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Research Article

# "By the time they run into the hospital, their life is already at stake": a qualitative study of healthcare professional perceptions on priorities for cervical cancer policy in Uganda

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## Background

Cervical cancer (CxCa) incidence in Uganda is three times the global average and a leading cause of mortality for women. While there is funding and infrastructure to support HIV control in Uganda, these are not in place for CxCa prevention and control. This study was conducted to explore the knowledge and perceptions of HIV professionals in Uganda to identify perceived barriers and facilitators to CxCa screening and treatment among women living with HIV (WLHIV) as a basis to guide and inform policies and programs for CxCa prevention and control, including service integration.

## Methods

This study used qualitative interviews to obtain primary data from professionals working in the HIV field in Uganda conducted from September 2020 to January 2022. Participants were identified through purposive and snowball sampling and consulted with colleagues at local service and academic agencies in Kampala. Both written and verbal informed consent was obtained. Hour-long interviews were conducted virtually and in person and recorded. Interviews consisted of open-ended questions exploring perspectives on, knowledge about, and practices surrounding HPV and CxCa among WLHIV in Uganda. Transcripts were analyzed and coded via MAXQDA software to identify facilitators and barriers to HPV vaccination, CxCa screening and treatment.

## Results

Fifty key informant (KI) interviews were conducted. Analysis revealed two themes regarding priorities for cervical cancer policy in Uganda after KIs reflected on improving barriers to CxCa care. These were: (1) decentralization of care through integration of services and (2) leadership on a national level by increasing funding and organizing advocacy initiatives. Practical recommendations identified by KI that derived from these themes included leveraging community institutions and mass media campaigns to target misconceptions surrounding screening, making CxCa screening opt-out and integrated with HIV care, strengthening a centralized database, organizing mass roll-out of self-testing, and organizing training of healthcare workers.

## Conclusions

Key informants call for solutions that address individual, community, and national barriers of cervical cancer care and emphasize the need for a strong national cervical cancer policy to coordinate currently fragmented services and the political will to adequately fund these.

Worldwide, cervical cancer (CxCa) is the third most common form of cancer among women.[1] In Africa, CxCa is the second most common cancer among women.[1] CxCa incidence in Uganda rose 1.5% annually between 1991 to 2015.[2] Mortality is exceptionally high; the age-standardized mortality rate is 41.4 deaths per 100,000 women, and the 5-year relative survival for CxCa is 17.7%.[3,4]

Since the human papillomavirus (HPV) is the main cause of CxCa, this cancer is to a substantial degree preventable through HPV vaccination. Uganda's Ministry of Health (MOH) CxCa policy largely rests on HPV vaccination, aiming to vaccinate 80% of girls aged 10-14 years.[5] However, as one study that interviewed professionals affiliated with the Ugandan government and other NGOs found, the MOH's CxCa policy has been perceived as uncoordinated and inadequate.[6] While commitment to CxCa has been made on paper, in practice, CxCa policy has been described as inadequately funded and supervised, as well as overly reliant on NGOs.[6]

CxCa guidelines in Uganda call for screening every three years for HIV-negative women and annually for women living with HIV (WLHIV).[5] Screening rates in Uganda are extremely low, with lifetime screening rates between 4.8 and 30% in rural and urban areas, respectively.[7,8] Thus, an alarming 80% of women diagnosed with CxCa present with advanced-stage disease at Uganda Cancer Institute, the sole comprehensive cancer care center in the country.[7]

Many fears and misconceptions exist related to screening, that, coupled with limited resources, explain the low uptake of CxCa screening. One systematic review about barriers to screening found that the most common barriers reported were an embarrassment, fear of the screening procedure, fear of the outcome, rural residence, income, and access to care.[9] Given the high mortality rate and the lack of understanding of CxCa symptoms or treatment, Ugandans have been characterized as fatalistic in their view of CxCa.[9]

Compared to HIV-negative women, HIV-positive women have six times the risk of CxCa, due to the immunosuppressive nature of HIV and shared risk factors.[10] Thus, the World Health Organization (WHO) recommends including CxCa screening into HIV testing programs.[11] Currently, Uganda has separate HIV and CxCa screening programs.

