BMJ Open

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

Kyra Guy ,[1] Jim Arinaitwe,[2] Fastone Mathew Goma,[3] Lynn Atuyambe,[2] David Guwatudde,[2] Cosmas Zyambo ,[3] Ronald Kusolo,[2] Musawa Mukupa,[3] Ezekiel Musasizi,[2] Heather Wipfli[1]

**To cite:** Guy K, Arinaitwe J, Goma FM, *et al*. Understanding stigma as a barrier to cancer prevention and treatment: a qualitative study among people living with HIV in Uganda and Zambia. *BMJ Open* 2025;**15**:e090817. doi:10.1136/bmjopen-2024-090817

► Prepublication history for this paper is available online. To view these files, please visit the journal online (https://doi.org/10.1136/bmjopen-2024-090817).

Received 04 July 2024
Accepted 26 February 2025

[1]University of Southern California Keck School of Medicine, Los Angeles, California, USA
[2]Makerere University School of Public Health, Kampala, Uganda
[3]University of Zambia School of Medicine, Lusaka, Zambia

**Correspondence to**
Dr Heather Wipfli;
hwipfli@usc.edu

## ABSTRACT

**Objectives** 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 behaviours and care, little is known about the intersections of cancer and HIV stigma and the effects on prevention and care behaviours for both conditions. This study aims to examine experiences and drivers of cancer stigma and their associations with access to and utilisation of cancer prevention services among PLWH.

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

**Setting** Data were 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 antiretroviral therapy 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 stigmatising conditions and behaviours 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 behaviours 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 counselling, and peer support.

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

**Trial registration number** This article is linked to an ongoing clinical trial registered on clinical trials.gov (clinical trial No: NCT05487807; Registration date: 27 November 2023) and relates to the pre-results stage.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Qualitative study methods offer unique perspectives from both people living with HIV (PLWH) 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 qualitative design, limited sample size and purposive sampling methods may limit the generalisability 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

AIDS-related morbidity and mortality among people living with HIV (PLWH) have decreased with the introduction of combination antiretroviral therapy (ART).[1] 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.[2] The now-ageing PLWH population is at an increased risk of other comorbidities, including cancer.[3] In part due to HIV-related immunosuppression, PLWH are more likely to receive cancer diagnoses when compared with the general population.[4]

While this has traditionally been true of AIDS-defining malignancies like Kaposi sarcoma, aggressive B-cell non-Hodgkin's 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.[5 6] This elevated risk is partially attributed to known behavioural risk factors among some PLWH, such as poor diet, low physical activity and higher use of tobacco, alcohol and other substances.[7] PLWH face not only a higher risk of being diagnosed with both AIDS-defining and NADCs because of these factors but also a greater likelihood of dying from those cancers when compared with people without HIV of the same age.[8]

The intersection of HIV and cancer presents a particularly complex health challenge in low-income and middle-income countries (LMICs) in SSA, where the prevalence of both conditions is substantial and cancer treatment capacity is limited.[9] 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 available treatment, and the presence of cancer-related stigma.[10] Stigma is being increasingly recognised as a significant determinant of health among PLWH. 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.[11] 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 behaviour, is contagious, or is fatal.[12] Far less research has focused specifically on the effects of cancer stigma within PLWH communities where services are already limited.[13] 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 1-year study examining experiences of cancer stigma and their potential impacts on access to and utilisation of cancer prevention, screening and care services among PLWH populations in Uganda and Zambia. The evaluation involves both formative focus group discussions (FGDs) 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 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. FGDs and KIIs 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 1 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 sociocultural ties.[14–16] 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.[17] 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

PLWH were recruited to participate in FGDs 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. A 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 person in charge of the health facility was identified and enlisted to help contact eligible focus group participants.

#### Healthcare provider KIIs

KIIs were conducted with healthcare providers (HCPs) from 3 to 4 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 person in charge of the health facility helped to identify HCPs for interviews. Eligibility criteria for HCP 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.

## 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 1 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 standardisation 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 behaviours, 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 counselling, while care included available surgeries, chemotherapy, radiotherapy, and immunotherapy treatments to those diagnosed and referred. Before beginning discussions and KIIs, 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 FGD 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 (eg, traditional medicine vs clinical care), stereotypes and potential stigmatisation, perceived relationships between individual behaviours and cancer risk, anticipated discrimination and behavioural coping strategies, and possible approaches to decreasing stigma in the community.

