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## Understanding stigma as a barrier to cancer prevention and treatment in Uganda and Zambia

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# Understanding stigma as a barrier to cancer prevention and treatment in Uganda and Zambia

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# ABSTRACT

**Background:** While 'AIDS-defining malignancies' have traditionally characterized cancer diagnoses among people living with HIV (PLWH) in Africa, extended life expectancy due to treatment has increased the diagnosis of non-AIDS-defining cancers (NADCs). Despite documented impacts of stigma on cancer preventive behaviors and care, little is known about the intersections of cancer and HIV stigma and the impacts on prevention and care behaviors for both conditions. This qualitative study examines the prevalence and drivers of cancer stigma and associations with access and utilization of, cancer prevention services among PLWH.

**Methods:** Qualitative data consisting of 8 focus group discussions with PLWH and 14 key informant interviews with HIV health workers, were conducted in two districts each of Uganda and Zambia in January 2024. Each study district held two PLWH focus groups (one male, another female) with 5-7 participants per group and 3-4 key informant interviews. Standardized discussion guides were used to explore types and drivers of cancer stigma and their impacts on PLWH services. Interviews were recorded, translated to English, and thematically analyzed.

**Results:** Cancer stigma drivers included false beliefs of cancer origins, structural issues, and perceptions that cancer is always a terminal illness. Limited provision of care, social isolation, and delayed diagnosis were identified as impacts of stigma. Participants recognized programmatic needs such as improved education for providers and patients, private counseling, and peer support.

**Conclusions:** Results underscore substantial stigma in the study population emphasizing the need for research informing culturally sensitive interventions that enhance educational outreach and promote engagement in care.

**Key words:** cancer; prevention; HIV; stigma

## SHORT SUMMARY

**What is already known on this topic:** While HIV stigma has been well-documented as a barrier to prevention and care, less is known about the impacts of cancer stigma within people living with HIV (PLWH) communities.

**What this study adds:** This study contributes to existing stigma research, which has primarily focused on HIV stigma alone, and highlights the impacts of intersecting stigmas for PLWH in Uganda and Zambia, including limited engagement in care, social isolation, and delayed cancer diagnosis and treatment.

**How this study might affect research, practice, or policy:** Study results emphasize the significant need for further research on stigma among PLWH to inform the development of evidence-based cancer prevention interventions.

## INTRODUCTION

Acquired immunodeficiency syndrome (AIDS)-related morbidity and mortality among people living with Human immunodeficiency virus (HIV) (PLWH) have decreased with the introduction of combination antiretroviral therapy (ART) <sup>1</sup>. Despite these advancements in care, HIV remains among the world's deadliest infectious diseases with 51% of new HIV infections occurring disproportionately in sub-Saharan Africa (SSA) <sup>2</sup>. The now-aging PLWH population is at an increased risk of other comorbidities, including cancer <sup>3</sup>. In part due to HIV-related immunosuppression, PLWH are more likely to receive cancer diagnoses when compared to the general population <sup>4</sup>. This has been especially true of AIDS-defining malignancies like Kaposi sarcoma, aggressive B-cell non-Hodgkin lymphoma, and cervical cancer, which place PLWH at a higher risk of cancer compared with people who are not living with HIV of the same age <sup>5</sup>. More recently, the risk of developing several non-AIDS-defining cancers (NADCs), including Hodgkin lymphoma and cancers of the mouth, throat, liver, lung, and anus, has also increased among PLWH <sup>6</sup>. This elevated risk is partially attributed to known behavioral risk factors among PLWH, such as poor diet, low physical activity, and higher use of tobacco, alcohol, and other substances <sup>7</sup>. Heightened susceptibility to risky behaviors among PLWH not only increases the incidence of cancer but also contributes to a higher likelihood of dying from those cancers when compared to people without HIV <sup>8</sup>. While this is true in countries of all income groups, the intersection of HIV and cancer presents a particularly complex health challenge in low- and middle-income countries (LMICs) in SSA, where the prevalence of both conditions is substantial and cancer treatment capacity is limited <sup>9</sup>.

In SSA, barriers to cancer prevention and care are numerous and complex. Major challenges include limited knowledge of cancer etiology and risk, delayed diagnosis, lack of



to accessing cancer prevention interventions among PLWH. More specifically, the qualitative data collection was designed to provide a more in-depth understanding of engagement in and access to cancer treatment and care. These findings will complement any associations found through the project's quantitative survey and further inform future cancer prevention interventions in Uganda, Zambia, and beyond.

## METHODS

### *Study Sites*

This qualitative portion of the study was carried out over a period of one month within the two selected study districts of each country in January 2024. In Uganda, the two districts selected were Arua in the northern West-Nile region and Moroto in the northeast Karamoja region. West-Nile (Arua) has a population of 776,700 and is an agrarian society. The Karamoja region (Moroto) is mainly a nomadic society with a population of 103,432 and has strong social-cultural ties <sup>14-16</sup>. Similar study sites were selected in Zambia, consisting of Mongu, located in the Western Province, and Chipata in the Eastern Province. Mongu, composed primarily of nomadic communities along the Zambezi River, has a population of 197,816. Chipata is an agrarian region and has a population of 197,816 <sup>17</sup>. Health services in the remote study districts of Uganda and Zambia are delivered by a range of health clinics (HC) including HCI (community level), HCII, HCIII, HCIV, General hospitals, and Regional Referral Hospitals. Care provided at these facilities ranges from curative to basic preventive to outpatient care.

### *Participants and Recruitment*

*PLWH focus group discussions (FGD).* Participants were recruited for focus groups at four clinics serving PLWH at each of the four study districts, Arua and Moroto (Uganda) and Mongu and Chipata (Zambia). Due to the discussion of sensitive topics and anticipated gender differences



quality control, two transcribers read each other's transcripts reviewing content and completeness. Transcribers were proficient in both English and the local language.

### ***Qualitative Measures***

To assure standardization across study countries/sites, discussion guides were used for both FGDs and KIIs. Guides contained thematic discussion questions focused on types, magnitude, and drivers of cancer stigma individually and in the community, and the impact of stigma on cancer prevention, screening and care services, and access to care among PLWH. Before beginning discussions and key informant interviews, participants completed a short, anonymous, questionnaire that recorded demographic information including age, gender, marital status, and when applicable, position within the clinic.

*PLWH FGDs.* Using the focus group discussion guide, participants of the PLWH focus groups were asked questions on topics including basic knowledge of cancer, preferred care options for cancer symptoms (e.g. traditional medicine vs. clinical care), stereotypes, perceived relationships between individual behaviors and cancer risk, anticipated discrimination and coping styles, and possible approaches to improving cancer outreach in the community.

*HCP KIIs.* Healthcare provider interview topics focused on discussions of basic knowledge of cancer, cancer myths, and stigma, perceived barriers to providing cancer-related screenings and care at HIV and non-HIV-focused clinics, and proposed strategies to address these barriers.

### ***Patient and Public Involvement***

Clinic patients and community members were not involved in setting the research question or the design of the qualitative study. They will be involved in disseminating baseline information, which will help enhance community involvement in the quantitative part of the study.

**Data Management and Analysis**

Transcripts of the PLWH FGDs and HCP KIIs were reviewed by study personnel. Participants’ anonymity was maintained throughout the research process using numbers and confidential data treatment. One research team member developed the first draft of the codebook based on the FGD and KII moderator guides. This draft was expanded during the early stages of coding as additional relevant topics emerged. Specifically, themes focused on each discussion topic area, including barriers to providing and receiving care, perceived stigma, and impacts of stigma. Subthemes were also identified from each key theme. Data were coded after interpretation and analyzed using Dedoose Software V.9.0.54<sup>18</sup>. Qualitative data was initially analyzed manually and separately by two study team investigators. Team members then met to discuss and compare emerging themes, where a third study investigator served as an arbitrator to resolve any coding discrepancies. Through this process, the codebook was finalized (e.g., refining definitions and inclusion/exclusion criteria for coding excerpts into specific themes) and transcripts were brought into 100% agreement. From the analysis, counts from each theme and related quotations from the FGD and KIIs are presented to support key findings.

**RESULTS**

**Participant Demographic Characteristics**

A total of 14 key informant interviews were conducted across the study districts. 3 interviews were completed at Arua and Moroto clinics and 4 at Mongu and Chipata clinics. KII participants were primarily females (78%) with an average age of 41. All interviews were conducted with staff holding first-line positions including nurses (9), midwives (1), and nursing officers (4).

Focus group discussions included 55 respondents, with average ages being between 40 and 47 years. There were more male participants than females in most of the study districts. In all districts, most respondents were married and unemployed. Arua District in Uganda had the highest number of unemployed participants (85.7%) (Table 1).

### *HCP Key Informant Interview Results*

For key informant interviews, one hundred and seventy-two individual excerpts were identified and coded into themes related to three topic areas (Table 2): barriers to providing cancer-related care, perceived stigma, and impacts of stigma on cancer-related care. Child codes were applied under these topic areas, resulting in 10 codes.

*Barriers to Providing Cancer-related Care (83 excerpts).* Six sub-themes were identified for the main theme of barriers to providing cancer-related care. HCPs noted a **Lack of Resources** (26 excerpts) as a prominent barrier to providing care. These differences in resources varied by district and clinic. HCPs cited some clinics as not having testing infrastructure like diagnostic tools, proper treatment facilities, medications, or specialist providers. Due to differences in resources, HCPs also discussed **Referrals** (10 excerpts) as being a barrier to providing care. This sub-theme included statements about the challenges of providing consistent care, as HCPs often had to refer patients to different clinics for screening or treatment. Consequently, they noted difficulties in following up on the care provided. Resource limitations also included a **Lack of Time** (6 excerpts). All HCPs stressed work overload and overburdened clinics as being barriers to providing care. Adding cancer screenings to strained treatment clinic environments was frequently mentioned as a worry of HCPs in multiple staffing positions. **Limited Training and Education** (9 excerpts) were raised as being a concern among HCPs. Some KIIs revealed training gaps in cancer prevention and care between clinics and providers.

Few could properly conduct screenings and some respondents shared that they could not talk to patients about cancer because they were unsure of how to do so. **Ethical Challenges** (3 excerpts) were also a complication for HCPs in providing cancer-related care. Most described not wanting to engage in care because of a lack of privacy within their clinics and stated that patients are not open and honest with providers because they cannot speak in private spaces. In addition to barriers, all HCPs pointed out specific **Strategies for Addressing Barriers** (29 excerpts). Some of these were regular healthcare worker trainings in cancer education and care, improvements to clinic infrastructure, and simplified screening measures.

*Perceived Stigma (64 excerpts).* Two sub-themes were applied to the code of perceived stigma. **Types of Stigma** (8 excerpts) included statements related to both personal stigmas as HCP and any observed stigma within treatment clinics or the surrounding community. Experiences of HIV, tobacco, and cancer stigma were introduced by all KIIs, and most stories detailed community perceptions of cancer, shame and embarrassment over a diagnosis, and an unwillingness to be truthful about behaviors. In addition to experiences, HCPs listed **Strategies to Help PLWH Overcome or Cope with Stigma** (16 excerpts). The most commonly identified strategies were tailored education for certain populations like tobacco users, sensitization workshops led by PLWH as opposed to health care workers, and peer support programming.

*Impact of Stigma on Cancer-related Care (66 excerpts).* Two sub-themes were applied to the impacts of stigma on cancer-related care. HCPs identified decreased **Provision of Care** (28 excerpts) among PLWH as being a common impact of experienced cancer stigma. It was agreed that there is a fear of being diagnosed with cancer within the communities and discussion of uncomfortable screening measures that are believed to ‘expose’ you to cancer. HCPs also believe that many women do not get screened for cervical cancer because their spouses might leave them

if they are found to be positive. **Strategies to Improve Engagement in Care** (35 excerpts) were also emphasized by HCPs. Community cancer awareness campaigns such as radio shows with community leaders were a priority for HCPs. HCPs acknowledged the importance of encouraging expert clients who have undergone screenings to sensitize community members and act as ambassadors for cancer prevention.

### ***PLWH Focus Group Results***

One hundred and forty-three individual excerpts were identified and coded into themes within three topic areas (Table 3): barriers to accessing cancer-related care, perceived stigma, and impacts of stigma on cancer-related care. Child codes were applied under these topic areas resulting in 14 distinct codes.

