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Barriers and facilitators of cervical cancer screening literacy among rural women with HIV attending rural public health facilities in East Central Uganda: a qualitative study using the integrated model of health literacy

Juliana Namutundu[1*], Juliet Kiguli[2], Edith Nakku-Joloba[1], Fredrick Makumbi[1], Fred C. Semitala[4,6], Rhoda K. Wanyenze[3], Miriam Laker-Oketta[7], Damalie Nakanjako[4,7] and Miriam Nakalembe[5,7]

Abstract

Background Several rural public health facilities in East Central Uganda have sub-optimal, below 50%, levels of uptake of cervical cancer screening services among women with HIV. This is attributed to low cervical cancer screening literacy: limited ability to access, understand, appraise, and apply cervical cancer screening information. This research identified multi-level (health facility, community, interpersonal and individual) barriers, and facilitators of accessing, understanding, and applying cervical cancer screening information among rural women with HIV attending rural public health facilities in East Central Uganda to inform interventions.

Methods We conducted ten Focus Group Discussions with rural women aged 25–49 years with HIV attending four selected rural public health facilities: thirty women who had ever screened for cervical cancer and thirty women who had never screened for cervical cancer across different age categories. Data was collected using a guide based on the Integrated model of health literacy. Thematic analysis was used for analysis. Competences (accessing, understanding and applying cervical cancer screening information) and categories of factors (health system, community, interpersonal and individual factors) of the integrated model of health literacy were deductively derived whereas barriers and facilitators were deductively derived from women's statements.

Results Lack of communication materials and inability to access information were health facility and individual barriers of accessing cervical cancer screening information respectively. Facilitators of accessing information were access to information at health facility, community, and interpersonal levels and women's ability to access information. Barriers and facilitators of understanding cervical cancer information were related to communication materials, provision of health education and women's concentration during health education. Barriers and facilitators of applying cervical cancer screening information were related to communication and provision of cervical cancer

*Correspondence:
Juliana Namutundu
jnamutundu@musph.ac.ug

Full list of author information is available at the end of the article

screening services at health facility level, and interpersonal level from peers, partners and other family members as well as women's ability to: understand information and access to cervical cancer screening services at individual level.

Conclusions This study emphasizes the influence of multi-level factors on cervical cancer screening literacy among rural women with HIV attending rural public health facilities in East Central Uganda. Improving uptake of cervical cancer screening services among these women requires multi-level interventions.

Keywords Barriers, Facilitators, Uptake of cervical cancer screening services, Cervical cancer screening information, Rural women, HIV

Background

Cervical cancer is one of the most common cancers among women with global reports of 570,000 cases and 311,000 deaths annually, 85% of whom are from Low and middle income countries, mostly Sub-Saharan Africa [1, 2]. Cervical cancer is the most commonly occurring cancer among Ugandan women with an incidence rate of 54.8 per 100,000 women per year [3]. Screening of women followed by treatment of detected precancerous lesions can prevent majority of cervical cancers [4, 5]. The World Health Organization, WHO, recommends a 'screen-and-treat' approach in Low and Middle Income Countries, whereby screening is done using: visual inspection with acetic acid (VIA) or cytology using the Papanicolaou (Pap) test or Human Papilloma Virus (HPV) testing where feasible, followed by immediate treatment of precancerous lesions using: ablative or excision modalities where indicated [4]. Women with HIV have a shorter period from HPV acquisition to invasive cervical lesions and therefore require more frequent cervical cancer screening than HIV negative women [6].

Cervical cancer screening in Uganda is mainly conducted using visual inspection with acetic acid (VIA) [7] and treatment of precancerous lesions is done using thermo-ablation [8]. The Ministry of Health recommends cervical cancer screening among women 25–49 years, once every year for women with HIV and once every three years for HIV negative women [9] since HIV positive women require more frequent cervical cancer screening than HIV negative women [6]. However, uptake of cervical cancer screening services among Ugandan women is very low, with studies reporting a once in a lifetime screening rates ranging from 4.8 to 30% [10, 11]. The low uptake of cervical cancer screening services among Uganda women has been attributed to various individual, interpersonal, community and health system level barriers [12].Consequently, majority of Ugandan women with cervical cancer (over 80%) are diagnosed with advanced disease [13] which leads to poor treatment outcomes and high mortality rates [14].

Cervical cancer screening services were integrated into HIV care in order to improve uptake of cervical cancer screening services among women with HIV in Uganda [15]. However, despite the integration, uptake of cervical cancer screening services among women with HIV is still low, 30.3% [16]. Within East Central region, integration of cervical cancer screening services into HIV care in 12 districts has been enhanced by support from the Makerere University Joint AIDS Program (MJAP) USAID Local Partner Health Services – East Central Region, (LPHS-EC), since October 2021 through training health workers in providing cervical cancer screening information and services and providing equipment and supplies for cervical cancer screening. Despite a general improvement in uptake of cervical cancer screening services among women with HIV in this region from 36% by end of March 2022 to 64% by mid-September 2022, a number of rural public health facilities still had sub-optimal levels of uptake of cervical cancer screening services: between 25 and 49% [17]. Moreover, 5% of women with HIV that were screened during this period had precancerous lesions [17]. As a result, there are missed opportunities for cervical cancer screening whereby rural women with HIV who interface with the health facilities and have an opportunity to screen for cervical cancer do not screen which leads to late presentation and disparities in cervical cancer burden among these rural women.

Limited knowledge about cervical cancer screening is a major barrier of uptake of cervical cancer screening services among Ugandan women with HIV [18]. Health literacy, the knowledge, motivation and competence to access, understand, appraise and apply health information [19] is a predictor of knowledge of cervical cancer screening [20]. Uptake of health services is affected by a person's ability to access, understand and use health information. This is influenced by individual, interpersonal, community and health facility factors [19] as well as the complexity of health services, and the demands they place on the individual [21, 22]. Individual factors like no or low education attainment, low socioeconomic status, poor risk perception and misconceptions and beliefs influenced by interpersonal relationships and community factors as well as challenges with engaging with the services [11] affect "cervical cancer screening literacy", the motivation and competence to access, understand, appraise and apply cervical cancer screening information to seek and cervical cancer screening services among rural women with HIV. Therefore, there is

need for interventions targeting multi-level barriers of cervical cancer screening literacy among these women.