### HCP KIIs

HCP 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 analysed using Dedoose Software V.9.0.54.[18] Qualitative data were initially analysed 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 finalised (eg, 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

## Participant demographic characteristics

FGDs 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 KIIs 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.

## PLWH focus group results

For FGD results, 143 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 behaviours, 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

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

| | Moroto | | Arua | | Mongu | | Chipata | |
|---|---|---|---|---|---|---|---|---|
| **Characteristic** | **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 | |

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 socialise 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 PLWH. As referenced by participants, there was a desire to keep both behaviours 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 behaviours, 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 stigmatised towards cancer diagnoses, reporting that within the PLWH community, having cancer was associated with negative perceptions of physical appearance and body odour (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, quotes 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, quotes 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, quotes 15, 16).

**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. | **HIV Stigma** *"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)."*<br>*"For me it was my movements that caused me to get HIV, that's why I am here it was my fault (2)."*<br>*"You lose interest in being alive (3)."*<br>**Tobacco Stigma***"We also experience tobacco stigma because we know that people do not like the odor that comes off us (4)."*<br>*"It is worse [tobacco stigma] in public when people segregate you and you feel shy and stigmatized (5)."*<br>**Cancer Stigma***"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)."*<br>*"The traditional healer will tell you that you are being bewitched (7)."*<br>*"It is better to avoid the hospital care (8)."* |
| Impact of stigma on cancer-related care | Statements about how stigma has impacted any engagement in cancer care for PLWH. | **Engagement in Care** *"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)."*<br>*"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)."*<br>*"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)."* |
| Structural factors related to stigma | Statements about structural challenges PLWH face in influencing stigma and access to cancer-related care. | **Resource Challenges***"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 (12)."*<br>*"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)."*<br>**Clinic Challenges***"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)."*<br>*"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)."*<br>**Comorbid Conditions** *"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)."* |
| Strategies to reduce stigma | Statements about any potential strategies to reduce stigma and improve engagement in care for PLWH. | **Strategies to Overcome Perceived Stigma***"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)."*<br>**Strategies to Overcome Impacts of Stigma***"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)."* |

PLWH, people living with HIV.

### 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 sensitisation 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).

## HCP KII results

For KIIs, 172 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

HCPs 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 behaviours, 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 HCPs that they were the only ones aware of their smoking habits because of the stigmatisation of the behaviour (table 3, quote 2).

**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. | **Observed Stigma** *"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>*"Most of the smokers will tell you that you [The Health Worker] are the only one who knows that they smoke (2)."*<br>**Personal Stigma** *"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>*"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. | **Provision of Care** *"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>*"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 by HCP that potentially influence stigma and ability to provide cancer-related care to PLWH within their clinics. | **Lack of Resources***"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)."*<br>**Referrals***"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)."*<br>**Ethical Challenges***"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)."*<br>**Limited Training/Education** *"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 (10)."* |
| Strategies to reduce stigma | Statements about any potential strategies to reduce stigma and improve engagement in care for PLWH. | **Strategies to Help PLWH Overcome or Cope with Stigma***"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)."*<br>**Strategies to Improve Engagement in Care** *"We can do radio programs, community engagement, and engage community leaders (12)."*<br>*"We can use expert clients who have gone through cancer screening to encourage the rest to participate in services (13)."* |

HCP, healthcare provider; PLWH, people living with HIV.

### Personal stigma

In addition to observing stigmatisation 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 stigmatised 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 localised 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, quotes 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 counselling and advice (table 3, quote 9). Finally, HCPs noted the limited training and education for HCPs 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 emphasised 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, sensitisation workshops led by PLWH as opposed to healthcare workers and peer support programming (table 3, quote 11). HCPs also emphasised 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 sensitise community members and act as ambassadors for cancer prevention (table 3, quotes 12, 13).

