A few patients who could not wait for long would leave the hospital without being reviewed by a healthcare provider. Experiences of long queues and late clinic starts could discourage patients from attending future review visits.

"The waiting time is too long!! Someone comes and ends up becoming impatient because of the delay in starting. And sometimes when she sees a long queue and [healthcare providers] having delayed starting, she decides to go back." (Married woman, 30 years).

Congestion and lack of privacy

Our study revealed that some women did not attend follow-up visits due to privacy concerns. It was reported that women felt shy when their private parts were exposed for cervical examination. Similarly, healthcare providers underscored the importance of privacy while communicating screening results to patients and individual counselling. They noted that patients had unique health education and counselling needs which could not be addressed without privacy.

"... women are shy because of the way [screening] is done; someone has to enter into your private parts. When a woman has some knowledge about the screening [and treatment] process, she will fear; when she does not have some of these signs, she ignores [follow-up]! (Married woman, 30 years).

"There is no privacy! ...when you want to do counselling... one patient is positive, and another is negative; another one has family issues she wants to discuss; yet you don't have where to talk to her from [in privacy]. Those are the challenges which I normally get." (Nurse, 30–39 years).

"Counselling is also important and needs more time, but because sometimes we're overwhelmed, we don't give them enough time to get information about the disease and management." (Nurse, 40–49 years).

Due to overwhelming patient numbers, time was never sufficient for healthcare providers to give detailed information about cervical cancer and its management and for patients to digest this information and seek clarification where needed.

Long turnaround time for results

We found that patients did not receive all their screening results on the day of sample collection, and some had to make more than one return visit to the hospital to know their status. Participants explained that waiting for laboratory results for so long was distressing due to fear of cervical cancer.

"You come back to receive your results, but you find that they are not ready. You go home and come back another time, but [the results] are not ready. You know, when you're being screened for a strange disease like cervical cancer, you develop that fear. Then you keep waiting for results, and they are not coming..." (Married woman, 23 years).

Scheduling follow-up visits on working days only

Some patients missed follow-up visits because they were scheduled during the same working hours as their jobs. As narrated by one of the participants, who was a teacher, employed women required days off to attend scheduled follow-up visits, which was challenging.

"For example, they called me, so I felt I was around and had to come. ...I'm a teacher, and now I'm supposed to be at school. But because they called me, I felt that love, and I had to come and honour that appointment." (Married woman, 23 years).

Weak follow-up system

The health facility's follow-up system was noted to have gaps. Beyond counselling sessions and the provision of clinic cards, the system did not systematically motivate patients to attend scheduled follow-up visits. For example, there was no systematic approach to reminding women to attend their reviews. Although clinic staff attempted to make phone calls to some women with positive screen results, this strategy was not systematically funded, and healthcare providers sometimes had to use personal finances.

"We have patients for [loop electrosurgical excision procedure]. Sometimes, we put our own airtime and call them back for that procedure...those patients with major issues...as a healthcare provider, you feel concerned. You call them to come for treatment or just for review." (Midwife, 30–39 years).

"Follow-up is very important...if we have airtime, I think every patient should be followed up...we are trying our best, most women we follow them up on our own." (Nurse, 30–39 years).

Healthcare providers suggested that the government should invest more in the cervical cancer program to cover all screening and treatment/management procedures, including funds for reminder calls, effective counselling and patient education.

Community level barriers

Use of herbal medicine and spiritual beliefs

Participants, especially healthcare providers, expressed concern that some patients with screen positive results resorted to using herbal medicine as remedies for precancerous lesions. Participants stated that some community members misled patients to believe that precancerous lesions could be effectively treated with herbs. As a result, some patients decided not to return to hospitals for follow-up on the assigned review dates.

"When you go to the community, many people think they can treat cancer! The moment a patient leaves the hospital without treatment, goes home, and tries to explain what [health care providers] have seen, even they will not talk of a pre-cancer; they will talk of a cancer. [The patient] will start taking herbs." (Nurse, 40–49 years).