Current strategies for improving uptake of cervical cancer screening services among rural women with HIV were developed based on research evidence from Ugandan women generally [12, 23–25] yet rural women with HIV have a unique context and require context specific and culturally sensitive information and interventions [26]. This is because available research evidence focuses on individual barriers and facilitators of uptake of cervical cancer screening services among Ugandan women generally [12] and Ugandan women with HIV [18]. Therefore, there is limited information on multi-level factors that affect cervical cancer screening literacy which is important for informing interventions for improving cervical cancer screening literacy among rural women with HIV. The purpose of this study was to identify health facility, community, interpersonal and individual barriers and facilitators of accessing, understanding and applying cervical cancer screening information among rural women with HIV in care at rural public health facilities in East Central Uganda.

Theoretical framework

This research was guided by the integrated model of health literacy [19]. According to this model, there are four major competences of health literacy namely, accessing, understanding, appraising, and applying health information to make judgments and take decisions concerning the three domains: healthcare, disease prevention and health promotion (Fig. 1). Accessing refers to the ability to seek, find and obtain health information, understanding refers to the ability to comprehend accessed health information, appraising refers to the ability to interpret, filter, judge and evaluate the health information that has been accessed: and applying refers to the ability to communicate and use the information to decide to seek and use health services. The four competences of health literacy are dependent on societal and environmental determinants which include: community and health facility factors, situational determinants which include interpersonal factors and personal determinants which are individual factors.

This model proposes four dimensions for measuring health literacy in healthcare (disease prevention and health promotion): ability to access health information, to understand health information, to interpret and evaluate health information and apply the information to make informed health decisions. We applied this model to identify multi-level: health facility, community, interpersonal and individual, barriers and facilitators of accessing, understanding and applying cervical cancer screening information among rural women with HIV in care at rural public health facilities in East Central Uganda.

Methods

Study design, setting and sites

This study was part of a larger study that sought to design and evaluate an implementation strategy [27] for improving cervical cancer screening literacy among rural women with HIV in care at rural public health facilities in East Central Uganda. In this paper, we used descriptive qualitative methods [28] to address part of the formative research: identifying multi-level barriers to and facilitators of cervical cancer screening literacy among rural women with HIV in care at rural public health facilities in East Central Uganda. This research was conducted in East Central Uganda which comprises of 12 districts namely: Bugiri, Bugweri, Busia, Buyende, Iganga, Jinja, Kaliro, Kamuli, Luuka, Mayuge, Namayingo, and

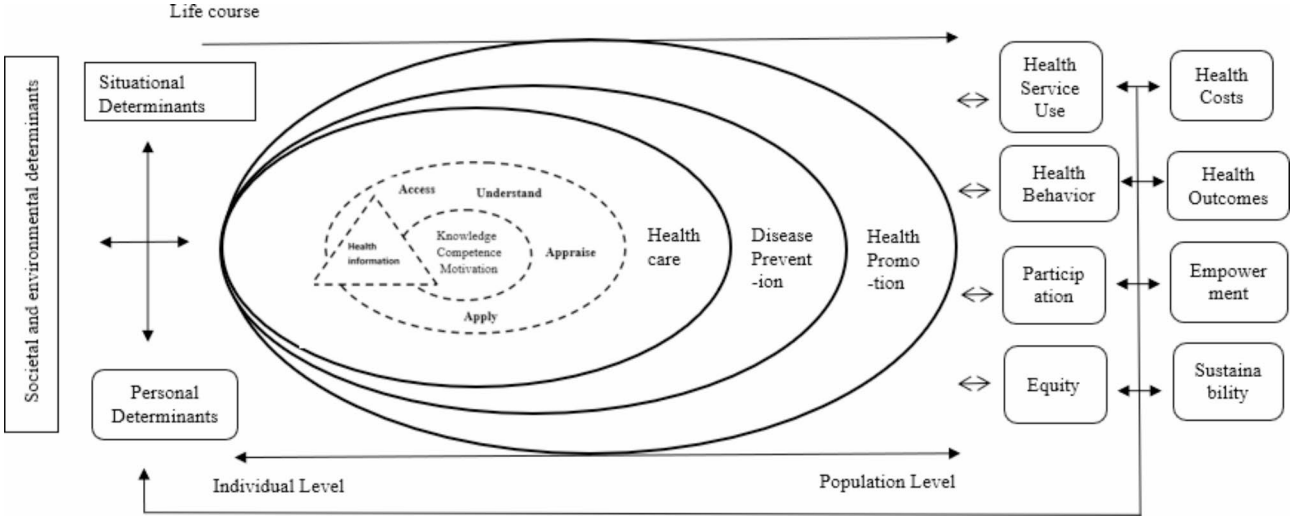

Fig. 1 The Integrated model of Health Literacy [19]

Namutumba. Cervical cancer screening services using VIA were integrated in HIV care at 42 public health facilities: Health Center IIIs and Health Center IVs, in the 12 districts whereby women with HIV aged 25–49 years are required to screen once every year. Within this region, 5% of women with HIV that were screened for cervical cancer between October 2021 and September 2022 had precancerous lesions [17].

The sites for this study were four purposively selected rural public health facilities in Mayuge and Namayingo districts, East Central Uganda. Wabulungu HCIII and Malongo HCIII in Mayuge district and Banda HCIII and Mutumba HCIII in Namayingo district. These health facilities were selected because they represented how cervical cancer screening services were provided at rural public health facility in East Central Uganda. They also had varying levels of uptake of cervical cancer screening services. By September 2022, the level of uptake of cervical cancer screening services among eligible women with HIV targeted for 2022 at Wabulungu HCIII and Malongo HCIII in Mayuge district was 82% (209/254) and 43% (286/671) respectively while that for Banda HCIII and Mutumba HCIII in Namayingo district was 143% (504/352), above the health facility target for the period and 39% (173/443) respectively [17].

