

Understanding barriers to access and utilization of cervical cancer screening services among women living with HIV in Kenya and Uganda

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Keywords

Cervical cancer screening, women with HIV/AIDs, Health Belief Model, Low-resource setting, Uganda and Kenya.

Abstract

Background: Invasive cervical cancer (ICC) is one of the most preventable and curable forms of cancer. In East Africa, primarily Uganda and Kenya, where HIV/AIDs are common, it is usually diagnosed late, resulting in a public health hazard due to its poor prognosis. ICC is the second most common malignancy causing maternal death. This study explored factors that impede access and utilization of ICC screening services among women living with HIV in low resource settings in Uganda and Kenya.

Methods: A cross-sectional study design employing qualitative and quantitative techniques were conducted in six selected health facilities in Uganda and Kenya. A systematic cluster randomized sampling was used to select health facilities from which women living with HIV were invited to participate in the interviews, including focus group discussions, and triangulated this with in-depth interviews and literature. Data collection, coding, categorization, and statistical analysis of quantitative data were employed to rank correlation among the most critical factors that hinder access to ICC screening services.

Findings: Two hundred thirty-two (232) out of 310 women completed the interviewer-administered questionnaire making the response rate 75%. The results uncovered a negative correlation between the perception of barriers to access the services. Two variables, the perceived risk for having ICC and the perceived severity, may impact the likelihood of undergoing ICC screening. There was a positive correlation between the perceived risk for ICC and the perceived severity. Statistical analysis shows that results are valid and reliable.

Conclusion: The study uncovered the health system barriers affecting ICC screening services at health facilities in Kenya and Uganda. It highlights the strengths and challenges while providing recommendations to promote health to include the most vulnerable women with HIV/AIDs living in socially deprived areas.

Introduction

Invasive cervical cancer (ICC) refers to uncontrolled squamous cells on the cervix (1). ICC is ranked as the fourth most common cancer in women globally. It accounts for approximately 570,000 new cases, with 311,000 deaths in 2018, representing 6.6% of all female cancers (1). Nearly 90% of ICC's global mortality occurs in low- and middle resource countries, including Uganda and Kenya (2). During the same year, Uganda (54.8%) and Kenya (33.8%) were ranked among the first 20 countries with the highest rates of ICC globally as 7th and 10th, respectively (2).

Recent studies indicate that HIV-positive women have a higher risk of co-infection with HPV types, HPV reactivation, and ICC (3). A study in Kenya uncovered that HIV could significantly increase the risk of cervical pre-cancer and cancer development and a 6% prevalence of cervical pre-cancer and cancer among HIV-positive women (4). Also, in Kenya and Uganda, ICC is a public health concern as it leads to morbidity and mortality among women, particularly those with HIV co-infection.

In 2019, Kenya and Uganda were among the two countries with the third-largest epidemic of HIV in the world, each with 1.5 million people living with HIV. Besides, there was a 5% of HIV prevalence among adults (ages 15-49), and among them, only 80% were receiving antiretroviral treatment (ART) among adults (1).

A recent study conducted in Kenya revealed that out of the 1180 women interviewed, 16.4% had been screened for ICC. For those unscreened women, 67.9% were already aware of ICC screening. The same study also revealed that high screening rates were observed in more educated women (5). However, the study did not explore more reasons for this and the need for more qualitative inquiry. Besides, the uptake of ICC screening services in Kenya is deficient at 3.2%, below the target of 70%, and hence, a dire need to study the factors that lead to low uptake of the screening services (6). In Uganda, Mitchell and colleagues' study indicated that 98.9% of women living with HIV did not think it was necessary to be screened for ICC despite being at higher risk than their HIV-negative counterparts (7). In 2013, the Uganda Ministry of Health planned to enhance targeted interventions to improve free access to essential health services, including ICC screening (8). In line with the above, a United States Agency for International Development (USAID) supported ICC screening programs in Kyenjojo District western Uganda through health workers' training. It provided cryotherapy equipment for two health facilities named Kyenjojo Hospital and Kyarusozi Health Center IV. However, the district's uptake of these services, especially for women with HIV, remained low (9). Other studies have also reported that three in four HIV-positive women remained under-screened for ICC (10). On top of this, various socio-political and cultural barriers may hinder effective HIV prevention programming in Kenya and Uganda, implying that new HIV infections are expected to rise in coming years, with annual new conditions projected to multiply around 340,500 in 2025 (11). Understanding the barriers to access and utilization of screening services is critical to addressing the above challenges amongst women with HIV. There is a lack of empirical research to explore the multi-faced barriers to uptake of ICC services amongst women with HIV in the hospital (5,12). Hence, this study aims to assess the factors that hinder access and utilization of ICC screening services among women with HIV in Uganda and Kenya based on the health belief model (HBM) framework.