Similarly, some participants revealed that community members perceived pre-cancer as a misdiagnosis and had alternative explanations for the cause of cervical cancer; for example, some people attributed precancerous lesions to witchcraft. Moreover, some patients believed God was in control of health outcomes and submitted to 'the will of God' when faced with challenges. Patients who held such beliefs were said to seek spiritual healing instead of keeping appointment dates for follow-up.

"Some [patients] still think that they are bewitched; they don't understand that this is a disease, a problem which needs a health intervention, which needs healthcare providers to work on not using witchcraft. You know most women still believe in witchcraft." (Nurse, 40–49 years).

It was noted that individual beliefs were embedded within community beliefs and norms of explaining causes of illness, influencing the choice of specific pathways to care for precancerous lesions. Community members attempted to provide traditional and herbal remedies to affected women, irrespective of the adequacy and accuracy of the information they relied on for decision-making.

Policy level barriers

Lack of integration of cervical cancer screening and treatment services in mainstream healthcare services

Participants indicated that the Uganda Ministry of Health had not prioritised cervical cancer screening and treatment. One of the healthcare providers explained that cervical cancer care had been neglected until recently when it was integrated into HIV care.

"At first, cervical cancer was nowhere in the Ministry of Health programs, not until recently when they integrated it into the non-communicable diseases! So, it was one of the neglected areas, yet many people are suffering." (Nurse, 40–49 years).

The lack of integration of cervical cancer screening, treatment and follow-up services was reportedly burdensome because women would spend more on transport if review appointments were separated from other healthcare visits. One woman explained that she postponed her postcervical cancer screening and treatment review to a later date to seek care for multiple morbidities in a single hospital visit and minimise transport expenses.

"I decided that since I would be coming back to receive medicines [for different health condition] on another date, I should do it all on the same day." (Single woman, 48 years).

Facilitators

Individual level facilitators

Fear of pain or death and perceptions of self-worth Participants described the influence of fear of pain and death on patient compliance with the treatment and follow-up plan. Healthcare providers mentioned that patients were motivated to go back for follow-up due to fear of progressing to advanced cancer disease associated with more pain.

"...one will be fear of cancer, others pain; fear of pain will bring them back and if they remember the counselling that 'you know at this stage I will progress to another stage'. So, that is all like fearing to progress

to cancer will motivate them to come." (Nurse, 40–49 years).

Some patients emphasised the importance of personal responsibility for well-being rooted in perceptions of self-worth. One participant exemplified this facilitator by excitedly stating "I still love my life!". Despite the challenges, such patients felt obligated to follow through with follow-up visits because it was the right thing to do.

"If you love your life, you must try to do what is right. ... life is valuable!" (Married woman, 42 years).

In addition, several patients explained that the fear of dying young coupled with the desire to live and 'to see their children grow' motivated them to honour their follow-up appointments. Study participants suggested adding cervical cancer and screening topics to the community health promotion and education toolkit for lay community health workers.

Organisational level facilitators Counselling and provider communication

Healthcare providers pointed out that counselling played a crucial role in ensuring that patients were retained in healthcare after cervical cancer screening. One provider explained that after the first screening, patients were counselled, health-educated, and encouraged to return to the health facility for review. Patients were also cautioned about possible undesirable health outcomes to deter them from falling out of care.

"And then counselling itself; we counsel them about the problem, they get to know that I will get better if she comes back for review and you look at her cervix, and it is clean, should be motivated to come back the next follow-up...We give them time, we give them enough counselling, we get them to understand the impact of the problem if they don't come back for review and what may come up. So, counselling is also important." (Nurse, 40–49 years).

"The [healthcare providers] welcome us very well, I can't tell lies...once you find that the [healthcare providers] are welcoming, you will feel relieved by the way!" (Married woman, 45 years).