Table 1 Sample questions from the focus group discussion guide

Competence	Sample questions
Accessing cervical cancer screening information	• How do you access cervical cancer screening information? • What makes it easy to access cervical cancer screening information? • What challenges do you face with accessing cervical cancer screening information? • How do your peers influence your ability to access cervical cancer screening information? • How do your family members influence your ability to access cervical cancer screening information? • How do your communities affect your ability to access cervical cancer screening information?
Understanding cervical cancer screening information	• What makes it easy for you to understand cervical cancer screening information? • What challenges do you face with understanding cervical cancer screening information? • How do opinions of your peers influence your ability to understand cervical cancer screening information? • How do opinions of your family members influence your ability to understand cervical cancer screening information? • How do your cultural norms or beliefs affect your ability to understand cervical cancer screening information?
Applying cervical cancer screening information	• How do you apply cervical cancer screening information? • What makes it easy for you to apply cervical cancer screening information? • What challenges do face while applying cervical cancer screening information to seek and use cervical cancer screening services? • How do opinions of your peers influence your decision to screen for cervical cancer? • How do opinions of your family members and relatives influence your decision to screen for cervical cancer? • How do your cultural beliefs influence your decision to screen for cervical cancer? • How do opinions of the people in the community you live influence your decision to screen for cervical cancer?

Data collection methods

We conducted ten Focus Group Discussions, FGDs, with rural women with HIV aged 25–49 years in care at selected rural public health facilities. Each FGD comprised of six women. FGD participants were selected using stratified purposive sampling based on cervical cancer screening status: ever or never screened for cervical cancer based on health facility records and women's self-report and age category: 25–29, 30–34, 35–39, 40–44 and 45–49. Each age category had separate FGDs of women who have ever screened for cervical cancer and those who had never screened. Participants were recruited by the ART clinic in-charge or designee together with the Principal Investigator. Data was collected using an FGD guide developed by formulating qualitative question from the questions of the European Health Literacy Questionnaire HLS-EU-Q47 [29] which was developed based on the integrated model of health literacy [19]. The FGD guide comprised of questions relating to individual, interpersonal, community and health system barriers and facilitators of the three cervical cancer screening literacy competences: accessing, understanding and applying cervical cancer screening information. Table 1 shows sample questions under each competence.

FGDs were conducted by two research assistants: a moderator and note taker following individual consent by each of the participants. The research assistants were supervised by JN. All FGDs were conducted in Lusoga which is the most common local language within the study setting and in a private setting which was agreed on by the participants. Interviews lasted about 1–2 h.

Data management and analysis

All FGDs were audio recorded. Each interviewer translated and transcribed their interviews. Template analysis was used for coding since it allows for flexibility in coding structure, use of a priori themes and use of a predetermined coding template [30, 31]. A codebook was developed using a coding template developed prior based on the integrated model of health literacy. We used both deductive and inductive categorization during thematic analysis [32]. Deductive categorization was used for

Table 2 Characteristics of participants

Variable	Had Ever screened for cervical cancer (*n* = 30)	Had never screened for cervical cancer (*n* = 30)	Overall (*N* = 60)
Age (completed years)			Age range (25–49)
25–29	6	6	12
30–34	6	12	18
35–39	6	-	6
40–44	6	6	12
45–49	6	6	12
Duration in HIV care (completed years)			Range (1–25)
1–5	18	17	35
6–10	5	6	11
11–15	5	5	10
16 and above	2	2	4
Highest Education level attained			
No education	3	1	4
Lower Primary	9	5	14
Upper Primary	9	8	17
Lower Secondary	9	15	24
Upper Secondary	0	1	1
Marital status			
Married	16	15	31
Widowed	4	4	8
Separated	10	8	18
Single	0	3	3
Number of children			Range (0–10)
0	1	1	2
1–3	9	10	19
4–6	10	10	20
7–10	10	9	19
Occupation			
Subsistence Farmer	20	17	37
Small scale business	8	9	17
Other	2	3	5
Unemployed	0	1	1
Number of times screened			
One time	17		
Two times	7		
Three times	5		
Four times	1		
Motivation for screening			
Recommendation by a health worker	11		
Perception of cervical cancer risk	11		
Health education at health facility	7		
Village announcement	1		

pre-determined competences (accessing, understanding and applying cervical cancer screening information) and categories of factors (health system, community, interpersonal and individual factors) of the integrated model of health literacy whereas inductive categorization was used for deriving barriers and facilitators from women's statements. Coding and data analysis were conducted manually in Excel by JN and an independent Research Assistant for quality control. Transcripts for each FGD were pasted in different excel sheets. Columns created representing themes (accessing, understanding or applying cervical cancer screening information), sub-themes (levels: health facility, community, interpersonal or individual) and codes (barrier or facilitator). Corresponding themes, sub-themes and coded were filled in for each statement. Steps in the analysis included: (1) developing the codebook based on the coding template, (2) reading each transcript to the familiarize ourselves with the data, (3) coding systematically across all transcripts while ensuring that we identify important quotes and capture the source FGD (4) sorting the data by competence, category and barriers and facilitators to retain only coded data and (5) combining all transcripts in one excel sheet and resorting using the same criteria (by competence, category and barriers and facilitators).

Results

The total number of participants was 60, ten FGDs with six women each. These included 30 women who had ever screened for cervical cancer and 30 women who had never screened distributed across different age categories. Majority of participants had been in HIV care for 1–5 years, attained lower secondary education, were married, had 4–6 children and were subsistence farmers. Among the 30 women who had ever screened for cervical cancer, more than half, 17, had screened once and the most mentioned motivations for screening were recommendation by a health worker, due to presence of symptoms and perception of cervical cancer risk. Table 2 shows details of participant characteristics.

Multi-level barriers to accessing, understanding and applying cervical cancer screening information

Barriers to accessing cervical cancer screening information

Lack of IEC materials was identified as a health system barrier to accessing cervical cancer screening information. Women requested for other types of IEC materials in local language and with illustrations.

…. They should bring us reading charts and teach you when you are seeing everything …. we don't see them…they are not there…. in Lusoga (local language). (FGD 2)

Stigma was mentioned as a major individual level barrier to accessing cervical cancer screening information. Women mentioned that they would be identified as HIV

positive if they were seen attending the health education sessions for cervical cancer screening which were only for HIV positive women. As a result, they shunned and missed health education sessions on cervical cancer screening due to stigma.

…Sometimes you have come for refill, and you are scared of people seeing you and you say now they are putting me in a group of HIV positive people and they see me and you say let me go I will come back and you come back when they have finished teaching. (FGD 2)

Other individual level barriers to accessing cervical cancer screening information were missing health education sessions, not owning a telephone and lack of access to mass media. Reasons for missing health education sessions included: reporting late on clinic days, having long drug refills, migration whereby women keep getting married in different places and lack of money for transport to the health facility. Women who lacked a telephone or had challenges with accessing mass media were unable to access cervical cancer screening information.