Materials and Methods

Study design. A cross-sectional study design employing both quantitative and qualitative techniques was employed. A quantitative study involving the single population proportion formula was used to calculate the sample size. Sample size calculation was based on the proportion of participants who were aware of cervical cancer. The qualitative study was underpinned by ethnographic theory to understand and interpret intricate behavioural patterns (13). Inductive and deductive (pseudo-deductive) approaches were employed based on the *health belief model (HBM) theoretical framework*. HBM has six main components founded on perception: barriers, benefits, perceived risk (or susceptibility), severity, which leads to action (14). This conceptual model was chosen because it addresses the participant's inner world (values, beliefs, feelings, memories). HBM was also used to design the research questions, collect empirical data, and analysis (14,15). The goal was to understand why not access and utilize the ICC screening services among women living with HIV in six selected health facilities of Kenya and Uganda.

This study involved three study participants: women living with HIV, key informants, and health-service providers. A purposive, flexible, and emergent sample was used to identify participants for the focus group discussions (FGDs), the in-depth interviews (IDIs), and key informants (KI) on the basis that they were likely to generate valuable data for the study (15). These three different data collection techniques capture diverse information and insights to complement each method until reaching convergence in the most critical aspects and triangulation while capturing the topic's multiple perspectives (using different moderators, locations to reach deep saturation, and comprehensiveness) (13). This could ensure the collected data's validity and reliability and its results (13,16).

The sample included only women living with HIV aged between 19-49 years and attending sexual and reproductive health care with antiretroviral therapy (ART). They were recruited from six hospitals that provide these services in Uganda and Kenya. They were invited by trained research assistants and randomly assigned to FGDs. The characteristics and number of participants are detailed in the table below (

Table 1).

Table 1. Kenya and Uganda: Number and socio-economic characteristics of participants

	Kenya				Uganda			
	Primary	Secondary	Primary	Secondary				
Level of education	73	47	22	15				
Distance from home to the hospital	< 10 Km	> 10 Km	< 10 Km	> 10 Km				
	68	52	30	7				
	Number ea. FGDs	Number ea. IDI	Number ea. KII	Total number of Participants	Number ea. FGDs	Number ea. IDI	Number ea. KII	Total number of Participants
Women Living with HIV (WHIV) (8-10 participants)	99	10	---	109	24	13	---	37
City	Name of the Hospital							
Nairobi	The Coptic Hospital							
Kiambu	Kiambu Referral Hospital							
	Ngong Hospital							
Kajiado	Kitengela Hospital							
	Isinya Hospital							
Service providers	11							
Hospital managers and Administrators	---	---	---	---	---	---	1	1
Partners supporting cervical cancer screening programs	---	---	---	---	---	---	1	1
Total participants	99	10	11	120	24	13	3	40
Total number that rejected to participate	16	5	3	24	5	1	1	7

In Uganda, the study was conducted in Kyenjojo Hospital, a public health facility in a deprived setting of Kyenjojo district, Western Uganda. It has a total population of 422,204 people, whereby 39.7% of the females above 18 years are illiterate (17). About 66% of the households are within five kilometers of proximity to the nearest public health facility (17). In Kenya, the study was conducted at five hospitals in three different counties of Kenya, Nairobi (3.2 million population), Kiambu (2.5 million), and Kajiado (1.18 million people) (17). The Coptic Hospital (Nairobi County) is a church-based health facility managed by the Orthodox church and is situated 4.5 km from the Nairobi Central Business District (CBD). The Kiambu hospital (Kiambu County) is located about 16 km from the Nairobi CBD. Kajiado County borders Nairobi to the South, with its headquarters about 80.5 km from Nairobi city center with three public hospitals for the study, namely, Ngong, Isinya, and Kitengela. Most residents in these two counties live in deprived-resource settings and are either peasant farmers or pastorals. In Uganda, 23% of the females aged above 18 years are illiterate (17). The data collection process lasted three weeks (Mid-January until February 2019) in Uganda and eight weeks (January until mid-March 2020) in Kenya. FGDs used structured guidelines based on the HBM model (risk perception of ICC, awareness of ICC screening programs, perceived severity, barriers that impede access to ICC, and motivators to ICC screening)

with open-ended questions (divergence). The content used literature and study experts to validate to pilot test.

