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## Research article

# “Telling my husband I have HIV is too heavy to come out of my mouth”: pregnant women’s disclosure experiences and support needs following antenatal HIV testing in eastern Uganda

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### Abstract

**Introduction:** Disclosure of HIV serostatus by women to their sexual partners is critical for the success of the prevention of mother-to-child transmission of HIV (PMTCT) programme as an integrated service in antenatal care. We explored pregnant HIV-positive and HIV-negative women’s partner disclosure experiences and support needs in eastern Uganda.

**Methods:** This was a qualitative study conducted at Mbale Regional Referral Hospital in eastern Uganda between January and May 2010. Data collection was through in-depth interviews with 15 HIV-positive and 15 HIV-negative pregnant women attending a follow up antenatal clinic (ANC) at Mbale Hospital, and six key informant interviews with health workers at the clinic. Data management was done using NVivo version 9, and a content thematic approach was used for analysis.

**Results:** All HIV-negative women had disclosed their HIV status to their sexual partners but expressed need for support to convince their partners to also undergo HIV testing. Women reported that their partners often assumed that they were equally HIV-negative and generally perceived HIV testing in the ANC as a preserve for women. Most of the HIV-positive women had not disclosed their HIV status to sexual partners for fear of abandonment, violence and accusation of bringing HIV infection into the family. Most HIV-positive women deferred disclosure and requested health workers’ support in disclosure. Those who disclosed their positive status generally experienced positive responses from their partners.

**Conclusions:** Within the context of routine HIV testing as part of the PMTCT programme, most women who test HIV-positive find disclosure of their status to partners extremely difficult. Their fear of disclosure was influenced by the intersection of gender norms, economic dependency, women’s roles as mothers and young age. Pregnant HIV-negative women and their unborn babies remained at risk of HIV infection owing to the resistance of their partners to go for HIV testing. These findings depict a glaring need to strengthen support for both HIV-positive and HIV-negative women to maximize opportunities for HIV prevention.

**Keywords:** pregnant women; HIV disclosure to partner; HIV testing by proxy; support needs; intersectionality.

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### Introduction

In Uganda, prevention of mother-to-child transmission of HIV (PMTCT) programme was initiated in 2000, originally using the voluntary counselling and testing (VCT) approach. Since 2006, HIV testing for PMTCT in Uganda has been provided routinely, integrated within the antenatal, child birth and post-partum healthcare clinics [1,2]. Routine HIV counselling and testing, though relatively new in most low-income settings, has been part of the standard of care in many high-income countries since the late 1980s and early 1990s [3–5]. In line with WHO recommendations, the main pillars of Uganda’s PMTCT programme are (1) preventing HIV infection in women of child-bearing age, (2) preventing unwanted pregnancies among women living with HIV, (3) reducing HIV transmission from women living with HIV to their infants and (4) providing care and support for women living with HIV, their children and families [2,6]. Disclosure of

HIV status by women to their sexual partners is critical for the success of each of the four pillars of the PMTCT programme. Therefore, disclosure is encouraged and promoted during pre- and post-test HIV counselling, but it could be a challenge for many women. Studies done in the African setting have documented fear of stigma [7], loss of economic security and accusations of infidelity [8], violence [9] as well as the desire to retain moral integrity and status [10] as some barriers to HIV status disclosure among pregnant women. In Uganda, HIV-related stigma remains a challenge for women in accessing HIV prevention and care services including PMTCT [11]. Stigma also hinders early initiation of antiretroviral therapy (ART) [12]. Rates of disclosure ranging from 17 to 86% have been documented among women in different African settings, with those tested at VCT clinics more likely to disclose their HIV status to their sexual partners than women tested in the context of antenatal care [8].

However, most studies on disclosure have focused on people who test HIV-positive [13,14] than those who test HIV-negative, more so HIV-negative women may have unique experiences and support needs. Besides, women's disclosure experiences could vary by HIV status or even within each of these sub-groups depending on the varied social groups women belong to.

In this paper, we draw upon intersectionality theory as an analytical framework to underscore the relationships between women's disclosure, or lack of disclosure, and the influence of various social categories assigned to women. Intersectionality was advanced by "feminists" to challenge the unitary concept of "women". For example, feminists have argued that race and gender interacted to shape the multiple dimensions of black women's employment experiences [15], and to speak of "women" as a homogeneous group who faced the same issues, marginalized other categories of oppression [15,16]. Intersectionality relates to the multi-dimensional nature of identity [15,16], focuses on differences among groups and seeks to illuminate various interacting social factors that affect human lives [17]. The basis for intersectionality is that various dimensions of social stratification including socio-economic status, gender and age, among others, can add up to great disadvantage for some people or advantage for others [17,18]. Intersectionality theory strives to elucidate and interpret multiple and intersecting systems of oppression and privilege [19]. The concept of intersectionality is particularly relevant in our study of women's disclosure experiences of their HIV status to sexual partners, as it aids an in-depth examination of how women's experiences are linked to their social identities like age, women's care giving roles as mothers, type of marital relationship, women's degree of dependency on men, among other social factors operating within the social context where women lead their lives. Indeed Gita and Ostlin [20] argued that an understanding of how gender intersects with economic inequality or a number of other social markers is important for awareness of how gender power relations work to produce health inequality, in our case how gender power relations influence women's disclosure experiences as a key determinant of access to HIV prevention, care and support services.

Within the context of the ongoing expansion of HIV counselling and testing services, integrated in the antenatal clinic (ANC) in Uganda [21], understanding women's experiences of HIV status disclosure to their partners and the support women require before and/or after disclosure could provide insights for how best to enhance programme success. This study explored pregnant HIV-positive and HIV-negative women's partner disclosure experiences and support needs at Mbale Regional Referral Hospital, eastern Uganda.