*Barriers to Accessing Cancer-related Care* (65). Seven subthemes were applied to the main theme of barriers to accessing cancer-related care. Cost was highlighted as a major barrier by participants. The child code of **Financial Challenges** (18 excerpts) included excerpts that specifically identified challenges related to the unaffordability of cancer-related services, costs of transport and travel to obtain services, or mentions of being unclear about what the costs of services are at the HIV clinics. Most participants concurred **Social Challenges** (18 excerpts) were also significant in the community. There was varied discussion on the fears of revealing HIV or cancer status to the community by using services, experienced stigma, lack of social support in cancer care, conflicting cancer education from various community members, and pressures to be treated by traditional healers. Respondents shared **Clinic Challenges** (13 excerpts) as being another major barrier. These were mainly a lack of clinic resources and staff, including the unavailability of female health workers. There were also reported inconsistencies in the provision of cancer education among clinics, with some providing comprehensive

education while others did not. In addition to clinic challenges, major **Treatment Specific Challenges** (6 excerpts) such as pain, discomfort, and privacy violations through screenings and treatment were also mentioned in a majority of the FGDs. **Geographic challenges** (4 excerpts) were seen as a barrier, this included excerpts that FGD participants mentioned that clinics with available care were often far away, leading to difficulty in accessing services. **Time Challenges** (2 excerpts) were also considered to be a barrier. FGD participants discussed long waiting periods to receive services and lack of time due to other obligations as key issues. Having **Multiple Conditions** (2 excerpts), such as diagnoses of both cancer and HIV, was also cited as a barrier to seeking cancer care among FGD respondents. They alluded to treatment fatigue and a preference for dealing with the treatment of just one condition at a time.

*Perceived Stigma (66 excerpts).* Two sub-themes were applied to perceived stigma. These included **Types of Stigma** (7 excerpts) and **Strategies to Overcome Perceived Stigma** (17 excerpts). All focus group participants shared having experienced multiple stigmas, primarily being related to HIV stigma, cancer stigma, and tobacco use stigma. This sub-theme included statements related to those experiences within their communities and featured instances of social isolation, shame, and perceptions of appearance. Cancer stigma statements underlined community beliefs that being diagnosed with cancer is a result of karma or bewitchment. Female participants also discussed specific experiences of stigma, stating that a cancer diagnosis could lead to their husbands leaving them and having cervical cancer can be associated with promiscuity. When discussing types of stigmas, participants also mentioned specific strategies that could be used to overcome these experiences. Frequent strategies offered by PWLH were community empowerment through cancer prevention sensitization campaigns and improved social support through support groups and family-based interventions.

*Impact of Stigma on Cancer-related Care (70 excerpts).* Two additional sub-themes were identified under impacts of cancer-related care. **Engagement in Care** (35 excerpts) was a major impact of cancer stigma reported by focus group participants. Engagement in cancer prevention and care was noted as being limited due to stigma because of the perception that a cancer diagnosis was an automatic 'death sentence'. Participants also stated they did not want to reveal their cancer status to community members and already felt social isolation from HIV stigma. Participants also explored some key **Strategies to Overcome Impacts of Stigma** (19 excerpts), suggesting increased cancer education within HIV clinics, free screening campaigns, travel clinics, and campaigns led by key community leaders and cancer survivors.

## DISCUSSION

Qualitative results indicate a substantial amount of cancer stigma in the study population among both healthcare providers and people living with HIV. Moreover, intersecting stigmas related to HIV, cancer, and substance use experienced by PLWH and HCPs in the study were identified as barriers to accessing and providing cancer-related treatment and care.

The stigma associated with HIV was marked by social alienation and a reluctance to share public spaces or items. The onset of cancer introduced further layers of stigma, including perceptions of physical changes such as altered appearance and unpleasant odors. Stigma intersectionality is common for PLWH, as studies have shown that individuals coinfect with HIV and tuberculosis perceived more stigma than individuals who had HIV alone<sup>19</sup>. Also seen with cancer diagnosis, a cross-sectional survey of women in rural Kenya found that cancer stigma was highly correlated with HIV stigma<sup>20</sup>. The intersectionality of stigma can potentially exacerbate existing mental health challenges for PLWH and contribute to the use of already stigmatized substances like tobacco, further complicating access to care and support services.

Intersectional experiences of stigma varied greatly between males and females. Overwhelmingly, women living with HIV were seen as more vulnerable to stigma, with female participants sharing fears that a cancer diagnosis would increase the risk of their husbands leaving them. Women living with HIV also emphasized experiencing stigma related to cervical cancer, citing that community members perceive them as being more promiscuous if they have both diseases. This aligns with existing literature on stigma in LMICs, which found that women associate HPV with prostitution and infidelity and believe that a cervical cancer diagnosis would result in blame and rejection by their partner<sup>21</sup>. These issues are particularly concerning given that female FGD participants noted prominent structural barriers contributing to stigma surrounding cervical cancer screening such as a lack of female providers within the clinics. As approximately 1 in 5 cervical cancer diagnoses in sub-Saharan Africa are attributed to HIV, stigma poses significant risks and impacts for women in this population<sup>22</sup>.

In addition to prevalence and experiences, study participants offered insights into some possible drivers and impacts of cancer-related stigma. PLWH commonly expressed concerns that being diagnosed with cancer was ultimately a death sentence. This was consistent with other studies measuring attitudes towards cancer diagnosis as being that it is incurable, and all individuals will die of their disease<sup>23</sup>. Participants also shared community beliefs that bewitchment and karma were the causes of cancer, leading many of them to seek care from traditional healers in place of medical treatment. The lack of knowledge of cancer causes and symptoms was not only brought up by PLWH but also HCPs. KIIs revealed a general lack of education in cancer information and screening practices for healthcare providers, possibly contributing further to misconceptions and misinformation within the community. Other environmental and provider-level drivers of stigma were cited as a lack of availability of cancer-related services, perceptions

of treatment being unaffordable, and the absence of private spaces for treatment. These factors hinder access to care and contribute to the perpetuation of stigma in the surveyed HIV clinics and beyond.

Major impacts of stigma identified by study participants included social isolation, avoidance of screening and treatment services, reluctance to disclose information to healthcare providers, and poor mental health outcomes. Stigma-related avoidance of screening and treatment contributes to late presentation to care which can significantly impact cancer prognosis, especially for PLWH<sup>24</sup>. Similar patterns have been observed across multiple studies involving women living with HIV who delayed seeking screenings and diagnosis of breast cancer due to fears of social exclusion<sup>25</sup>. Impacts of stigma on mental health were also apparent in our study, with participants experiencing ongoing stigma and feelings of shame and diminished self-worth following their cancer diagnosis. A body of research has linked stigma to depression and anxiety among PLWH, which have been seen to manifest as low motivation to seek and adhere to treatment and increased engagement in maladaptive coping mechanisms such as alcohol misuse and tobacco use<sup>26</sup>.

Study participants expressed a desire for community and individual-level solutions to address the origins and impacts of intersecting stigma faced by PLWH. These included community sensitization and education campaigns, clinic-based training and counseling, and peer support programs. Educational radio programs and media campaigns have been used to promote community awareness and empowerment in many LMICs. When utilized to target stigma reduction, these methods were successful for PLWH in India and Ethiopia, suggesting that they could be a promising strategy for Uganda and Zambia<sup>27</sup>. Such interventions have also been shown to support compassion, improved communication, self-esteem, and confidence, which are important in encouraging care-seeking behaviors among PLWH<sup>28</sup>. Both PLWH and HCPs stressed

the importance of having ‘champions’ or leaders of interventions being community members, traditional healers, or religious leaders instead of healthcare providers. A community support initiative in South Africa found that ‘treatment buddy’ models successfully decreased levels of HIV stigma, while stigma increased when a healthcare professional provided the same support <sup>29-30</sup>. While this method has proven to be effective in addressing HIV stigma, it has not been tested widely for other forms of stigma for PLWH such as cancer.

Many PLWH also discussed the importance of having a strong social support network to overcome the impacts of stigma. Whether this is in the form of cancer survivor support groups, peer counseling, or family support, social support successfully cultivates trust and a sense of belonging among certain minority groups, potentially reducing the effects and likelihood of experiencing stigma <sup>31</sup>. Given the complex nature and intersections of stigma within these communities, it is unlikely that one intervention alone will have a meaningful impact. Interventions should integrate into existing HIV care programs and aim to manage the multidimensional mechanisms through which stigma influences engagement in cancer treatment and care services.

Future research is also important for developing an evidence base for stigma reduction interventions. Based on our qualitative findings, it is evident that stigma influences the health outcomes of PLWH; however, research in this area is limited and often focuses on HIV stigma alone. Other qualitative studies and mixed-methods designs should be prioritized to properly define cultural differences and examine the causal pathways of intersecting stigmas as they relate to cancer prevention and care.

This study not only provides a valuable model for researching cancer-related stigma for PLWH in Uganda and Zambia but also offers important insights into closing the cancer prevention and service delivery gap for these populations in SSA. Perspectives and experiences defined by

participants should be disseminated widely to cancer researchers, community health workers, and policymakers with the long-term goal of improving implementation strategies that reduce stigma and increase access to cancer care for PLWH in LMICs and beyond.

### ***Study Limitations***

Several study limitations were identified. While the qualitative nature of the research provided a more detailed exploration of the feelings, opinions, and experiences of stigma among people living with HIV and healthcare providers, this approach does not always allow for generalizability and transferability of findings. The study's sample for KIIs was selective and purposive and may not be representative of the views of all HCPs holding other staff positions within the HIV clinics. As the information presented by key informants and focus groups was self-reported, data from this study may be subject to recall bias. Focus group discussions also contained information that participants may have found to be culturally sensitive or controversial, increasing the likelihood of social desirability bias. To mitigate social desirability and recall bias, FGDs took place in private locations, and moderators were encouraged to establish respectful rapport with participants allowing participants to share truthful and thoughtful insights. Additionally, the FGDs had a higher number of male participants when compared to females. This may be attributed to stigma targeted towards females; and could have potentially resulted in the exclusion of key gender-specific narratives from the larger female study population. The sample size for both KIIs and FGDs was also small, raising concerns of applicability beyond the study setting. While study results may not be generalizable to all low and middle-income countries, they do provide information on what is likely the cancer care environment in most parts of Uganda and Zambia. These findings can ultimately complement quantitative findings being collected, allowing for a

comprehensive understanding of the impacts of stigma on cancer care and prevention among PLWH.

**Conclusions**

This study explored qualitative data on the intersecting stigmas associated with cancer, barriers to providing or accessing care, and methods to improve access to interventions among PLWH. Study results provide useful insight into the impacts of stigma on cancer prevention and treatment for PLWH in Uganda and Zambia. Findings highlight the impacts of stigma on cancer prevention and treatment, emphasizing the need for culturally sensitive interventions. Further research is needed to explore the intersections of stigma and its effects on health-seeking behaviors among PLWH, informing future interventions that address stigma in LIMCs and beyond.

**List of abbreviations:****PLWH** People Living with HIV**NACDs** Non-Aids Defining Cancers**AIDS** Acquired immunodeficiency syndrome**HIV** Human immunodeficiency virus**ART** Antiretroviral Therapy**SSA** Sub-Saharan Africa**LMICs** Low and Middle-Income Countries**FGD** Focus Group Discussion**KII** Key Informant Interviews**HC** Health Clinics**HCP** Healthcare Provider**Declarations**

**Ethics approval and consent to participate.** This study, including all procedures and consent materials, was approved by the IRBs of the University of Southern California (HS-22-0006), Makerere University School of Public Health in Uganda (SPH-2021-178), and University of Zambia Biomedical Research (2377-2021) and the Zambian Ministry of Health (RFA-CA-23-033).

**Consent for publication.** Not applicable.

**Competing interests.** The authors declare that they have no competing interests.

**Availability of data and material.** Once collected, unidentified data from this study will be available from the corresponding author on reasonable request one year after all aims of the project are completed. Requestors of data will be asked to complete a data-sharing agreement that provides for (1) a commitment to using the data only for research purposes and not to identify any individual participant; (2) a commitment to securing the data using appropriate computer technology; and (3) a commitment to destroying or returning the data after analyses are completed.