The Research Assistants (RA) trained for two days and piloted the data collection tools to collect later in the field using local language (Runyoro-rutooro in Uganda and Swahili in Kenya) FGDs informed consent was signed.

Analysis and findings

The information was transcribed verbatim by the principal and co-investigator, who also coded within the HBM themes. Qualitative data analysis involved; coding, memo writing, comparison, categorization of emerging data (18). No software was employed. A thematic analysis was applied by the aggregation method with scoring (per number of participants in each hospital's FGD) to synthesize information and explain the main perceived aspects in a rank-order per HBM component (19). The quantitative analysis involved logistic regression in creating odds ratios to determine the strength of association between independent and dependent variables using a significance level of $p < 0.05$. This obtained the shares, the main descriptive statistics, and the 95% confidence interval ($\alpha=0.05$). Statistical tests were applied to check for external validity and reliability (20) with a correlation test among the HBM components (19). A normality test to check if the sample size was large enough to reflect the population is a standard probability distribution in the natural world (16,20). Incomplete questionnaires were excluded from all analyses.

Ethics approval

The study was reviewed and registered in Uganda by the Texila American University School of Public Health Ethics and Research Committee. The University of Nairobi School of Public health's ethics and research committee approved the study in Kenya.

Results

Thirty-eight (38) sub-themes for Kenya and 61 for Uganda were categorized within the HBM components (appendix 1). Table 2 displays describe 50% of the data with the most mentioned sub-themes in Kenya and Uganda.

Table 2. HBM components with the top 50% sub-themes mentioned.

HBM: Perceived barriers (challenges) to access ICC screening services	Grand Total	Quotations from FGD
Kenya		
Limited female health workers causing male partners cease support for services	11.0%	"We sometimes have busy schedules, and we see no time available to go and screen since we don't have pain due to cancer as of now. (FGD-1 HIV+ Ngong Hospital, Kenya)
Some health workers are uncooperative	8.5%	
Limited staff to work on ICC	8.4%	
Language barrier on ICC information and communication	8.2%	"This issue of exposing our nakedness to doctors without any urgent need is stopping most of us from getting tests, in our tradition it is not permitted for a man who is not your husband to see your nakedness, I wish Kenya Government could recruit female specialists for these services" (FGD 3- Ngong Hospital)
Long queues waiting for services	8.2%	
Poor Cultural beliefs limiting women to access ICC services	7.7%	
	52%	
Uganda		
Lack of knowledge on ICC	5%	
Lack of information	4%	
Non-functional IEC Materials	4%	
Lack of interest to screen	4%	
Fear of procedure effects worsening current HIV condition	4%	"To be sincere to you, I have spent 7 years coming to this clinic and I have heard our Health workers teach about many diseases like Malaria, TB and how we can live positively with HIV but I don't hear them talk about cervical cancer". (FGD-3 HIV+ participant, Kyenjojo Hospital)
Cost of transport means	4%	
Poor mobilization issues	4%	
Fear of post-screening complications	4%	
Fear of stress from HIV and ICC co-infection test results	4%	
Confusing media information-traditional healers/herbalist in social media	3%	"We have school-going children, we have to do domestic work, but when we come here the line is so big, we are spending a lot of time here since morning it's now past lunchtime, I am still waiting for drugs, I cannot afford another queue lining up for cervical cancer screening. It means I have to go back home so late" (FGD-2 HIV+ participant, Kyenjojo Hospital, Uganda)
Fear of pill burden for HIV and ICC after testing	3%	
Poverty	3%	
Referral is not helpful, you will still die.	3%	
	50%	
HBM: Perceived benefits (motivators) to access ICC screening services		
Kenya		
Receiving free ICC services	26%	" We are motivated to attend the CC screening services because it is free. Also, we have been assured of confidentiality during the process which makes us more comfortable and discourages us from seeking services from traditional healers and herbalists". (FGD – 1 The Coptic Hospital)
Unwillingness to visit traditional herbalists again	18%	
Confidential information and privacy maintained	15%	
	59%	
Uganda		
Free screening services	16%	
Trust in government services	15%	We have no issues with the doctors; they only complain when some of us become uncooperative. For example, when I went to test for cervical cancer, I went with an elderly lady. They asked her to remove her clothes she refused, and HWs chased her away. If you cooperate, they can help and be supportive. (FGD-1 HIV+ client, Kyenjojo Hospital, Uganda)
The willingness of expert clients to pass over information to other clients once trained	15%	
Trust in health care providers at the hospital	14%	
	60%	
HBM: Perceived Risk to have ICC		
Kenya		
All women are at risk regardless of sexual activity	27%	"We are all women and any of us is at risk of CC even if you're not sexually active. The traditional healers can increase our risk further by luring us to use their un professional services. (FGD 1-Ngong Hospital).
Women living with HIV more vulnerable to ICC	18%	
Having multiple sexual partners	16%	"I think having multiple sexual partners or having HIV virus may contribute to our vulnerability to CC". (FGD 1-Ngong Hospital).
	60%	
Uganda		
Being poor exposes you to Cervical Cancer (ICC)	31%	We also believe cervical cancer is caused by family planning, not witchcraft. Those with poor nutrition and those who are poor and look for men to get money are coerced into unprotected sex and are exposed to cervical cancer' (FGD-1, HIV+ client Kyenjojo Hospital).
Screening is mandatory for only those with signs and symptoms	26%	
	57%	
HBM: Perceived severity of having ICC		
Kenya		
Its life-threatening disease	34%	"ICC is a life-threatening disease; if you get it at the end, you will have to die because there is no cure for it. We also don't have enough information about cancers; we need to be informed...." (FGD 1 Ngong Hospital).
No cure for ICC	17%	
	51%	
Uganda		
Cervical Cancer leads to death	35%	Once you get cancer, it's a gone case, even if they pray for you. We know and trust our health worker's ability to diagnose cervical cancer, but they cannot cure it....' (FGD-5 HIV+ Participant, Kyenjojo Hospital)
ICC is worse than HIV	21%	'cervical cancer is not like HIV. For HIV, people are diagnosed here and started on treatment, while those with cancer are only referred very far; they spend a lot of money there and come back to the village when they are dying. For HIV, we pick our drugs monthly, and I have lived with this condition for more than 15 years. I still feel strong and
	55%	