## Methods

### Study area

The study was conducted in the ANC at Mbale Regional Referral Hospital, eastern Uganda, between January and May 2010. Mbale Regional Referral Hospital is located in Mbale District, about 245 km east of Kampala, the capital city of

Uganda. The district has a population of 428,800 people [22], the majority being rural dwellers [23]. Mbale Regional Referral Hospital serves an estimated catchment population of 1.9 million people [24] from 13 districts in eastern Uganda. In Uganda, 94% of the women attend antenatal care at least once, while 47% of the women make at least four ANC visits [22]. In 2005, overall HIV prevalence in eastern Uganda, where Mbale District is located, was estimated at 5.3% while prevalence was 6.3% among women aged 15 to 49 years [25] in the same period.

The ANC at the hospital operates daily on weekdays and serves about 60 pregnant women per clinic day. All antenatal attendees are given HIV education, which doubles as pre-test HIV counselling in line with the Uganda national HIV counselling and testing guidelines [1]. The pre-test health education covers the general maternal and child healthcare, as well as HIV-specific issues including HIV prevention, transmission, testing and care. Since 2006, all women who attend ANC at Mbale Hospital are tested for HIV, unless they opt not to be tested, and they are encouraged to disclose their HIV status to their sexual partners. A previous study conducted at the Mbale Hospital ANC in 2009 documented a high, almost universal, HIV testing rate among pregnant women [26]. Mbale Hospital was chosen for being one of the oldest PMTCT sites in Uganda and for serving largely rural residents like the vast majority of Uganda's population [22].

### Study design

We conducted a qualitative study to explore pregnant women's experiences of routine HIV counselling and testing as part of antenatal care, including women's experiences as in disclosure of their HIV status to their sexual partners. In this paper, we focus on the disclosure aspects of the study. A qualitative research design was deemed appropriate to obtain an in-depth understanding of pregnant HIV-positive and HIV-negative women's partner disclosure experiences as well as the support that women feel they required before and after disclosure [27]. In addition, a qualitative design facilitated an in-depth examination of the influence of factors, such as gender, age, economic status and women's roles as mothers, on women's HIV status disclosure to their sexual partners.

### Study participants and sampling

Thirty pregnant women (15 HIV-positive and 15 HIV-negative) participated in the study during their follow up ANC visit at Mbale Regional Referral Hospital. Study participants were selected purposively from women who had gone through routine HIV counselling and testing in their previous ANC visit during the current pregnancy. Study participants who provided written consent to participate in the study, were pregnant, had taken an HIV test on a previous ANC visit and were 18 years old or more were eligible. Variation in age, parity and education level were considered in selection of study participants. Only women who came back for subsequent ANC visits after HIV testing were included in the study. Tracing pregnant women who had tested for HIV as part of ANC at community level was not feasible in our case, given the challenges of HIV stigma, especially, for those who tested HIV-positive. Eligible women who agreed to participate in

the study were identified through health workers at the ANC who served as gatekeepers (people who can allow and facilitate access to study participants) [28] and referred to members of the study team stationed at the ANC. The researchers obtained consent and enrolled study participants consecutively after undergoing their routine consultation and assessment. After interviewing 15 women in each of the two groups, we felt that the information generated by later interviews did not vary from earlier interviews, and thus no further interviews were conducted.

## Data collection

### *Individual interviews with pregnant women*

A pre-tested interview guide [29,30] was used to explore study concerns. The interview guide was pre-tested by the research team at the ANC at Mbale Hospital. Data from this phase were not included in the final analysis. Semi-structured individual interviews [31] rather than focus group discussions were conducted to allow free and confidential interaction between researchers and women as HIV is still a sensitive condition in the study setting. The interview guide consisted of structured questions on women's background characteristics as well as open-ended qualitative questions with probes, to allow an in-depth understanding of women's disclosure experiences. The key issues explored were: whether women had disclosed their HIV status to their partners or not, how women found the process of disclosure, anticipated benefits and fear of disclosure, partners' reaction to disclosure as well as the support required by women before and after disclosure. The interviews lasted for about 40 to 45 minutes, and most interviews (27) were audio recorded, with exception of three women (one HIV-positive and two HIV-negative) who did not consent for audio recording. For all interviews, interviewers were paired up (one asked questions and the other took notes). We made this provision after the pre-test, where we realized that if one person were to interview and take notes the interview would become stilted and would take longer. Interviews were conducted in Lumasaba, Luganda (main languages in the study area) and a few in English. JR conducted interviews in Luganda, and English and was assisted by three female research assistants (university graduates, experienced in qualitative research and conversant with the three languages). Audio-recorded interviews were transcribed and translated into English. JR, together with one research assistant, cross-checked the transcripts. While it was possible that the male gender of one researcher (JR) could have influenced women's responses, this influence might have been minimal. Being a social scientist with extensive training and experience in conducting qualitative interviews involving women might have helped to neutralize this likely bias. In all interviews, JR paired up with a female research assistant and took time to build rapport with study participants before commencing interviews. Besides, the findings that were obtained from interviews conducted by female researchers did not vary from those conducted by JR. The study also benefited from peer briefing sessions involving multi-disciplinary male and female investigators, which we believe improved the credibility of study results.

### *Key informant interviews*

Six health workers (one doctor, two counsellors and three nurse midwives), involved in the antenatal care clinic, participated in key informant interviews. These were intended to contribute to a better understanding of women's disclosure experiences as well as providing an opportunity for data triangulation involving comparing results from women and healthcare providers [28]. A key informant interview guide was used to conduct the interviews. Interviews explored whether women tested for HIV as part of antenatal care services, disclosed their HIV status to partners, women's experiences, fears and support required before and after disclosure.