Uganda has often been upheld as an HIV success story for decreasing prevalence rates of 18-30% in the 1990s to 6.5% in the 2000s.[12] From 2006 to 2011, HIV testing and receipt of results among Ugandan women increased from 25% to 71%.[13] Early governmental response was instrumental; the MOH, with the help of NGOs and other non-state actors, developed awareness campaigns and established improved screening capacities.[14,15] While health infrastructure and HIV policy was weak, political will coupled with external help dramatically decreased HIV incidence.[16]

Leveraging existing HIV infrastructure is a promising approach to addressing the high burden of CxCa and establishing a CxCa policy that is sustainable, coordinated, and preventative. This study was conducted to identify perceived barriers and facilitators to CxCa screening and treatment among WLHIV of key informants (KI) who are HIV professionals in Uganda as a basis to guide and inform policies and programs for CxCa prevention and control.

## METHODS

### STUDY DESIGN

Semi-structured individual interviews with KI (n=50) were conducted. According to their expertise, interviews assessed KI's knowledge and perceptions regarding HPV vaccination and CxCa screening and care in Uganda. The Institutional Review Boards approved the study at the Medical College of Wisconsin, Makerere University School of Public Health, and the Uganda National Council for Science and Technology.

### STUDY POPULATION AND SAMPLING PROCEDURE

KI included health professionals with HIV experience that fell into five groups: clinicians(n=12), community health workers (8), nurses (n=10), counselors (10), and other health professionals (n=10). KIs were purposively selected and identified by colleagues at Makerere University, The AIDS Support Organisation, literature searches and snowball sampling and recruited through email, telephone calls, and WhatsApp messaging. Inclusion criteria required the respondent to be a health professional with HIV experience in Uganda and conversant in English. Exclusion criteria included age younger than 18 years. KIs consented to follow both the Medical College of Wisconsin and Makerere University human subjects' protection protocols.

### DATA COLLECTION

A semi-structured list of open-ended questions was prepared and internally validated to guide interviews before data collection. Interviews explored KI's knowledge and perceptions of HPV vaccination and infection, CxCa screening, and CxCa care, and probes were utilized according to each participant's area of expertise.

KIs were provided with the objectives, methodology, and advantages and disadvantages of participation. KI interviews were conducted from September 2020 to January 2022 and audio recorded if participants consented. Interviews were conducted by four female (NA, KL, NP and CJ) and 1 male (AM) interviewers, one of whom was African. The five authors who conducted research all had experience in carrying out research and the protocol was internally to align interviewing style. All author completed CITI Training: Research, Ethics and Compliance Training. Interviews took place in-person and virtually, either on Zoom or Whatsapp. KI were informed that all information they provided was confidential. Interviews took 30 minutes to 1 hour to complete. Field notes were made during interviews. Incentives of $5 USD were given to thank KI for their time after the completion of the interviews.

### QUALITATIVE DATA ANALYSIS APPROACH

All interviews were transcribed verbatim, and text data was coded line-by-line and analyzed for key themes and patterns of response using MAXQDA 2020 with a thematic analysis approach in an inductive manner by authors NA, KL, and NP. Key words and quotes were identified in an

iterative process as themes, and subthemes evolved surrounding facilitators and barriers to HPV vaccination, CxCa screening and CxCa treatment. The research team met and discussed the coding framework as themes and subthemes evolved. The final codebook was applied to all transcripts. Adequate representation was sought out from each professional group to explore unique perspectives associated with different professional backgrounds and roles. To establish inter-rater reliability and harmonization, a team-based approach to coding was used. Discrepancies in codes were discussed between reviewers until an agreement was reached. Then, authors NA and KL applied the final codebook to all transcripts.

## RESULTS

Fifty participants were identified as KI and agreed to be interviewed, 50% male. KIs identified two priorities for cervical cancer policy in Uganda. These were: (1) decentralization of care through integration of services and (2) leadership on a national level by increasing funding and organizing advocacy initiatives. We discuss each of these themes below, including specific strategies identified by KI.