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**Author's contributions.** HW is the PI of the project and has overall responsibility for its execution and is the corresponding author. HW, JA, and FG co-led the design of the study, with DG and RK guiding statistical and analytic issues. KG and HW wrote the first draft of the manuscript. All authors contributed to and have approved the final manuscript.

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**Table 1. Demographic characteristics of focus group discussion participants from HIV clinics in 4 districts of Uganda and Zambia in 2024**

| Characteristic           | Moroto   |       | Arua     |       | Mongu    |       | Chipata  |       |
|--------------------------|----------|-------|----------|-------|----------|-------|----------|-------|
|                          | <i>n</i> | %     | <i>n</i> | %     | <i>n</i> | %     | <i>n</i> | %     |
| Gender                   |          |       |          |       |          |       |          |       |
| <i>Female</i>            | 6        | 46.1% | 7        | 50%   | 6        | 40%   | 6        | 46.1% |
| <i>Male</i>              | 7        | 53.9% | 7        | 50%   | 9        | 60%   | 7        | 53.9% |
| Marital status           |          |       |          |       |          |       |          |       |
| <i>Single</i>            | 0        | 0.0   | 1        | 7.1%  | 3        | 20%   | 2        | 15.4% |
| <i>Married/partnered</i> | 11       | 84.6% | 6        | 42.9% | 7        | 46.7% | 7        | 53.9% |
| <i>Divorced/widowed</i>  | 2        | 15.4% | 7        | 50%   | 5        | 33.3% | 4        | 30.8% |
| Employment               |          |       |          |       |          |       |          |       |
| <i>Unemployed</i>        | 9        | 69.2% | 12       | 85.7% | 1        | 6.7%  | 7        | 53.9% |
| <i>Employed</i>          | 4        | 30.8% | 2        | 14.3% | 14       | 93.3% | 6        | 46.1% |
| Average Age              |          |       |          |       |          |       |          |       |
| <i>Female</i>            | 46.5     |       | 44.4     |       | 47       |       | 41.5     |       |
| <i>Male</i>              | 43.3     |       | 40       |       | 43.8     |       | 43.1     |       |

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**Table 2. Healthcare provider key informant interview themes, description of themes, and example quotes from HIV clinics in 4 districts of Uganda and Zambia in 2024**

| Theme                                     | Description                                                                                                   | Subthemes and Example Quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|-------------------------------------------|---------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Barriers to Providing Cancer-related Care | Statements about any barriers faced by HCP to providing any cancer-related care to PLWH within their clinics. | <p><b>Lack of Resources</b> “Many people are diagnosed at a later stage: you’ll find that you are unable to give them adequate services because you do not have that level for management of advanced cases of cancer.”</p> <p><b>Referrals</b> “To a smaller extent, this is because the clients fear the fact that if they are tested, the results may turn to be positive. Generally if it is advanced, they don’t have ways of getting help since we refer them to Mulago.”</p> <p><b>Lack of Time</b> “There is also a challenge of over workload. So there’s no time for tests or room for them to rest in my leave days. We really need more health workers.”</p> <p><b>Ethical Challenges</b> “There is no privacy for our clients to conduct the screening or discussion. With no privacy the patient may become open now to reveal everything and are able to tell the health personnel.”</p> <p><b>Limited Training/Education</b> “There are knowledge gaps among health workers where all workers are not trained on how to screen for cancer. However much we take histories and see some signs and symptoms, it’s difficult to screen a patient for cancer when you don’t know how.”</p> <p><b>Strategies for Addressing Barriers</b> “I think the first change would be for a lot of health care workers to be trained so that people don’t just think that cervical cancer screening is an ART.”</p> <p>“Another thing that could be changed is to bring in more measures that would simplify screening if there were self tests or something that would really help.”</p> |
| Perceived Stigma                          | Statements about any personal stigma or observed stigma by HCP within their clinics.                          | <p><b>Types of Stigma</b> “There is a perception that a female client that has cervical cancer is seen as promiscuous.”</p> <p>“It is HIV stigma, some of the clients come out of the ART clinic and hide their face, they wear caps or glasses and are unsettled.”</p> <p>“Most of the smokers will tell you that you [The Health Worker] are the only one who knows that they smoke.”</p> <p><b>Strategies to Help PLWH Overcome or Cope with Stigma</b> “I think on the increase of motivating them, maybe not calling only health workers to do some things. Selecting some HIV positive clients to have a workshop, maybe teaching them how they can sensitize in the community. The type of counseling should be tailored.”</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| Impact of Stigma on Cancer-related Care   | Statements about any impacts of stigma on care within their clinics.                                          | <p><b>Provision of Care</b> “They are afraid, fear of being diagnosed positive with cervical cancer and others speak the level of screening is very uncomfortable. Word has gone out that when you are screened for cervical cancer even if they didn’t have it once they are screened it’s like you have exposed them to the cancer.”</p> <p>“When health care workers try to talk to women about cancer their fear is that if they are diagnosed maybe their spouse will leave them, so they would rather not know.”</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |

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|                                                 |                                                                                                                             |
|-------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------|
| <b>Strategies to Improve Engagement in Care</b> | <i>"We can do radio programs, community engagement, and engage community leaders."</i>                                      |
|                                                 | <i>"We can use expert clients who have gone through cancer screening to encourage the rest to participate in services."</i> |

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**Table 3. People living with HIV focus group themes, description of themes, and example quotes from HIV clinics in 4 districts of Uganda and Zambia in 2024**

| Theme                                     | Definition                                                                  | Subthemes and Example Quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|-------------------------------------------|-----------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Barriers to Accessing Cancer-related Care | Statements about any challenges PLWH face in accessing cancer-related care. | <p><b>Financial Challenges</b> “They think they will be charged for the check up because things are very difficult here. You start to think of going to the hospital yet there is no sugar and soap. The children might sleep hungry if you spend the money, so you cannot waste money at the hospital.”</p> <p>“When they say the word “Mulago”, fear takes over you because the transport money alone is a lot. You just decide and you choose to die, you just surrender to die though you need to try and go to the hospital.”</p> <p><b>Geographic Challenges</b> “There is no diagnostic equipment in the regional referral hospital to detect cancer. Instead one must travel to Mulago which is several hundreds of kilometers away for screening and confirmation that they really have cancer.”</p> <p><b>Time Challenges</b> “Sometimes I don’t know whether it is because of low staffing, there are moments whereby someone comes to the hospital and spends nearly the whole day waiting to be served and yet we do have some other responsibilities.”</p> <p><b>Social Challenges</b> “When you rely so much on the community beliefs you cannot go to the hospital because certain talks of the people are very difficult. Where we stay they say, ‘It is right there at the hospitals you go to where they inject you with cancerous drugs.’ As such people from the village will never accept that cancer comes in different ways.”</p> <p><b>Clinic Challenges</b> “Fear of male health workers is a factor. When you reach the hospital and find that a man is going to check you, you will not accept it. For me I refused until a woman came.”</p> <p>“We go to different health facilities and the teaching we get varies. There are some clinics where they don’t teach you anything so you only go and get your medicine and go home.”</p> <p><b>Multiple Conditions</b> “For me I will not want to merge herbal and exotic medications from cancer. I am already on ARVs, I feel it might cause me more illness and complications.”</p> <p><b>Treatment Specific Challenges</b> “I have fear of the testing mechanism for cancer. I wish they could only use blood to test for cancer instead of having to inconvenience someone by tough ways of collecting the sample for testing like cervical cancer screening.”</p> |
| Perceived Stigma                          | Statements about any instances or experiences of stigma.                    | <p><b>Types of Stigma</b> “For people who discover they have cancer, it is a big problem. They say you could be with a colleague who has cancer and you would smell a certain scent even if that person has bathed.”</p> <p>“So it is better to go to the hospital because all the traditional healer will tell you is that you are being bewitched.”</p> <p>“They don’t allow you to enter the toilet because you will leave AIDs there, they don’t allow you to move or even a meter. When you go to the market they will say see AIDs moving around see how AIDs looks, that is how we are described in the community.”</p> <p>“We also experience tobacco stigma because we know that people do not like the odor that comes off us. It is worse in public when people segregate you and you feel shy and stigmatized.”</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |

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|-----------------------------------------|----------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                         |                                                                                  | <p><b>Strategies to Overcome Perceived Stigma</b> “The most important thing is to sensitize people about stigma and also encourage people to accept and live with their positive status and people will be free.”</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| Impact of Stigma on Cancer-related Care | Statements about how stigma has impacted any engagement in cancer care for PLWH. | <p><b>Engagement in Care</b> “What they say in the community is that cancer is the worst sickness in the whole world, and it leads to death. This now brings fear. The fear is too much that they don’t go for a check-up because if they are diagnosed with cancer they might just die.”</p> <p>“Some of us have girlfriends here so we fear to come for treatment because we don’t want them to know we are HIV+. Then let’s say we have also been diagnosed with cancer! It is better if you die silently.”</p> <p><b>Strategies to Overcome Impacts of Stigma</b> “What can really help is that for those of us who are on medication, we need to be free and open with those who are not. That way we will find the needed help and there will be no more barrier, that person will understand the situation.”</p> |

# BMJ Open

## Understanding stigma as a barrier to cancer prevention and treatment: A qualitative study among people living with HIV in Uganda and Zambia

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## Understanding stigma as a barrier to cancer prevention and treatment: A qualitative study among people living with HIV in Uganda and Zambia

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## ABSTRACT

**Introduction:** Extended life expectancy due to treatment improvements has increased the diagnosis of cancer among people living with HIV (PLWH) in Africa. Despite documented impacts of stigma on cancer preventive behaviors and care, little is known about the intersections of cancer and HIV stigma and the effects on prevention and care behaviors for both conditions.

**Objectives:** This study aims to examine experiences and drivers of cancer stigma and their associations with access to and utilization of cancer prevention services among PLWH.

**Design:** This was a qualitative study consisting of 8 focus group discussions with PLWH and 14 key informant interviews with HIV healthcare providers collected in January 2024.

**Setting:** Data was collected from two districts of Uganda and Zambia. In Uganda, the two selected districts were Arua, in the northern West Nile region, and Moroto, in the northeast Karamoja region. In Zambia, the study districts were Mongu, in the Western Province, and Chipata in the Eastern Province.

**Participants:** Each study district held two PLWH focus groups (one male, another female) with 5-7 participants per group and 3-4 key informant interviews for a total of 55 participants. PLWH and healthcare providers were eligible if they were: (1) aged 18 years or older and (2) an HIV-positive client receiving ART services at the participating clinic or working in a health services capacity at the clinic.

**Results:** Cancer stigma drivers included widespread misconceptions about disease origins and outcomes, associations with other stigmatizing conditions and behaviors such as HIV, TB, and substance use, limited treatment options that heightened fears of diagnosis, and inadequate training of healthcare providers. Study participants noted that experiences of stigma led to reduced treatment-seeking behaviors among PLWH, increased social isolation, and poor cancer-related care practices within clinics. Recommended interventions to combat stigma included improved education for providers and patients, private counseling, and peer support.

**Conclusions:** Results underscore the presence and impacts of stigma in the study population, emphasizing the need for research informing culturally sensitive interventions that enhance educational outreach and promote engagement in care amongst targeted populations.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- Qualitative study methods offer unique perspectives from both people living with HIV and healthcare providers, providing a greater understanding of stigma as a barrier to cancer prevention and treatment in Uganda and Zambia.
- This study contributes to existing research on stigma, which has primarily focused on HIV stigma alone, by highlighting the impacts of intersectional stigmas - including those related to gender, cancer, and substance use, - for PLWH.

- The study's sample size and purposive sampling methods may limit the generalizability of findings beyond the study setting; however, the results are likely relevant to similar healthcare settings in sub-Saharan Africa and will be complemented further by future quantitative findings.