## Data analysis

Interim data analysis occurred concurrently with data collection through daily research team meetings, where emerging issues and further data collection needs were identified. This process was important in keeping track of the number of interviews that were conducted and in identifying emerging issues as well as those that required further probing. For instance, the fears of HIV-positive women of disclosure and men assuming similar HIV status as that of their partners were probed further in interviews with health workers. In addition, JR, who supervised data collection, briefed all co-authors on preliminary insights and emerging issues of the study. Further analysis was conducted by JR in close collaboration with HKH using a content thematic approach [32]. The English version of transcripts were imported into NVivo version 9.0 [33] for coding and analysis. The analysis was guided by the themes already contained in the interview guide, which were further refined following multiple readings of interview scripts to better understand the data, identify sub-themes and to group the data according to themes for analysis and interpretation. Quotations reflecting pregnant women's HIV disclosure experiences and support needs were identified and have been used in the presentation of study findings. The identities of study participants were masked; for women we use "marital status, age and HIV status" as key identifiers. The term "married" in this regard is used for women who are formally married and those in informal unions (cohabiting). A similar categorization was used in the Uganda HIV/AIDS sero-behavioural survey [25] and is a common practice for collecting routine health information at health facilities in Uganda. For health workers we use "health worker".

Concurrent triangulation was conducted in analysis of data from pregnant women and those of key informants. This enabled us to have an in-depth understanding of HIV-positive and HIV-negative women's disclosure experiences, response from partners and the support women require before and after disclosure. In addition, we conducted sub-group analysis for similarities and differences in disclosure experiences of HIV-positive and HIV-negative women.

## Ethical considerations

Ethical approval for the study was obtained from the Uganda National Council for Science and Technology, Makerere University, College of Health Sciences, Research and Ethics Committee and Mbale Regional Referral Hospital Institutional

Review Committee. Permission was also obtained from management of Mbale Hospital and the Mbale District administration. All study participants provided written consent to participate in the study. Ink pads for thumb print were provided for those who could not read or write. Research assistants were trained on the approach to data collection and the ethical issues involved in HIV research. Study participants were assured of confidentiality, and each interview was conducted in a separate room provided by the ANC management.

## Results

### Characteristics of study participants

The age of women ranged between 18 and 43 years, most of them (25/30) were married and (26/30) depended on agriculture for survival, and half of them had attained primary education (Table 1).

The women's experiences of disclosing their HIV status to sexual partners are organized on the basis of major themes that emerged from the interviews. These were (1) the

divergent and complex path to disclosure, which denotes the difference in disclosure among pregnant HIV-negative and HIV-positive women; (2) anticipated benefits and losses of disclosure; (3) partner reaction to disclosure; and (4) the support needed before and after disclosure (Table 2).

### The divergent and complex path to disclosure of HIV status to sexual partner

Different and complex paths to disclosure of HIV status to sexual partners emerged for HIV-positive and HIV-negative pregnant women. All pregnant women who had tested HIV-negative reported that they had disclosed their HIV status to their sexual partners and found the process easy, as one woman explained:

Since I was HIV-negative, I was excited. When I reached home I told my husband that when I went for pregnancy check up, health workers tested my blood and found I do not have HIV ... I felt happy because I was safe from HIV and I could not hide this from my husband. I wanted him to know so that he can remain faithful to me ... if I was positive it would have been difficult for me to tell him. HIV-positive! ... the man can say you gave him HIV and he can chase you away or beat you ... (Married, 24 years old, HIV-negative)

**Table 1. Characteristics of study participants**

Characteristic	HIV-negative women (n = 15)	HIV-positive women (n = 15)	Frequency (n = 30) (%)
<i>Age (years)</i>			
18 to 20	4	2	06 (20)
21 to 25	6	5	11 (37)
26 to 30	1	3	04 (13)
31 to 39	4	3	07 (23)
40 to 43	0	2	02 (07)
<i>Education attained</i>			
None	1	1	02 (07)
Primary	7	8	15 (50)
Secondary	4	5	09 (30)
Tertiary	3	1	04 (13)
<i>Main source of income</i>			
Agriculture	12	14	26 (87)
Formal employment	3	1	04 (13)
<i>Marital status</i>			
Single	2	3	05 (17)
Married/ cohabiting	13	12	25 (83)
<i>Type of marriage (N = 25)</i>			
Monogamy	10	7	17 (68)
Polygamy	3	5	08 (32)
<i>Number of children ever given birth to</i>			
None	1	3	04 (13)
1 to 2	7	6	13 (43)
Three and more	7	6	13 (43)

The common terminologies that run through HIV-negative women's disclosure narratives included "... I don't have HIV, I am negative, ... we are safe, ... I don't have the virus, ... I know you are faithful to me, we should remain faithful to each other" among others. As indicated in the quotation above, HIV-negative women acknowledged that disclosure would have been difficult if they had tested HIV-positive, for fear of being accused of infecting their partners with HIV, being sent away from home or being beaten.

On the contrary, most of the HIV-positive women (11/15) had not disclosed their HIV status to their sexual partners. They described the process of disclosure to their sexual partners as "very difficult and too heavy" for them to undertake; some did not know how to go about it, while many preferred to defer it:

No, I have not told anyone since I tested, not even my sister! The nurses advised me to tell my husband, but every time I think about it I find myself crying ... I don't know how to start or how he will take it. He may think I have been cheating on him. No, not now! I feel telling my husband I have HIV is too heavy to come out of my mouth. I do not even want to think about it. Not now. May be after giving birth we will go together and test so that health workers can tell us when we are together. (Married, aged 22 years, HIV-positive)

Many HIV-positive women found disclosure very difficult, especially when women thought that their partners would react negatively or interpret women's HIV status to mean women have been unfaithful. Only four of the fifteen HIV-positive women interviewed had disclosed to their sexual partners. Analysis of disclosure narratives indicated that fear

