# ORIGINAL RESEARCH **Experiences of HIV Positive Serostatus Disclosure** to Sexual Partner Among Individuals in Discordant Couples in Mbarara City, Southwestern Uganda

Humphrey Atwijukiire <sup>1</sup>, Gladys Nakidde<sup>1</sup>, Anne Tweheyo Otwine<sup>1</sup>, Jane Kabami<sup>2</sup>

<sup>1</sup>Nursing Department, Bishop Stuart University, Mbarara, Uganda; <sup>2</sup>Department of Nursing and Midwifery, Kabale University, Kabale, Uganda

Correspondence: Humphrey Atwijukiire, Email atwijukiireh@gmail.com

**Purpose:** Disclosure of HIV status is key in HIV management. Despite many studies on serostatus disclosure, there is a gap in experiences regarding HIV status disclosure among discordant couples. The current study addressed this research gap, and explored the lived experiences of serostatus disclosure among discordant couples in Mbarara City, South Western Uganda.

Participants and Methods: We conducted 12 in-depth interviews with the help of a translated interview guide, and they were audio recorded. Participants were purposively enrolled in the study, which employed a phenomenological qualitative design. The study was conducted at three public health facilities in Mbarara City. The data was analyzed using thematic content analysis. Approval for this research was obtained from the Mbarara University Research Ethics Committee (MUST-REC) and administrative clearance from the city clerk of Mbarara City.

Results: The mean age of the participants was 38 years old, ranging from 20 to 67 years. An equal number of males (six) and females participated in this study. Most of them had at least secondary level education, and only three had primary education. Half of the participants disclosed their serostatus to partners immediately after testing HIV positive. Key emerging themes as experienced benefits of HIV serostatus disclosure included: 1) social support and care; 2) decisions regarding health, fertility, and child bearing; 3) sharing information on HIV prevention and protection measures; 4) positive living; and 5) ease of HIV serostatus disclosure. The challenges associated with serostatus disclosure were summarized as one theme: misunderstandings in the families of the discordant couples.

**Conclusion:** Socially, psychologically and financially HIV positive individuals have benefited from their negative partners. Healthwise, they have been supported, and cared for after disclosing their positive status, but some have faced challenges, such as family misunderstandings. Couple HIV counseling and testing by a trained health worker is beneficial in HIV care and could mitigate the challenges related HIV serostatus disclosure.

Keywords: discordant couples, disclosure, experiences, HIV

#### Introduction

The disclosure of having a positive HIV status to a sexual partner is a challenging public health issue but is an important health promotion initiative that could reduce the stigma and discrimination attached to HIV, prevent further spread of HIV and facilitate greater social support and increased adherence after a successful disclosure process.<sup>1</sup> However substantial proportions of individuals diagnosed with HIV do not reveal their serostatus to those around them.<sup>2</sup>

People living with HIV (PLWHIV) face not only the challenges of living with an incurable disease, but also struggle to make the decision of whether or not to disclose their status to their partners, families, and friends.<sup>3</sup> The disclosure of HIV to a sexual partner is a preventive goal when it's done early enough, but it may expose the individual to rejection.<sup>4</sup> HIV testing<sup>5</sup> and disclosure<sup>6</sup> are hampered by high levels of stigma and discrimination.

Negotiating when and how to disclose a positive HIV status remains difficult, resulting in an internal conflict about whether or not to disclose, with women being more vulnerable than men due to more stigmatizing attitudes and intimate violence<sup>3</sup> from their male partners.<sup>7</sup> HIV discordance is more feared because of complex dynamics that

partners are less equipped to manage (violence, abandonment, and divorce) and which negatively affect rates of partner disclosure.<sup>7,8</sup>

Non-disclosure of HIV-positive status leads to HIV transmission in couples through continuous exposure to un protected sexual partners particularly if appropriate prevention measures such as condom use, pre-exposure prophylaxis and, post-exposure prophylaxis are not implemented,<sup>9</sup> posing a serious dilemma for couples considering child bearing and fertility decisions.<sup>10</sup> About 60% of all new HIV infections in Uganda occur in HIV serodiscordant couples, and 30% of married PLWHIV have a negative spouse, and non-disclosure fuels HIV transmission between partners, evidence shows that a substantial number of women are hesitant to disclose their HIV status due to fear of negative outcomes such as violence, abandonment, relationship dissolution, and stigma. People who disclose their HIV status to sexual partners may receive social support, adherence to HIV care, treatment services, increased rates of HIV testing, reduce transmission risk behaviors, and reduced stigma.<sup>11</sup> There is a gap in documentation regarding what HIV positive individuals in discordant couples' experience while disclosing their positive serostatus to their HIV negative partners in Southwestern Uganda. This study, therefore sought to explore the experiences of HIV positive serostatus disclosure sexual partners among individuals in discordant couples in Mbarara City, Southwestern Uganda.

