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RESEARCH ARTICLE

HIV-related stigma experiences and coping strategies among pregnant women in rural Uganda: A qualitative descriptive study

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Abstract

Background

HIV-related stigma is a global problem among HIV clients with far-reaching effects including increased rates of mother-to-child transmission of HIV. However, HIV-related stigma experiences and coping strategies have received little attention, especially among pregnant women in rural settings. We explored the HIV-related stigma experiences and coping strategies among pregnant women in rural northern Uganda.

Methods

This was a qualitative descriptive study conducted among HIV-positive pregnant women seeking care at Aboke Health Center IV, Kole district, northern Uganda. We conducted 12 in-depth interviews using a semi-structured interview guide. Data were analyzed using the inductive thematic approach of Braun and Clarke.

Results

The age range of the 12 participants was 17 to 35 years while the average duration with HIV since diagnosis was five years. The majority of the participants were subsistence farmers who had attained a primary level of education. Social rejection and public ridicule were identified as HIV-related stigma experiences while ignoring, social support, and prayers were identified as HIV-related coping strategies among the study participants.

Conclusion

Enacted HIV-related stigma is common among pregnant women in rural northern Uganda. Healthcare providers should work closely with HIV-positive women and other stakeholders to identify and strengthen HIV-related stigma coping strategies among pregnant women in rural settings.

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Introduction

HIV-related stigma remains a global public health problem with far-reaching consequences [1, 2]. HIV-related stigma refers to prejudice, negative attitudes, and abuse directed at people living with HIV and AIDS that is believed to be socially unacceptable [1, 2]. The stigma can either be a) enacted/experienced stigma- actual experiences of discrimination, b) anticipated/perceived/felt *stigma*-the fear of experiencing discrimination when associating with an HIV-positive person or testing positive, c) self/internalized stigma-acceptance of shame, blame, guilt and fear associated with being HIV-positive, and d) intersecting/layered stigma-HIV stigma that is layered on top of the pre-existing stigma that is frequently directed toward most-at-risk groups [1, 3].

Globally, one in eight people living with HIV experience some form of stigma [1]. The burden of stigma and discrimination is highest in Sub-Saharan Africa where the burden of HIV is high [4]. In Uganda, it is estimated that 33% of persons living with HIV have ever experienced some form of stigma [5]. The perpetual HIV-related stigma is partly because of the myths and misconceptions surrounding the transmission and prognosis of HIV/AIDS [5].

The stigma that accompanies being HIV positive has numerous negative ramifications such as loss of income and livelihood, loss of a marriage, and childbearing options, poor care within the health sector, withdrawal of caregiving in the home, loss of hope, feelings of worthlessness, and loss of reputation [6]. HIV-related stigma among pregnant women has also been associated with depression, violence, loss to follow-up, poor adherence to treatment, increased viral load, and increased risk of mother-to-child transmission of HIV [7, 8]. Ninety percent of pediatrics HIV infection is due to mother-to-child transmission which occurs during pregnancy, delivery, and breastfeeding [9]. Despite these challenges, limited studies have explored how pregnant mothers in rural settings living with HIV live and cope with these challenges.

The fight against HIV-related stigma has taken different strategies such as open campaigns against stigma and discrimination, legislation against stigma and discrimination, integration of services, and creation of communities of practices with an emphasis on experience sharing [9–12]. However, there remain gaps in addressing HIV-related stigma among pregnant women which may hamper the uptake of elimination of mother-to-child transmission (EMTCT) services thus increasing the rates of pediatric HIV. To address these gaps, there is a need to explore the HIV-related stigma experiences that pregnant mothers go through and how they cope with these experiences.

HIV-related stigma against people living with HIV (PLWHIV) have been extensively documented in Ethiopia, the United States of America, Zambia, South Africa, and Uganda [13–24]. However, most of these studies were quantitative, focused on the general HIV population, and gave little attention to how the victims cope with HIV-related stigma. In Uganda, there is a dearth of literature on HIV-related stigma among pregnant women since the country's renewed interest in EMTCT. To achieve EMTCT, it is important to explore the HIV-related stigma experiences and coping strategies of pregnant women across cultural contexts within the country. The purpose of the current study was to explore HIV-related stigma experiences and coping strategies among pregnant women in Kole District, northern Uganda.