1. Perceived access barriers

Table 2 displays the reasons that women with HIV do not access ICC screening services. A common sense in both countries is that health workers with a lack of interest or poor cooperation hinder access to services. Other reasons are particular to each country among which is the unawareness of the ICC services, for the examination procedure (metallic instruments, the pain, and exposure), a lack of knowledge and information about ICC screening services, complications of referral (transport costs, accessing the services, time in the queue). Besides, confusing media information regarding traditional healers' capacity to cure every disease misleads towards cancer prevention.

2. Perceived benefits

Table 2 shows driver factors as motivators for the uptake of ICC screening services. Common drivers are based on free ICC screening services, trust in health services, and healthcare providers. Women that make regular visits to the facility for their HIV conditions may be offered to get the screening at no cost. Understanding the benefits of knowing their ICC status and the hope to access free treatment is crucial for screening. And the willingness of expert clients to be trained to provide health education on ICC (Uganda).

3. Perceived risk

Table 2 shows the main aspects that women living with HIV feel about the risk of (having) cervical cancer. There are no common factors among the 50% topics. Still, the ones mentioned in Kenya are that all women are at risk regardless of sexual activity, multiple sexual partners, or women with HIV who are vulnerable to ICC. In Uganda, most women with HIV believe that ICC testing was only mandatory for women who had symptoms or that poverty is a significant factor.

4. Perceived severity

Table 2 shows the main aspects that women living with HIV feel about cervical cancer severity (to their body). In both countries, women living with HIV coincide that cervical cancer leads to death and no cure.

Validity, reliability, and generalizability

In social science, robustness cannot be assumed because of small sample sizes. Hence, to test the results' robustness, a normality test is a necessary condition to obtain parameter estimates that are efficient and unbiased (20). Table 3 shows a skewness probability with a p-value of skewness > 0.05 for all topics except for perceived severity implying that

skewness is asymptotically normally distributed. Similarly, the Kurtosis probability indicates that it is also asymptotically distributed for all subjects (p-value of kurtosis > 0.05). Finally, the joint probability chi-square of Skewness and Kurtosis is more significant than 0.05 ($\alpha = 0.05$) for all topics except for the perceived severity. Subsequently, the null hypothesis cannot be rejected, which means that residuals show a normal distribution for all components except for Kenya's perceived severity. Perceived risk and severity in Uganda could not be tested due to insufficient observations. These results provide an external validity or generalizability of the products for these two countries.