### **Materials and Methods**

#### Study Design

This was a purely qualitative, descriptive research study using a phenomenological approach. Data was collected by conducting in-depth face-to-face interviews to explore the experiences of HIV positive serostatus disclosure among individuals in discordant couples to their sexual partners. Qualitative research is an approach that seeks to tell the story of a particular topic under study based on the experiences of the individuals and or groups using their own words.<sup>12</sup> The study was conducted between November and December 2021.

### Study Setting

The study was conducted in three public health care facilities in Mbarara City, Western Uganda. Mbarara City is 269.6km from Kampala, the capital city. It has a population of 97,500 (2021). Mbarara City is located in the Mbarara District which borders Kiruhura the north, Isingiro in east, Rwampara in south, and Sheema District in west. The surrounding area is part of the historical Ankole kingdom.

According to the person in charge of the HIV clinic, Mbarara City Health Centre IV offers care to around 3000 people living with HIV in total, with over 50 couples in discordant relationships. The services offered in these facilities include HIV testing and counseling, Anti-Retroviral Therapy (ART) counseling and initiation, laboratory services (viral load tests), HIV transmission preventive measures, and prevention of mother-to-child transmission of HIV/AIDS. Public health facilities were specifically chosen because they offer free HIV services to people living in Mbarara City.

### Inclusion and Exclusion Criteria

People living with HIV/AIDS aged 18 years and above, able to provide informed consent, in discordant relationships, and receiving HIV care at the selected public health facilities for the last six months within Mbarara City were enrolled in the study. PLWHIV in discordant relationships were confirmed from their health facilities where they receive care, by verbally asking themselves and later consulting with the care providers, and by confirming from their records at the health facilities. The study excluded participants who were critically ill at the time of data collection.

### Sample Size

We enrolled 12 participants as determined by saturation of information, and a small sample size of participants is adequate for qualitative studies,<sup>13</sup> as the emphasis is put on the richness of the data collected rather than the number of subjects. Information saturation was reached when there was enough information to replicate in the study and when the ability to obtain new information had been attained. None of the study participants dropped out of the study.

#### Sampling Criteria and Data Collection

After obtaining the Research Ethics Committee approval and administrative clearance from the three public health facilities in Mbarara City, the researcher then explained to the study participants the study topic, objectives as well as the purpose of this research. With the help of the counselors, expert clients (people living positively with HIV), and health workers, we purposively recruited PLWHIV in discordant relationships who were on ART for the last six months or more from the start date of the study. A Purposive sampling technique was used to select the participants who were exposed to the phenomenon of interest (HIV positive individuals in discordant couples).

Data was collected using a translated interview guide and an audio recorder. The interview guide consisted of three sections. Section A consisted of questions regarding biographic data of the participants. Section B consisted of questions regarding experienced benefits, while section C consisted of questions on experienced challenges of serostatus disclosure among discordant couples.

The interview guide that was developed from the existing literature was translated into a local language (Runyankole) by the researchers for the participants who do not understand English to freely give information. The interview guide was pilot tested on 3 participants at Biharwe Health Centre III in Mbarara City, and final adjustments (rephrasing questions to make them understandable to participants, combining related questions, and shortening lengthy questions while maintaining the meaning) were made to make the questions clear to the participants.

We obtained Written informed consent from the participants before they participated in the study. Using the translated interview guide, the participants were asked questions and their views were captured with an audio recorder. Each interview was conducted in a private, quiet place and lasted between 45 and 60 minutes. Only one participant was allowed inside the interview room to ensure privacy. Field notes were taken during the interviews. For bracketing purposes, the researchers documented the participant's experiences and non-verbal cues. In order to facilitate recruitment and ensure participants' privacy and confidentiality, interviews were conducted at the participants' own time when they were free. The intent was to reassure the participants and also to allow them to speak freely about their experiences. To ensure broadness, trustworthiness, and adherence of data, we observed credibility (prolonging the interviews 45–60 minutes), transferability (interviewing one participant at a time and allowing them enough time for interaction), dependability (going back to participants to confirm their findings) and confirmability (including their narrative quotes in the findings). Two repeat interviews were carried out to check for the consistence of the participants.

#### Data Management and Analysis

The recorded interviews were transcribed verbatim immediately after the interviews. The researchers listened to the recordings and compared them with the transcripts to ensure that the transcribed information was from the recordings. The transcripts were translated from Runyankole into English and back translated into Runyankole by independent translators (K.M & S.K who are fluent in the language) to check for consistency. The recorded interviews and transcripts were kept under lock and key only accessible by the researchers. The audio recordings and soft copies of the transcripts were saved on a flash disk with passcodes only known to the researchers.