Trust in the health facility

Patients who gained trust in the hospital's services were motivated to honour their follow-up visits. The way healthcare providers handled women during the initial cervical cancer screening was a key ingredient of trust building.

"I think most people get trust when they come here, are tested, and then they are treated. So most of them feel comfortable to come back here". (Nurse, 40–49 years)

Community level facilitators Availability of digital communication platforms

The increasing popularity and usage of digital platforms like WhatsApp have eased information sharing among healthcare providers. Some healthcare providers used WhatsApp to streamline the referral of suspected cervical cancer cases from lower health centres to higher-level facilities for screening and treatment. These digital platforms were being utilised to give healthcare providers at lower health facilities feedback about the screening outcomes of referrals. Thus, healthcare providers could keep track of positive cases and retain them in care.

"We have a WhatsApp group for [district health-care providers of two districts]. Sometimes, when they refer, they even send messages and ask me to give feedback. ... Sometimes, they can make calls on WhatsApp when referring such cases that I need feedback too. I think forming the WhatsApp group helps a lot...we can even teach them because I have been teaching them what I have seen on a ... I describe for them, I say 'If you see this, please immediately refer', and they get the information also. And that motivates them to screen more women" (Nurse, 40–49 years).

The healthcare provider, a national trainer for the cervical cancer program, suggested that digital technologies like WhatsApp could enhance continuing medical education for staff at lower health facilities, which may boost confidence and motivation to achieve screening goals.

Discussion

Cervical cancer can be prevented through routine screening, timely initiation of treatment of women with abnormal results and post-treatment follow-up [27]. Evidence of recurrence of high-grade cervical dysplasia post-treatment of preinvasive cervical lesions is accumulating [17–20], underscoring the need for patient follow-up. However, in high-burden, low-income countries like Uganda, loss to follow-up rates remain high [14]. Our study revealed that patients' attendance of scheduled follow-up visits was influenced by a complex interplay of factors, including transportation challenges, psychological distress associated with painful cervical examination procedures and misperceptions about precancerous lesions, inadequate and inaccurate information, limited social capital and support, health facility gaps and

fragmented service delivery. Interrelationships between factors across levels of the socioecological framework [26] were noted, suggesting interdependencies and multiple pathways to the attendance of scheduled follow-up visits post cervical cancer screening.

Psychological distress from health care examinations and misperceptions about diagnoses and prognosis may affect follow-up care [23, 28] by reducing patients' motivation to honour review appointments consistently. Our study findings are in agreement with previous studies in low and middle-income countries, which showed that embarrassment and shyness were psychological barriers to cervical cancer care [29]. In our study, patients who missed follow-up post cervical cancer screening were labelled as 'careless' - resigned to the natural course without considering the consequences of missed followup appointments, including the potential for the progression of precancerous lesions to cancer. While carelessness may be a personality trait, Eggleston and colleagues [30] suggest that the level of social support a woman receives and her emotional reaction can affect her attitude towards abnormal screen results and adherence to follow-up. Indeed, in our study, a positive perception of self-worth, fear of pain and fear of premature death were the most frequently reported patient-level facilitators of attendance of scheduled follow-up visits. Women with these traits could tap into personal strengths and creativity [13, 31] to navigate the barriers to accessing care and ensure they attend follow-up visits.

Low socioeconomic status is commonly reported as a barrier to care seeking, specifically impeding transportation to the health facility and purchase of medicines/ diagnostics when they are not freely available at health facilities. Consistent with health behaviour elsewhere in sub-Saharan Africa, studies in Malawi [32] and Rwanda [33] found that transportation and long distances from the healthcare facility were significant barriers to followup after cervical cancer treatment. Patients from rural communities were less likely to have reliable and steady sources of income to meet expenses associated with follow-up visits. Moreover, their residences were often too far from treatment and follow-up centres to walk. Rural women were particularly vulnerable to socio-economic barriers to health care because of their dependency on men and complex relational dynamics, which they must navigate while protecting their identity. Obtaining financial support and encouragement from family members was identified as a critical factor for patients' adherence to the follow-up schedule. We found that failure to obtain financial support or permission from male partners was the most important interpersonal barrier to attending scheduled follow-up visits. This was explained in part by a woman's choice not to disclose her health status and related healthcare procedures to significant others