**Table 2. Thematic presentation of pregnant women's experiences and fears of HIV disclosure to sexual partner**

Sub-themes		
HIV-negative women	HIV-positive women	Main themes
<ul style="list-style-type: none"> <li>● All disclosed</li> <li>● Process was easy</li> </ul>	<ul style="list-style-type: none"> <li>● Most not disclosed</li> <li>● Very difficult</li> <li>● Too heavy to tell</li> </ul>	The divergent and complex path to disclosure
<ul style="list-style-type: none"> <li>● Expected partner to test for HIV</li> <li>● Partner will be faithful</li> </ul>	<ul style="list-style-type: none"> <li>● Expected partner to test for HIV</li> <li>● Fear of:                             <ul style="list-style-type: none"> <li>● Abandonment</li> <li>● Violence</li> <li>● Accusation of bringing infection in family</li> </ul> </li> </ul>	Anticipated benefits and losses of disclosure
<ul style="list-style-type: none"> <li>● Partner said he was also HIV-negative</li> <li>● No need to test</li> <li>● Partner assumed HIV-negative status based on woman's/women's results</li> </ul>	<ul style="list-style-type: none"> <li>● Kept quiet</li> <li>● Partner tested</li> <li>● Partner disclosed own HIV status</li> <li>● Partner supportive</li> <li>● Partner denied HIV-positive results</li> </ul>	Partners' reaction to disclosure
<ul style="list-style-type: none"> <li>● Guidance on convincing partner to go for HIV testing</li> <li>● Needed health workers to convince male partners to go for HIV testing</li> </ul>	<ul style="list-style-type: none"> <li>● Guidance on convincing partner to go for HIV testing</li> <li>● Needed health workers to convince male partners to go for HIV testing</li> <li>● Needed health workers to assist with disclosure</li> </ul>	Support needed before and after disclosure

and stress underlie the complexities of HIV disclosure to sexual partners:

I did not tell any one immediately when I went home, but later in the night, I had many thoughts, I could not sleep so I had to tell my husband on phone (husband had travelled). It was not easy but my heart pushed me to tell him. I was feeling bad and I said to myself if I don't tell him, I might die of stress. I told him with a lot of fear that when I went for antenatal they found me with the HIV virus (akawuka ka silimu). He first kept quiet and later told me we shall help each other. I felt some relief because I had told him, but I did not sleep that night, I prayed to God that my husband does not react badly because of what I had told him ... (Married, 36 years, HIV-positive)

Interviews with health workers confirmed that indeed most HIV-negative women find disclosure to their partners easy while those who test HIV-positive encountered disclosure as a difficult process: "Most, if not all, women who test HIV negative tell their husbands but those who test HIV positive, many don't tell their partners, women fear that their husbands will abandon them or beat them for bringing HIV ..." (Health worker).

#### Anticipated benefits and losses of disclosure

Pregnant women were always involved in appraising the anticipated benefits and losses of their HIV status disclosure to their sexual partners. All HIV-negative women anticipated that their partners would be happy with the negative test results, accept to go for HIV testing and be faithful once they

had disclosed to them. These anticipated benefits were major drivers of disclosure for such women: "I told my husband because I felt he should know that I do not have HIV, I think it can help him to remain faithful to me and we avoid HIV in our marriage" (Married, 25 years, HIV-negative). Another woman noted that: "... I told my husband because I wanted him to go and also get the test" (Married, 24 years, HIV-negative).

Narratives of most HIV-positive women who had not disclosed revealed profound fear of abandonment, violence and accusation of bringing HIV infection into the family as key anticipated losses, which made disclosure risky for them. HIV-positive women feared that their husbands would abandon them if they told them that they had HIV, which would mean loss of support for themselves and their children because they largely depend on their husbands as bread winners:

... It is now 2 months, I have never told any one about my HIV status, not even to my husband ... I fear that if I tell him, he can desert me and I don't want my children to suffer. Men are very difficult, he can decide to get another woman and then leave me to suffer alone. (Married, 30 years, HIV-positive)

The fear to lose material and financial support emerged as a key barrier to disclosure and was related to situations where men were sole providers and women being pregnant, which made it difficult for them to find jobs to support themselves in case their partners discontinued support:

I have not told my boy friend, I fear if he knows he can stop supporting me. Where will I go with this

pregnancy? I am not working and he is the only one who gives me money for food, rent, . . . Maybe after giving birth and the baby grows, I will tell him we go and test together, if he accepts the counsellor will tell him. If he stops giving me support, the child will have grown I will look for a job, but now with this pregnancy no one can give me a job. (Married, aged 19 years, HIV-positive)

The fear of abandonment by male partners was more pronounced among HIV-positive women in polygamous marital relationships and was compounded by the need to ensure that the care that husbands provided for the women and their children would remain uninterrupted:

If I tell him, he may never come back to my place and shift forever to the second wife. How will I and my children survive? He can even send me away or say I brought HIV yet I have been faithful to him; I feel bad that I have HIV yet I have not been having other men. (Married, aged 28 years, HIV-positive)

Some HIV-positive women explained that their male partners would interpret women's HIV-positive results to mean that they (women) have killed their husbands:

I cannot tell my husband, he will think I have been sleeping with other men . . . he will say I have killed him. Before I tested, I once talked to him about the issue of going to test for HIV and he told me that he will never test because that is one way of knowing and die quickly . . . (Married, 28 years old, HIV-positive)

The above narrative reveals that some HIV-positive women fear that their partners might interpret the HIV-positive status to mean promiscuity by women as a source of HIV infection and HIV is still understood as a fatal infection.

In consonance with the above, health workers at the ANC revealed that some HIV-positive women opted not to disclose their HIV status for fear of being accused of having been promiscuous and thus infecting their husbands, which would result in the breakdown of the marriage: "We got one woman here who tested HIV positive, when she told the man, he told her to go away and called her a prostitute . . . those are the things that make women fear to tell their husband . . ." (Health worker).

Although all HIV-negative women believed disclosure was good for themselves and their sexual partners, some HIV-positive women thought not disclosing protected their partners from worry and was thus beneficial: "I don't have plans of telling my boyfriend. I don't want him to know that I have HIV. It is better for him not to know. He will worry a lot. May be if he goes for testing himself . . ." (Married, 21 years, HIV-positive).

#### **Partner reaction to women's disclosure of HIV status**

Most HIV-negative women expected their male partners to go for HIV testing, but most women reported that their partners instead assumed that they were equally HIV-negative (HIV testing by proxy):

I told him that I did not have HIV; he said that it was good, we are both safe from HIV. I told him the nurse had said he should go and test, he just laughed and asked me why? Since they tested you . . . we both don't have HIV. (Married, 24 years, HIV-negative)

Narratives of women also revealed that men who had more than one wife tended to use HIV-negative results of their wives to confirm their assumed HIV-negative status: "When I asked him to go and test for HIV, my husband told me that since me and my co-wife had tested HIV negative, our family is free from HIV, we should remain faithful to each other . . ." (Married, 32 years, HIV-negative).