Data analysis was done by the researchers using thematic content analysis. This was done through the following steps: Reading and rereading the participants' descriptions of the phenomenon to acquire a feeling for their experience, making sense of their account, extracting significant statements and formulating meaning out of them, similar statements were given codes. Similar codes were grouped together to form sub themes. Finally, related sub themes were merged to form themes, that provided an exhaustive description of the experiences and roles of expert clients in reducing HIV related stigma and discrimination. The findings were validated by returning to participants and asking them to compare them with their findings, and final changes were incorporated into the findings.

### Ethics and Approvals

This study was conducted under the 2013 Declaration of Helsinki, and was approved by the Mbarara University of Science and Technology Research Ethical Committee (MUST-REC: 2021–200). Administrative clearance was sought from the principal medical officer and city clerk of Mbarara City. Before data collection, participants were informed about the purpose of the study and informed consent was obtained from them including publication of their anonymised

responses. Participants were assured that their participation in this study was voluntary and that they were free to withdraw at any time they wished. Confidentiality was ensured by assigning participants' codes 1–12, keeping their information anonymous, and providing privacy by conducting the interviews in quiet private rooms.

### Results

### Demographic Characteristics of the Study Participants

The participants' mean age was 38 (20–67) years, and they were all married. An equal number of males (six) and females participated in this study. Most of the participants had at least secondary education, and only three had primary education. Half of the participants (six) disclosed their serostatus to their partners immediately after a positive HIV test.

According to our findings, some means 3-6 participants and most means above 6 participants.

### Experienced Benefits of HIV Serostatus Disclosure Among Discordant Couples

Five key themes emerged as experienced benefits of HIV serostatus disclosure: 1) social support and care, 2) decisions regarding health, fertility and child bearing, 3) sharing information on HIV prevention and protection measures, 4) positive living and 5) ease of HIV serostatus disclosure.

### Social Support and Care

This theme emerged from four subthemes: increased care, support from family members, increased trust, and financial support. Regardless of their gender, PLWHIV experienced increased care from their HIV negative partners and family members after disclosing their positive HIV status. In comparison to the care, they were receiving before disclosing their status, participants experienced an increased level of care and being attended to by their HIV negative partners. HIV positive partners attributed increased care to disclosure of their status.

She has been caring for me since she knew I was on drugs. She makes sure that I eat and drink on time (Male, 48 years).

He started bringing fruits every day and he is willing to do all that he can for me (Female, 30 years).

People living with HIV who disclosed their positive status experienced support from their HIV negative partners in the form of physical, social, and financial support. Physically, there was a decrease in the daily activities they had to do. Socially they were comforted, not blamed, not abused, and attended to. They were further support financial by covering some of their transport bills when they are going for refills at the health facilities. This enabled adherence to the treatment regimen prescribed by the health workers.

She kept supporting me. Whenever we have money problems, she gets some from her friends. She comforted and assured me that people with HIV/AIDS can live for more than 10 years (Male, 38 years).

PLWHIV reported that disclosing a positive HIV status is a lifesaving step because it informs the HIV negative partner about their current health status. They also become aware when it is early and then go for HIV testing. This creates peace at home unlike when the negative partner finds out before telling them, they lose trust and respect and may even divorce.

Whoever is still facing the challenge of disclosing should be polite and tell the truth to their partner however much it might look to be hard, it brings peace (Male, 54 years).

### Decisions Regarding Health, Fertility, and Child Bearing

This theme emerged from three subthemes; better family planning options, child bearing, uninterrupted intimacy, and stable living. All these sub themes contributed to better fertility and child bearing decisions. Some of the PLWHIV revealed that disclosing to their HIV negative partners helped them make informed fertility decisions when planning for the next pregnancy and child bearing proper planning as well as the growth of their children with the help of the health workers. This resulted from a timely and successful process of HIV serostatus disclosure.

I know we have a child together, so I told him because it's necessary to plan for the child early enough and in case we need to have another child, we plan early (Female, 24 years).

Some participants reported that disclosing their positive serostatus to their HIV negative partners did not interfere with their intimacy but instead helped them to utilize protective measures such as the use of a condom while having sex. With guidance from the health workers, discordant couples were able to make informed fertility decisions. This helped them to produce HIV-uninfected babies and raise them when they were free from HIV.

She did not even put me aside. She is even pregnant for the third time, that's why you see me coming with her to the hospital (Male, 28 years).

Despite being discordant couples, HIV positive partners reported living stably and happily with their negative partners and family members. This happened after a successful disclosure process, and getting advice from the health workers, which helped them to stay together and rely on the use of condoms or sometimes not having intercourse, especially when one of the partners is having other sexually transmitted infections.