## INTRODUCTION

Acquired immunodeficiency syndrome (AIDS)-related morbidity and mortality among people living with Human immunodeficiency virus (HIV) (PLWH) have decreased with the introduction of combination antiretroviral therapy (ART) <sup>1</sup>. Despite these advancements in care, Sub-Saharan Africa (SSA) continues to carry a disproportionate burden of HIV, with more than 70% of global infection occurring within this region<sup>2</sup>. The now-aging PLWH population is at an increased risk of other comorbidities, including cancer <sup>3</sup>. In part due to HIV-related immunosuppression, PLWH are more likely to receive cancer diagnoses when compared to the general population <sup>4</sup>. While this has traditionally been true of AIDS-defining malignancies like Kaposi sarcoma, aggressive B-cell non-Hodgkin lymphoma, and cervical cancer, the risk of developing several non-AIDS-defining cancers (NADCs), including Hodgkin lymphoma and cancers of the mouth, throat, liver, lung, and anus, has also increased among PLWH <sup>5, 6</sup>. This elevated risk is partially attributed to known behavioral risk factors among some PLWH, such as poor diet, low physical activity, and higher use of tobacco, alcohol, and other substances <sup>7</sup>. PLWH face not only a higher risk of being diagnosed with both AIDS-defining and non-AIDS-defining cancers because of these factors but also a greater likelihood of dying from those cancers when compared to people without HIV of the same age <sup>8</sup>.

The intersection of HIV and cancer presents a particularly complex health challenge in low- and middle-income countries (LMICs) in SSA, where the prevalence of both conditions is substantial and cancer treatment capacity is limited <sup>9</sup>. In SSA, barriers to cancer prevention and



explored the stigmas associated with cancer, possible stereotypes, anticipated forms of discrimination, coping styles, and barriers to accessing cancer prevention interventions and care among PLWH. These findings will complement any associations found through the project's quantitative survey and further inform future cancer prevention interventions in Uganda, Zambia, and beyond.

## METHODS

### *Study Sites*

This qualitative portion of the study was carried out over a period of one month within the two selected study districts of each country in January 2024. In Uganda, the two districts selected were Arua in the northern West-Nile region and Moroto in the northeast Karamoja region. West-Nile (Arua) has a population of 776,700 and is an agrarian society. The Karamoja region (Moroto) is mainly a nomadic society with a population of 103,432 and has strong social-cultural ties<sup>14-16</sup>. Similar study sites were selected in Zambia, Mongu, located in the Western Province, and Chipata in the Eastern Province. Mongu, composed primarily of nomadic communities along the Zambezi River, has a population of 197,816. Chipata is an agrarian region and has a population of 197,816<sup>17</sup>. Health services in the study districts of Uganda and Zambia are delivered by a range of health clinics (HC) including HCI (community level), HCII, HCIII, HCIV, General hospitals, and Regional Referral Hospitals. Care provided at these facilities ranges from curative to basic preventive to outpatient care.

### *Participants and Recruitment*

*PLWH focus group discussions (FGD).* PLWH were recruited to participate in focus group discussions across the four study districts. Due to the discussion of sensitive topics and anticipated gender differences concerning stigma, two focus groups were conducted at each clinic, one for

men and one for women. Each focus group included 6-8 participants, resulting in eight total focus groups (N=55). Eligibility criteria were: (1) aged 18 years or older and 2) an HIV-positive client receiving ART services at the participating clinic during the recruitment visit. Past cancer diagnosis was not included as an inclusion or exclusion criterion, allowing for perspectives from both individuals eligible for cancer screening services and those who may have had a previous or current cancer diagnosis. At each clinic, the in charge of the health facility was identified and enlisted to help contact eligible focus group participants.

*Healthcare Provider (HCP) key informant interviews (KIIs).* KIIs were conducted with healthcare providers from three to four of the selected clinics serving PLWH in each study district of Uganda and Zambia, resulting in 14 total interviews. The number of interviews conducted in each clinic was selected based on staff availability and participation capacity. The in charge of the health facility helped to identify healthcare providers for interviews. Eligibility criteria for healthcare provider KII participation were: (a) aged 18 years or older; and (b) working in a health services position at the clinic. Compensation in the form of payment for transportation and a meal was provided for FGD and KII participation. Written informed consent was obtained from all participants after the moderator explained the study’s aims, benefits, potential risks, and participant rights. The study protocol was approved by the University of Southern California (HS-22-0006), Makerere University (SPH-2021-178), and The University of Zambia (REF.2377-2021) internal review boards.

**Data Collection**

Two facilitators were present at each focus group and KII: one facilitator moderated the discussion, and another assisted with the notetaking, materials, and logistics. The FGDs and KIIs lasted approximately one hour and were conducted in the local language. Sessions were audio

recorded with permission from the participants and then directly transcribed into English. For quality control, two transcribers read each other's transcripts reviewing content and completeness. Transcribers were proficient in both English and the local language.

### *Qualitative Measures*

To assure standardization across study countries/sites, discussion guides were used for both FGDs and KIIs. Guides contained thematic discussion questions focused on types, magnitude, and drivers of stigma individually and in the community, impacts on care-seeking behaviors, and structural factors that potentially exacerbate experiences of stigma within the community including access to care among PLWH. Cancer prevention services were defined as available screenings, testing, vaccination, and counseling, while care included available surgeries, chemotherapy, radiotherapy, and immunotherapy treatments to those diagnosed and referred. Before beginning discussions and key informant interviews, participants completed a short, anonymous, questionnaire that recorded demographic information including age, gender, marital status, and when applicable, position within the clinic.

*PLWH FGDs.* Using the focus group discussion guide, participants of the PLWH focus groups were asked questions on topics including their experiences with HIV, basic knowledge of cancer, preferred care options for cancer symptoms (e.g. traditional medicine vs. clinical care), stereotypes and potential stigmatization, perceived relationships between individual behaviors and cancer risk, anticipated discrimination and behavioral coping strategies, and possible approaches to decreasing stigma in the community.

*HCP KIIs.* Healthcare provider interview topics focused on discussions of basic knowledge of cancer, cancer myths, and stigma, perceived barriers to providing cancer-related screenings and care at HIV and non-HIV-focused clinics, and proposed strategies to address these barriers.

*Data Management and Analysis*

Transcripts of the PLWH FGDs and HCP KIIs were reviewed by study personnel. Participants’ anonymity was maintained throughout the research process using numbers and confidential data treatment. One research team member developed the first draft of the codebook based on the FGD and KII moderator guides. This draft was expanded during the early stages of coding as additional relevant topics emerged. Specifically, themes focused on each discussion topic area including the presence of stigma, drivers and impacts of stigma across interpersonal, intrapersonal, and structural levels, and potential stigma-reduction strategies. Subthemes were also identified from each key theme. Data were coded after interpretation and analyzed using Dedoose Software V.9.0.54<sup>18</sup>. Qualitative data was initially analyzed manually and separately by two study team investigators. Team members then met to discuss and compare emerging themes, where a third study investigator served as an arbitrator to resolve any coding discrepancies. Through this process, the codebook was finalized (e.g., refining definitions and inclusion/exclusion criteria for coding excerpts into specific themes) and transcripts were brought into 100% agreement. For key informant interviews, one hundred and seventy-two individual excerpts were identified and coded into themes and subthemes related to chosen topic areas (Table 2): stigma presence, impacts of stigma on cancer-related care, structural factors related to stigma, and strategies to reduce stigma. For focus group discussion results, one hundred and forty-three individual excerpts were identified with themes and subthemes from the same topic areas (Table 3). From the analysis, details of each theme and related quotations from the FGD and KIIs are presented to support key findings.

**RESULTS**

**Table 1. Demographic characteristics of focus group discussion participants from HIV clinics in 4 districts of Uganda and Zambia in 2024**

| Characteristic           | Moroto   |       | Arua     |       | Mongu    |       | Chipata  |       |
|--------------------------|----------|-------|----------|-------|----------|-------|----------|-------|
|                          | <i>n</i> | %     | <i>n</i> | %     | <i>n</i> | %     | <i>n</i> | %     |
| Gender                   |          |       |          |       |          |       |          |       |
| <i>Female</i>            | 6        | 46.1% | 7        | 50%   | 6        | 40%   | 6        | 46.1% |
| <i>Male</i>              | 7        | 53.9% | 7        | 50%   | 9        | 60%   | 7        | 53.9% |
| Marital status           |          |       |          |       |          |       |          |       |
| <i>Single</i>            | 0        | 0.0   | 1        | 7.1%  | 3        | 20%   | 2        | 15.4% |
| <i>Married/partnered</i> | 11       | 84.6% | 6        | 42.9% | 7        | 46.7% | 7        | 53.9% |
| <i>Divorced/widowed</i>  | 2        | 15.4% | 7        | 50%   | 5        | 33.3% | 4        | 30.8% |
| Employment               |          |       |          |       |          |       |          |       |
| <i>Unemployed</i>        | 9        | 69.2% | 12       | 85.7% | 1        | 6.7%  | 7        | 53.9% |
| <i>Employed</i>          | 4        | 30.8% | 2        | 14.3% | 14       | 93.3% | 6        | 46.1% |
| Average Age              |          |       |          |       |          |       |          |       |
| <i>Female</i>            | 46.5     |       | 44.4     |       | 47       |       | 41.5     |       |
| <i>Male</i>              | 43.3     |       | 40       |       | 43.8     |       | 43.1     |       |

### ***Participant Demographic Characteristics***

A total of 14 KIIs were conducted across the study districts. 3 interviews were completed at Arua and Moroto clinics and 4 at Mongu and Chipata clinics. KII participants were primarily females (78%) with an average age of 41. All interviews were conducted with staff holding first-line positions including nurses (9), midwives (1), and nursing officers (4).

FDGs included 55 respondents total, with average ages being between 40 and 47 years. There were more male participants than females in most of the study districts. In all districts, most respondents were married and unemployed. Arua district in Uganda had the highest number of unemployed participants (85.7%) (Table 1).

**Table 2. Healthcare provider key informant interview themes, description of themes, and example quotes from HIV clinics in 4 districts of Uganda and Zambia in 2024**

| Theme | Description | Subthemes and Example Quotes |
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|-----------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Stigma Presence                         | Statements about any personal stigma or observed stigma by HCP within their clinics.                                                                             | <b>Types of Stigma</b> “There is a perception that a female client that has cervical cancer is seen as promiscuous (1).”<br><br>“It is HIV stigma, some of the clients come out of the ART clinic and hide their face, they wear caps or glasses and are unsettled (2).”<br><br>“Most of the smokers will tell you that you [The Health Worker] are the only one who knows that they smoke (3).”                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| Impact of Stigma on Cancer-related Care | Statements about any impacts of stigma on care within their clinics.                                                                                             | <b>Provision of Care</b> “They are afraid, fear of being diagnosed positive with cervical cancer and others speak the level of screening is very uncomfortable. Word has gone out that when you are screened for cervical cancer even if they didn’t have it once they are screened it’s like you have exposed them to the cancer (4).”<br><br>“When health care workers try to talk to women about cancer their fear is that if they are diagnosed maybe their spouse will leave them, so they would rather not know (5).”                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| Structural Factors Related to Stigma    | Statements about any structural barriers faced by HCP that potentially influence stigma and ability to provide cancer-related care to PLWH within their clinics. | <b>Lack of Resources</b> “Many people are diagnosed at a later stage: you’ll find that you are unable to give them adequate services because you do not have that level for management of advanced cases of cancer (6).”<br><br><b>Referrals</b> “To a smaller extent, this is because the clients fear the fact that if they are tested, the results may turn to be positive. Generally if it is advanced, they don’t have ways of getting help since we refer them to Mulago (7).”<br><br><b>Ethical Challenges</b> “There is no privacy for our clients to conduct the screening or discussion. With privacy the patient may become open now to reveal everything and are able to tell the health personnel (8).”<br><br><b>Limited Training/Education</b> “There are knowledge gaps among health workers where all workers are not trained on how to screen for cancer. However much we take histories and see some signs and symptoms, it is difficult to screen a patient for cancer when you don’t know how (9).” |
| Strategies to Reduce Stigma             | Statements about any potential strategies to reduce stigma and improve engagement in care for PLWH.                                                              | <b>Strategies to Help PLWH Overcome or Cope with Stigma</b> “I think on the increase of motivating them, maybe not calling only health workers to do some things. Selecting some HIV positive clients to have a workshop, maybe teaching them how they can sensitize in the community. The type of counseling should be tailored (10).”<br><br><b>Strategies to Improve Engagement in Care</b> “We can do radio programs, community engagement, and engage community leaders (11).”<br><br>“We can use expert clients who have gone through cancer screening to encourage the rest to participate in services (12).”                                                                                                                                                                                                                                                                                                                                                                                                     |

**HCP Key Informant Interview Results**

*Stigma Presence.* Healthcare providers frequently discussed the presence of perceived stigma both in terms of personal stigmas they may hold and the stigma they observed within treatment clinics or the surrounding community. HCPs reported witnessing various **types of stigmas** related to co-occurring conditions and behaviors including HIV status, tobacco use, and cancer. A common belief in the clinics was that a cervical cancer diagnosis in female patients

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was often associated with promiscuity (Table 2, Quote 1). HIV stigma was also commonly reported within clinics, with HCPs noting that patients would often attempt to conceal their HIV status because of stigma, sometimes by wearing caps and glasses to avoid recognition by others (Table 2, Quote 2). Tobacco use was also frequently hidden by patients, with many smokers telling healthcare providers that they were the only ones aware of their smoking habits, as they did not want anyone around them to know due to the stigmatization of the behavior ((Table 2, Quote 3).