…. In most of times we miss education talks (at the health facility). Sometimes we reach when maybe they have finished teaching. (FGD 4)

Now for me, lack of a cell phone. Without a cell phone, I am unable to access information or updates regarding cervical cancer screening. (FGD 9)

Barriers to understanding cervical cancer screening information

Health facility barriers to understanding cervical cancer screening information included: not having translated IEC materials, rude health workers, contradicting information, lengthy health education sessions and health workers not giving one on one health education sessions. Women who could read mentioned that it would be easy for them to read and understand IEC materials if they were in the local language. Therefore, having IEC materials in English is a barrier to understanding cervical cancer screening information even among a few women who can read local languages. Provision of cervical cancer screening information by rude health workers demotivated women from understanding the information. Women also mentioned that sometimes they received contradicting cervical cancer screening information at different places.

…. If the IEC materials are put in the language that person understands best, it will be easy for them to read and understand on their own. (FGD 10)

…We can be taught here and then go somewhere and we are told another thing that contradicts with what you have been told …… (FGD 10).

Other health facility barriers to understanding cervical cancer screening information included prolonged health education sessions covering different topics and inability of health workers to provide an opportunity for women to ask personal questions in one on one sessions. Lack of concentration was mentioned as the only barrier to understanding cervical cancer screening information at individual level.

The health worker might be teaching about cancer but also brings in vaccinations remember you were on cancer then the topic changes and you lose track and leave without understanding. (FGD 1)

Barriers to applying cervical cancer screening information

Identified health facility barriers to applying cervical cancer screening information were categorized into barriers to accessing cervical cancer screening services and barriers to utilizing cervical cancer screening services. Health facility barriers to accessing cervical cancer screening services included: provision of inadequate information, coercion by health workers to screen for cervical cancer, providing cancer screening services outside the ART clinic, challenges with accessing cervical cancer screening services, unavailability of cervical cancer screening services and group screening whereby midwives only provide cervical cancer screening services if they receive at least five women for screening.

…Most our friends we have heard from come and tell us that they came without having any idea of screening and they are just told to have the screening by force because the health worker says without screening no medicine, so they just go in because they know the importance of the medicines …… but this is something they are just forcing on her …. it affects them because the thing is abrupt…… That is why I persist on being taught when we are taught, we can make the decision ourselves…… (FGD 4).

You have to move to another place within the same facility to get another service (cervical cancer screening), so that moving from here to there also affects and you tell me I will not be going there because I will have to move from here to there that can also discourage someone. (FGD 10)

The health worker can say the box has 5 but if your 1 or 2 then it is spoilt it …… They want a complete number so these ones the 1 or2 who were interested are given another day of appointment and that other day can reach when you are no longer interested. (FGD 4)

Health facility barriers encountered by women in the process of using cervical cancer screening services included: long waiting time, rude health workers and lack of privacy during screening.

…. Most times the health worker is one giving the service so if we are 5 or 10 others might get tired and leave because the health worker is one that is giving the service. (FGD 7)

Cultural beliefs were identified as a barrier to seeking and using cervical cancer screening services at community level. Women mentioned that some cultures believe

that they do not get cervical cancer and therefore discourage their women from screening.

…If no one has ever suffered from cervical cancer others stop you from going for cervical cancer screening saying that no one suffers from cancer in their clan …… (FGD 10).

Interpersonal barriers to seeking and using cervical cancer screening services were misconceptions among peers, partners, and other family members, fear mongering by peers who have screened, lack of partner support and discouragement by family members. Peer misconceptions about: cervical cancer screening generally, the screening procedure and outcomes of screening were mentioned as barriers that affect women's motivation to screen for cervical cancer.

They (peers) discourage us, imagine telling you that they remove your uterus. That discourages and you don't go for cervical cancer screening because you might go, and they remove your uterus and put it aside. (FGD 7)

Another barrier that women mentioned was fear mongering among peers who had ever screened for cervical cancer. Women mentioned that their peers who had ever screened for cervical cancer had informed them that the screening procedure is 'rough' and that they experienced a lot of pain after screening. These discouraged women who had never screened from screening.

Those who were screened tell us that when they put the machine inside you, you will have vaginal discharge all the time …… So that can stop me because if am with my husband and he ask why am like that and I tell him that I was the health facility for screening he might refuse me to come for my refills the next time. (FGD 10)

There is a friend of mine that was screened and she said that you remain with pain in the fallopian tube and I am a farmer, I can't leave my food is in the bushes. (FGD 4)

Additionally, lack of partner support and discouragement by other family members like mothers and grandmothers were mentioned as barriers to using cervical cancer screening services.

Some women like us are in relationships that are discordant so if the man hears that for him, he is negative and you have it, he feels that it's your responsibility whether you go for screening or not is not his concern. If you don't have money for transport, then that's your problem because he knows that if you die tomorrow, he can bring another woman. (FGD 5)

…. Others it is the parents that refuse them (to screen for cervical cancer) I will say they refuse us. Your husband can allow you and then your mother or grandparents can refuse you. (FGD 4)

At individual level, fear of cervical cancer screening was a major barrier of uptake of cervical cancer screening services. Women attributed fear of cervical cancer screening to fear of the screening procedure, fear of contracting infections from the screening machine and fear of consequences of cervical cancer treatment in case they were found to have cervical cancer.

…… They fear that they normally use the same machine maybe you have just screened me, and you use that very machine to screen another person at that very time: so, they fear getting STIs. (FGD 5)

…. You can say when they find me positive, now giving me drugs, I spend this period without a man and the man will get to know yet I don't want him to know" so you fear that. (FGD 2)

Women also mentioned that they already had HIV and did not want to undergo the additional trauma of being told that they had cervical cancer. This fear of a positive test demotivated some women from screening for cervical cancer.

…. Remember you are on medication and then you hear that you have cancer and others know that cancer is not curable so that also scares you and you think what if I have cancer and HIV: will I really do this. So others stay there scared and say let me be with my HIV and not add more stress. (FGD 5)

Women had misconceptions about: cervical cancer screening generally, the screening procedure and outcomes of screening most of which they had heard from their peers. These misconceptions affected women's motivation to screen for cervical cancer.