Nothing happened, it became our secret ... he uses condoms, and I kept on using my drugs carefully (Female, 29 years).

#### Sharing Information on HIV Prevention and Protection Measures

Disclosing a positive HIV status to a negative partner was credited with creating a platform for sharing HIV protective and preventive measures between the partners, as depicted in the sub themes below: early testing, good drug adherence and retention in care, knowledge sharing, and use of protective measures.

PLWHIV gained and shared their knowledge with the negative partners on how to prevent the transmission of HIV after HIV serostatus disclosure. Participants reported that they learnt and acquired enough knowledge about HIV management from health workers, which they shared with their HIV negative partners.

... and Now That We Have More Knowledge About HIV Management, We Know What to Do (Male, 67 Years).

Proper use of protective measures and prevention of the spread of HIV to negative partners was reported by PLWHIV after a successful process of serostatus disclosure, and it encouraged their partners to go for testing to know their status. Disclosing acted as a protective and preventive measure to the immediate partners and to other family members and the community.

They gave me condoms, so I told her that we shall be using condoms, and there will be no more sharing razor blades ... then I asked her to go and test (Male, 38 years).

#### Positive Living

Positive living is defined as living in harmony with a discordant partner irrespective of the differences regarding HIV status. This theme emerged from three sub themes, which included: relieving stress and fears among couples; improving health status; encouraging others to test HIV; good adherence to the treatment regimen.

It was reported that disclosing a positive serostatus relieves the stress that PLWHIV always have before disclosing. Participants reported that disclosing helped them to live in harmony with their partners without fear, and they took their drugs on time as prescribed by the health workers.

I was having a lot of stress before, but after telling her, I am now relieved and living happily. Sometimes you miss taking drugs because of fear to be seen by a partner (Male 48, years).

Participants reported that by disclosing their positive HIV serostatus, they created awareness among their HIV negative partners on the importance of HIV testing and serostatus disclosure, who later tested to know their HIV serostatus.

Currently, there is a lot of sensitizations these days, not like in the past, and that has eased the disclosure process, not like in the past. When you disclose to your partner, he/she also goes to test (Male, 65 years).

Disclosure of a positive HIV serostatus to an HIV negative partner promoted good drug adherence and retention in care. HIV positive individuals reported being reminded to take their medication on a daily basis by their negative partners and also going for refills at the health facilities.

You would find the time for medication had passed and you feared taking the medication, so you would not take the medication, but when I told him, he also reminded me (Female, 20 years).

In a discordant relationship, PLWHIV reported an improved health status after disclosing. They reported that disclosing relieves stress, creates peace of mind, and improves health status. Disclosure promoted care and support from the negative partner, ensured timely medication and meals.

When I started drugs and also told my wife, it helped me so much. At first, I had 20 kg. When I started drugs, and my wife cared for me, I gained weight now I have 50 kg (Male, 28 years).

Participants reported that disclosing their positive serostatus to a partner assisted them in resolving a number of family conflicts that would have resulted in divorce, lack of support and care, and constant family conflicts among the family members.

Being open to one another and telling the truth is helpful. It prevents problems like divorce and conflicts at home (Female, 36 years).

#### Ease of Disclosure

This refers to the different ways in which one can disclose their serostatus to a discordant partner with ease. This theme originated from three sub themes: self-disclosure, facilitated disclosure, and sensitization.

Disclosure in the presence of a health worker, counselor, or trained expert client eases the process of disclosing to a negative partner. It was reported that disclosing their status to a partner in the presence of a counselor kept the couple together without separating because of the counseling they received at the time of disclosure.

You can also tell her, let's go to test, so when you go together to the clinic, they test. After that they counsel you and go when you are fine ... (Male, 28 years).

Some PLWHIV in a discordant relationship employed self-disclosure, by directly telling their negative partners about their positive HIV status after positive test results. This was used as a means of notifying the other partner to test and know their status as well.

I never wanted him to die ignorantly, so I told him that I was sick and suffering from HIV, and then I asked him to go and test (Female, 32 years).

The study found that currently, disclosing is not challenging, unlike in the past, because the community is already sensitized, there is reduced stigma in the community and the people living with HIV are very assured of the availability of the drugs. There is increased access to counselling services in the community all over.

There is a lot of sensitizations, and that has eased the disclosure process, unlike in the past. People are assured of treatment after testing positive, and the knowledge towards the management of HIV has increased (Male, 67 years).

# Experienced Challenges of HIV Serostatus Disclosure Among Discordant Couples

The challenges of disclosing a positive serostatus to an HIV negative partner are summarized in one theme as; Misunderstandings in the families of discordant couples.