Table 3. Aggregation of mentioned items, descriptive statistics, and normality test

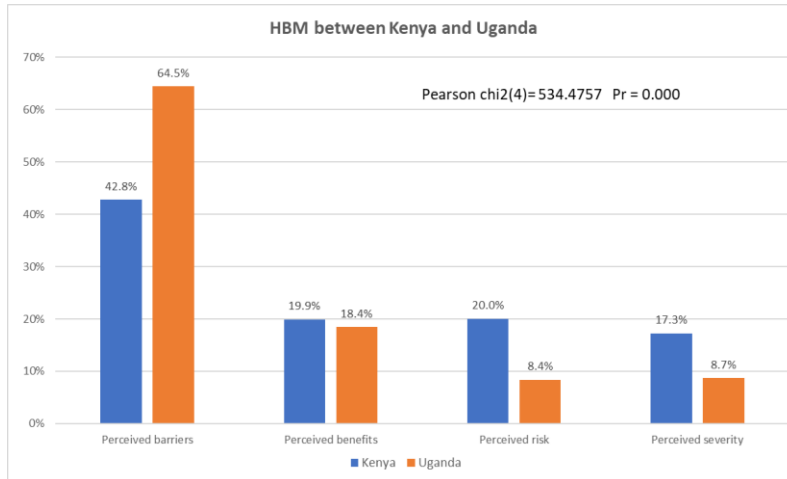
Kenya	HBM Topic	Perceived barriers	Perceived benefits	Perceived Risk	Perceived severity	Grand Total
# of mentioned sub-themes per HBM component, per person and per hospital	Coptic Hospital	17.62	7.15	9.08	7.00	40.85
	Isinya Hospital	11.48	6.96	6.30	5.85	30.59
	Kiambu Hospital	16.31	8.00	5.56	5.38	35.25
	Kitengela Hospital	14.79	7.37	8.47	6.42	37.05
	Ngong Hospital	16.06	6.17	6.44	6.22	34.89
HBM component, per person	share in percentage	42.7%	20.0%	20.1%	17.3%	100%
	mean	15.3	7.1	7.2	6.2	35.73
	Lower bound, 95% CI	12.7	6.4	5.5	5.5	
	Upper bound, 95% CI	17.8	7.9	8.9	6.9	
	SD	2.1	0.6	1.4	0.5	
Normality test of sub-themes within HBM	Pr(Skewness)	0.05	0.09	0.86	0.01	
	Pr(Kurtosis)	0.31	0.66	0.37	0.48	
	joint Prob>chi2	0.090	0.179	0.643	0.046	

Uganda	HBM Topic	Perceived barriers	Perceived benefits	Perceived Risk	Perceived severity	Grand Total
# of sub-themes, per person	share in percentage	64%	18%	8%	9%	100%
	mean	128.83	36.83	16.79	17.38	199.83
Normality test of sub-themes within HBM	Pr(Skewness)	0.979	0.640		few observations	
	Pr(Kurtosis)	0.309	0.480		few observations	
	joint Prob>chi2	0.581	0.686		few observations	

Figure 2 shows a chi-square test of independence to examine the relationship among the two countries' HBM components. The chi-square value is 534.476 with a p-value below 0.05 validates the alternative hypothesis, indicating a relationship between countries and the HBM components, rejecting the null hypothesis. This figure shows that the HBM components are comparable, even though each country has its particularities, as presented above (table 2). For both countries, perceived barriers have the highest share (42.8% for Kenya and 64.5% for Uganda), followed by the perceived benefits or motivators (19.9% for Kenya and 18.4% for Uganda). The illness's perceived risk and severity are lower than 20% in Kenya and even lower than 9% in Uganda. This means that the factors that affect the uptake of ICC screening services among women that live with HIV in Kyenjojo District, Western Uganda,

and in the three counties of Kenya (Nairobi, Kiambu, or Kajiado) were mainly based on the health system's barriers rather than in the risk or severity.

Figure 1. Comparative HBM components per country



This analysis can uncover more detail running categorical correlations among both countries' HBM components (table 4). Table 4 displays a matrix of Pearson correlation which describes the direction and strength of the linear relationship between two HBM components under the assumption of normal distribution (19,20). This shows the validity and reliability of results for the HBM framework. There is also a negative relation between the perceived barriers and the perceived risk (-0.9528, p-value 0.0033). This implies that if women with HIV have higher perceived barriers, their perceived risk for ICC is lower, which leads to a longer time to go to the hospital. Finally, there is a negative relation between the perceived barriers and the perceived severity (-0.9482, p-value 0.004). This means that if women with HIV have higher perceived barriers, the lower is their perceived severity for ICC, which leads to a longer time to go to the hospital. Finally, the perceived severity and perceived risks are positively correlated (0.9, p-value 0.0143), meaning that if women with HIV have a high perceived risk of ICC, this will also increase their perceived severity.