### DECENTRALIZATION OF CARE THROUGH UNTEGRATION OF SERVICES

Many KI mentioned how many barriers prevent women from seeking care, such as long distances to health facilities, financial restrictions, lack of transportation, and a poor understanding of the necessity of CxCa prevention, could be addressed through the integration of services. KI emphasized decentralizing women's health services to increase overall CxCa utilization by making it accessible at other health facilities where women are already present; currently, the burden is placed on women to seek out separate appointments.

#### *TRAINING OF HEALTHCARE WORKERS*

When asked to reflect on CxCa screening, most KIs reported a lack of technical expertise among healthcare workers. They emphasized the need for the government to organize training on how to perform CxCa screening and strategies to simplify explanations of CxCa symptoms and treatment course to patients. One KI revealed his shock that there was no mention of HPV in their training manuals. The necessity of regular training and monitoring of healthcare workers across Uganda regarding the cause, prevention, and treatment of CxCa was mentioned by several KI.

> *KI-1 (M, Clinician) – "The extent of women's understanding is based on how the information is delivered... In the long term, we need more training of healthcare workers, because the fact is that we have a few, but if there is a delivery plan to decentralize, that will come along with training of healthcare workers and specialized training."*
> *KI-14 (M, Community Health Worker) - "I also discovered the health training manuals for health workers... there's nowhere where they put HPV, most of the manuals...when I sit at the facility and hear all the health workers doing all the health talks, they talk about nutrition. they talk about condom use. but they rarely talk about cervical cancer screening... the health workers' attitude towards cervical cancer is that it's not an immediate problem."*

While the interviews focused on elucidating barriers of WLHIV, a few KI who directly work with WLHIV seemed to share the misconception that only virgins were eligible for the HPV vaccination, when in fact HPV vaccination is recommended regardless of whether girls are virgins or not. This misconception held by health professionals was an incidental finding of our study.

> *KI-17 (M, Other) – "The HPV vaccination targets girls of six to twelve years with the assumption that they've not yet had sex."*

#### *INTEGRATING OF OPT-OUT CXCA SCREENING*

When asked to reflect on their successes in the HIV epidemic in the context of CxCa, several KI remarked how integration of HIV services into health infrastructure was key to lowering HIV incidence.

> *KI-10 (F, Other) – "My experience working with the HIV field is that the best approaches are often through integrated service delivery... where the [HPV] vaccination as well as the [CxCa] screening procedures are taken as part of the package of the services is often more successful if the providers are trained to be able to deliver, not only the information, but the vaccination or the screening for whatever might be needed."*

After a referral to CxCa screening, women can be lost to follow up due to competing priorities such as household work, transportation costs, or other fears. Training providers to screen women presenting at healthcare facilities is essential to increasing early CxCa diagnoses. Interviewees suggested a myriad of ways to integrate CxCa screening. These included:

- Every time WLHIV come for viral loads – *KI (20, 43)*
- Before dispensing antiviral medication – *KI (20, 22, 30, 40, 43, 50)*
- Alongside HIV testing in the community HIV clinics – *KI (8, 14, 18, 21, 39)*
- When women present at mother-baby care points – *KI (3, 11, 28, 38)*

Screening at HIV care points removes the inconvenience of seeking care at another place and time. Many KI noted the utility of a policy that would mandate CxCa screening as a routine, opt-out test for WHLIV. This would not only screen more women, but also normalize screening so that women expect it as a routine part of health care.

> *KI-18 (F, Clinician) - "Someone will lose interest very easily because we describe the procedure to them then they get interested, then all of a sudden you're telling the person to go somewhere else, and then they lose interest and won't go ahead with it... it's much easier if the services are right there when you're telling them about it."*
> *KI- 10 (F, Other) – "Because we know that for HIV-infected women, a lot of challenges until we decided to use*

> *to the opt out approach as well, we'd tell somebody to test for HIV unless they said no, I think we should be doing the same for cervical cancer."*

INCREASING NATIONAL FUNDING AND ADVOCACY

KIs mentioned the need to strengthen CxCa services through funding and certain advocacy measures. CxCa care is largely funded by international donors which can be erratic and restricted. Garnering national commitment to reducing CxCa incidence is a first step for adequate funds, and also, as many KI mentioned, necessary for ensuring women are aware of CxCa symptoms. Three specific solutions KI identified that the government should implement were mass media campaigns, equipping community institutions with CxCa knowledge, and the roll-out of self-testing.