#### Misunderstandings in the Families of Discordant Couples

This theme emerged from four sub themes; child bearing and fertility issues, child raising, psychological torture, neglect, and divorce.

Differences in HIV status among discordant couples affected their marital life negatively, and some PLWHIV reported being denied sex, irrespective of the available options such as using condoms. This is most commonly reported

among participants whose HIV negative partners never received counselling and health education during the period of disclosure.

Of course, changes occurred, sex stopped. We spent like one week without having sex, he would come in the evening, sleep without asking me anything, and that was after telling him (Female, 30 years).

The decision of when and how to have another child was less considered after a positive HIV status disclosure. Some participants reported having challenges with fertility decisions and failing to have as many children as they would wish to have. This was because the HIV negative partners feared being infected by the HIV positive partners after knowing their serostatus.

She would like to have more children, but we could not, we opted to use condoms and she never got another chance of getting more children. She was not okay with the use of condoms (Male, 54 years).

HIV positive partners reported being neglected by their negative partners after disclosing their status, and they were challenged with taking care of themselves and their children. Most of the PLWHIV neglected were females with low-income status, and they were faced with lots of challenges in raising their children and meeting their family needs.

I have children whom I have to take care of and I am in the house alone with no rent, no food for my children, I once thought that I should go and throw myself in the river ... (Female, 29 years).

After disclosing their positive HIV status there was decreased support and care from their partners. The unanswered question of how you get HIV when you were negative could not spared PLWHIV, particularly females. The financial support and care they used to receive from their partners declined, and some regretted having disclosed their status.

The money he used to leave at home was reduced. Now he leaves only 4000 Ugshs, but before he would leave 10000 Ugshs, generally the care and support he was giving me reduced (Female, 20 years).

Being psychologically tortured, and abused, as well as being accused of prostitution, and having contracted a sexually transmitted infection from other partners outside marriage when they were already married, was reported by some participants as one of the reasons why they regret disclosing their serostatus to partners.

Sometimes we quarrel and you find her saying, I carried a cross to stay with a person who is sick. She abuses you that take away your sickness, but I think she says it out of anger (Male, 38 years).

Some participants reported they temporarily separated when their HIV negative partners knew their serostatus. The cases of temporal separation were common among couples that delayed disclosing their status or when the HIV negative partner found out the status of the HIV positive partner before he or she disclosed it.

We had a temporal separation, went home, then came back. He refused eating my food. I did not have peace so I chose to first leave him and go home (Female, 24 years).

#### Discussion

Previous research studies showed that PLWHIV in discordant relationships struggle to disclose their HIV status to discordant partners and face multiple challenges after disclosure,<sup>3</sup> not only due to the incurable disease but also psychsocial torture from their partners, friends, family members, and the community. The HIV related stigma continues to be a barrier to HIV disclosure,<sup>9</sup> with females being the most likely to report it in the previous studies.<sup>11,14</sup> However, it was unclear if there were differences between discordant and concordant couples in terms of their experiences with HIV disclosure. Our study found that most PLWHIV in discordant relationships experienced a lot of benefits<sup>15</sup> such as social support and care, knowledge sharing on HIV protection from their HIV negative partners after disclosure compared to the few challenges they faced, this is different from what has been previously reported in sub-Saharan Africa. This is because there are HIV project supporting PLWHIV especially in discordant couples. In addition, PLWHIV have been helped by counselors and health workers<sup>16</sup> to disclose to their partners, and it played a leading role in HIV positive serostatus disclosure to an HIV negative partner. These findings provide an insight into various ways stakeholders could leverage the experienced benefits of serostatus disclosure among discordant couples to help them overcome their challenges, with the goal of improving serostatus disclosure.

#### Experienced Benefits of HIV Serostatus Disclosure Among Discordant Couples

The findings of our study revealed that disclosing a positive HIV serostatus to partners was beneficial to the HIV positive individuals unlike what other researchers reported this is because currently there has been a lot awareness created on the importance of HIV disclosure especially among couples, presence of many HIV projects in the local area that support disclosure and also HIV positive individual are assured of continuous treatment and good health. In contrast to previous findings, regardless of their gender, this study discovered that PLWHIV who disclosed their serostatus to HIV negative partners were cared for and supported<sup>17</sup> socially, economically and financially<sup>14,18</sup> by their discordant partners and family members after disclosing their positive individuals to feel accepted by their partners and this enabled to them adhere to their ART and retain in HIV care. In comparison to care they were receiving before disclosing their status, PLWHIV noted an improvement. The supportive roles played by health workers, counselors and expert clients enabled successful disclosure to a partner,<sup>16</sup> with positive men being more supported by their HIV negative partners than women.<sup>1</sup> However, a study in Thailand revealed that non-disclosure was related to fear of marital conflict and of losing social and financial support<sup>9</sup> this was only reported by a few female HIV positive individuals. The female participants refused to disclose because of fear to be blamed, rejected or denied support by their partners.

