PEER REVIEW HISTORY

ARTICLE DETAILS

Title (Provisional)

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

Authors

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VERSION 1 - REVIEW

Reviewer	**1**
Name	**Montealegre , Jane**
Affiliation	**University of Texas, MD Anderson Cancer Center,**
Date	**22-Oct-2024**
COI	**None**

I was very enthusiastic about this paper. However, I unfortunately have major concerns about the conclusions not being supported by the findings, the outcomes and study population not being clearly defined (i.e, are we talking about PLWH eligible for cancer prevention services or PLWH who also have cancer?), and the clarity of the methods. The Introduction and Discussion are well written and organized around the theme of stigma and intersectionality between cancer and HIV stigma. However, the Methods and Results are disorganized, lack clarity regarding who the data pertain to and what the data measure. I encourage a re-write of these sections following the structure and style of published qualitative studies as a model. The conclusions presented in the Discussion should be supported by data in the Results section, including illustrative quotes that convey the experiences of the participants.

The paper has lots of potential and the authors certainly have valuable data to share with the scientific community. I hope that with a re-write of the Methods and Results they can present a future version of the manuscript that conveys the important findings described in the Discussion.

Major comments:

1. I am confused about the central research question. The Intro indicates that the paper is about cancer and HIV stigma. However, the results presented are broadly about barriers to cancer screening, with somewhat more weight given to stigma within the context of other barriers. I think these are two separate manuscripts: 1) describing barriers to care for PLWH and 2) exploring in-depth the role of HIV and cancer stigma. At this point, the authors have not really delved into the role of stigma in a meaningful way. Many aspects of stigma are often presented in a single sentence, whereas each should be elaborated fully and supported with quotes. For example: “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.” Fear of revealing HIV status: in what way? Why? Fear of revealing cancer status: in what way? Why? Experienced stigma: what are some of the experiences? Who is doing stigmatization? Is there self-stigma too? Another example: This sub-theme included statements related to those experiences within their communities and featured instances of social isolation, shame, and perceptions of appearance.” What were those experiences? How did it affect them? Direct quotes from participants would help build the narrative and provide illustrative examples.

2. I’m unclear as to which population the focus group discussions pertain. Is it PLWH receiving HIV care and eligible for cancer screening services? Or PLWH who have cancer? The Methods suggest the first but some of the results imply that that some already are living with cancer? These two populations are very heterogenous and their specific experiences should be explored separately--- PLWH eligible for cervical cancer screening (but free of cancer/precancer) will have barriers to screening. PLWH who have cancer would inform barriers to cancer treatment.

3. Related to above, cancer care and cancer prevention are used interchangeably yet usually have very different meanings? What cancer care are we talking about? Chemotherapy, radiotherapy for cancer or screening tests like VIA/cytology for cervical cancer screening?

4. The discussion concludes with findings that were never supported in the Results section. E.g., “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.” I didn’t see any results regarding the role of substance abuse by PLWH. Also, intersecting stigma seems to be a main topic to explore but the results don’t really delve into how they intersect. Another example, “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.” Again this was never presented in the Results.

Minor comments:

1. Introduction:

a. HIV as one of the deadliest infectious diseases: not supported by second part of statement and is contrary to other messages in the same paragraph.

b. A blanket statement about having higher prevalence of risk behaviors as the cause of elevated cancer risk is not supported by evidence. Please see: Chiao EY, Coghill A, Kizub D, Fink V, Ndlovu N, Mazul A, Sigel K. The effect of non-AIDS-defining cancers on people living with HIV. Lancet Oncol. 2021 Jun;22(6):e240-e253. doi: 10.1016/S1470-2045(21)00137-6. PMID: 34087151; PMCID: PMC8628366.

2. Methods

a. It seems strange to attract attention to Patient and Public involvement and then say that clinic patient and community members were not involved in the research. This is a limitation.

b. Specify that 55 patients participated in 4 focus group discussions (based on Table 1, assuming that there was 1 FGD per site?)

3. Results

a. Not sure how number of excerpts is relevant. I imagine that the purpose is to quantify the importance and/or frequency of the theme. However, that should be included in the thematic analysis… i.e., the most frequent barriers were x and y, rather than trying to use numeric data to convey frequency.

b. The paragraphs on broad barriers to care doesn't seem to be in line with the focus of the paper, stigma, and should be removed. The word count saved should go into describing the impact of stigma in greater depth. Currently, this is only presented in a very superficial/cursory manner. More attention and word count should be given to elaborating on these topics. Central themes should be supported by direct quotes that illustrate the theme.