*INADEQUATE FUNDING*

Most KI reported lack of funding as a major barrier to CxCa screening and treatment, resulting in inadequate personnel, training, facilities, reagents, equipment, and advocacy. One KI explained that this was because CxCa, along with other cancers and non-communicable diseases, competes with communicable diseases in terms of resources.

> *KI-7 (M, Other) – "If whatever you're doing is not a priority, then it will not have funding."*
> *KI-10 (F, Other) – "We haven't had sufficient investments in noncommunicable diseases, especially cancer screening. It hasn't had as much investment as we've had for some of the conditions like HIV itself, so there's a bit of a disconnect there in terms of the investments and support systems."*

Countries in LMIC have often relied on international donors to support health initiatives as MOH budgets are often limited. However, international donations often come through Global Health Initiatives (GHIs), and is restricted, limited, and unpredictable. Generally, HIV donors restrict their funding to HIV activities, and have not funded other health priorities like CxCa.

> *KI-24 (M, Other) – "Relying on the donor may not be the best. We need to find a more sustainable way of doing things, rather than relying on the external support… cervical cancer screening should be part of our system, the Ugandan health system, whereby the commodities for screening should be available at the facilities at no cost. We shouldn't need a donor to say that we are giving you this for the screening."*

*NATIONAL ADVOCACY IS IMPERATIVE*

Multiple KI reflected on how the key to the HIV epidemic was political commitment at the national level and called for a top-down approach that organizes and disseminates clear messages about CxCa.

> *KI-15 (M, Community Health Worker) – "HIV in Uganda is from the commitment from the political leadership-from the office of the president to the lower level. The message was very clear, everyone was very committed….. A similar approach [for CxCa is needed] of making sure information is clear, making sure the service is available, so that these girls when they go are not turned down and they get the right information."*
> *KI-4 (F, Clinician) –"I think there are like three things: one is the advocacy at the highest level– it has to be national advocacy that people think cervical cancer is a priority in HIV infected women because everybody agrees HIV is a priority… getting down to the grass-roots– getting down to the health centers at the lower levels so advocacy across the board, that's number one."*

AWARENESS OF CXCA

Most KI reported how many women have no concept of cervical cancer and are unaware of the CxCa symptoms. If women have heard about CxCa, they fear the screening will be painful, or a positive diagnosis. In the traditional Ugandan context, like other African cultures, there is much stigma surrounding women's reproductive organs, leading to hesitancy to disclose any abnormal smells or bleeding, reluctancy to agree to the vulnerable screening procedure, and a general ignorance about the importance of screening. Because women typically present so late, many women associate CxCa with a death sentence.

> *KI-1 (M, Clinician) - "There is generally no knowledge on cervical cancer. Very few of them have that understanding [of what the cervix is]."*
> *KI- 18 (F, Clinician) - "They assume that it's something where you cut off a whole chunk of their vagina wall or something so there are really scared of the screening procedure."*

Several KI mentioned the utility of mass media campaigns in distributing information about HIV and COVID-19. National TV, radio, posters, and social media campaigns were all mentioned as specific ways the government could increase CxCa service demand. Some KI reflected that advocacy and screening should be prioritized before investing in new treatment centers.