Materials and methods

Study design

A qualitative descriptive study [25, 26] was conducted in August 2020 to explore the HIV-related experiences and coping strategies of pregnant women in Kole District, rural northern Uganda. We used a semi-structured interview guide with open-ended questions to explore the

phenomenon in its natural setting using face-to-face interviews. The interview guide was pilot tested among pregnant women who were not included in the study and revisions were made accordingly.

Study setting

The study was conducted in the EMTCT clinic of Aboke Health Center IV which is located in Kole District, northern Uganda. Kole District is bordered by Lira District to the east, Apac District to the south, and Oyam District to the west and north. The district is located approximately 290 kilometers by road to Kampala, the capital city of Uganda. The EMTCT clinic offers antiretroviral therapy services to pregnant, lactating mothers, and HIV-exposed infants. The unit is run by midwives, counselors, and medical officers, and it operates on Wednesday and Friday from 9:00 to 17:00 hours.

Study participants and sample size

The study was conducted among HIV-positive pregnant women who have ever sought EMTCT services at Aboke Health Center IV. The study included pregnant women who were 15 years of age and above and could speak either *Lango* or the English language. Pregnant women who were ill or busy at the time of data collection and did not provide consent to participate in the study were excluded. Purposive sampling was used to sample 15 participants who could speak to the research aims and have knowledge and experience of the phenomenon under scrutiny [27]. The principle of information power which indicates that the more information the sample holds, relevant for the actual study, the lower amount of participants is needed was used to estimate the sample size [28].

Participants' recruitment and data collection tool

The facility-community linkage facilitators helped the data clerks to recruit the eligible study participants who could express themselves in a manner that would allow us to capture a rich perspective of HIV-related stigma experiences and coping strategies of pregnant women. Data were collected using a semi-structured interview guide. The interview guide was developed by SU and AK and questions were adapted from the conceptual framework on HIV-related stigma and discrimination developed by Turan *et al.* in 2012 [29]. The interview guide had three sections comprising socio-demographic characteristics (age, level of education, marital status, number of children, occupation, and duration with HIV), HIV-related stigma experiences, and coping strategies. The socio-demographic characteristics had closed-ended questions while the questions on HIV-related stigma and coping strategies had open-ended questions.

Data collection method and procedure

Data were collected using face-to-face in-depth interviews. The interviews were conducted in *Lango* and English language in a private setting within the health facility premises. To elicit information on HIV-related stigma experiences and coping strategies, the study participants were asked to describe their experiences as pregnant women who are HIV positive (S1 Appendix). The interviews lasted for 30 to 45 minutes and they were audio-recorded using a smartphone while filed notes were also taken on body language and feelings of the participant at the time of data collection.

Data management and analysis

Data were transcribed verbatim and the transcripts were verified against the audio recordings to clarify any unclear information before conducting the next sets of interviews. Follow-up interviews were organized with respondents. Semantic data coding was independently done following the guidelines for the inductive thematic analysis described by Braun and Clarke [30]. Themes were generated based on the frequency of codes and sufficiency of data extracts to back up the codes. Discrepancies in codes and themes were resolved through group discussions involving the authors. Data were presented as direct quotes while providing a contextual understanding of HIV-related stigma and coping strategies among the study participants.

Trustworthiness

Four strategies and principles of credibility, dependability, confirmability, and transferability were used to ensure and maintain trustworthiness in our study [31]. Credibility was ensured and maintained by performing member checks and prolonged engagements with the study participants while observing and noting body language during the engagements. Member checking was done by restating and summarizing information during the interviews. Dependability and confirmability were ensured by audio-recording of interviews and taking field notes against which findings and interpretations could later be tested. Group discussions in moments of disagreement during data analysis also ensured the dependability and confirmability of our data. Finally, transferability was maintained through identifying a sufficient sample size of study participants who could fully express themselves and making a thick description of the study setting & context, study population, and research methods.

Ethics and approvals

The study protocol was reviewed and approved by the Gulu Research Ethics Committee (GUREC-047-20). The protocol was further cleared for data collection by the Uganda National Council for Science and Technology (RESCLEAR/01). Permission was sought from the Chief Administrative Officer & District Health Officer of Kole District, and the in-charge of EMTCT clinic, Aboke Health Center IV. Written informed consent was obtained from all the participants. Privacy and confidentiality were maintained during the entire process and the participants had the right to withdraw from the study without any notification or consequences. Standard operating procedures of coronavirus disease 2019 (COVID-19) prevention such as social distancing, hand washing, and wearing of face-masks were maintained through the study process.