*Impact of Stigma on Cancer-related Care.* From the HCP perspective, the most frequently discussed impact of stigma on cancer-related care was the decreased **Provision of Care** among PLWH. HCPs reported that PLWH often avoid cervical cancer screenings due to the stigmatized belief that undergoing screening could lead to a terminal cancer diagnosis. There was a shared understanding among HCPs that the fear of screening procedures, including the risk of getting cancer from the procedure, within clinics deters many individuals from seeking care (Table 2, Quote 4). Some HCPs also noted conversations with female clients who expressed reluctance to undergo cervical and breast screenings. These women feared that a positive result might lead their spouses to leave them because of the social stigma of promiscuity associated with the cancers (Table 2, Quote 5).

*Structural Factors Related to Stigma.* HCPs identified several structural factors contributing to the stigma surrounding cancer care and hindering abilities to provide services to PLWH within their clinics. The most prominent factor was a **lack of resources** and equipment for cancer screening, diagnosis, and treatment. As described by HCPs, **referrals** to central cities because of an absence of localized cancer care service options result in late-stage cancer diagnosis, which not only reduces treatment success but also perpetuates cancer stigma through

fear of diagnosis (Table 2, Quote 6,7). HCPs also shared **ethical challenges** in providing care without private spaces in clinics. HCPs highlighted that the absence of privacy and confidentiality during consultations prevents patients from openly discussing health concerns, seeking care, or receiving potentially stigma-reducing counseling and advice. (Table 2, Quote 8). Finally, HCPs noted the **limited training and education** for healthcare providers as a significant structural challenge. These gaps in knowledge were cited as resulting in difficulties in providing quality care and addressing stigma and beliefs related to cancer for patients in their clinics (Table 2, Quote 9).

*Strategies to Reduce Stigma.* In addition to stigma experiences and related structural factors, HCPs emphasized possible stigma reduction and care engagement strategies for PLWH in healthcare settings and surrounding communities. From the HCP perspective, possible **strategies identified to help PLWH overcome or cope with stigma** were trainings for HCPs in delivering tailored education for certain PWLH populations like tobacco users, sensitization workshops led by PLWH as opposed to health care workers, and peer support programming (Table 2, Quote 10). HCPs also emphasized **strategies to encourage and improve overall engagement in care** for PLWH. Community cancer awareness campaigns such as radio shows with community leaders were a priority for HCPs. HCPs acknowledged the importance of encouraging expert clients who have undergone screenings to sensitize community members and act as ambassadors for cancer prevention (Table 2, Quote 11,12).

Table 3. People living with HIV focus group themes, description of themes, and example quotes from HIV clinics in 4 districts of Uganda and Zambia in 2024

| Theme | Definition | Subthemes and Example Quotes |
|-------|------------|------------------------------|
|-------|------------|------------------------------|

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|-----------------------------------------|-----------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Stigma Presence                         | Statements about any instances or experiences of stigma.                                                  | <p><b>Types of Stigma</b> “They don’t allow you to enter the toilet because you will leave AIDs there, they don’t allow you to move for even a meter. When you go to the market they will say see AIDs moving around see how AIDs looks, that is how we are described in the community (1).”</p> <p>“We also experience tobacco stigma because we know that people do not like the odor that comes off us. It is worse in public when people segregate you and you feel shy and stigmatized (2).”</p> <p>“For people who discover they have cancer, it is a big problem. They say you could be with a colleague who has cancer and you would smell a certain scent even if that person has bathed (3).”</p> <p>“So it is better to go to the hospital because all the traditional healer will tell you is that you are being bewitched (4).”</p>                                                                                                                                                                                                                                                                                                         |
| Impact of Stigma on Cancer-related Care | Statements about how stigma has impacted any engagement in cancer care for PLWH.                          | <p><b>Engagement in Care</b> “What they say in the community is that cancer is the worst sickness in the whole world and it leads to death. This now brings fear. The fear is too much that they don’t go for a check-up because if they are diagnosed with cancer they might just die (5).”</p> <p>“Some of us have girlfriends here so we fear to come for treatment because we don’t want them to see or know we are HIV+. Then let’s say we have also been diagnosed with cancer! It is better if you die silently (6).”</p> <p>“I have fear of the testing mechanism for cancer. I wish they could only use blood to test for cancer instead of having to inconvenience someone by tough ways of collecting the sample for testing like cervical cancer screening (7).”</p>                                                                                                                                                                                                                                                                                                                                                                         |
| Structural Factors Related to Stigma    | Statements about structural challenges PLWH face in influencing stigma and access to cancer-related care. | <p><b>Resource Challenges</b> “When they say the word [Referral Hospital], fear takes over you because the transport money alone is a lot. You just decide and you choose to die, you just surrender to die though you need to try and go to the hospital (8).”</p> <p>“There is no diagnostic equipment in the regional referral hospital to detect cancer. Instead one must travel to the referral hospital which is several hundreds of kilometers away for screening and confirmation that they really have cancer (9).”</p> <p><b>Clinic Challenges</b> “Fear of male health workers is a factor. When you reach the hospital and find that a man is going to check you, you will not accept it. For me I refused until a woman came (10).”</p> <p>“We go to different health facilities and the teaching we get varies. There are some clinics where they don’t teach you anything so you only go and get your medicine and go home (11).”</p> <p><b>Cormorbid Conditions</b> “For me I will not want to merge herbal and exotic medications from cancer. I am already on ARVs, I feel it might cause me more illness and complications (12).”</p> |
| Strategies to Reduce Stigma             | Statements about any potential strategies to reduce stigma and improve engagement in care for PLWH.       | <p><b>Strategies to Overcome Perceived Stigma</b> “The most important thing is to sensitize people about stigma and also encourage people to accept and live with their positive status and people will be free (13).”</p> <p><b>Strategies to Overcome Impacts of Stigma</b> “What can really help is that for those of us who are on medication, we need to be free and open with those who are not. That way we will find the needed help and there will be no more barrier, that person will understand the situation (14).”</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |

## PLWH Focus Group Results

**Stigma Presence.** PLWH discussed **Types of Stigma** and **Strategies to Overcome Perceived Stigma**. All focus group participants shared having experienced stigma related to multiple conditions and behaviors, with examples related to HIV stigma, cancer stigma, and

tobacco use stigma being discussed. Social isolation, shame, and low self-worth were mentioned as being byproducts of an HIV diagnosis, and participants detailed continued exclusion from their communities since diagnosis (Table 3, Quote 1). Participants also discussed frequent tobacco use and the use of other substances such as alcohol as being more common among people living with HIV. As referenced by participants, there was a desire to keep both behaviors hidden from others because of the stigma associated with tobacco smell and perceptions of risky behaviors (Table 3, Quote 2). In addition to experiencing stigma related to HIV and tobacco use, participants also shared having felt stigmatized towards cancer diagnoses, reporting that within the PLWH community having cancer was associated with negative perceptions of physical appearance and body odor (Table 3, Quote 3). Participants also referenced inaccurate beliefs of cancer origins within communities and underlined perceptions that being diagnosed with cancer is a result of karma or bewitchment, leading some individuals to seek treatment primarily from spiritual healers instead of trained medical providers (Table 3, Quote 4).

*Impact of Stigma on Cancer-related Care.* Reduced **Engagement in Care** was the major effect of cancer stigma reported by focus group participants. Participants noted hesitation and fear in engaging in cancer care services because of the stigma of cancer diagnoses being an automatic ‘death sentence’ and fears of testing mechanisms (Table 3, Quote 5). Participants noted avoidance of care clinics because of the preference to “die silently” and stated they did not want to reveal their cancer status to community members or partners because of the social isolation they already felt from HIV-related stigma (Table 3, Quote 6,7).

*Structural Factors Related to Stigma.* PLWH identified several structural factors that influence perceptions of stigma and access to cancer services within their communities.

**Resource challenges**, such as the reluctance to travel to cancer referral hospitals for often

unaffordable services, were mentioned by participants as factors that made them hesitant to seek care at HIV clinics (Table 3, Quote 8, 9). **Clinic challenges** were also highlighted specifically by female patients, who expressed discomfort due to the lack of female healthcare workers, particularly for procedures and conversations perceived as invasive and sensitive for women (Table 3, Quote 10). PLWH also voiced concerns about receiving inconsistent education about their conditions across different clinics driving a lack of accurate cancer knowledge and described feeling fatigued by the need to address and treat potentially **co-occurring conditions** like HIV and cancer (Table 3, Quote 11, 12).

*Strategies to Reduce Stigma.* Like HCPs, PLWH offered strategies they felt could be used to reduce experiences of stigma. When discussing types of stigmas, participants mentioned specific **strategies that could be used to overcome perceived stigma**. Frequent strategies offered by PLWH were community empowerment through cancer prevention sensitization campaigns and improved social support through support groups and family-based interventions (Table 3, Quote 13). Participants also explored some key **strategies to overcome impacts of stigma** for PLWH, suggesting increased cancer education within HIV clinics, free screening campaigns, mobile and pop-up clinics, and campaigns led by key community leaders and cancer survivors (Table 3, Quote 14).

## DISCUSSION

Qualitative results indicate intersecting and co-occurring stigmas related to HIV, cancer, and substance use in the study population among both healthcare providers and people living with HIV. Structural barriers highlighted by study participants were also identified as compounding and perpetuating stigma-related experiences, further limiting access to and provision of cancer prevention, treatment, and care services.

The stigma associated with HIV felt by study participants was marked by social alienation and a reluctance to share public spaces or items. The onset of cancer introduced further layers of stigma, including perceptions of physical changes such as altered appearance and unpleasant odors. Stigma intersectionality is common for PLWH, as studies have shown that individuals coinfectd with HIV and tuberculosis perceived more stigma than individuals who had HIV alone<sup>19</sup>. Also seen with cancer diagnosis, a cross-sectional survey of women in rural Kenya found that cancer stigma was highly correlated with HIV stigma<sup>20</sup>. The intersectionality of stigma can potentially exacerbate existing mental health challenges for PLWH and contribute to the use of already stigmatized substances like tobacco, which was seen in our study population. These layered stigmas and psychological burdens can further complicate the already limited access to care and support services in low-resource environments.

Intersectional experiences of stigma varied greatly between males and females. Overwhelmingly, women living with HIV felt more vulnerable to stigma, with female participants sharing fears that a cancer diagnosis would increase the risk of their husbands leaving them. Women living with HIV also emphasized experiencing stigma related to cervical cancer, citing that community members perceive them as being more promiscuous if they have both diseases. This aligns with existing literature on stigma in LMICs, which found that women associate HPV with prostitution and infidelity and believe that a cervical cancer diagnosis would result in blame and rejection by their partner<sup>21</sup>. These issues are particularly concerning given that female FGD participants noted prominent structural barriers contributing to stigma surrounding cervical cancer screening such as a lack of privacy, female providers within the clinics, and independence to seek care in capital cities. These structural barriers not only discourage women from seeking preventive care but also perpetuate stigma by reinforcing social perceptions about seeking care as a female.

As approximately 1 in 5 cervical cancer diagnoses in sub-Saharan Africa are attributed to HIV, stigma poses significant risks and impacts for women in this population <sup>22</sup>.