….just recently we buried a lady who had suffered that disease, but they were telling her to go and screen in the health facility and she refused that no this is not cancer disease but it's just witchcraft. She was brought at private facility; they screened her and told her that it's cervical cancer but still she refused and didn't care about it much and eventually she died in December last year. (FGD 10)

Stigma was mentioned as a major barrier of uptake of cervical cancer screening services. Women mentioned that cervical cancer screening services at these health facilities were provided to only HIV positive women so they never wanted to be seen attending these services since they would be identified as HIV positive. Therefore, stigma affected women's motivation to screen for cervical cancer.

…. What affects us is they say that it is mainly for HIV patients, ……. Sometimes you didn't disclose your status to anyone or community …… and even some have not disclosed to some family members and even some have husbands and they have not told them so that affects us in the community. (FGD 4)

Women were not comfortable with the screening procedure since it involves examining their genitalia and this stops them from screening. Some women mentioned that they are not comfortable with being examined by a male health worker. Even women who were screened by a male

health worker mentioned that they would not re-screen if it was a male health worker doing the screening.

…. Fear of exposing their bodies to medical workers. Many women feel uncomfortable or self-conscious about undergoing a procedure that involves revealing intimate areas of their bodies. (FGD 9)

I saw a male nurse coming and I said that "Eh, it is a male that is going to screen us" Even me what scared me is the male nurse..... the nurse told me that "No, be strong". I became strong but I said I will not go back if it is a male nurse who will open my legs…. (FGD, 30–34, Ever, Screened)

Lack of knowledge about cervical cancer, cervical cancer screening and availability of cervical cancer screening services were also mentioned as barriers to using cervical cancer screening services.

…. We hear about cervical cancer screening, but truth is we have not yet been taught very well to know the advantages and disadvantages in it. So now that some of us have not yet got the depth of it… (FGD 4).

I have ever heard about it but I don't know how they screen it. (FGD 2)

Some women who had never screened for cervical cancer mentioned that they didn't feel the need to screen for cervical cancer since they had never had symptoms of cervical cancer. Others lacked: motivation, time to seek for cervical cancer screening services and money for seeking cervical cancer treatment.

…. I don't have anything paining me and I don't have any signs showing, I will say why am going there (to screen for cervical cancer). (FGD 8)

Table 3 shows multi-level barriers to accessing, understanding and applying cervical cancer screening information.

Multi-level facilitators of accessing, understanding and applying cervical cancer screening information

Facilitators of accessing cervical cancer screening information Health education and research studies at the health facility were mentioned as facilitators of accessing cervical cancer screening information at health facility level. Women mentioned that they obtained information on cervical cancer screening from the health education sessions and research studies conducted at their health facilities.

I got information about cervical cancer here at the facility from the ART clinic. It was my appointment and had come in care and the clinician told me about cervical

Table 3 Multi-level barriers to accessing, understanding and applying cervical cancer screening information

Category	Accessing cervical cancer screening information	Understanding cervical cancer screening information	Applying cervical cancer screening information
Health facility barriers	Lack of IEC materials	IEC materials not in local language Rude health workers Provision of contradicting information Lengthy health education sessions Health workers not giving one on one health education sessions	Provision of inadequate information Health workers coercing women to screen for cervical cancer Cervical cancer screening not done at the ART clinic Challenges with accessing screening services Unavailability of cervical cancer screening services Group screening Long waiting time Rude health workers Lack of privacy during screening
Community barriers			Cultural beliefs
Interpersonal barriers			Misconceptions among peers Misconceptions among partners Misconceptions among other family members Fear mongering by peers who have screened Lack of partner support Discouragement by other family members
Individual barriers	Stigma Missing health education sessions Not owning a telephone Lack of access to mass media	Lack of concentration	Fear of cervical cancer screening Fear of a positive result Misconceptions Stigma Discomfort with being examined Discomfort with being examined by a male health worker Lack of knowledge Unpreparedness Absence of symptoms Lack of time Lack of motivation Lack of money for seeking for cervical cancer treatment

cancer and also said if it's like that let me also go and screen, you never know. (FGD 1)

At community level, women mentioned that they accessed information about cervical cancer screening through communication by community health workers who included Village Health Teams (VHTs) and mentor mothers, and community-based organizations like saving groups, and announcements within their communities which included: church announcements, mobile vans and motorcycles and funeral announcements.

The VHT tells people that "we have such and such a study and the doctors are coming to the health center and whoever feels like they want to screen for cervical cancer." So that also makes it easy for us to know. (FGD 3)

…. Religious leaders, such as pastors, encourage us to seek cervical cancer screening services. They emphasize the importance of taking care of one's health and often advise us to undergo regular screenings…… (FGD 9).

Health workers on a moving car move around telling us where and when the health workers will come, and they announce that they will carry out cervical cancer screening. (FGD 5)

At interpersonal level, women mentioned that they obtained information about cervical cancer screening from their partners and that they share information among themselves (peers).

My husband frequently attends health talks so he can't stop me from going for screening. So even he gets to hear of certain information, he is in position to deliver it to me…… (FGD 10).

Facilitators of understanding cervical cancer screening information Use of local language and illustrations by health workers during health education sessions, and consumer centered communication were reported as facilitators of understanding cervical cancer screening information.

…We understand when she teaches us in the language that we understand. (FGD 2)

They were teaching with illustrations, they had papers that had illustrations of the disease and how it looks like, and they were showing us the pictures as they taught so we understood… (FGD 8).

Facilitators of applying cervical cancer screening information Communication related facilitators of uptake of cervical cancer screening services included: provision of health education, consumer centered communication and health education by peers.

They can give you that information and you know that the information they are giving you is important, and it will help you decide to let me go and screen and know whether my life is in danger or not. And if it's in danger I can start on treatment. (FGD 5)

If you get a chance and the linkage facilitator (peer) is the one educating she will talk to you because she pictures herself in you so she will talk referring to herself and will tell you her experiences …. That thing has played a big role in motivating other people…. (FGD 4)

Service provision related facilitators of uptake of cervical cancer screening services included: integration of cervical cancer screening services into HIV care, cervical cancer screening being free of charge, availability of cervical cancer screening services, provision of HPV self-sampling method and availability of cervical cancer treatment which improve accessibility of cervical cancer screening services.

…. You come only one time on your appointment date and screen. They move together without having to waste transport to come and then go back then again come again. (FGD 1)

Since they teach and tell us if you get a bad chance and your found positive, they treat you at zero cost: that made me happy and motivated most to come and screen because I can't afford it as a person. (FGD 1)

…. Now days things have been simplified even here at this health facility we are being screened (FGD 5).