4. Discussion

a. Intersectionality of stigma: these conclusions need to be backed by the results.

VERSION 1 - AUTHOR RESPONSE

Reviewer: 1

Comment: I am confused about the central research question. The Intro indicates that the paper is about cancer and HIV stigma. However, the results presented are broadly about barriers to cancer screening, with somewhat more weight given to stigma within the context of other barriers. I think these are two separate manuscripts: 1) describing barriers to care for PLWH and 2) exploring in-depth the role of HIV and cancer stigma. At this point, the authors have not really delved into the role of stigma in a meaningful way. Many aspects of stigma are often presented in a single sentence, whereas each should be elaborated fully and supported with quotes. For example: "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." Fear of revealing HIV status: in what way? Why? Fear of revealing cancer status: in what way? Why? Experienced stigma: what are some of the experiences? Who is doing stigmatization? Is there self-stigma too? Another example: This sub-theme included statements related to those experiences within their communities and featured instances of social isolation, shame, and perceptions of appearance." What were those experiences? How did it affect them? Direct quotes from participants would help build the narrative and provide illustrative examples.

Response: We thank the reviewers for this important and thoughtful comment about the structure and content of the manuscript. We agree that there was confusion in including barriers to accessing and providing cancer-related care for PLWH. We believe that with the overall changes we have made in rewriting our results section and clarifying the themes we included, our manuscript now focuses solely on stigma. We also believe that the rewritten results and associated quotations now support the discussion section and build the narrative by providing illustrative examples.

Comment: I'm unclear as to which population the focus group discussions pertain. Is it PLWH receiving HIV care and eligible for cancer screening services? Or PLWH who have cancer? The Methods suggest the first but some of the results imply that that some already are living with cancer? These two populations are very heterogenous and their specific experiences should be explored separately--- PLWH eligible for cervical cancer screening (but free of cancer/precancer) will have barriers to screening. PLWH who have cancer would inform barriers to cancer treatment.

Response: Thank you for your comment on the study population. The focus group discussion participants were all PLWH who were receiving care at the HIV clinics at the time of the study allowing for a range of unique perspectives. This included both PLWH who were eligible for cancer screening services and those who may have had a previous or current cancer diagnosis. We chose to include both populations as they all receive their primary HIV care and medication from these local clinics and they serve as a point of entry for most healthcare. As the qualitative data collection was a part of a larger quantitative study we wanted to include both of these populations and did not note cancer diagnosis as a part of inclusion/exclusion criteria. A sentence clarifying this has been added to the methods section of the manuscript.

Comment: Related to above, cancer care and cancer prevention are used interchangeably yet usually have very different meanings? What cancer care are we talking about? Chemotherapy, radiotherapy for cancer or screening tests like VIA/cytology for cervical cancer screening?

Response: Thank you for the comment on clarification of what is included in cancer prevention and care. Prevention discussed by participants included available screenings, testing, vaccination, and counseling, while discussion of care aimed to include and was not limited to available surgeries, chemotherapy, radiotherapy, and immunotherapy treatments. In Uganda and Zambia, cancer treatments are only available at central referral cancer hospitals limiting care access for the rural communities included in the study. To make this more clear in the manuscript these definitions have been added to the methods section.

Comment: The discussion concludes with findings that were never supported in the Results section. E.g., "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." I didn't see any results regarding the role of substance abuse by PLWH. Also, intersecting stigma seems to be a main topic to explore but the results don't really delve into how they intersect. Another example, "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." Again this was never presented in the results.

Response: We appreciate the reviewers comments on making the manuscripts discussion section better supported by the study's findings. In order to further highlight the intersectionality of stigma within the study population we have rewritten the results section to better support the discussion. This is detailed further in an additional comment about the discussion section.

Introduction

Comment: HIV as one of the deadliest infectious diseases: not supported by second part of the statement and is contrary to other messages in the same paragraph.

Response: Thank you for pointing this discrepancy out. We agree that this statement is not supported by the second part of the statement and is contrary to other messages in the same paragraph. For clarification, we have edited this statement in the manuscript to read, "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 region2". The citation has also been changed to support data in the new sentence (2).