Interviews with health workers also indicated that while they did not have any statistics about men who assume they are HIV-negative based on their female partner results, this practice was common: "Men think that since their women have tested HIV negative, they are also negative and so men see no need to go for HIV testing" (Health worker).

Some women repeatedly mentioned that their partners perceived HIV testing as part of antenatal care to be meant only for pregnant women and not the men:

Yes, I told him but he said he cannot test because he is not a woman and he is not pregnant. He said that since both of his two wives were HIV negative there is no need for him to test. (Married, 24 years, HIV-negative)

When probed, women revealed that they often gave up trying to persuade their male partners to go for HIV testing whenever men showed unwillingness to go for the test. Women also assumed and hoped that they and their male partners were really HIV-negative:

I told him that the nurse had said he should also go and test, he said why should he? The good thing they tested me and I am negative. Even if he has not tested I think we do not have HIV . . . (HIV-negative 32 years old, married)

The four HIV-positive women who had disclosed encountered varying outcomes from their partners. One woman, with tremendous fear, disclosed her serostatus to her partner and she discovered that he was already receiving HIV treatment from The AIDS Support Organisation (TASO), which is one of the major HIV and AIDS care organizations in Uganda:

I told my husband, but with a lot of fear, he first kept quiet and later told me we shall help each other. He then told me that he is a member of TASO. He advised me to join TASO to get treatment, and that I should be strong. I had a lot of fear but God was on my side that he was also positive . . . When he told me at first I felt bad and I was annoyed with him for infecting me with HIV. These men, I asked myself why he had kept it to himself. I remembered how he used to go to Mbale town every end of month; I knew that is when he was picking his drugs. As a Christian I have forgiven him . . . (Married, 36 years old, HIV-positive)

The discovery by this woman after disclosure that her partner already knew his HIV status before the woman tested elicited anger, but the profound fear and expectation of negative reaction from the man, together with faith in God, helped her to cope.

The second HIV-positive woman disclosed to the partner out of anger, but she was surprised by her husband's response; he became supportive and went for HIV testing:

I had to tell him because anger was killing me. We spent some days without talking. I would find myself crying most of the time at home. Although, I was annoyed, my husband kept encouraging me. He also went and tested. They found him positive ... he started ARVs. (Married, 43 years, HIV-positive)

For the third HIV-positive woman, aged 18 years, who disclosed, the partner denied her HIV-positive test results and insisted that they both did not have HIV. The fourth HIV-positive woman explained that her religious conviction helped her in disclosure. The partner was angry but later tested HIV-positive and encouraged his wife to go for treatment so that they can care for their children:

I told my husband because I wanted him also to go and test. When I told him, he was annoyed, but I reminded him about the many women he has so he kept quiet ... he went to the field and stayed longer than usual. Later, he came and told me that he had also tested HIV positive, he said we should start treatment and bring up our children. After testing positive, he realized his mistake. What helped me to disclose was my faith in God. I didn't want to stay with a lie in my heart .... (Married, aged 40 years, HIV-positive)

What is emerging from the four narratives is that most of the HIV-positive women who disclosed were between 36 and 43 years, while only one was 18 years old. This in part depicts young age as a likely barrier to disclosure among women. In addition, two of the women who disclosed had attained secondary education. In view of age, healthcare providers indicated that disclosure was more difficult for young women:

What I have seen, it is more hard for young women to disclose to their partners especially those in their early 20s or younger. They have many fears and they are not sure if the relationship will continue; for the older women it is easier, for them they have children and they are known in the family so they cannot easily be chased away .... (Health worker)

#### **Support needed before and after disclosure**

Generally, most HIV-positive and HIV-negative women expressed need for support from health workers to convince their male partners to undergo HIV testing:

Health workers need to find a way of telling men to test. When we tell them they say they are also negative others say they do not have time to come to hospital. (Married, aged 24 years, HIV-negative)

Some women explained that their partners fear to test thinking that if they are found HIV-positive they will die quickly:

But I once talked to him about the issue of HIV testing and he told me that he will never test because that is one way of knowing and die quickly. (Married, aged 28 years, HIV-positive)

HIV-positive women also felt that they should be provided with more counselling after HIV testing to address fears related to living with HIV and coping with the HIV-positive diagnosis:

Even counsellors visiting people who have recently tested may help, but they should not go with TASO uniform. After being told you have HIV you get many thoughts, you fail to sleep, you don't know where to begin from. More help is needed. (Married, aged 36 years, HIV-positive)

#### **Discussion**

The narratives of women in this study showed that disclosure of HIV status to sexual partners was common and easy for pregnant women who had tested HIV-negative. However, disclosure of HIV status to partners was frightening for most HIV-positive women. Thus, most HIV-positive women had not disclosed their HIV status to sexual partners mainly due to fear of abandonment, being sent away from home, domestic violence and accusation of bringing HIV infection into the family. Our findings on HIV-positive women's fear of serostatus disclosure to their partners support what have been documented in other sub-Saharan African settings [7–10,13].

Non-disclosure by HIV-positive women in our study for fear of being accused by their partners for bringing HIV infection into the family underpins HIV prevalence as a sexually transmitted disease, which in this case would be interpreted to mean HIV-positive women have been promiscuous or had other sexual partners. Having other sexual partners among women goes against the expected gender norms in the study setting, where, for instance, it is acceptable for a man to have more than one partner but a taboo for women to do so.

Using the intersectionality framework [16,17,19,20], our study adds to the understanding of how these barriers to disclosure are compounded by the intersection of gender and other social positions that women occupy. For instance, the fear of abandonment among HIV-positive women was associated with the profound fear to lose support for the women and their children. This finding shows how women's economic dependency on men and women's roles as mothers caring for children intersect to act as a barrier for HIV serostatus disclosure to partner. This finding is not surprising given that within the study setting, like other parts of Uganda, most women depend on their male partners for their care and that of children. In eastern Uganda, 72% of the households are headed by men, implying that men have power and control over allocation of resources [34] and can choose to withdraw such resources as a form of punishment.