Additionally, women mentioned that recommendation of cervical cancer screening by a health worker, coercion to screen, clear pathways to access cervical cancer screening services and support to navigate these pathways enabled them to use cervical cancer screening services.

I told the health worker that I sometimes get pains in my stomach and back pains. He asked me that have you ever screened for cervical cancer, and I told him no. he told me about the signs like milky discharge and he told me that you need to have screening for cervical cancer we talked, and he asked me if am willing and I told him I was willing to screen. (FGD 1)

…. I got so worried, because they told me they would not give me tablets (ARVs) if we did not get screened, I saw it was very hard, but I went ahead… God helped me ame, the results came out negative. (FGD 9)

Other service-related facilitators of using cervical cancer screening services included: privacy during screening, consumer centered services and confidentiality among health workers.

…Since we are only two in the room it doesn't matter what the health worker tells me what do, there is no one else who can see that they saw me so that motivates me because we are only two in the room. (FGD 5)

Me what motivates me when I come here the health workers are friendly, they handle me with care and so whatever happens to me, I must come and report to them because they are good to me. ((FGD 9).

Facilitators of seeking and using cervical cancer screening services at interpersonal level included: peers sharing

experiences and encouragement by peers, partners and other family members.

"…. If she (a peer) stands up and says she has ever gone through it, and we are seeing her alive up to now that gives me courage and also say that let me also go and screen if am positive I will also be alive like how she is alive." (FGD 5).

"My husband came to this facility, when they sensitized them about it, he came and told me that on such a day, there will be screening for cervical cancer. So, he is the one who encouraged me. I came here and screened." (FGD 3).

Women mentioned various individual level facilitators of using cervical cancer screening services that relate to accessing and understanding cervical cancer screening information. These included: access to information, understanding cervical cancer screening information, ignoring misconceptions, perception of cervical cancer risk and knowledge.

My first time I feared a lot and I delayed waiting for others to come out and tell me what is happening there and believed that the first ones were lies but later accepted. So, people's words are there but it is me to decide because it is my life. (FGD 1)

Knowledge of cervical cancer symptoms, benefits of cervical cancer screening and knowledge of how to access cervical cancer screening services enabled women to access and use cervical cancer screening services.

…. By being informed about the potential risks and the benefits of timely intervention, I am motivated to act and seek cervical cancer screening services. (FGD 9)

Having symptoms of cervical cancer was a major facilitator of cervical cancer screening among women who have ever screened for cervical cancer. Some women mentioned that they were screened for cervical cancer when they were very ill.

…. When I discovered that I was experiencing signs or symptoms of cervical cancer, it motivated me to seek cervical cancer screening services. There was no community influence. (FGD 9)

Women who had ever screened for cervical cancer also mentioned that they were motivated to screen for cervical cancer because they had seen other people who had suffered from cervical cancer while others were just willing to screen for cervical cancer.

…. Witnessing the experiences of cervical cancer patients motivates me to take immediate action and prioritize my own cervical health……I think it reinforces the critical need for cervical cancer screening by highlighting the potential benefits of early detection and intervention. (FGD 9)

Table 4 shows multi-level facilitators of accessing, understanding and applying cervical cancer screening information.

Discussion

This study applied the Integrated model of health literacy to identify multi-level barriers and facilitators of accessing, understanding, and applying cervical cancer screening information among rural women with HIV in care at rural public health facilities in East Central Uganda. Barriers to accessing cervical cancer screening information were identified at health facility and individual levels whereas facilitators were identified at all levels: community, health facility, interpersonal and individual. Barriers and facilitators of understanding cervical cancer screening information were identified at health facility and individual levels whereas barriers and facilitators of applying cervical cancer screening information were identified at all levels: community, health facility, interpersonal and individual.

Multi-level barriers and facilitators of accessing cervical cancer screening information

Lack of IEC materials was reported as a barrier to accessing cervical cancer screening information at health facility level. Women reported that the IEC materials provided are few and therefore not easily accessible, yet adequate cervical cancer screening education tools are important in addressing cervical cancer screening information needs of women with HIV [33] Therefore, providing more IEC materials is key to improving access to cervical cancer screening information.

Health facility facilitators of access to cervical cancer screening information included: health education and communication from research studies conducted at the health facilities. Health education has previously been reported as a major [34] and important source of information on cervical cancer screening. Research studies were reported as sources of information due to ongoing research on cervical cancer in the study setting. At community level: accessing cervical cancer screening information through Community Health Workers, community-based organizations and community announcements were reported as facilitators of accessing cervical cancer screening information. This study therefore highlights the role of community health workers, organization, and communication channels in disseminating cervical cancer screening information.

This study revealed that peers and partners are a major source of information about cervical cancer screening for the study population. Participants reported that peers and partners sharing information facilitated their access to cervical cancer screening information. These findings therefore highlight the need to engage peers and partners in communicating cervical cancer screening information.

Individual level barriers to accessing cervical cancer screening information included: stigma, missing health education sessions, lack of a telephone and lack of access

Table 4 Multi-level facilitators of accessing, understanding and applying cervical cancer screening information

Category	Accessing cervical cancer screening information	Understanding cervical cancer screening information	Applying cervical cancer screening information
Health facility facilitators	Health education Research studies at the health facility	Use of local language Using illustrations Consumer centered communication	Provision of health education Consumer centered communication Health education by peers Integration of cervical cancer screening services into HIV care Provision of free cervical cancer screening services Availability of cervical cancer screening services Provision of HPV self-sampling method Availability of cervical cancer treatment Health workers recommending cervical cancer screening Health workers coercing women to screen for cervical cancer Clear pathways to access cervical cancer screening services Support to navigate cervical cancer screening services Privacy during screening Consumer centered services Confidentiality among health workers
Community facilitators	Communication by Community Health Workers Communication by community-based organizations Community Announcements		
Interpersonal facilitators	Partners sharing information Peers sharing information		Encou-ragement by peers Encouragement by partners Peers sharing experiences Encouragement by other family members
Individual facilitators	Owning a telephone	Being attentive during health education sessions Asking questions	Access to information Understanding cervical cancer screening information Ignori/ng peer misconceptions Perception of cervical cancer risk Knowledge Cervical cancer is curable if detected early Having symptoms Being very ill Knowing someone who suffered from cervical cancer Willingness to screen for cervical cancer