In addition to experiences, study participants offered insights into some possible drivers of cancer-related stigma. PLWH commonly expressed concerns that being diagnosed with cancer was ultimately a death sentence. This was consistent with other studies measuring attitudes towards cancer diagnosis as being that it is incurable, and all individuals will die of their disease <sup>23</sup>. Structural barriers discussed by study participants likely contribute to this idea that cancer diagnosis is ultimately deadly, as treatment provision and survivability were seen as being rare due to financial and environmental circumstances. Participants also shared community beliefs that bewitchment and karma were the causes of cancer, leading many of them to seek care from traditional healers in place of medical treatment. The lack of knowledge of cancer causes and symptoms was not only brought up by PLWH but also HCPs. KIIs revealed a general lack of education in cancer information and screening practices among healthcare providers, possibly contributing further to misconceptions and misinformation within the community. Other environmental and provider-level drivers of stigma were cited as a lack of availability of cancer-related services, perceptions of treatment being unaffordable, and the absence of private spaces for treatment. These factors further isolate individuals, reinforcing stigmas and hindering access to care in the surveyed HIV clinics and beyond.

Major impacts of stigma identified by study participants included social isolation, avoidance of screening and treatment services, reluctance to disclose information to healthcare providers, and poor mental health outcomes. Both HCPs and PLWH discussed avoidance of care within clinics, indicating that PLWH purposefully did not seek care because of their fears of a deadly diagnosis, exposure of cancer status to community members, and lack of knowledge of

screening procedures. Stigma-related avoidance of screening and treatment contributes to late presentation to care which can significantly impact cancer prognosis, especially for PLWH <sup>24</sup>. Similar patterns have been observed across multiple studies involving women living with HIV who delayed seeking screenings and diagnosis of breast cancer due to fears of social exclusion <sup>25</sup>. Impacts of stigma on mental health were also apparent in our study, with participants experiencing ongoing stigma and feelings of shame and diminished self-worth following their cancer diagnosis. A body of research has linked stigma to depression and anxiety among PLWH, which have been seen to manifest as low motivation to seek and adhere to treatment and increased engagement in maladaptive coping mechanisms such as alcohol misuse and tobacco use <sup>26</sup>.

Study participants expressed a desire for community and individual-level solutions to address the origins and impacts of intersecting stigma faced by PLWH. These included community sensitization and education campaigns, clinic-based training and counseling, and peer support programs. Educational radio programs and media campaigns have been used to promote community awareness and empowerment in many LMICs. When utilized to target stigma reduction, these methods were successful for PLWH in India and Ethiopia, suggesting that they could be a promising strategy for Uganda and Zambia <sup>27</sup>. Such interventions have also been shown to support compassion, improved communication, self-esteem, and confidence, which are important in encouraging care-seeking behaviors among PLWH <sup>28</sup>. Both PLWH and HCPs stressed the importance of having ‘champions’ or leaders of interventions being community members, traditional healers, or religious leaders instead of healthcare providers. A community support initiative in South Africa found that ‘treatment buddy’ models successfully decreased levels of HIV stigma, while stigma increased when a healthcare professional provided the same support <sup>29</sup>.

<sup>30</sup>. While this method has proven to be effective in addressing HIV stigma, it has not been tested widely for other forms of stigma for PLWH such as cancer.

Many PLWH also discussed the importance of having a strong social support network to overcome the impacts of stigma. Whether this is in the form of cancer survivor support groups, peer counseling, or family support, social support successfully cultivates trust and a sense of belonging among certain minority groups, potentially reducing the effects and likelihood of experiencing stigma <sup>31</sup>. Given the complex nature and intersections of stigma within these communities, it is unlikely that one intervention alone will have a meaningful impact. Interventions should address structural barriers and integrate into existing HIV care programs to manage the multidimensional mechanisms through which stigma influences engagement in cancer treatment and care services.

Future research is also important for developing an evidence base for stigma reduction interventions. Based on our qualitative findings, it is evident that stigma influences the health outcomes of PLWH; however, research in this area is limited and often focuses on HIV stigma alone. Other qualitative studies and mixed-methods designs should be prioritized to properly define cultural differences and examine the causal pathways of intersecting stigmas as they relate to cancer prevention and care.

This study not only provides a valuable model for qualitatively researching cancer-related stigma for PLWH in Uganda and Zambia but also offers important insights into closing the cancer prevention and service delivery gap for these populations in SSA. Perspectives and experiences defined by participants should be disseminated widely to cancer researchers, community health workers, and policymakers to improve implementation strategies that reduce stigma and increase access to cancer care for PLWH in LMICs and beyond.

*Study Limitations*

Several study limitations were identified. While the qualitative nature of the research provided a more detailed exploration of the feelings, opinions, and experiences of stigma among people living with HIV and healthcare providers, this approach does not always allow for generalizability and transferability of findings. The study’s sample for KIIs was selective and purposive and may not be representative of the views of all HCPs holding other staff positions within the HIV clinics. As the information presented by key informants and focus groups was self-reported, data from this study may be subject to recall bias. Focus group discussions also contained information that participants may have found to be culturally sensitive or controversial, increasing the likelihood of social desirability bias. To mitigate social desirability and recall bias, FGDs took place in private locations, and moderators were encouraged to establish respectful rapport with participants allowing participants to share truthful and thoughtful insights. Additionally, the FGDs had a higher number of male participants when compared to females. This may be attributed to stigma targeted towards females; and could have potentially resulted in the exclusion of key gender-specific narratives from the larger female study population. The sample size for both KIIs and FGDs was also small, raising concerns of applicability beyond the study setting. While study results may not be generalizable to all low and middle-income countries, they do provide information on what is likely the cancer care environment in most parts of Uganda and Zambia. These findings can ultimately complement quantitative findings being collected, allowing for a comprehensive understanding of the impacts of stigma on cancer care and prevention among PLWH.

*Conclusions*

This study explored qualitative data on intersecting stigmas, associated barriers to providing or accessing care, and methods to reduce stigma and improve access to interventions and treatment services among PLWH. Study results highlight the impacts of stigma on cancer prevention and treatment for PLWH in Uganda and Zambia. Further research is needed to explore the intersections of stigma and its effects on health-seeking behaviors among PLWH, informing the development of future interventions in LMICs and beyond.



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3 authors contributed to and have approved the final manuscript, and HW is responsible for the  
4 overall content as guarantor.  
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# BMJ Open

## Understanding stigma as a barrier to cancer prevention and treatment: a qualitative study among people living with HIV in Uganda and Zambia

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## Understanding stigma as a barrier to cancer prevention and treatment: a qualitative study among people living with HIV in Uganda and Zambia

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- The study's qualitative design, limited sample size and purposive sampling methods may limit the generalizability of findings beyond the study setting; however, the results are likely relevant to similar healthcare settings in sub-Saharan Africa and will be complemented further by future quantitative findings.

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Operating across multiple levels including interpersonal, intrapersonal, and structural, stigma has been linked to lower uptake of disease screenings, poor adherence to care, and limited social support for multiple conditions, including cancer<sup>11</sup>. Extensive research has been carried out on the impacts of HIV stigma as a barrier to HIV prevention, testing, and care. In SSA, HIV stigma and shame often originate from cultural stereotypes and many cancer patients have reported believing that their diagnosis is a punishment for immoral behavior, is contagious, or is fatal<sup>12</sup>. Far less research has focused specifically on the effects of cancer stigma within PLWH communities where services are already limited<sup>13</sup>. Additional research to understand the extent and effects of cancer and other intersecting stigmas within this population is essential for the development of culturally sensitive interventions that promote adherence to cancer preventive treatments.

We approach this gap in research with a one-year study examining experiences of cancer stigma and their potential impacts on access to and utilization of cancer prevention, screening, and care services among PLWH populations in Uganda and Zambia. The evaluation involves both formative focus group discussions and quantitative survey data collected from HIV clinics within two remote districts of Uganda and two districts of Zambia. This paper presents results from the formative phase of this project, which consisted of focus group discussions (FGDs) conducted with PLWH and key informant interviews (KIIs) with health service workers who provide services to these patients in local HIV clinics. Qualitative data collection was designed to provide an in-depth understanding of how stigma impacts engagement in and access to cancer prevention, treatment, and care services. Focus group discussions and key informant interviews explored the stigmas associated with cancer, possible stereotypes, anticipated forms of discrimination, coping styles, and barriers to accessing cancer prevention interventions and care among PLWH. These findings will complement any associations found through the project's



clinic during the recruitment visit. Past cancer diagnosis was not included as an inclusion or exclusion criterion, allowing for perspectives from both individuals eligible for cancer screening services and those who may have had a previous or current cancer diagnosis. At each clinic, the in charge of the health facility was identified and enlisted to help contact eligible focus group participants.

### *Healthcare Provider (HCP) key informant interviews (KIIs)*

KIIs were conducted with healthcare providers from three to four of the selected clinics serving PLWH in each study district of Uganda and Zambia, resulting in 14 total interviews. The number of interviews conducted in each clinic was selected based on staff availability and participation capacity. The in charge of the health facility helped to identify healthcare providers for interviews. Eligibility criteria for healthcare provider KII participation were: (a) aged 18 years or older; and (b) working in a health services position at the clinic. Compensation in the form of payment for transportation and a meal was provided for FGD and KII participation. Written informed consent was obtained from all participants after the moderator explained the study's aims, benefits, potential risks, and participant rights. The study protocol was approved by the University of Southern California (HS-22-0006), Makerere University (SPH-2021-178), and The University of Zambia (REF.2377-2021) internal review boards.

### ***Data collection***

Two facilitators were present at each focus group and KII: one facilitator moderated the discussion, and another assisted with the notetaking, materials, and logistics. The FGDs and KIIs lasted approximately one hour and were conducted in the local language. Sessions were audio recorded with permission from the participants and then directly transcribed into English. For quality

control, two transcribers read each other's transcripts reviewing content and completeness. Transcribers were proficient in both English and the local language.

*Qualitative measures*

To assure standardization across study countries/sites, discussion guides were used for both FGDs and KIIs. Guides contained thematic discussion questions focused on types, magnitude, and drivers of stigma individually and in the community, impacts on care-seeking behaviors, and structural factors that potentially exacerbate experiences of stigma within the community including access to care among PLWH. Cancer prevention services were defined as available screenings, testing, vaccination, and counseling, while care included available surgeries, chemotherapy, radiotherapy, and immunotherapy treatments to those diagnosed and referred. Before beginning discussions and key informant interviews, participants completed a short, anonymous questionnaire that recorded demographic information including age, gender, marital status, and, when applicable, position within the clinic.

*PLWH FGDs*

Using the focus group discussion guide, participants of the PLWH focus groups were asked questions on topics including their experiences with HIV, basic knowledge of cancer, preferred care options for cancer symptoms (e.g. traditional medicine vs. clinical care), stereotypes and potential stigmatization, perceived relationships between individual behaviors and cancer risk, anticipated discrimination and behavioral coping strategies, and possible approaches to decreasing stigma in the community.

*HCP KIIs*

Healthcare provider interview topics focused on discussions of basic knowledge of cancer, cancer myths, and stigma, perceived barriers to providing cancer-related screenings and care at HIV and non-HIV-focused clinics, and proposed strategies to address these barriers.

### ***Data management and analysis***

Transcripts of the PLWH FGDs and HCP KIIs were reviewed by study personnel. Participants' anonymity was maintained throughout the research process using numbers and confidential data treatment. One research team member developed the first draft of the codebook based on the FGD and KII moderator guides. This draft was expanded during the early stages of coding as additional relevant topics emerged. Specifically, themes focused on each discussion topic area including the presence of stigma, drivers and impacts of stigma across interpersonal, intrapersonal, and structural levels, and potential stigma-reduction strategies. Subthemes were also identified from each key theme. Data were coded after interpretation and analyzed using Dedoose Software V.9.0.54<sup>18</sup>. Qualitative data was initially analyzed manually and separately by two study team investigators. Team members then met to discuss and compare emerging themes, where a third study investigator served as an arbitrator to resolve any coding discrepancies. Through this process, the codebook was finalized (e.g., refining definitions and inclusion/exclusion criteria for coding excerpts into specific themes), and transcripts were brought into 100% agreement. From the analysis, details of each theme and related quotations from the FGD and KIIs are presented to support key findings.

### ***Patient and public involvement***

Clinic patients and community members were not involved in setting the research question or the design of the qualitative study. They will be involved in disseminating baseline information, which will help enhance community involvement in the quantitative part of the study.