Our findings also showed that young women and those in polygamous relationships who tested HIV-positive found

disclosure extremely difficult. Young women feared that disclosure would mean an end to their relationships while women in polygamous relationships feared that their partners would abandon them and shift to co-wives, which would lead to loss of support for the women and their children. These findings reflect a real case in which gender intersects and works in tandem with other social identities to shape the lived experiences of women, in our case, non-disclosure of HIV status to partners was influenced by women's economic dependency on men, women's roles as mothers caring for children and polygamy as a form of marital relationship. Polygamy as a barrier to disclosure has also been documented in Ivory Coast [14]. In this regard, our findings are in agreement with proponents of intersectionality theory who argue that individual's social identities profoundly influence one's experience of gender [16] and that the various social stratifications like age, gender and socio-economic status can lead to greater disadvantage or advantage [18,19]. In our case, while all our study participants were women, their varied identities in addition to being women worked together to hinder disclosure. The implication here is that health workers should consider the varying social positions in preparing and supporting women for disclosure, for instance, young women, those in polygamous relationships and those largely dependent on their male partners, may require more counselling and support for disclosure and convincing men to test for HIV.

Our finding that some HIV-positive women felt non-disclosure helped to protect their sexual partners from stress and worry was a surprise, but could in part be a reflection that these women are aware of the risks of HIV disclosure to their partners and re-echoes the need to facilitate disclosure as a process. Some HIV-positive women reported that they do not disclose to their partners because they (partners) would associate HIV-positivity to quickening their death. In this regard, the perception of HIV-related disease as fatal seems to persist despite ARVs increasingly becoming available in Uganda [21].

Most of the HIV-positive women in our study deferred disclosure of their HIV status to partners until after giving birth or until their male partners would agree to go with them for HIV counselling and testing. These findings depict the challenges that HIV-positive women are confronted with but also represent a threat to primary HIV prevention in case of discordant relationships, which is a common reality in Uganda [35,36]. Moreover, non-disclosure can prevent HIV-positive women from adhering to PMTCT interventions, thus increasing the risk of HIV transmission to the infants.

While all HIV-negative women in our study reported that they had disclosed to their partners, most men did not go for HIV testing, but instead many of them assumed that they were HIV-negative like their female partners "testing by proxy" [37]. The practice of "testing by proxy" among men is a big problem indicating that disclosure support interventions need to focus on women who test HIV-negative as well as those who test HIV-positive to enable them convince their male partners to test for HIV. Some HIV-negative women in polygamous relationships reported that their husbands often

used HIV-negative test results of their wives as "confirmatory tests" for men's HIV-negativity. For such women, attempts to convince their partners to go for HIV testing were more problematic, again indicating how polygamous relationships as a social classification kept women and their babies at risk of HIV infection.

The practice of "testing by proxy" [37] by male partners of women who tested HIV-negative is worrying, given that in Uganda, an incidence modelling study indicated that 43% of the new HIV infections among adults in the reproductive age group in 2008 occurred in discordant, supposedly monogamous, relationships [35]. While a recent community cohort in Rakai District revealed that new HIV infections within identifiable HIV-discordant couples were lower (18% in the pre-ART and 14% in post-ART period) [38], studies in Uganda have documented HIV sero-discordance among married or cohabiting relationships of 5 to 65% [25,36,39]. The assumption of HIV-negative status by men is a threat to the effectiveness of the PMTCT programme and to the attainment of the goal of eliminating new HIV infections in children [6]. These findings question the effectiveness of the dominant model of reaching men for HIV testing through their female partners and provide further support for the need to expand couple counselling and testing. Couple counselling and testing provides opportunities to address the gender imbalanced power relations including relieving women of the burden of disclosure [40], and it is associated with increased uptake of PMTCT interventions [41].

Women who tested HIV-negative generally gave up on attempts to convince their male partners to go for HIV testing, whenever the men refused, indicating how gender and power relations come into play to shape the lived experiences of women. Indeed, HIV-negative and HIV-positive women alike expressed the need for support from health workers to convince their male partners to go for HIV testing. Male partner testing for HIV infection is key to preventing new HIV infections among women [42] but remains a challenge in many high HIV prevalent settings. Some interventions with promising results on male partner HIV testing include use of an invitation letter [43,44], home-based VCT [45,46] and routine HIV counselling and testing within the hospital setting [47].

Generally, the few HIV-positive women, who had shouldered the fear of disclosure, reported positive responses from their partners. These included male partner going for HIV testing, men already receiving HIV treatment disclosed their own status, as well as encouragement and support for the woman. The positive outcomes experienced by HIV-positive women in our study concur with what has been revealed by other scholars [13,14]. However, the fact that most HIV-positive women in our study encountered enormous fear of negative outcome for themselves and their children as a barrier to disclosure raises concern about the need for health workers to identify such women and develop appropriate support mechanisms to deal with their fears and negative outcomes when they really occur. Health worker mediated disclosure and collaboration with support groups of men and women living with HIV like those under the



AIDS Support Organization (TASO) could be of help to such women.

### Strengths and limitations

The use of in-depth qualitative methods facilitated understanding of women's disclosure experiences and the implications these have on HIV prevention including PMTCT. The inclusion of HIV-positive and HIV-negative women in our study provided an opportunity to uncover the unique experiences and support needs for each of the two groups of women. Indeed most studies on disclosure tend to focus only on HIV-positive women. Our findings should be interpreted in view of the following limitations: (1) our study involved only women, thus we did not get firsthand information from men on their reactions and feelings about serostatus disclosure by their female partners. Women's reports of disclosure may have been affected by social desirability bias. Thus, future studies should seek to capture perspectives of both men and women. (2) Only women who came for their subsequent ANC visit after HIV testing were included in the study, implying a possible selection bias. Given the stigma that still surrounds HIV and AIDS in Uganda, identifying women who have recently tested for HIV infection at community level, especially those who tested HIV-positive, would have been difficult. However, the findings of our study on women's fear of disclosure are in consonance with what has been documented in other African settings [7,8,10]. In addition, findings from women were highly consistent with those of health workers, suggesting that the influence of selection bias on our findings might have been minimal. Although conducting all interviews at the health facility might have biased respondent's responses, there was an attempt to minimize this by the use of qualitative interviews with room for probing, as well as triangulation of data from interviews with women and those of health workers. This improved the trustworthiness of our findings.