to mass media. Stigma among women with HIV at these facilities is attributed to provision cervical cancer screening services to only HIV positive women and yet health education on cervical cancer screening are provided in open exposed spaces. As a result, women with HIV feared to be seen attending these sessions and this led to stigma. Stigma is therefore an important context specific barrier to accessing cervical cancer screening information among women with HIV attending rural public health facilities. The Ministry of Health and implementing partners should consider providing cervical cancer screening services to all women to reduce stigma women with HIV while seeking for cervical cancer screening services. Women also sometimes missed health education sessions for various reasons including reporting late on clinic days. On top of health education sessions, health facilities should adapt more accessible modalities of communicating cervical cancer screening information like videos and use peers to improve access to cervical cancer screening information. Additionally, our participants were rural women most of whom have no phones and access to mass media. This therefore affects their ability to access cervical cancer screening information. Owning a telephone was identified as a facilitator of accessing cervical cancer screening information at individual level. This is because telephones are a major source of health information including information on cervical cancer screening and facilitate direct communication of this information from health workers.

Multi-level barriers and facilitators of understanding cervical cancer screening information

Having IEC materials that are not translated to local language, rude health workers, provision of contradicting information, lengthy health education sessions and not providing one on one health education sessions were identified as health facility barriers of understanding cervical cancer screening information. Language barrier and inability of women to ask questions have previously been reported as impediments to patient education and

involvement in decision making [35]. Women reported that available IEC materials are only in English language yet most rural women who can read can only read their local language. Therefore, these women are unable to read the available IEC materials. Also, health education sessions are provided in groups, yet majority of women would prefer asking questions privately. As a result, most women do not ask questions, and this affects their ability to understand the information provided.

Health facility facilitators of understanding cervical cancer screening information included: using local language during health education sessions, using illustrations and consumer centered communication. These findings indicate that use of local language and illustrations and consumer centered communication during health education sessions is key to ensuring that these women understand the cervical cancer screening information being provided.

Women reported lack of concentration during health education as an individual level barrier to understanding cervical cancer screening information. The lack of concentration was attributed to the many thoughts these women harbor due to the challenges they go through in their lives. Individual level facilitators of understanding cervical cancer screening information included: being attentive during health education sessions and asking questions. It therefore important to ensure that women concentrate during education sessions and to provide them with one-on-one sessions and opportunities to ask questions.

Multi-level barriers and facilitators of applying cervical cancer screening information

This study identified multi-level factors that affect women's ability to apply cervical cancer screening information to seek and use cervical cancer screening services which are barriers and facilitators of uptake of cervical cancer screening services.

Previously reported health facility barriers to uptake cervical cancer screening services among women reported by this study include: provision of inadequate information [16, 18], unavailability of cervical cancer screening services [36] and long waiting time [18]. Identified context specific health facility barriers to uptake cervical cancer screening services included: health workers coercing women to screen for cervical cancer, not performing cervical cancer screening at the ART clinic, challenges with accessing cervical cancer screening services, rude health workers, lack of privacy and group screening. Women reported that coercion by health workers to screen for cervical cancer and this keeps them away from screening. Some women who were previously screened due to coercion reported that they would not screen again. Coercion should not be used as a strategy of improving uptake of cervical cancer screening services among these women since it is unethical and not sustainable. Women in some health facilities reported that midwives only screen for cervical cancer if they receive at least five women willing to screen and therefore individuals or less numbers are denied the opportunity to screen. Midwives should provide an opportunity for all interested women to screen even when they present alone.

Provision of health education, health education by peers, integration of cervical cancer screening services into HIV care, provision of free cervical cancer screening services and availability of cervical cancer screening services were identified as health facilitators of uptake of cervical cancer screening services as reported by previous studies [15, 37–39]. Other previously reported health facility facilitators of uptake of cervical cancer screening services identified by this study were: health workers recommending cervical cancer screening [40], providing women with support to navigate cervical cancer screening services [41] and provision of HPV self-sampling which addresses challenges of other methods of cervical cancer screening [38]. In addition, consumer centered communication, clear pathways to navigate cervical cancer screening services, privacy during screening, consumer centered services and confidentiality among health workers were reported as health facility facilitators of uptake of cervical cancer screening services among the study population. Surprisingly, the present study identified coercion of women to screen for cervical cancer as both a barrier and facilitator of uptake of cervical cancer screening. Despite this finding, coercion has been discouraged in similar services [42]. It is therefore important for these rural public health facilities to stop using coercion as a strategy for improving uptake of cervical cancer screening services among women with HIV.

Cultural beliefs were identified as community level barriers to uptake of cervical cancer screening services. Women reported that some cultures believe that their women do not get cervical cancer, and this discourages these women from screening for cervical cancer. This finding agrees with a previous study [43] that reported that some women do not screen for cervical cancer because cervical cancer screening is against their cultural beliefs.

At interpersonal level, Peers sharing experiences during health education sessions and encouragement by peers [38] and partners [23, 43] were identified as major facilitators of uptake of cervical cancer screening services among participants. However, this study also revealed that peers, partners and other family members also instill fear and misconceptions and discourage women with HIV from screening for cervical cancer. A surprising finding from this study is that some women who had never screened for cervical cancer reported that they had

been discouraged by peers who had ever screened. This study therefore underscores the importance of engaging of peers, partners and other family members in improving cervical cancer screening knowledge, addressing fears and misconceptions and improving motivation of rural women with HIV to screen for cervical cancer.