## **RESULTS**

**Table 1. Demographic characteristics of focus group discussion participants from HIV clinics in four districts of Uganda and Zambia in 2024**

| Characteristic    | Moroto |       | Arua |       | Mongu |       | Chipata |       |
|-------------------|--------|-------|------|-------|-------|-------|---------|-------|
|                   | n      | %     | n    | %     | n     | %     | n       | %     |
| Gender            |        |       |      |       |       |       |         |       |
| Female            | 6      | 46.1% | 7    | 50%   | 6     | 40%   | 6       | 46.1% |
| Male              | 7      | 53.9% | 7    | 50%   | 9     | 60%   | 7       | 53.9% |
| Marital status    |        |       |      |       |       |       |         |       |
| Single            | 0      | 0.0   | 1    | 7.1%  | 3     | 20%   | 2       | 15.4% |
| Married/partnered | 11     | 84.6% | 6    | 42.9% | 7     | 46.7% | 7       | 53.9% |
| Divorced/widowed  | 2      | 15.4% | 7    | 50%   | 5     | 33.3% | 4       | 30.8% |
| Employment        |        |       |      |       |       |       |         |       |
| Unemployed        | 9      | 69.2% | 12   | 85.7% | 1     | 6.7%  | 7       | 53.9% |
| Employed          | 4      | 30.8% | 2    | 14.3% | 14    | 93.3% | 6       | 46.1% |
| Average Age       |        |       |      |       |       |       |         |       |
| Female            | 46.5   |       | 44.4 |       | 47    |       | 41.5    |       |
| Male              | 43.3   |       | 40   |       | 43.8  |       | 43.1    |       |

**Participant demographic characteristics**

Focus group discussions included 55 respondents total, with average ages between 40 and 47 years. There were more male participants than females in most of the study districts. In all districts, most respondents were married and unemployed. Arua district in Uganda had the highest number of unemployed participants (85.7%) (Table 1).

A total of 14 key informant interviews were conducted and included nurses (n=9), midwives (n=1), and nursing officers (n=4). Across the study districts, three interviews were completed at Arua and Moroto clinics (n=3) and four at Mongu and Chipata clinics (n=4). KII participants were primarily females (78%) with an average age of 41.

**Table 2. People living with HIV focus group themes, description of themes, and example quotes from HIV clinics in four districts of Uganda and Zambia in 2024**

| Theme | Definition | Subthemes and Example Quotes |
|-------|------------|------------------------------|
|-------|------------|------------------------------|

|                                         |                                                                                                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|-----------------------------------------|-----------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Stigma Presence                         | Statements about any instances or experiences of stigma.                                                  | <p><b>HIV Stigma</b> “They don’t allow you to enter the toilet because you will leave AIDs there, they don’t allow you to move for even a meter. When you go to the market they will say see AIDs moving around see how AIDs looks, that is how we are described in the community (1).”</p> <p>“For me it was my movements that caused me to get HIV, that’s why I am here it was my fault (2).”</p> <p>“You lose interest in being alive (3).”</p> <p><b>Tobacco Stigma</b> “We also experience tobacco stigma because we know that people do not like the odor that comes off us (4).”</p> <p>“It is worse [tobacco stigma] in public when people segregate you and you feel shy and stigmatized (5).”</p> <p><b>Cancer Stigma</b> “For people who discover they have cancer, it is a big problem. They say you could be with a colleague who has cancer and you would smell a certain scent even if that person has bathed (6).”</p> <p>“The traditional healer will tell you that you are being bewitched (7).”</p> <p>“It is better to avoid the hospital care (8).”</p>                                                                                  |
| Impact of Stigma on Cancer-related Care | Statements about how stigma has impacted any engagement in cancer care for PLWH.                          | <p><b>Engagement in Care</b> “What they say in the community is that cancer is the worst sickness in the whole world and it leads to death. This now brings fear. The fear is too much that they don’t go for a check-up because if they are diagnosed with cancer they might just die (9).”</p> <p>“Some of us have girlfriends here so we fear to come for treatment because we don’t want them to see or know we are HIV+. Then let’s say we have also been diagnosed with cancer! It is better if you die silently (10).”</p> <p>“I have fear of the testing mechanism for cancer. I wish they could only use blood to test for cancer instead of having to inconvenience someone by tough ways of collecting the sample for testing like cervical cancer screening (11).”</p>                                                                                                                                                                                                                                                                                                                                                                             |
| Structural Factors Related to Stigma    | Statements about structural challenges PLWH face in influencing stigma and access to cancer-related care. | <p><b>Resource Challenges</b> “When they say the word [Referral Hospital], fear takes over you because the transportation money alone is a lot. You just decide and you choose to die, you just surrender to die though you need to try and go to the hospital (12).”</p> <p>“There is no diagnostic equipment in the regional referral hospital to detect cancer. Instead one must travel to the referral hospital which is several hundreds of kilometers away for screening and confirmation that they really have cancer (13).”</p> <p><b>Clinic Challenges</b> “Fear of male health workers is a factor. When you reach the hospital and find that a man is going to check you, you will not accept it. For me I refused until a woman came (14).”</p> <p>“We go to different health facilities and the teaching we get varies. There are some clinics where they don’t teach you anything so you only go and get your medicine and go home (15).”</p> <p><b>Comorbid Conditions</b> “For me I will not want to merge herbal and exotic medications from cancer. I am already on ARVs, I feel it might cause me more illness and complications (16).”</p> |
| Strategies to Reduce Stigma             | Statements about any potential strategies to reduce stigma and improve engagement in care for PLWH.       | <p><b>Strategies to Overcome Perceived Stigma</b> “The most important thing is to sensitize people about stigma and also encourage people to accept and live with their positive status and people will be free (17).”</p> <p><b>Strategies to Overcome Impacts of Stigma</b> “What can really help is that for those of us who are on medication, we need to be free and open with those who are not. That way we will find the needed help and there will be no more barrier, that person will understand the situation (18).”</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |

### PLWH focus group results

For FGD results, one hundred and forty-three individual excerpts were identified with themes and subthemes from the same topic areas as the KIIs (Table 2).

*Stigma presence*

PLWH focus group participants shared having experienced stigma related to multiple conditions and behaviors, with examples related to HIV stigma, cancer stigma, and tobacco use stigma being discussed.

*HIV stigma*

Social isolation, shame, and low self-worth were mentioned as being byproducts of an HIV diagnosis, and participants detailed continued exclusion from their communities since diagnosis. One participant shared that after their HIV diagnosis, they were often excluded from public areas, including restrooms and marketplaces (Table 2, Quote 1). They perceived this was due to community members not wanting to socialize with PLWH. For some, HIV status was a source of shame. For example, one participant described feeling responsible for their diagnosis (Table 2, Quote 2). Low self-worth was also expressed by several participants, with some stating that once you are diagnosed with HIV, there is no more motivation to be alive (Table 2, Quote 3).

*Tobacco stigma*

Participants also discussed frequent tobacco use and the use of other substances, such as alcohol, as being more common among people living with HIV. As referenced by participants, there was a desire to keep both behaviors hidden from others. One participant described wanting to conceal their use because of the stigma associated with tobacco smell (Table 2, Quote 4). Another participant described the community perceptions of the risky behaviors, saying that they are often segregated from social events if they are tobacco users (Table 2, Quote 5).

*Cancer stigma*

In addition to experiencing stigma related to HIV and tobacco use, participants also shared having felt stigmatized towards cancer diagnoses, reporting that within the PLWH community, having cancer was associated with negative perceptions of physical appearance and body odor (Table 2, Quote 6). Participants also referenced inaccurate beliefs of cancer origins within communities and underlined perceptions that being diagnosed with cancer is a result of karma or bewitchment (Table 2, Quote 7). These beliefs led some individuals to seek treatment primarily from spiritual healers and avoid trained medical providers in hospital settings (Table 2, Quote 8).

#### *Impact of stigma on cancer-related care*

Reduced engagement in care was the major effect of cancer stigma reported by focus group participants. Participants noted hesitation and fear in engaging in cancer care services because of the stigma of cancer diagnoses being an automatic ‘death sentence’ and fears of testing mechanisms (Table 2, Quote 9). Participants noted avoidance of care clinics because of the preference to “die silently”, stating they did not want to reveal their cancer status to community members or partners because of the social isolation they already felt from HIV-related stigma (Table 2, Quote 10,11).

#### *Structural factors related to stigma*

PLWH identified several structural factors that influence perceptions of stigma and access to cancer services within their communities. Resource challenges, such as the reluctance to travel to cancer referral hospitals for often unaffordable services, were mentioned by participants as factors that made them hesitant to seek care at HIV clinics (Table 2, Quote 12, 13). Clinic challenges were also highlighted specifically by female patients, who expressed discomfort due to the lack of female healthcare workers, particularly for procedures and conversations perceived as invasive and sensitive for women (Table 2, Quote 14). PLWH also voiced concerns about

receiving inconsistent education about their conditions across different clinics. They shared that they believed this drives a lack of accurate cancer knowledge and described feeling fatigued by the need to address and treat potentially co-occurring conditions like HIV and cancer (Table 2, Quote 15, 16).

Strategies to reduce stigma

Like HCPs, PLWH offered strategies they felt could be used to reduce experiences of stigma. When discussing types of stigmas, participants mentioned specific strategies that could be used to overcome perceived stigma. Frequent strategies offered by PWLH were community empowerment through cancer prevention sensitization campaigns and improved social support through support groups and family-based interventions (Table 2, Quote 17). Participants also explored key strategies to overcome the impacts of stigma for PLWH, suggesting increased cancer education within HIV clinics, free screening campaigns, mobile and pop-up clinics, and campaigns led by key community leaders and cancer survivors (Table 2, Quote 18).

Table 3. Healthcare provider key informant interview themes, description of themes, and example quotes from HIV clinics in four districts of Uganda and Zambia in 2024

| Theme                                   | Description                                                                          | Subthemes and Example Quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|-----------------------------------------|--------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Stigma Presence                         | Statements about any personal stigma or observed stigma by HCP within their clinics. | <b>Observed Stigma</b> “It is HIV stigma, some of the clients come out of the ART clinic and hide their face, they wear caps or glasses and are unsettled (1).”<br><br>“Most of the smokers will tell you that you [The Health Worker] are the only one who knows that they smoke (2).”<br><br><b>Personal Stigma</b> “Maybe they were educated on cancer sometime back. So they try to remember the signs and symptoms of cancer and can say the wrong thing creating confusion for patients (3).”<br><br>“There is a perception that a female client that has cervical cancer is seen as promiscuous, they use words like those on ART are promiscuous people (4).” |
| Impact of Stigma on Cancer-related Care | Statements about any impacts of stigma on care within their clinics.                 | <b>Provision of Care</b> “They are afraid, fear of being diagnosed positive with cervical cancer and others speak the level of screening is very uncomfortable. Word has gone out that when you are screened for cervical cancer even if they didn’t have it once they are screened it’s like you have exposed them to the cancer (5).”<br><br>“When health care workers try to talk to women about cancer their fear is that if they are diagnosed maybe their spouse will leave them, so they would rather not know (6).”                                                                                                                                           |
| Structural Factors Related to Stigma    | Statements about any structural barriers faced                                       | <b>Lack of Resources</b> “Many people are diagnosed at a later stage: you’ll find that you are unable to give them adequate services because you do not have that level for management of advanced cases of cancer (7).”                                                                                                                                                                                                                                                                                                                                                                                                                                              |

|                             |                                                                                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|-----------------------------|-------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                             | by HCP that potentially influence stigma and ability to provide cancer-related care to PLWH within their clinics. | <p><b>Referrals</b> “To a smaller extent, this is because the clients fear the fact that if they are tested, the results may turn to be positive. Generally if it is advanced, they don’t have ways of getting help since we refer them to Mulago (8).”</p> <p><b>Ethical Challenges</b> “There is no privacy for our clients to conduct the screening or discussion. With privacy the patient may become open now to reveal everything and are able to tell the health personnel (9).”</p> <p><b>Limited Training/Education</b> “There are knowledge gaps among health workers where all workers are not trained on how to screen for cancer. However much we take histories and see some signs and symptoms, it is difficult to screen a patient for cancer when you don’t know how (10).”</p> |
| Strategies to Reduce Stigma | Statements about any potential strategies to reduce stigma and improve engagement in care for PLWH.               | <p><b>Strategies to Help PLWH Overcome or Cope with Stigma</b> “I think on the increase of motivating them, maybe not calling only health workers to do some things. Selecting some HIV positive clients to have a workshop, maybe teaching them how they can sensitize in the community. The type of counseling should be tailored (11).”</p> <p><b>Strategies to Improve Engagement in Care</b> “We can do radio programs, community engagement, and engage community leaders (12).”</p> <p>“We can use expert clients who have gone through cancer screening to encourage the rest to participate in services (13).”</p>                                                                                                                                                                      |

### *HCP key informant interview results*

For KIIs, one hundred and seventy-two individual excerpts were identified and coded into themes and subthemes related to chosen topic areas (Table 3): stigma presence, impacts of stigma on cancer-related care, structural factors related to stigma, and strategies to reduce stigma.