In this study, we found that health workers, counselors and expert clients provided counseling, health education, and participated in the process of HIV disclosure to a negative partner<sup>16</sup> (facilitated disclosure) this greatly influenced disclosure and enabled most HIV positive individuals to disclose to their negative partners.

PLWHIV regard disclosing a positive HIV status to a partner as lifesaving, the HIV negative partner is informed about HIV and early testing can be done<sup>14</sup> if they had not tested before. Furthermore, timely and or early disclosure creates more peace at home than when the negative partner finds out before telling them, this is in agreement with the findings of a study done in Uganda which reported that participants had reduced relationship dissolution, and reduced fear of HIV transmission<sup>19</sup> as a result of new HIV pre-exposure prophylaxis (PrEP) drugs that have enabled PLWHIV to give birth to HIV uninfected babies and reduce the dilemmas of intimacy and childbearing. A lot of sensitizations were done and the majority of the people were aware of the approaches to give birth to HIV uninfected babies. Further sensitization should be done to ensure that the entire population is aware of the benefits of serostatus disclosure to a partner.

According to the current study, disclosing to the discordant partners aided in making informed fertility decisions when planning for the next pregnancy and child bearing as well as the giving birth to HIV-free babies<sup>19–21</sup> with help of the health workers, discordant couples engaged in actions preventing the further spread of HIV. However, disagreements were shown by other studies which reported that HIV serodiscordant couples with a strong desire for childbearing had a dilemma of risking HIV infection or infecting their spouse and that practicing safer sex was hindered by the desire to have children.<sup>10,22–25</sup> The resilience to live with serodiscordance and fertility goals of childbearing made, conception an urgent desire so that partners could experience childrearing together, and multiple children were a commonly expressed desire. However, male preferences were more influential when the individual desires differed in fertility decision-making.<sup>26</sup>

Serodiscordance disclosure did not interfere with the intimacy and sexual affairs of the couples. Instead, they gained courage to utilize the available protective measures such as condoms,<sup>14,27</sup> PrEP drugs for seronegative partners, adhering to ART and retaining in HIV care<sup>22</sup> for the seropositive partners. Discordant couples were able to make informed decisions, support each other and live together with the help of health workers, expert clients and counselors, however, previous studies revealed that intimacy had been harmed by their discordant status<sup>23</sup> due to accusation of bringing HIV infection into the family<sup>28</sup> and experiencing stigma as a result of gossip, rumor, and HIV negative partners being labelled as HIV positive.<sup>29</sup>

In this study, we found that disclosure of a positive HIV status, helped negative partners acquire relevant knowledge on the prevention of further spread of HIV,<sup>30</sup> through attending counselling services and health education talks together as a couple, from where they were equipped with knowledge on how to prevent further spread of HIV and they also learnt about HIV management from health workers and other stake holders.<sup>31</sup>

Regarding HIV testing, disclosure by PLWHIV encouraged their partners to test<sup>25</sup> themselves to know their status, especially those that had never tested before. Disclosure acted as a warning not only to the immediate partner but also to other family members and the community. It was noted that in a family where one member tests HIV positive, the other family members are encouraged to test and know their status. Participants reported raising awareness among partners and family members who were later following their disclosure. However due to gender norms and economic dependence, most women who tested positive found disclosure to their partners very difficult, and pregnant HIV-negative women with their unborn babies remained at risk of HIV infection owing to the resistance of their partners to go for HIV testing.<sup>1,28</sup>

In terms of living status, positive living is defined as living in harmony with a discordant partner irrespective of the differences in HIV status. The current study revealed that disclosing a positive serostatus relieves stress<sup>32</sup> that PLWHIV always have before disclosing. They reported that disclosing relieves stress, creates peace of mind, gain of body weight, and improved health status. Participants reported that [disclosing helped them to live in harmony with their couples without fear, and they took their drugs in time as prescribed by the health workers, which promoted good drug adherence<sup>33</sup> and retention into care.<sup>17</sup> Participants reported being reminded to take their medication on daily basis by their discordant partners and also going for refills at the health facilities when it's time.