### Conclusions

Within the context of routine HIV testing as part of the PMTCT programme, women who tested HIV-positive found disclosure of their HIV status to their sexual partners extremely difficult. The general fear of disclosure among HIV-positive women was influenced by the intersection of gender norms, women's economic dependency on men, women's roles as mothers caring for children, being in polygamous relationships and young age. Pregnant HIV-negative women and their unborn babies remained at risk of HIV infection owing to the reluctance of their partners to go for HIV testing. These findings depict a glaring need to strengthen the support for both HIV-positive and HIV-negative women to maximize opportunities for HIV prevention. Pregnant women who test HIV-positive should be supported to disclose and those who test HIV-negative need support to get their partners tested. Further research is needed to shed more light on the prevalence of "testing by proxy" as well as how HIV-positive and HIV-negative women accessing antenatal care can be better supported.

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### Competing interests

The authors declare that they have no competing interests.

### Authors' contributions

JR conceived the study. JR, SN, JKT, TT, & HKH participated in the design of the study. JR participated in data collection. JR, RB and HKH participated in data analysis. JR wrote the initial draft of the manuscript. All authors (JR, SN, RB, JKT, TT, & HKH) participated in the interpretation, revision of manuscript and approved the final manuscript.

### Abbreviations

AIDS, acquired immune deficiency syndrome; ANC, antenatal clinic; ART, antiretroviral therapy; ARVs, antiretroviral drugs; CDC, Centers for Disease Control and Prevention, USA; HIV, human immune-deficiency virus; IDC, infectious diseases clinic; JCRC, Joint Clinic Research Centre; MTCT, mother-to-child transmission; NVP, nevirapine; PMTCT, prevention of mother-to-child transmission of HIV; RCT, routine HIV counselling and testing; TASO, The AIDS Support Organisation; UAC, Uganda AIDS Commission; VCT, voluntary HIV counselling and testing.

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### References

1. MOH. Uganda national policy guidelines for HIV counseling and testing. Kampala: Ministry of Health Uganda; 2005. p. 1–41.
2. Ministry of Health (MOH). Policy guidelines for prevention of mother-to-child transmission of HIV. Kampala: The Republic of Uganda, Ministry of Health; 2006.
3. Aavitsland P, Nilsen O, Lystad A, Bjørndal A. Impact of antenatal HIV screening to prevent HIV infection in children in Norway 1987–99. *J Med Screen.* 2002;9(2):57–9.
4. Lindgren S, Bohlin AB, Forsgren M, Arneborn M, Ottenblad C, Lidman K, et al. Screening for HIV-1 antibodies in pregnancy: results from the Swedish national programme. *BMJ.* 1993;307(6917):1447–51.
5. Rey D, Obadia Y, Carrieri M-P, Jean-Paul M. HIV screening for pregnant women in South Eastern France: evolution 1992-1994-1996. *Eur J Obstet Gyn Reprod Biol.* 1998;76(1):5–9.
6. WHO. Global health sector strategy on HIV/AIDS 2011–2015. Geneva: World Health Organisation; 2011. p. 1–40.
7. Awiti Ujiji O, Ekström AM, Ilako F, Indalo D, Wamalwa D, Rubenson B. Reasoning and deciding PMTCT-adherence during pregnancy among women living with HIV in Kenya. *Cult Health Sex.* 2011;13(7):829–40.
8. Medley A, Garcia-Moreno C, McGill S, Maman S. Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes. *Bull World Health Organ.* 2004;82(4):299–307.
9. Larsson EC, Thorson A, Pariyo G, Conrad P, Arinaitwe M, Kemigisa M, et al. Opt-out HIV testing during antenatal care: experiences of pregnant women in rural Uganda. *Health Policy Plan.* 2011;27(1):69–75.
10. Bond VA. "It is not an easy decision on HIV, especially in Zambia": opting for silence, limited disclosure and implicit understanding to retain a wider identity. *AIDS Care.* 2010;22(Suppl 1):6–13.
11. Duff P, Kipp W, Wild TC, Rubaale T, Okech-Ojony J. Barriers to accessing highly active antiretroviral therapy by HIV-positive women attending an antenatal clinic in a regional hospital in western Uganda. *J Int AIDS Soc.* 2010;13(1):37.