#### *Stigma presence*

Healthcare providers frequently discussed the presence of perceived stigma both in terms of personal stigmas they may hold and the stigma they observed within treatment clinics or the surrounding community.

#### *Observed stigma*

As observed in the communities, HCPs reported witnessing various types of stigmas related to co-occurring conditions and behaviors, including HIV status and tobacco use. According to HCPs, HIV stigma was common within clinics, with patients often attempting to conceal their HIV status because of stigma, sometimes by wearing caps and glasses to avoid recognition by

others (Table 3, Quote 1). Tobacco use was also frequently hidden by patients. Many smokers told their healthcare providers that they were the only ones aware of their smoking habits because of the stigmatization of the behavior (Table 3, Quote 2).

*Personal stigma*

In addition to observing stigmatization within clinics and the surrounding communities, some HCPs held personal beliefs that contributed to stigma. Certain HCPs noted that their training on health topics like cancer prevention occurred long ago, sometimes leading them to potentially share inaccurate information with patients, which may reinforce existing stigma and stereotypes within clinics (Table 3, Quote 3). HCPs also exhibited personal stigma towards female patients, at times associating cervical cancer diagnoses or ART use with promiscuity (Table 3, Quote 4)."

*Impact of stigma on cancer-related care*

From the HCP perspective, the most frequently discussed impact of stigma on cancer-related care was the decreased provision of care among PLWH. HCPs reported that PLWH often avoid cervical cancer screenings due to the stigmatized belief that undergoing screening could lead to a terminal cancer diagnosis. There was a shared understanding among HCPs that the fear of screening procedures, including the risk of getting cancer from the procedure, within clinics deters many individuals from seeking care (Table 3, Quote 5). Some HCPs also noted conversations with female clients who expressed reluctance to undergo cervical and breast screenings. These women feared that a positive result might lead their spouses to leave them because of the social stigma of promiscuity associated with the cancers (Table 3, Quote 6).

*Structural factors related to stigma*

HCPs identified several structural factors contributing to the stigma surrounding cancer care and hindering their ability to provide services to PLWH within their clinics. The most prominent

factor was a lack of resources and equipment for cancer screening, diagnosis, and treatment. As described by HCPs, referrals to central cities because of an absence of localized cancer care service options result in late-stage cancer diagnosis, which not only reduces treatment success but also perpetuates cancer stigma through fear of diagnosis (Table 3, Quote 7,8). HCPs also shared ethical challenges in providing care without private spaces in clinics. HCPs highlighted that the absence of privacy and confidentiality during consultations prevents patients from openly discussing health concerns, seeking care, or receiving potentially stigma-reducing counseling and advice. (Table 3, Quote 9). Finally, HCPs noted the limited training and education for healthcare providers as a significant structural challenge. These gaps in knowledge were cited as resulting in difficulties in providing quality care and addressing stigma and beliefs related to cancer for patients in their clinics (Table 3, Quote 10).

### *Strategies to reduce stigma*

In addition to stigma experiences and related structural factors, HCPs emphasized possible stigma reduction and care engagement strategies for PLWH in healthcare settings and surrounding communities. From the HCP perspective, possible strategies identified to help PLWH overcome or cope with stigma were training for HCPs in delivering tailored education for certain PWLH populations like tobacco users, sensitization workshops led by PLWH as opposed to health care workers, and peer support programming (Table 3, Quote 11). HCPs also emphasized strategies to encourage and improve overall engagement in care for PLWH. Community cancer awareness campaigns such as radio shows with community leaders were a priority for HCPs. HCPs acknowledged the importance of encouraging expert clients who have undergone screenings to sensitize community members and act as ambassadors for cancer prevention (Table 3, Quote 12,13).

DISCUSSION

Qualitative results indicate intersecting and co-occurring stigmas related to HIV, cancer, and substance use in the study population among both healthcare providers and people living with HIV. Structural barriers highlighted by study participants were also identified as compounding and perpetuating stigma-related experiences, further limiting access to and provision of cancer prevention, treatment, and care services.

The stigma associated with HIV felt by study participants was marked by social alienation and a reluctance to share public spaces or items. The onset of cancer introduced further layers of stigma, including perceptions of physical changes such as altered appearance and unpleasant odors. Stigma intersectionality is common for PLWH, as studies have shown that individuals coinfectd with HIV and tuberculosis perceived more stigma than individuals who had HIV alone<sup>19</sup>. Also seen with cancer diagnosis, a cross-sectional survey of women in rural Kenya found that cancer stigma was highly correlated with HIV stigma<sup>20</sup>. The intersectionality of stigma can potentially exacerbate existing mental health challenges for PLWH and contribute to the use of already stigmatized substances like tobacco, which was seen in our study population. These layered stigmas and psychological burdens can further complicate the already limited access to care and support services in low-resource environments.

Intersectional experiences of stigma varied greatly between males and females. Overwhelmingly, women living with HIV felt more vulnerable to stigma, with female participants sharing fears that a cancer diagnosis would increase the risk of their husbands leaving them. Women living with HIV also emphasized experiencing stigma related to cervical cancer, citing that community members perceive them as being more promiscuous if they have both diseases. This aligns with existing literature on stigma in LMICs, which found that women associate HPV

with prostitution and infidelity and believe that a cervical cancer diagnosis would result in blame and rejection by their partner <sup>21</sup>. These issues are particularly concerning given that female FGD participants noted prominent structural barriers contributing to stigma surrounding cervical cancer screening such as a lack of privacy, female providers within the clinics, and independence to seek care in capital cities. These structural barriers not only discourage women from seeking preventive care but also perpetuate stigma by reinforcing social perceptions about seeking care as a female. As approximately one in five cervical cancer diagnoses in sub-Saharan Africa are attributed to HIV, stigma poses significant risks and impacts for women in this population <sup>22</sup>.

In addition to experiences, study participants offered insights into some possible drivers of cancer-related stigma. PLWH commonly expressed concerns that being diagnosed with cancer was ultimately a death sentence. This was consistent with other studies measuring attitudes towards cancer diagnosis as being incurable and all individuals will die of their disease <sup>23</sup>. Structural barriers discussed by study participants likely contribute to this idea that cancer diagnosis is ultimately deadly, as treatment provision and survivability were seen as being rare due to financial and environmental circumstances. Participants also shared community beliefs that bewitchment and karma were the causes of cancer, leading many of them to seek care from traditional healers in place of medical treatment. The lack of knowledge of cancer causes and symptoms was not only brought up by PLWH but also HCPs. KIIs revealed a general lack of education in cancer information and screening practices among healthcare providers, possibly contributing further to misconceptions and misinformation within the community. Other environmental and provider-level drivers of stigma were cited as a lack of availability of cancer-related services, perceptions of treatment being unaffordable, and the absence of private spaces for

treatment. These factors further isolate individuals, reinforcing stigmas and hindering access to care in the surveyed HIV clinics and beyond.

Major impacts of stigma identified by study participants included social isolation, avoidance of screening and treatment services, reluctance to disclose information to healthcare providers, and poor mental health outcomes. Both HCPs and PLWH discussed avoidance of care within clinics, indicating that PLWH purposefully did not seek care because of their fears of a deadly diagnosis, exposure of cancer status to community members, and lack of knowledge of screening procedures. Stigma-related avoidance of screening and treatment contributes to late presentation to care, which can significantly impact cancer prognosis, especially for PLWH <sup>24</sup>. Similar patterns have been observed across multiple studies involving women living with HIV who delayed seeking screenings and diagnosis of breast cancer due to fears of social exclusion <sup>25</sup>. Impacts of stigma on mental health were also apparent in our study, with participants experiencing ongoing stigma and feelings of shame and diminished self-worth following their cancer diagnosis. A body of research has linked stigma to depression and anxiety among PLWH, which have been seen to manifest as low motivation to seek and adhere to treatment and increased engagement in maladaptive coping mechanisms such as alcohol misuse and tobacco use <sup>26</sup>.

Study participants expressed a desire for community and individual-level solutions to address the origins and impacts of intersecting stigma faced by PLWH. These included community sensitization and education campaigns, clinic-based training and counseling, and peer support programs. Educational radio programs and media campaigns have been used to promote community awareness and empowerment in many LMICs. When utilized to target stigma reduction, these methods were successful for PLWH in India and Ethiopia, suggesting that they could be a promising strategy for Uganda and Zambia <sup>27</sup>. Such interventions have also been shown

to support compassion, improved communication, self-esteem, and confidence, which are important in encouraging care-seeking behaviors among PLWH<sup>28</sup>. Both PLWH and HCPs stressed the importance of having ‘champions’ or leaders of interventions who are community members, traditional healers, or religious leaders instead of healthcare providers. A community support initiative in South Africa found that ‘treatment buddy’ models successfully decreased levels of HIV stigma, while stigma increased when a healthcare professional provided the same support<sup>29-30</sup>. While this method has proven to be effective in addressing HIV stigma, it has not been tested widely for other forms of stigma for PLWH such as cancer.

Many PLWH also discussed the importance of having a strong social support network to overcome the impacts of stigma. Whether this is in the form of cancer survivor support groups, peer counseling, or family support, social support successfully cultivates trust and a sense of belonging among certain minority groups, potentially reducing the effects and likelihood of experiencing stigma<sup>31</sup>. Given the complex nature and intersections of stigma within these communities, it is unlikely that one intervention alone will have a meaningful impact. Interventions should address structural barriers and integrate into existing HIV care programs to manage the multidimensional mechanisms through which stigma influences engagement in cancer treatment and care services.

Future research is also important for developing an evidence base for stigma reduction interventions. Based on our qualitative findings, it is evident that stigma influences the health outcomes of PLWH; however, research in this area is limited and often focuses on HIV stigma alone. Other qualitative studies and mixed-methods designs should be prioritized to properly define cultural differences and examine the causal pathways of intersecting stigmas as they relate to cancer prevention and care.

This study not only provides a valuable model for qualitatively researching cancer-related stigma for PLWH in Uganda and Zambia but also offers important insights into closing the cancer prevention and service delivery gap for these populations in SSA. Perspectives and experiences defined by participants should be disseminated widely to cancer researchers, community health workers, and policymakers to improve implementation strategies that reduce stigma and increase access to cancer care for PLWH in LMICs and beyond.

Several study limitations were identified. While the qualitative nature of the research provided a more detailed exploration of the feelings, opinions, and experiences of stigma among people living with HIV and healthcare providers, this approach does not always allow for the generalizability and transferability of findings. The study’s sample for KIIs was selective and purposive and may not be representative of the views of all HCPs holding other staff positions within the HIV clinics. As the information presented by key informants and focus groups was self-reported, data from this study may be subject to recall bias. Focus group discussions also contained information that participants may have found to be culturally sensitive or controversial, increasing the likelihood of social desirability bias. To mitigate social desirability and recall bias, FGDs took place in private locations, and moderators were encouraged to establish respectful rapport with participants, allowing participants to share truthful and thoughtful insights. Additionally, the FGDs had a higher number of male participants than females. This may be attributed to stigma targeted towards females and could have potentially resulted in the exclusion of key gender-specific narratives from the larger female study population. The sample size for both KIIs and FGDs was also small, raising concerns of applicability beyond the study setting. While study results may not be generalizable to all low and middle-income countries, they do provide information on what is likely the cancer care environment in most parts of Uganda and Zambia. These findings can

ultimately complement the quantitative findings being collected, allowing for a comprehensive understanding of the impacts of stigma on cancer care and prevention among PLWH.

## CONCLUSIONS

This study explored qualitative data on intersecting stigmas, associated barriers to providing or accessing care, and methods to reduce stigma and improve access to interventions and treatment services among PLWH. Study results highlight the impacts of stigma on cancer prevention and treatment for PLWH in Uganda and Zambia. Further research is needed to explore the intersections of stigma and its effects on health-seeking behaviors among PLWH, informing the development of future interventions in LMICs and beyond.



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