Table 4. Correlation between HBM components, Kenya and Uganda

	Perceived benefits	Perceived risk	Perceived severity	Perceived barriers
Perceived benefits	1			
Perceived risk	0.2207	1		
p-value	0.6743			
Perceived severity	0.3174	0.9007	1	
p-value	0.5398	0.0143		
Perceived barriers	-0.4739	-0.9528	-0.9482	1
p-value	0.3424	0.0033	0.004	

Discussion

The uniqueness of this research is its focus on a vulnerable population, women living with HIV. They might have a higher risk of ICC due to their immunocompromised body system but do not access or use the ICC screening services. The study was carried among the countries with the highest rate of cervical cancer, Kenya and Uganda. The findings uncover a negative relation between the perception of barriers to access the services, two variables, the perceived risk for having ICC, and the perceived severity. Consequently, this impacts the likelihood of undergoing ICC screening. There is a positive relationship between the perceived risk for ICC and the perceived severity. Statistical analysis shows that results are valid and reliable. This is in line with the study of Mitchell, indicating that 98.9% of women with HIV did not think it was necessary to be screened for ICC despite being at higher risk than their HIV-negative counterparts (Mitchell et al., 2017). More, the uptake of ICC-screening in Kenya is at 3.2%, below the targeted 70% (Munoru et al., 2019)

Perceived Barriers and the negative correlation with perceived risk and perceived severity

Despite both governments' efforts to train staff and provide ICC screening infrastructure and services to vulnerable persons, there were barriers to access services (64.5% and 42.8% in Uganda and Kenya, respectively). The hindrances described included problems with the health personnel and long queues in Kenya and lack of knowledge, interest, or fear to access the ICC services. These findings are to a certain extent related to women with HIV conducted in urban settings in Uganda (21) (22), Kenya (23), and Nigeria (24), which could positively influence the validity of this research. Other studies mention that ICC screening's knowledge and awareness do not translate into increased service uptake (25). However, these studies focused on specific aspects while our research is rank-ordered and correlated the most critical components to present cues to action.

Our study indicates that the higher the perceived barriers, the less perceived risk. Phrases like "...visiting health facilities is common only when one has developed pain or symptoms of the disease...". Before this happens, the patient has a lower level of perceived risk or severity for ICC. Some studies focus on the need for culture-specific, sensitive information and interventions to improve the ICC screening uptake among women with fear (26)(21,26,27). Other studies just focused on monetary barriers like Zimbabwe, as many could not afford ICC screening because of its costs (26).

In theory, women who knew the underlying risks or perceived severity would get ICC screening to know their status. However, when the barriers are too high, they tend to ignore these perceptions. In Uganda survey revealed that Cervical Screening uptake was deficient among HIV-infected women (9). Also, poor treatment outcomes and death and inaccessible

referral facilities that manage ICC were mentioned barriers in Uganda (12) and Kenya (28). This may show that the higher the barriers, the lower their perception of risk or severity until the first symptoms appear.

The study reveals a positive correlation between the perceived risk to ICC with the perceived severity. Unfortunately, we did not find any study that could sustain this specific aspect more than the relationship with the barriers presented above.

Limitations

One of the limitations is that although many FGDs were organized in Uganda, this was done only in one hospital. The inclusion of more facilities could enhance the perspective.

Furthermore, the HBM components were assessed as one. A split of perceived barriers or benefits in the availability, accessibility, acceptability, contact-use, and effectiveness, could bring more insights (29).

Conclusions

This study uncovered a myriad of sub-themes for ICC screening services at six selected health facilities in Uganda and Kenya. These factors were analyzed within the HBM framework and unveiled the relations between the perceived barriers and the length for accessing and utilizing the ICC services. And the positive relationship between the perceived risk and severity of the ICC. This could imply future actions to strengthen the health systems focusing on these factors and their main elements elicited within the HBM framework, particularly for vulnerable groups like women with HIV or deprived settings, which can positively contribute to the Sustainable Development attainment Goals.

Consent for publication

All authors and participants gave their consent for publication.

Availability of data and material

The datasets used and analyzed during the current study are available from the corresponding author on reasonable request.

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