for fear of being stigmatised. Bateman and colleagues [34] found that stigma was fuelled by perceptions that women with cervical cancer could no longer serve their spouses' sexual needs. Women treated for precancerous lesions or cervical cancer were deemed useless to their spouses. Moreover, this study found that stigmatising misperceptions of the causes of cervical cancer were common, including perceiving women with a cancerrelated diagnosis as promiscuous. In patriarchal societies like Uganda, husbands are in a position of authority on issues concerning women, including their health; men control resources, and power relations are imbalanced [23, 34, 35]. When husbands disapprove and deny women permission to go to the hospital for follow-up visits, they break the continuity of monitoring women's cervical health and compromise outcomes. Positive family involvement may be influenced by the quality of preexisting social relationships and knowledge about disease and procedures for care.

Misconceptions and traditional or religious beliefs regarding disease causation, diagnosis, and treatment are pervasive. Our study revealed that women and community members did not differentiate between cervical precancerous lesions and cervical cancer and thought that both had a poor prognosis. The belief that cancer was a result of nonmedical causes obstructed women from attending health facility follow-up visits. They chose alternative care pathways, including spiritual interventions and traditional medicine. Rendle and colleagues [36] found that most women perceived cancer as a disease with no treatment. Such misconceptions affect women's retention in care because the other alternative forms of care are more accessible and readily available to them. Additionally, misconceptions about cervical cancer are drivers of internalised and anticipated stigma [32], which may influence cervical cancer risk perception and perceptions about the urgency of post-treatment follow-up.

Furthermore, the lack of accurate information in the community, mistrust of intentions of new health programs like cervical cancer screening, and numerous obstacles in conventional medicine healthcare facilities, including long distance to access and intermittent availability of services [37, 38], are likely to perpetuate beliefs about traditional approaches to treating cervical cancer. Healthcare providers in our study were aware of the significant role of counselling in retaining women in cervical cancer care. Counselling and educational interventions have shown the potential to increase follow-up compliance [30]. However, misinformation and misperceptions among patients may persist due to limited time for patient counselling in overcrowded, busy clinics and the limited capacity of healthcare providers to communicate complex health information [28, 39]. Also, women's comprehension of information received may be influenced by their literacy level and personal composure/distress [39] during provider-patient interactions. Women with lower literacy levels are less likely to comprehend medical information correctly. Lindau and colleagues found that a lower level of patient literacy as perceived by a healthcare provider was a strong predictor of loss to follow-up [40]. Women without adequate and accurate information about the negative implications of not adhering to the follow-up plan may not assign high priority to their scheduled visits. Patients in our study regarded healthcare provider communication behaviour as the most important organization-level facilitator of follow-up. Healthcare providers' welcoming attitude and phone call reminders enhance trust, thus encouraging patients to honour their follow-up appointments [13, 30].

However, concerns about delays in obtaining care after arriving at the hospital were common and likely to affect patients' motivation to attend future follow-up appointments. Delays occur at multiple points of care, including the cervical cancer screening and treatment clinic and laboratory. Long wait times have been previously reported to hinder treatment compliance among cervical cancer patients [41]. We found that employed patients were concerned about conflicts between work and posttreatment follow-up appointment schedules. The work versus healthcare-seeking dilemma can be complicated by previous experiences of delay in obtaining care. Delays affecting patient follow-up have been reported in other countries in sub-Saharan Africa [34, 36]; they are complex and require multi-sectoral interventions to reduce patient wait times and incentivise women to complete their post-screening follow-up schedules.