Results

Participants' characteristics

Although we conducted a total of 15 in-depth interviews, only 12 in-depth interviews were analyzed. The other three interviews were discarded because the audio recordings were corrupted and thus missing critical pieces of the interview. Nonetheless, the 12 interviews gave us sufficient information to warrant further analysis without going back to the field to collect more data. Table 1 describes the study participants.

HIV-related enacted stigma experiences among pregnant women

We identified 18 codes under HIV-related stigma experiences among pregnant women. Overall, two themes of public ridicule and social rejection were generated as HIV-related stigma experiences among pregnant women in Kole District, northern Uganda.

Table 1. Description of the study participants.

Participants	Age in years	Level of education	Marital status	Parity*	Occupation	Duration with HIV in years
P1	24	Primary	Divorced	04	Subsistence farmer	15
P2	22	Secondary	Married	00	Business	01
Р3	33	Primary	Married	05	Business	03
P4	25	Primary	Married	02	Subsistence farmer	02
P5	22	Primary	Divorced	04	Subsistence farmer	01
P6	25	Primary	Married	02	Business	01
P7	17	Primary	Single	00	Business	02
P8	24	Primary	Divorced	01	Subsistence farmer	01
Р9	25	Secondary	Single	01	Subsistence farmer	14
P10	33	Secondary	Married	03	Business	01
P11	31	Primary	Married	05	Subsistence farmer	02
P12	35	No formal education	Married	04	Subsistence farmer	11

^{*}Parity is the number of times a woman has given a birth to alive or dead baby who had reached viability (> 28 weeks of gestation for Uganda's context) [32]; primary education is equivalent to grade one to seven; secondary education is equivalent to grade eight to twelve

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Social rejection. Social rejection was defined as actual or attempted acts of excluding HIV-positive pregnant women from social relations and or social interactions in a manner that was noticeable by the victim. Social rejection was a big part of the negative experiences that HIV-positive pregnant women went through. The majority of women were rejected and isolated by members of their community or their family members. The social rejection experienced by these pregnant women are typified by expressions from some of these participants:

"What annoys me is [that] sometimes people don't want to associate with you, even with your children some time they don't like [them]. That one annoys me the more. Sometimes people avoid your place". Participant 3

"Sometimes you may go home and people refuse to eat together with you and people don't allow you to carry their children". **Participant 7**

A 22-years-old first-time pregnant woman added her experience with social rejection:

"People do not even want to take water from...people keep fearing you. These things make me wonder whether I should be alive or dead....I am getting used to it anyway. But these days it is not rampant like those days". **Participant 2**

These experiences bothered these women and they implicitly expressed their reservation of reaching out to such persons to share their problems. These experiences could probably undermine their willingness to seek medical care and social support in the future.

Public ridicule. We defined public ridicule as contemptuous and dismissive language and or behaviours. Appallingly, there is still overwhelming public ridicule of HIV-positive persons in rural Uganda and pregnant women are no exception. In this study, the majority of the participants expressed public ridicule as the number one form of HIV-related stigma experience. These experiences are explicated by these quotes from some of the participants:

"People keep on abusing me that even you who can die anytime you are also talking. I feel like responding but maybe they are right....after all my uncle also recently died of AIDS". Participant 2

"Look at this person, she has just come and is still very young but she is already on medication and yet for us who are already old are still healthy. I wish they listened to advise like us those days". Participant 6

A similar experience was echoed by a 17-year old first-time pregnant woman who to part in the study:

"The one which annoyed me most was a statement from people that I started taking at early age and comments from my brother that I refused to listen to their advice". **Participant 8**

Community members are also fond of ridiculing pregnant women that they will transmit HIV to their unborn children as elucidated by this 31-year old participant woman has now given birth five times:

"When I go to fetch water, I sometimes hear people bickering that that so and so's wife is HIV positive. That my husband is very unfortunate because all my children will have HIV". Participant 11

HIV-related stigma coping strategies among pregnant women. We identified 39 codes under HIV-related stigma coping strategies among pregnant women from the 12 interviews. Out of these codes, ignoring, social support, and prayers were generated as themes for HIV-related stigma coping strategies among pregnant women in Kole District, northern Uganda. These themes are expounded below:

Ignoring. Ignoring as a theme was defined as intentionally refusing to take notice of or acknowledge stigma directed to a participant. The majority of the respondents coped with HIV-related stigma experienced by simply ignoring what people said about them or did to them. This is epitomized by the statements from some of these participants:

"... I thought about it but later I decided to ignore what people were saying and concentrate on taking my drugs. My drugs gave me assurance that I can still live for long despite peoples' words. I just kept on ignoring". **Participant 8**

When participant 6, a 25-year-old married pregnant woman with two children was probed how she coped with the enacted stigma directed towards her, she simply responded that;

"....For me, I don't respond to such because I know it can affect anyone, his may even be worse than mine". Participant 6

Participant, 9 who was diagnosed with HIV 14 years ago clarified that her focus was on living a descent life instead of focusing on negative comments from people.

"....That's how I feel because I have to be free, I have to live like other people without thinking of how I am, and that might bring me another sickness". **Participant 9**

Although most of the participants had learned to ignore stigma and discrimination directed towards them, most of them reported that they were initially disturbed by negative comments from family and community members before they developed some of these coping mechanisms.

Social support. Social support was defined as psychological, emotional, and material support provided by friends, family, and peers to help cope with stigma experiences. Respondents reported that they gained a lot of support from friends, family members, and intimate partners even after the HIV diagnosis. In particular, support from the husband and close relatives was invaluable for many respondents. One respondent who had recently tested positive for HIV described how her mother and husband has been supportive to her:

"I always consult my mother, my own mother. I tell her what is hurting me, she teaches me, and talks to me. He (husband) is HIV negative, but he always encourages me to keep taking my drugs and forget about the bad them people are saying about me." Participants 2

Some women on the other hand gained invaluable support from community members who helped them deal with the fears of living positively in the face of public ridicule. This is epitomized by a quote from a 17-year-old single mother:

"Some of the community members assisted me to keep living. They gave me material things including food. I have friends I talk to and encourage me and I feel better because they don't see me differently, nothing changed anyway. I thank God for them every day because without them I would have given up" Participant 7

Additionally, the EMTCT clinic became a very good meeting place for some of these participants to link up with their peers from where they shared their HIV- related stigma experiences and how they were coping with them. This is exemplified by a comment from one of the participants:

"If you come for getting the drugs you find the people you know also, sometimes other complicated diseases kill you but not even AIDs. I look for a friend who is also like me and I stay with". **Participant 3**

Prayers. Prayer as a theme was conceptualized as an act of seeking divine intervention either individually or in groups for comfort in moments of distress emanating from HIV-related stigma experiences. During our interviews, it became apparent that prayer was a common way of coping with HIV-related experiences among the study participants. This was demonstrated by extracts of comments from some of these participants:

"......I also pray to God to add me more days, I love to pray. I am a catholic that is where I pray. I normally ask God to forgive me because it was not my intention to contract HIV. Of course, sometimes I feel down but when I talk to my God to give me strengths to overcome what people are doing to me, I feel much better and in control". Participant 12

Although the participants held the doctors' advice and or consolation in high regard, most of them still felt that the divine power was the superior means of overcoming the stigma and discrimination experiences they were experiencing. This is epitomized by this quote from a 33-year old married woman who had five children:

"......the doctors have been very supportive in this facility. One day I came crying in his office, and when he asked me why I was crying, I told him what I was going through [stigma and discrimination]. He was very compassionate and supportive. But for me with these things

[stigma and discrimination] now, the most important thing is prayers and following the doctors' advice". **Participant 3**

Discussion

We aimed to explore HIV-related stigma experiences and coping strategies among pregnant in rural northern Uganda. Social rejection and public ridicule were identified as HIV-related stigma experiences while ignoring, social support, and prayers were identified as HIV-related coping strategies among the study participants.

Our results showed that social rejection was a big part of the negative experiences that HIV-positive pregnant women went through. The women living with HIV are shunned by family, peers, and wider community while others face poor treatment which has mental health problems. HIV-positive women are normally held responsible for their condition and therefore social rejection is almost inevitable [33]. Such conditions limit disclosure of HIV status, access to HIV testing, treatment, and other HIV services [34]. This isolation that social rejection brings can lead to low self-esteem, depression, and suicide [35]. Our results mirror the report by the International Center for Research on Women in Bangladesh, Ethiopia, and the Dominican Republic indicating that many women living HIV have experienced social rejection [35]. Our results also echo the findings of a survey conducted in five continents showing that one-third of HIV-positive patients experienced social rejection [36]. These findings suggests that more effort is still required to eradicate social rejection of persons living with HIV.