Individual level barriers to uptake of cervical cancer screening services were fear of screening and a positive test, misconceptions, stigma, discomfort with screening and being screened by a male health worker, lack of knowledge, unpreparedness, absence of symptoms and lack of money to seek for cervical cancer screening treatment and time, motivation to screen for cervical cancer. Previous studies that reported fear as a barrier of cervical cancer screening attributed this fear to fear of pain during screening and fear of contracting infections during screening [18, 34, 36, 44]. In this study we also found that fear of cervical cancer screening was also due to fear of cervical cancer treatment and fear not being able to engage in sexual intercourse after screening which led to gender-based violence due to non-disclose of HIV status to partners. Previous studies also reported positive test [44, 45], misconceptions [18], absence of symptoms [44] and lack of time to seek for cervical cancer screening services [16, 34, 45] and money to seek for cervical cancer treatment [46] as barriers of uptake of cervical cancer screening services. Like in a previous study among women with HIV [44], fear of a positive test among participants was associated to the fear of the additional burden of having cervical cancer on top of having HIV. Stigma was reported as a major barrier to uptake of cervical cancer screening services among participants. A previous study reported community stigma as a barrier of uptake of cervical cancer screening services among women in informal settlements [34]. In the current study, stigma was attributed to selected health facilities providing cervical cancer screening services to only HIV positive women, yet these health facilities lack the infrastructure to provide privacy these women while they seek for cervical cancer screening services. As a result, women with HIV do not want to be seen seeking cervical cancer screening services. This study therefore highlights the role of stigma in deterring women with HIV attending rural public health facilities from seeking cervical cancer screening services. Participants also reported discomfort with being examined [18, 38] and discomfort with being examined by a male health worker [23, 36, 45] as barriers to uptake of cervical cancer screening services. The latter is of great interest since some women who had ever screened mentioned that they would not screen again if it were a male health worker performing screening. In agreement with previous studies [36, 39, 43, 44], this study also found that lack of knowledge about: cervical cancer, cervical cancer screening and where to seek cervical cancer screening services was a barrier of uptake of cervical cancer screening. Some women reported that they lack the motivation to screen for cervical cancer whereas others were unprepared, contacted to screen for cervical cancer when they were not prepared or unfit for screening at the time they are contacted. Like previous studies, this study also identified: access to information [39], perception of cervical cancer screening risk [16], knowledge about cervical and cervical cancer screening [16, 34, 44], having symptoms [34, 39], and knowing someone who has ever suffered from cervical cancer [34, 39]. Other identified individual level facilitators of uptake of cervical cancer screening services were understanding the information provided, ignoring misconceptions, knowing that cervical cancer is curable and being very ill all of which emphasize the need for adequate education of women with HIV about cervical cancer screening.

Strengths and limitations

Unlike previous studies which only focused on barriers and facilitators of uptake of cervical cancer screening services, this study also identified multi-level barriers and facilitators of accessing and understanding and applying cervical cancer screening information among rural women with HIV. This study was conducted at rural public health facilities in East Central Uganda that had high and low levels of uptake of cervical cancer screening services among women with HIV. This enabled us to identify barriers and facilitators of accessing understanding and applying cervical cancer screening information among these women. We conducted Focus Group Discussions with women who had ever screened for cervical cancer and those who had never screened for cervical cancer across different age categories. This allowed enabled us to adequately capture barriers and facilitators and have representativeness across different age categories which represent different levels of education attainment. Data collection, analysis and results' reporting were guided by the Integrated model of Health Literacy. This framework enabled us to get detailed information on multi-level barriers and facilitators of accessing, understanding and applying cervical cancer screening information among rural women with HIV. This study was limited to only four rural public health facilities in East Central Uganda. Therefore, findings from this study may not be generalizable to all rural public health facilities in Uganda. The health facility and community barriers and facilitators of accessing, understanding and applying cervical cancer screening information presented in this study are from rural women with HIV and do not represent views of health care providers, Village Health Teams and policy makers. Therefore, these may not fully represent the barriers and facilitators at these levels.

Conclusions

This study identified barriers and facilitators of accessing, understanding and applying cervical cancer screening information at health facility, community, interpersonal and individual among rural women with HIV in care at rural public health facilities in East Central Uganda. Findings from this study underscore the influence of these multi-level factors on the ability of rural women with HIV to access, understand and apply cervical cancer screening information. Improving uptake of cervical cancer screening services among these women requires multi-level interventions targeting identified multi-level factors. This will require Health facilities should improve communication materials, quality of cervical cancer screening and processes of providing of cervical cancer screening information and services Implementing partners should empower peers and partners with the right information and engage them in communicating cervical cancer screening information and in motivating these women to screen for cervical cancer. The Ministry of Health and implementing partners should provide cervical cancer screening services at these health facilities to all women to avoid stigma associated with accessing cervical cancer screening information and services among women with HIV. Additional research is needed to identify the most appropriate interventions for improving cervical cancer screening literacy among rural women with HIV and to engage these women in designing these interventions.

Abbreviations

ART	Antiretroviral therapy
FGD	Focus group discussion
HC	Health center
HIV	Human immunodeficiency virus
HPV	Human papilloma virus
IEC	Information, education and communication
IP	Implementing partner
MJAP	Makerere university joint AIDS program
MOH	Ministry of health
VHT	Village health team
VIA	Visual inspection with acetic acid
WHO	World health organization

Supplementary Information

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Supplementary Material 1

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Author contributions

Conception: JN, FM Writing the proposal: JN, RKW, FCS, JK, ENJ, MLO, DN, MN Data analysis and interpretation: JN, JK, ENJ, MN Drafting the manuscript: JN. All authors reviewed the manuscript and approved the final version.

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Data availability

A dataset is not publicly available. Data in form of narratives from interviews may be available on reasonable request from the corresponding Author: Juliana Namutundu: jnamutundu@musph.ac.ug.

Declarations

Ethics approval and consent to participate

The larger study was approved by the Makerere University School of Public Health Research Ethics Committee (Protocol Number: SPH-2022-355). We also sought written permission from authorities in the two districts and the study was registered by the Uganda Council for Science and Technology (Registration Number: HS2753ES) which gave us permission to conduct the research. We obtained written informed consent from all participants and we used unique identifiers to ensure the collected information would not be linked to participants. All methods were carried out in accordance with relevant guidelines and regulations.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Author details

[1]Department of Epidemiology and Biostatistics, School of Public Health, Makerere University College of Health Sciences, Kampala, Uganda
[2]Department of Community Health and Behavioral Sciences, School of Public Health, Makerere University College of Health Sciences, Kampala, Uganda
[3]Department of Department of Disease Control and Environmental Health, School of Public Health, Makerere University College of Health Sciences, Kampala, Uganda
[4]Department of Medicine, School of Medicine, Makerere University College of Health Sciences, Kampala, Uganda
[5]Department of Obstetrics and Gynecology, School of Medicine, Makerere University College of Health Sciences, Kampala, Uganda
[6]Makerere University Joint AIDS Program (MJAP), Kampala, Uganda
[7]Infectious Diseases Institute, College of Health Sciences, Makerere University,, Kampala, Uganda

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