12. Muhamadi L, Nsabagasani X, Tumwesigye MN, Wabwire-Mangen F, Ekström A-M, Peterson S, et al. Inadequate pre-antiretroviral care, stock-out of antiretroviral drugs and stigma: Policy challenges/bottlenecks to the new WHO recommendations for earlier initiation of antiretroviral therapy (CD <350 cells/ $\mu$ L) in eastern Uganda. *Health Policy*. 2010;97(2-3):187-94.
13. King R, Katuntu D, Lifshay J, Packer L, Batamwita R, Nakayiwa S, et al. Processes and outcomes of HIV serostatus disclosure to sexual partners among people living with HIV in Uganda. *AIDS Behav*. 2008;12(2):232-43.
14. Brou H, Djohan G, Becquet R, Allou G, Ekouevi DK, Viho I, et al. When do HIV-infected women disclose their HIV status to their male partner and why? A study in a PMTCT programme, Abidjan. *PLoS Med*. 2007;4(12):e342.
15. Crenshaw K. Mapping the margins: intersectionality, identity politics, and violence against women of color. *Stanford Law Rev*. 1991;43(6):1241-99.
16. Shields S. Gender: an intersectionality perspective. *Sex Roles*. 2008;59(5):301-11.
17. Hankivsky O, Reid C, Cormier R, Varcoe C, Clark N, Benoit C, et al. Exploring the promises of intersectionality for advancing women's health research. *Int J Equity Health*. 2010;9(1):5.
18. Warner L. A best practices guide to intersectional approaches in psychological research. *Sex Roles*. 2008;59(5):454-63.
19. Hankivsky O, Christoffersen A. Intersectionality and the determinants of health: a Canadian perspective. *Crit Public Health*. 2008;18(3):271-83.
20. Gita S, Ostlin P, editors. *Gender equity in health: the shifting frontiers of evidence and action*. 1st ed. New York: Routledge; 2010.
21. UAC. Government of Uganda-UNGASS Country progress report January 2008-December 2009; Kampala: Uganda AIDS Commission; 2010. p. 1-103.
22. UBOS. Statistical abstract. Kampala: Uganda Bureau of Statistics; 2011.
23. UBOS. 2002 Uganda population and housing census. Analytical report, population size and distribution. Kampala: Uganda Bureau of Statistics; 2006. p. 1-72.
24. Byamugisha R, Tylleskar T, Kagawa MN, Onyango S, Karamagi CA, Tumwine JK. Dramatic and sustained increase in HIV-testing rates among antenatal attendees in eastern Uganda after a policy change from voluntary counselling and testing to routine counselling and testing for HIV: a retrospective analysis of hospital records, 2002-2009. *BMC Health Serv Res*. 2010;10:290.
25. Ministry of Health (MOH) (Uganda). ORC Macro. Uganda HIV/AIDS Sero-behavioural Survey 2004-2005. Calverton, MD, USA: Ministry of Health and ORC Macro; 2006. p. 1-201.
26. Byamugisha R, Tumwine J, Ndeezi G, Karamagi C, Tylleskär T. Attitudes to routine HIV counselling and testing, and knowledge about prevention of mother to child transmission of HIV in eastern Uganda: a cross-sectional survey among antenatal attendees. *J Int AIDS Soc*. 2010;13(1):1-11.
27. Pope C, Mays N. Qualitative research: reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ*. 1995;311(6996):42-5.
28. Pope C, Mays N, editors. *Qualitative research in health care*. 3rd ed. Malden, MA: Blackwell Publishing Ltd; 2006.
29. Hudelson PM. *Qualitative research for health programmes*. Geneva: Division of Mental Health, World Health Organization; 1994.
30. Kvale S. *Interviews: an introduction to qualitative research interviewing*. Thousand Oaks, California: Sage; 1996.
31. Britten N. *Qualitative interviews*. In: Pope C, Mays N, editors. *Qualitative research in health care*. 3rd ed. Malden, MA: Blackwell Publishing; 2006. p. 12-20.
32. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004;24(2):105-12.
33. QSR International. NVivo9, Software package. Manningham, Victoria: QSR International; 2010.
34. UBOS. Uganda National Household Survey 2009/10. Kampala: Uganda Bureau of Statistics; 2010.
35. UAC. Uganda HIV modes of transmission and prevention response analysis. Kampala: Uganda National AIDS Commission; 2009.
36. Were WA, Mermin JH, Wamai N, Awor AC, Bechange S, Moss S, et al. Undiagnosed HIV infection and couple HIV discordance among household members of HIV-infected people receiving antiretroviral therapy in Uganda. *J Acquir Immune Defic Syndr*. 2006;43(1):91-5.
37. Morrill AC, Noland C. Interpersonal issues surrounding HIV counseling and testing, and the phenomenon of "testing by proxy". *J Health Commun*. 2006;11(2):183-98.
38. Gray R, Sempijija V, Shelton J, Serwadda D, Nalugoda F, Kagaayi J, et al. The contribution of HIV-discordant relationships to new HIV infections in Rakai, Uganda. *AIDS (London England)*. 2011;25(6):863-5.
39. Kizito D, Woodburn PW, Kesande B, Ameke C, Nabalume J, Muwanga M, et al. Uptake of HIV and syphilis testing of pregnant women and their male partners in a programme for prevention of mother-to-child HIV transmission in Uganda. *Trop Med Int Health*. 2008;13(5):680-2.
40. Grabbe KL, Bunnell R. Reframing HIV prevention in sub-Saharan Africa using couple-centered approaches. *JAMA*. 2010;304(3):346-7.
41. Farquhar C, Kiarie JN, Richardson BA, Kabura MN, John FN, Nduati RW, et al. Antenatal couple counseling increases uptake of interventions to prevent HIV-1 transmission. *J Acquir Immune Defic Syndr*. 2004;37(5):1620-6.
42. UNICEF. Children and AIDS fifth stocktaking report. In: *Unite for children, unite against AIDS*. New York: United Nations Children's Fund; 2010. p. 1-48.
43. Byamugisha R, Astrom A, Ndeezi G, Karamagi C, Tylleskar T, Tumwine J. Male partner antenatal attendance and HIV testing in eastern Uganda: a randomized facility-based intervention trial. *J Int AIDS Soc*. 2011;14(1):43.
44. Mohlala BKF, Boily M-C, Gregson S. The forgotten half of the equation: randomized controlled trial of a male invitation to attend couple voluntary counselling and testing. *AIDS (London England)*. 2011;25(12):1535-41.
45. Mutale W, Michelo C, Jurgensen M, Fylkesnes K. Home-based voluntary HIV counselling and testing found highly acceptable and to reduce inequalities. *BMC Public Health*. 2010;10(1):347.
46. Were W, Mermin J, Bunnell R, Ekwaru JP, Kaharuzza F. Home-based model for HIV voluntary counselling and testing. *Lancet*. 2003;361(9368):1569.
47. Wanyenze RK, Nawavvu C, Namale AS, Mayanja B, Bunnell R, Abang B, et al. Acceptability of routine HIV counselling and testing, and HIV seroprevalence in Ugandan hospitals. *Bull World Health Organ*. 2008;86(4):302-9.