## DISCUSSION

Qualitative results indicate intersecting and co-occurring stigmas related to HIV, cancer and substance use in the study population among both HCPs and PLWH. 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 odours. Stigma intersectionality is common for PLWH, as studies have shown that individuals coinfected with HIV and tuberculosis perceived more stigma than individuals who had HIV alone.[19] Also seen with cancer diagnosis, a cross-sectional survey of women in rural Kenya found that cancer stigma was highly correlated with HIV stigma.[20] The intersectionality of stigma can potentially exacerbate existing mental health challenges for PLWH and contribute to the use of already stigmatised 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 emphasised 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.[21] 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 SSA are attributed to HIV, stigma poses significant risks and impacts for women in this population.[22]

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 that all individuals will die of their disease.[23] 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 HCPs, 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 HCPs 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.[24] 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.[25] 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.[26]

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 sensitisation and education campaigns, clinic-based training and counselling and peer support programmes. Educational radio programmes and media campaigns have been used to promote community awareness and empowerment in many LMICs. When used 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.[27] Such interventions have also been shown to support compassion, improved communication, self-esteem and confidence, which are important in encouraging care-seeking behaviours among PLWH.[28] 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 HCPs. 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.[29 30] 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 counselling 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.[31] 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 programmes 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 prioritised 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 policy-makers 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 PLWH and HCPs, this approach does not always allow for the generalisability 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. FGDs 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 generalisable to all LMICs, 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 behaviours among PLWH, informing the development of future interventions in LMICs and beyond.

**X** Heather Wipfli @hwipfli

**Contributors** HW is the PI of the project and has overall responsibility for its execution and is the corresponding author. HW, JA and FMG co-led the design of the study, with DG and RK guiding statistical and analytic issues. KMG and HW wrote the first draft of the manuscript. All authors contributed to and have approved the final manuscript and HW is responsible for the overall content as guarantor.

**Funding** Research reported in this publication was supported by the National Cancer Institute of the National Institutes of Health under Award Number U01CA261624 (PI: HW).

**Disclaimer** The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Not applicable.

**Ethics approval** 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.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available on reasonable request. Deidentified data from this study will be available from the corresponding author on reasonable request 1 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.

**ORCID iDs**

Kyra Guy http://orcid.org/0009-0000-6630-9770
Cosmas Zyambo http://orcid.org/0000-0003-1913-3367