Comment: A blanket statement about having higher prevalence of risk behaviors as the cause of elevated cancer risk is not supported by evidence. Please see: Chiao EY, Coghill A, Kizub D, Fink V, Ndlovu N, Mazul A, Sigel K. The effect of non-AIDS-defining cancers on people living with HIV. Lancet Oncol. 2021 Jun;22(6):e240-e253. doi: 10.1016/S1470-2045(21)00137-6. PMID: 34087151; PMCID: PMC8628366.

Response: Thank you for pointing this out. To avoid having non-evidence-based claims this statement has been changed in the introduction of the manuscript to reflect information from the provided article. The citation for this sentence has also been updated (8).

Methods

Comment: It seems strange to attract attention to Patient and Public involvement and then say that clinic patients and community members were not involved in the research. This is a limitation.

Response: Thank you for highlighting this section. As it is not necessary to include in the manuscript for submission to BMJ Open, it has been removed for clarity.

Comment: Specify that 55 patients participated in 4 focus group discussions (based on Table 1, assuming that there was 1 FGD per site?)

Response: Thank you for pointing out that this needed to be specified in the results section. For easier understanding, the participants and recruitment section has been edited to reflect that there were 55 participants total in the 8 focus group discussions, two in each study district.

Results

Comment: Not sure how number of excerpts is relevant. I imagine that the purpose is to quantify the importance and/or frequency of the theme. However, that should be included in the thematic analysis… i.e., the most frequent barriers were x and y, rather than trying to use numeric data to convey frequency.

Response: Thank you for bringing this comment to our attention. We had originally included the number of excerpts of each theme to show importance and frequency. While we believe this is important to show in the paper, we agree that it should be emphasized in the thematic analysis instead of using numeric data in a qualitative manuscript. Numbers have been removed from the manuscript results and language has been updated to reflect this change and allow for better interpretation. Additionally, sentences detailing how many excerpts were coded total were moved to the methodology section of the manuscript.

Comment: The paragraphs on broad barriers to care doesn't seem to be in line with the focus of the paper, stigma, and should be removed. The word count saved should go into describing the impact of stigma in greater depth. Currently, this is only presented in a very superficial/cursory manner. More attention and word count should be given to elaborating on these topics. Central themes should be supported by direct quotes that illustrate the theme.

Response: Thank you for the insightful feedback. We agree that a deeper exploration of stigma and its impacts is essential. As authors, we believe that the sections on barriers to care help to provide important context to understanding the scope of challenges and environmental factors faced by PLWH in Uganda and Zambia and how they potentially amplify the experiences of stigma, which may be relevant to other countries in sub-Saharan Africa. While this is true, we recognize the need to maintain a focus on stigma as the central theme. To fix this we have decided to remove the broad barriers section in the results and change it to structural factors related to stigma, removing barriers that do not relate to stigma and emphasizing those that do. This has been reflected for both key informant interviews and focus group discussions.

Discussion

Comment: Intersectionality of stigma: these conclusions need to be backed by the results.

Response: Thank you for highlighting this important point. Based on other comments and edits that we have made by rewriting our results section, we hope that our conclusions in the discussion are now well supported. Quotes our tables (Table 2,3) have also been referenced specifically in the results to better support our claims.

VERSION 2 - REVIEW

Reviewer **1**

Name	**Montealegre , Jane**
Affiliation	**University of Texas, MD Anderson Cancer Center,**
Date	**15-Feb-2025**
COI	

I congratulate the authors on their extensive and thoughtful revision to the manuscript to address the reviewers comments. The manuscript is significantly more organized and compelling. I have a few last suggestions that will hopefully be helpful in really driving home the findings from this important paper. Once revised, I enthusiastically support the publication of the paper.

Methods—Minor edits:

The themes listed (as well as reference to Tables 2 and 3) should go in the Results, since the themes you came up with are the results of your coding and analysis.

For key informant interviews, one hundred and seventy-two individual excerpts were identified and coded into themes and subthemes related to chosen topic areas. 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:

Fist, just a minor edit: Switch order of first and second paragraph since in the Intro, FGDs are first and KII are second. Likewise, switch order of the results from the KIIs with HCPs and the FGDs with PLWH. (This is also important because PLWH voices should come first based on topic of paper).