> *KI-1 (M, Clinician)- "If you give me a choice to choose between constructing treatment centers or investing in community sensitization, I would definitely say community sensitization, screening and early detection."*
> *KI-15 (M, Community Health Worker) - "Mass media campaigns should be sustained, sustained campaign…. Like COVID has just come, but now everyone knows about it, is aware about the danger, about the need to protect, that's the kind of thing we need."*

Most KI emphasized the need to utilize community institutions in the fight against CxCa. 8 KI (*14, 15, 17, 20, 21, 24, 40, 47*) mentioned the role that teachers and 10 KI *(14, 21, 24, 40, 41, 42, 43, 45, 49, 50*) mentioned the role that religious institutions could play as trusted sources to disseminate information. One KI explained that equipping community leaders with information about CxCa would ensure accurate information reaches the population.

> *KI-24 (M, Other) – "If we can be able to reach out to the schools, even at a primary level, we build a capacity of teachers. Let's bring the teachers on board. Let's bring the*

> *parents on board. Let's bring the people from civil society organizations. The churches, they have a very big role they play. Most of our community, they do listen to them so much."*

One KI talked about the utility in coordinating vaccination efforts with school management to ensure that girls do not miss doses of the HPV vaccine, an effort that would need input and cooperation with teachers, community leaders, and families.

> *KI-38 (M, Clinician) - "It would be really great if they could work out with a school management system so that the children or the girls who are eligible for the vaccination take it and arrangements are made to make sure that they don't miss the dose. This needs some better understanding how the mechanism to set up the vaccination program and bring together all the players: the school, the community health department, and then the families, and communities."*

Two KI brought up self-administered HPV testing that is being rolled out, and reflected on how the government plays a role in increasing uptake of this method. Participants explained that self-testing is not only logistically convenient in that it allows women to test anywhere but removes the embarrassment associated with pelvic exams.

> *KI-18 (F, Clinician) - "The way we communicate is what affects the take up of the screening... when the HPV testing is rolled out, that would be much easier because all of the people who have the strange perceptions about speculum insertion, so all the misconceptions they have about the VIA procedure and that, will be alleviated when they use the self-testing using the HPV kits."*

## DISCUSSION

Viewing the challenges of CxCa prevention and control through the lens of HIV expertise and infrastructure allows for policy recommendations that are holistic and preventative and stem from longstanding lessons learned in HIV prevention and control. This study is notable in that it elucidated barriers WLHIV have in terms of CxCa and went beyond previous studies in allowing HIV experts to voice specific solutions in the context of their HIV experience through open-ended interviews.

One key KI reflection is that the Uganda government has been effective at HIV and COVID sensitization through media campaigns but noted the lack of political will to address CxCa. Currently, CxCa falls under the NCD category of the Ministry of Health[7]; line items for CxCa are few.[17] One study claimed that this NCD designation results in erratic funding with no budget for prevention activities.[6] Current funding allocated for NCDs is wholly insufficient: one study that interviewed governmental and NGO leaders emphasized the need for a strategic plan that invests in NCD infrastructure, with the goal of moving away from NGO reliance and fragmentation on care.[18]

A vital contribution to curbing HIV incidence worldwide is due to the role of Global Health Initiatives (GHIs). GHIs are able to channel large funds directly to NGOs and MOHs, and have been used for emergent responses to communicable diseases.[19] While many efforts funded by GHIs have been successful, GHIs have faced much criticism, especially early on.[19]

Several have noted the potential of GHI interventions to weaken government infrastructure due to the formation of parallel health systems. If resources allocated for HIV exceed the resources of a MOH, personnel may transition to HIV care for higher salaries, weakening a fragile system. Disease specific mandates can create tension when health ministries want to focus on their own agenda.[20] Funds allocated for HIV are restricted to HIV, and there are often extensive reporting requirements.[19] If a health system is already weak, GHIs may hinder the development of sustainable infrastructure, leaving countries at a loss when funds are no longer available.[20]

Despite criticism, GHIs have had numerous successes as they have evolved. GHIs are useful in linking NGO efforts with government infrastructure and in instances when an infusion of funds is needed.[19] GHIs also have been useful in the large-scale training of health personnel: in Uganda, one GHI funded the training of teachers on HIV/AIDS.[19]