In this study, the majority of the participants expressed public ridicule as another form of HIV-related stigma experience. There is still overwhelming public ridicule of HIV-positive persons in rural Uganda and pregnant women are no exception. HIV-positive pregnant women are increasingly stigmatized and marginalized from society. This result suggests that stigma is prevalent in the context of HIV measured in terms of the attitude of those who are not infected. This is reflected in a range of behaviours such as labeling, insulting, avoidance, and negative stereotype which is in line with previous studies [37]. A survey in 2014 in Ghana assessing respondents' level of stigma against people living with HIV showed that only 8% and 14% of women and men respectively had positive attitudes overall to stigma indicators [38]. Also similar to our findings, a survey of married HIV-positive women in India showed that 88% of the participants experienced stigma from the community particularly the neighbors [39]. These findings suggest that a big portion of the rural population still do not view HIV/AIDS as a chronic condition with many modes of transmission but rather a lethal disease emanating from one's promiscuity.

Our results revealed that the majority of the respondents coped with stigma and discrimination experienced by simply ignoring what people said about them or did to them. Coping by ignoring is a passive way of protecting oneself. Researchers believe that being protective in the disclosure may expose the stigmatized individuals to more stigma including violence and thus adopting a passive strategy [40, 41]. Our results mirror the findings of a study conducted in five African countries and parts of Spain on HIV-related stigma coping strategies [40, 42]. Ignoring is a negative coping strategy that may affect the psychological wellbeing of HIV-positive pregnant women [42]. Therefore, HIV positive pregnant women should be supported to identify better HIV-related stigma coping strategies.

Our findings indicated that social support was one of the positive coping strategies adopted by HIV-positive pregnant women. The respondents reported that they gained a lot of support from friends, family members, and intimate partners even after their HIV diagnosis. In particular, support from the husband and close relatives was invaluable for many respondents. Studies assessing social support and stigma among HIV-positive clients point to the role of social

support as a buffering factor [43]. Consistent with our results, a meta-analysis in North America demonstrated that high levels of stigma were significantly associated with low social support and poor psychological outcome [44]. These findings are also consistent with the results of other studies conducted in Uganda [45, 46] among HIV-positive women during pregnancy and the postpartum period. According to a systematic review by Beres, Narasimhan [47], informal social support from family, friends, and relatives are by far one of the best copying strategy used by women living with HIV. Justifiably, social support has been shown to promote adherence to antiretroviral therapy which is positive for PLWHIV [48, 49]. These findings suggest that social support is invaluable to HIV-positive pregnant women in mitigating HIV-related stigma experiences.

In our findings, it became apparent that prayer was a common way of coping with HIV-related experiences among the study participants. Prayers significantly shape an individual's outlook on living HIV-related stigma. Prayers seem to provide a sense of peace and hope and help people to accept any condition [50]. Prayers and faith in God have been cited as major coping strategies for coping with HIV-related stigma in Uganda and other African countries [40, 51]. Therefore, it is imperative that HIV-positive pregnant women are linked to spiritual support networks as a way of coping with HIV-related stigma experiences.

Limitations of the study

This was a qualitative study are therefore the results of this study may not be generalizable to other contexts which are not identical to that of this study. Additionally, social-desirability bias could have been introduced during our in-depth interviews since the interviews were conducted within the healthcare facility thus preventing the emergence of healthcare-based HIV-related stigma and discrimination experiences.

Conclusions

Enacted stigma in the form of social rejection and public ridicule was the dominant type of HIV-related stigma experienced by HIV-positive pregnant women in rural northern Uganda. Meanwhile, HIV-positive pregnant women coped with these challenges through ignoring, social support, and prayers. The results of this study give insight into the dominant form of HIV-related stigma among pregnant women in rural Uganda and how they cope with the problem. These results can be used to inform the design of future interventions to mitigate HIV-related stigma experiences among pregnant women. Future studies should compare the current results with research previously done studies to see if there are differences in HIV-related stigma experienced over the years as the context of HIV care continues to evolve with the advent of antiretroviral therapy. More research is also needed to elucidate the link between HIV-related stigma experiences and mother-to-child transmission of HIV among rural pregnant women.

Supporting information

S1 Appendix. In-depth interview guide. (DOCX)

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