Section on FGDs with PLWH:

These results are very interesting. Other than the first theme, the second two themes are very nicely developed. I have a suggestion that the results from the first theme be delved into to a greater extent to really unpack the findings. I suggest breaking it into its component parts: HIV stigma and cancer stigma, tobacco stigma. Here is a suggestion:

Theme 1: Perceptions of Stigma

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 (Table 3, Quote 1).” Then talk about each of the three conditions you list-- social isolation, shame, low self-worth—with a quote to illustrate each. For example, “One woman in Moroto described not being welcomed at social events in her community (Quote X). She perceived that this was due to community members not wanting to socialize with PLWH. For some, their HIV status was a source of shame. For example, one participant described feeling responsible for his diagnosis (Quote Y). Low self-worth was expressed by several participants; for example one participant…. (Quote Z).

Cancer Stigma: 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 (Quote X). , This leading some individuals to seek treatment primarily from spiritual healers instead of trained medical providers (Table 3, Quote 4).

Tobacco stigma: [Similar to above]

KII among HCPs

First, a minor edit for the first paragraph:

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

Theme 1: Stigma Presence. There is a lot going on here—first, that HCPs witness stigma and second that they also hold personal stigmatizing perceptions. I would delve into each.

For example, first paragraph: "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." [Include examples as you have in this paragraph].

2nd paragraph: In addition to observing stigmatization within the clinic and the surrounding communities, HCPs held their own beliefs that contribute to stigma. [Elaborate….]

I hope these comments are helpful to the authors.

VERSION 2 - AUTHOR RESPONSE

Reviewer: 1

Methods:

Comment: The themes listed (as well as reference to Tables 2 and 3) should go in the Results, since the themes you came up with are the results of your coding and analysis.
For key informant interviews, one hundred and seventy-two individual excerpts were identified and coded into themes and subthemes related to chosen topic areas. 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.

Response: Thank you for this comment. We agree that the themes listed should be part of the results. These sentences have been moved to the results section in the manuscript.

Results:
Comment: Fist, just a minor edit: Switch order of first and second paragraph since in the Intro, FGDs are first and KII are second. Likewise, switch order of the results from the KIIs with HCPs and the FGDs with PLWH. (This is also important because PLWH voices should come first based on topic of paper).

Response: Thank you for this comment. We agree that the order of results should be switched to emphasize the importance of the PLWH voices. This change has been reflected in the manuscript.

Comment: Section on FGDs with PLWH: These results are very interesting. Other than the first theme, the second two themes are very nicely developed. I have a suggestion that the results from the first theme be delved into to a greater extent to really unpack the findings. I suggest breaking it into its component parts: HIV stigma and cancer stigma, tobacco stigma. Here is a suggestion:

Theme 1: Perceptions of Stigma
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 (Table 3, Quote 1).” Then talk about each of the three conditions you list-- social isolation, shame, low self-worth—with a quote to illustrate each. For example, “One woman in Moroto described not being welcomed at social events in her community (Quote X). She perceived that this was due to community members not wanting to socialize with PLWH. For some, their HIV status was a source of shame. For example, one participant described feeling responsible for his diagnosis (Quote Y). Low self-worth was expressed by several participants; for example one participant…. (Quote Z).

Cancer Stigma: 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 (Quote X). , This leading some individuals to seek treatment primarily from spiritual healers instead of trained medical providers (Table 3, Quote 4).

Tobacco stigma: [Similar to above]

Response: Thank you for this comment. We agree that it would further enhance the results section to break up this section and delve into the types of stigma more specifically. Based on this feedback we have separated this theme into additional sections and expanded on the information provided.

KII among HCPs

Comment: First, a minor edit for the first paragraph: “A total of 14 key informant interviewsKIIs were conducted and included nurses (n=9), midwives (n=1), and nursing officers (n=4). By district, across the study districts. 3 interviews were completed at Arua (n=3), and Moroto (n=3), clinics and 4 at Mongu (n=4), and Chipata clinics (n=4). KII participants were primarily females (78%) with an average age of 41."

Response: Thank you for this comment. We agree that the edits to this paragraph improve the grammar and readability. These changes have been reflected in the manuscript.

Comment: Theme 1: Stigma Presence. There is a lot going on here—first, that HCPs witness stigma and second that they also hold personal stigmatizing perceptions. I would delve into each. For example, first paragraph: “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.” [Include examples as you have in this paragraph].

2nd paragraph: In addition to observing stigmatization within the clinic and the surrounding communities, HCPs held their own beliefs that contribute to stigma. [Elaborate….]

Response: Thank you for this comment. Similar to the above comment we agree that the stigma presence section of the results for the health service workers would benefit from separating the theme into sections and expanding further. These changes have been made in the manuscript.