This study found that disclosure in the presence of a health worker, counselor, or expert client eased the process of disclosing to a negative partner, reducing anticipated fear of stigma and violence.<sup>28,34</sup> Facilitated disclosure kept the couples together because of the counseling they received as a couple at the time of disclosure from the health workers. Similarly previous studies displayed a strong preference for couples HIV counseling and testing (CHCT) with mutual disclosure facilitated by a trained health worker.<sup>16</sup>

#### Experienced Challenges of HIV Serostatus Disclosure Among Discordant Couples

Regardless of how much the study's findings, revealed the benefits of HIV serostatus disclosure among partners, there were also some challenges as it has been reported in other previous studies. Differences in HIV status among couples affected their marital life negatively, and some PLWHIV reported being denied sex,<sup>10</sup> irrespective of the available options such as using condoms.<sup>17</sup> This was most commonly reported among participants whose HIV negative partners never received counselling and health education during the period of disclosure. The decision of when and how to have another child was less considered after a positive HIV status disclosure. Some participants reported having challenges with fertility decisions and failure to have as many children<sup>10</sup> as they would wish to have. This was due to fear of getting infected by the HIV negative partner after knowing the status of the positive partner. Similarly, a study in Botswana found that couples experienced intense emotional, psychological, sexual, and social stress<sup>35</sup> during three phases of initial shock, conflict, and resolution and these influenced child bearing and fertility decisions.

HIV positive partners in a discordant relationship were neglected by their partners after disclosing their status, and they were challenged with taking care of themselves and their children. Most of the PLWHIV neglected were females with low-income status,<sup>36</sup> and they were faced with lots of challenges in raising their children and meeting their family needs.<sup>37</sup>

Decreased support, care, and mistrust<sup>7,38</sup> from partners were reported after disclosure of a positive HIV status. The unanswered question of "where did you get HIV from when you were negative" could not spare PLWHIV, especially the females. The financial support and care they used to receive from their partners declined<sup>34</sup> and some regretted why they disclosed their status which concurs with the findings of other studies, which reported that the reasons for disclosure included gaining social support,<sup>28</sup> preventing disease transmission<sup>30</sup> and the need to be at peace with the partner.<sup>39</sup>

The most commonly reported challenges with serostatus disclosure were psychological torture, stigma, and abuse as well as accusations for prostitution<sup>3</sup> for having contracted a sexually transmitted infection from other partners outside marriage when they were already married, and were cited by some participants as reasons why they regret disclosing their serostatus to partners. The main reasons for not disclosing HIV status to sexual partners were fear of shame, rejection, stigma, being judged, fear of being separated or divorced, and having a violent partners.<sup>9,28,34,40–42</sup> Combined couples counseling is necessary to minimize the challenges that come with serostatus disclosure. Cases of divorce were common among couples that delayed disclosing their status and or when the HIV negative partner found out the status of the HIV positive partner before disclosure.<sup>1</sup>

# Conclusion

Socially, psychologically and financially HIV positive individuals have benefited from their negative partners. Healthwise, they have been supported, and cared for after disclosing their positive status, but some have faced challenges, such as family misunderstandings. Couple HIV counseling and testing by a trained health worker is beneficial in HIV care and could mitigate the challenges related HIV serostatus disclosure.

### Study Strengths

The study was conducted in local language familiar to all the participants and each interview was given enough time to capture all the views of the study participants, was more selective to the target thus reliable data was collected and analyzed.

#### **Study Limitations**

The study was conducted among HIV positive individuals who had disclosed to their HIV negative partners, we might have missed out the experiences of the PLWHIV who had not disclosed to their HIV negative partners. More studies should be conducted among discordant couples that have not yet disclosed to explore their experiences. The study enrolled a small sample size and we also anticipate potential bias while responding to questions during interviews.

### **Abbreviations**

MUST-REC, Mbarara University Research Ethics Committee; HIV, human immunodeficiency virus; PLWHV, people living with HIV; PrEP, pre-exposure prophylaxis.

### **Ethics and Approvals**

This study was conducted under the 2013 Declaration of Helsinki, and was approved by the Mbarara University of Science and Technology Research Ethical Committee (MUST-REC: 2021-200). Administrative clearance was sought from the principal medical officer and city clerk of Mbarara City. Informed consent was sought from the participants including publication of their anonymised responses and they were assured of confidentiality by assigning them codes 1-12, keeping their information anonymous, and providing privacy.

### Acknowledgments

We give thanks to God for His mercies throughout this study. We acknowledge the support of Ajuna Noble, Kasande Meble, Akankunda Sandra, Karungi Syson, and Owobusingye Whitney for their contribution to this study. We acknowledge the management and staff of the nursing department of Bishop Stuart University, the health workers of the facilities where this study was conducted in Mbarara City and all the study participants.

# **Author Contributions**

All authors made a significant contribution to the work reported, that is in the conception, study design, execution, acquisition of data, analysis, interpretation, gave final approval of the version to be published, have agreed on the journal to which the article has been submitted, and agree to be accountable for all aspects of the work.

# Disclosure

The authors report no conflicts of interest in this work.