## REFERENCES

1. McGettrick P, Barco EA, Mallon PWG. Healthcare (Basel, Switzerland). *Ageing with HIV* 2018;17.
2. Moyo E, Moyo P, Murewanhema G, *et al*. Key populations and Sub-Saharan Africa's HIV response. *Front Public Health* 2023;11:1079990.
3. Corrigan KL, Wall KC, Bartlett JA, *et al*. Cancer disparities in people with HIV: A systematic review of screening for non-AIDS-defining malignancies. *Cancer* 2019;125:843–53.
4. Rodés B, Cadiñanos J, Esteban-Cantos A, *et al*. Ageing with HIV: Challenges and biomarkers. *EBioMedicine* 2022;77:103896.
5. Mathoma A, Sartorius B, Mahomed S. The Trends and Risk Factors of AIDS-Defining Cancers and Non-AIDS-Defining Cancers in Adults Living with and without HIV: A Narrative Review. *J Cancer Epidemiol* 2024;2024:7588928.
6. Mahale P, Engels EA, Coghill AE, *et al*. Cancer Risk in Older Persons Living With Human Immunodeficiency Virus Infection in the United States. *Clin Infect Dis* 2018;67:50–7.
7. Satre DD, Levine-Hall T, Sterling SA, *et al*. The relationship of smoking and unhealthy alcohol use to the HIV care continuum among people with HIV in an integrated health care system. *Drug Alcohol Depend* 2021;219:S0376-8716(20)30646-3.
8. Chiao EY, Coghill A, Kizub D, *et al*. The effect of non-AIDS-defining cancers on people living with HIV. *Lancet Oncol* 2021;22:e240–53.
9. Chinula L, Moses A, Gopal S. HIV-associated malignancies in sub-Saharan Africa: progress, challenges, and opportunities. *Curr Opin HIV AIDS* 2017;12:89–95.
10. Bray F, Parkin DM, African Cancer Registry Network. Cancer in sub-Saharan Africa in 2020: a review of current estimates of the national burden, data gaps, and future needs. *Lancet Oncol* 2022;23:719–28.
11. Oystacher T, Blasco D, He E, *et al*. Understanding stigma as a barrier to accessing cancer treatment in South Africa: implications for public health campaigns. *Pan Afr Med J* 2018;29:73.
12. Maree JE, Wright SCD. Cervical cancer: does our message promote screening? A pilot study in a South African context. *Eur J Oncol Nurs* 2011;15:118–23.
13. Earnshaw VA, Chaudoir SR. From conceptualizing to measuring HIV stigma: a review of HIV stigma mechanism measures. *AIDS Behav* 2009;13:1160–77.
14. Uganda Bureau of Statistics (UBOS). *Uganda national household survey 2016/2017*. Kampala, Uganda: UBOS, 2018.
15. Uganda Bureau of Statistics (UBOS). *Uganda national household survey 2016/2017*. Kampala, Uganda: UBOS, 2017.
16. Uganda Bureau of Statistics. The National Population and Housing Census 2014 – Area Specific Profile Series (Arua), Kampala, Uganda. 2017.
17. Central Statistics Office. Zambia 2010 Census of Population and Housing: Populations Summary Report. 2012. Available: https://www.zamstats.gov.zm/index.php/publications/category/14-2010
18. SocioCultural Research Consultants. Dedoose Version 9.0.107, cloud application for managing, analyzing, and presenting qualitative and mixed method research data (2023). Los Angeles, CA, Available: www.dedoose.com
19. George LS, Rakesh PS, Vijayakumar K, *et al*. Social stigma associated with TB and HIV/AIDS among Kudumbashree members: A crosssectional study. *J Family Med Prim Care* 2020;9:4062–6.
20. Rosser JI, Njoroge B, Huchko MJ. Cervical Cancer Stigma in Rural Kenya: What Does HIV Have to Do with It? *J Cancer Educ* 2016;31:413–8.
21. Morse RM, Brown J, Gage JC, *et al*. "Easy women get it": Pre-existing stigma associated with HPV and cervical cancer in a low-resource setting prior to implementation of an HPV screen-and-treat program. *Res Sq* 2023.:rs.3.rs-3256535.
22. Castle PE, Einstein MH, Sahasrabuddhe VV. Cervical cancer prevention and control in women living with human immunodeficiency virus. *CA Cancer J Clin* 2021;71:505–26.
23. Watt MH, Suneja G, Zimba C, *et al*. Cancer-Related Stigma in Malawi: Narratives of Cancer Survivors. *JCO Glob Oncol* 2023;9:e2200307.
24. Scott N, Crane M, Lafontaine M, *et al*. Stigma as a barrier to diagnosis of lung cancer: patient and general practitioner perspectives. *Prim Health Care Res Dev* 2015;16:618–22.
25. Suneja G, Kimani SM, Gill H, *et al*. Addressing the Intersectional Stigma of Kaposi Sarcoma and HIV: A Call to Action. *JCO Glob Oncol* 2024;10:e2300264.
26. Ziersch A, Walsh M, Baak M, *et al*. "It is not an acceptable disease": A qualitative study of HIV-related stigma and discrimination and impacts on health and wellbeing for people from ethnically diverse backgrounds in Australia. *BMC Public Health* 2021;21:779.
27. Nambiar D, Ramakrishnan V, Kumar P, *et al*. Knowledge, stigma, and behavioral outcomes among antiretroviral therapy patients exposed to Nalamdana's radio and theater program in Tamil Nadu, India. *AIDS Educ Prev* 2011;23:351–66.
28. Lowther K, Harding R, Simms V, *et al*. Effect of participation in a randomised controlled trial of an integrated palliative care intervention on HIV-associated stigma. *AIDS Care* 2018;30:1180–8.
29. Masquillier C, Wouters E, Mortelmans D, *et al*. The impact of community support initiatives on the stigma experienced by people living with HIV/AIDS in South Africa. *AIDS Behav* 2015;19:214–26.
30. Andersson GZ, Reinius M, Eriksson LE, *et al*. Stigma reduction interventions in people living with HIV to improve health-related quality of life. *Lancet HIV* 2020;7:e129–40.
31. Frost DM, Meyer IH. Minority stress theory: Application, critique, and continued relevance. *Curr Opin Psychol* 2023;51:S2352-250X(23)00024-6.