Leveraging low-cost digital communication technologies could improve the dissemination of information for health education [42] and patient follow-up. In our study, healthcare providers reported using WhatsApp to coordinate referred patients for cervical cancer screening and management and then give feedback to colleagues in lower health centres. The use of mobile applications to support service efficiency and client retention in care has been documented [43]. Given the wide acceptance of the WhatsApp platform, this approach could become a healthcare provider- and client-friendly modality to improve follow-up and retention of women [44] in cervical cancer care.

Integration of cervical cancer screening and post-treatment follow-up was still limited to HIV clinics despite the increasing burden of non-communicable diseases requiring long-term care. Integration of cervical cancer services into primary healthcare is an inclusive approach to healthcare and could fast-track the reduction of cervical cancer burden in LMICs [36, 45]. It allows information sharing between different healthcare centres, and

patient appointments for multiple services can be scheduled on the same day, reducing the number of patient visits to the health facility and the associated expenditure [31]. Considering existing gaps in the healthcare system, additional studies are required to determine cost-effective approaches to scaling up the integration of cervical cancer screening, treatment, and follow-up services at different levels of primary healthcare.

Strengths and limitations

Although we invited women lost to follow-up for faceto-face interviews at the clinic for higher quality data (compared to telephone interviews), many women classified as lost to follow-up who were initially selected from the clinic register could not be reached due for various reasons, including phone switched off on several call attempts. Subsequently, enrolment of patients categorised as lost to follow-up included even those who had been lost to follow-up for more than two years but were reachable via phone call, risking possible survivorship bias. Patients' HIV serostatus may influence loss to follow-up or retention in care; however, patients' HIV status data was not collected. In addition, our understanding of barriers and facilitators could have been enriched by interviewing patients' spouses, other immediate family and community members. Despite these limitations, this study provides valuable insights into barriers and facilitators of retention in cervical cancer screening and care. It has identified potential gaps in our setting for further investigation. Patients' and healthcare providers' responses were triangulated during analysis, and there was high concordance on issues identified by both groups of participants. The data was collected and analysed by local researchers familiar with the nuances of local dialect and culture. Detailed exemplars of participants' views have been provided to support the assessment of the potential for transferability of findings to similar settings. Future studies could target a wider study population to obtain perspectives from multiple influencers of decision-making and care for patients screened for precancerous cervical lesions.

Conclusions

Our study revealed barriers to retention in care after cervical cancer screening, including lack of partner support, financial and educational constraints, and inadequate information. It also found facilitators that included social support, positive self-perception, and effective counselling. A strengths-based approach to counselling women should be tested to increase adherence to scheduled appointments to achieve the goals of cervical cancer screening. Resources to reduce turnaround time for results so that one-day screen-and-treat is achieved and support for systematic reminders to patients could go a long way to reduce loss to follow-up. In addition, quality improvement interventions for healthcare providers and infrastructure support could help reduce waiting time and improve the adequacy of counselling. Integration of cervical cancer screening and treatment services in mainstream primary healthcare services is recommended.

Abbreviations

MRRH Mbarara Regional Referral Hospital

CCCervical cancer HPV Human Papilloma Virus SFM Socio-ecological model

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Author contributions

FS, ET, DT, NK, SM, RK and MG conceptualized and designed the study. JO and PM collected and analyzed the data and drafted the manuscript. ET coordinated data collection, analyzed the data, and critically revised the first draft of the manuscript. TCR, CMC and ECA guided overall data analysis and the final write up. All authors read, revised, and approved the final manuscript for publication.

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Data availability

All data generated in this study were analysed and included in this article.

Declarations

Ethics approval and consent to participate

Ethical review and approval were obtained from Mbarara University of Science and Technology Research Ethics Committee (MUST-2022-670). All methods involved in this study were executed following relevant guidelines and regulations. All patient and healthcare provider participants signed a written informed consent before the interview.

Consent for publication

Not Applicable.

Competing interests

The authors declare no competing interests.

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