Currently, GHIs are not funding CxCa care. In this study multiple KI called for political will at the highest level. While some efforts were made to bolster NCD policy in 2011, inconsistent commitment has resulted in few of these policies being implemented.[21] However, this appears to be a cycle: increased funding is purported to increase governmental power while political will is a perceived barrier to sufficient funding, leading some to specifically call for sustainable and actionable priority setting.[21] The need for national policy to address delivery of CxCa services and prevent the high mortality in LMICs has been established. In an analysis of CxCa policy in 194 countries, authors found a stark disconnect in CxCa screening and treatment services in most African countries, advocating for simultaneous primary and secondary prevention methods.[22] GHIs may play a role in providing investment in both CxCa care and Ugandan health infrastructure to increase both primary and secondary prevention of CxCa. While funding alone will not change the trajectory of CxCa care, the need for financial investment was mentioned by the majority of KI as barriers to comprehensive care.

Our study highlights CxCa priorities that would benefit from a top-down approach. Specially, KI called for training manuals that include HPV and CxCa and an organized training schedule for health workers. This finding is consistent with previous studies that mentioned the urgent need for training.[23,24] The goal should be opportunistic screening, in which all health workers are educated on CxCa symptoms to able to refer women for screening.[23]

Many of the screening barriers noted by KI regarded stigma associated with pelvic exams, as well as limited HPV testing availability, implying the need for large-scale screening initiatives.[17] A recent alternative to HPV testing allows women to self-collect using vaginal swabs. Not only does self-testing remove some stigma, but allows women to be screened in their homes or in other private settings.[25] Plus, a widespread self-collection campaign would be a

cost-effective method to reach the vast majority of women. Several KI expressed the need for targeted CxCa screening for women who live in rural settings, for which self-collection would be ideal.

This decentralized approach would ideally engage existing NGOS and partners. As many KI mentioned, it would be advantageous for the government to organize campaigns targeting teachers and other community leaders. This study emphasized the necessity to ensure all stakeholders have accurate information to increase the trust of women, as evidenced by the misconceptions held by KI themselves about vaccine eligibility and KI reports of women's lack of awareness of CxCa symptoms.

A key finding of this study emphasized that CxCa control and care should be integrated with HIV care, validating literature that has established the manifold benefits of an integrated approach.[26] Zambia is notable for successfully integrating CxCa screening by expanding capacity of HIV facilities; a governmental report emphasizes leveraging "the availability, momentum, and capacity-building efforts" of HIV care.[27] A similar policy that covers both public and private HIV facilities and considers health infrastructure constraints before incorporating integration is imperative. While our findings do suggest the utility of CxCa and HIV integration, the results of this study do highlight ways in which national policy on CxCa can be improved.

Our study investigated perceptions of a diverse group of HIV experts. Social desirability is a potential bias in this study as KI may have wished to present themselves positively. However, KI were assured that they would remain anonymous to enable them to share openly. Additionally, while we sought a variety of respondents from rural and urban areas, it was logistically challenging to interview KI from rural areas, which are reported to be under-resourced. Future studies should include a broader area of Uganda and concentrate on lower-level health facilities in rural areas.

## CONCLUSIONS

Recurring solutions to CxCa care barriers identified by KI implicate the need for a strong national CxCa policy. Integration of CxCa and HIV care can widely improve access of care, but lack of funding and coordination makes integration difficult. Practical recommendations identified by KI that derived from major themes included leveraging community institutions and mass media campaigns to target misconceptions surrounding screening, making CxCa screening opt-out and integrated with HIV care, better coordination for HPV vaccination, and organizing mass roll-out of self-testing, and training of healthcare workers. Ultimately, political will lies at the crux of a CxCa approach that addresses both the demand and supply sides of CxCa services.


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### AUTHORSHIP CONTRIBUTIONS

KB, CJ, and KL conceived the study. NA, KL, NP, AM, and CJ collected the data, and NA NP, and KL analyzed the data. NA wrote the first draft. All of the authors reviewed manuscript drafts, provided input, and approved the final version.

### COMPETING INTERESTS

The authors completed the ICMJE Unified Competing Interest form (available upon request from the corresponding author) and declare no conflict of interest.


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