# References

- 1. Maeri I, El Ayadi A, Getahun M, et al. "How can I tell?" Consequences of HIV status disclosure among couples in Eastern African communities in the context of an ongoing HIV "test-and-treat" trial. *AIDS Care*. 2016;28(Suppl 3):59–66. doi:10.1080/09540121.2016.1168917
- 2. Obermeyer CM, Baijal P, Pegurri E. Facilitating HIV disclosure across diverse settings: a review. Am J Public Health. 2011;101(6):1011–1023. doi:10.2105/AJPH.2010.300102
- 3. Arrey AE, Bilsen J, Lacor P, Deschepper R. "It's my secret": fear of disclosure among sub-Saharan African migrant women living with HIV/AIDS in Belgium. *PLoS One.* 2015;10(3):e0119653. doi:10.1371/journal.pone.0119653

- 4. Maman D, Ben-Farhat J, Chilima B, et al. Factors associated with HIV status awareness and linkage to care following home based testing in rural Malawi. *Trop Med Int Health*. 2016;21(11):1442–1451. doi:10.1111/tmi.12772
- Turan JM, Bukusi EA, Onono M, Holzemer WL, Miller S, Cohen CR. HIV/AIDS stigma and refusal of HIV testing among pregnant women in rural Kenya: results from the MAMAS Study. AIDS Behav. 2011;15(6):1111–1120. doi:10.1007/s10461-010-9798-5
- Vreeman RC, Scanlon ML, Inui TS, et al. 'Why did you not tell me?': perspectives of caregivers and children on the social environment surrounding child HIV disclosure in Kenya. AIDS. 2015;29(Suppl 1):S47–S55. doi:10.1097/QAD.00000000000669
- 7. Nannozi V, Wobudeya E, Gahagan J. Fear of an HIV positive test result: an exploration of the low uptake of couples HIV counselling and testing (CHCT) in a rural setting in Mukono District, Uganda. *Glob Health Promot.* 2017;24(4):33–42. doi:10.1177/1757975916635079
- 8. Hardon A, Gomez GB, Vernooij E, et al. Do support groups members disclose less to their partners? The dynamics of HIV disclosure in four African countries. *BMC Public Health*. 2013;13(1):589. doi:10.1186/1471-2458-13-589
- Ayuttacorn A, Tangmunkongvorakul A, Musumari PM, Srithanaviboonchai K, Jirattikorn A, Aurpibul L. Disclosure of HIV status among Shan female migrant workers living with HIV in Northern Thailand: a qualitative study. *PLoS One*. 2019;14(5):e0216382. doi:10.1371/journal. pone.0216382
- 10. Tchakounté C, Nkenfou CN, Tchouangueu TF, et al. HIV serodiscordance among couples in Cameroon: effects on sexual and reproductive health. *Int J MCH AIDS*. 2020;9(3):330–336. doi:10.21106/ijma.370
- 11. Kennedy CE, Haberlen S, Amin A, Baggaley R, Narasimhan M. Safer disclosure of HIV serostatus for women living with HIV who experience or fear violence: a systematic review. J Int AIDS Soc. 2015;18(Suppl 5):20292. doi:10.7448/IAS.18.6.20292
- 12. Creswell JW. Research Design: Qualitative, Quantitative, and Mixed Methods Approaches. Thousand Oaks (CA): SAGE Publications; 2014.
- 13. Bradshaw C, Atkinson S, Doody O. Employing a qualitative description approach in health care research. *Glob Qual Nurs Res.* 2017;4:2333393617742282. doi:10.1177/2333393617742282
- 14. Dessalegn NG, Hailemichael RG, Shewa-Amare A, et al. HIV Disclosure: HIV-positive status disclosure to sexual partners among individuals receiving HIV care in Addis Ababa, Ethiopia. *PLoS One*. 2019;14(2):e0211967. doi:10.1371/journal.pone.0211967
- 15. Damian DJ, Ngahatilwa D, Fadhili H, et al. Factors associated with HIV status disclosure to partners and its outcomes among HIV-positive women attending care and treatment clinics at Kilimanjaro region, Tanzania. *PLoS One.* 2019;14(3):e0211921. doi:10.1371/journal.pone.0211921
- Walcott MM, Hatcher AM, Kwena Z, Turan JM. Facilitating HIV status disclosure for pregnant women and partners in rural Kenya: a qualitative study. BMC Public Health. 2013;13:1115. doi:10.1186/1471-2458-13-1115
- 17. Evangeli M, Wroe AL. HIV disclosure anxiety: a systematic review and theoretical synthesis. *AIDS Behav.* 2017;21(1):1–11. doi:10.1007/s10461-016-1453-3
- Yonah G, Fredrick F, Leyna G. HIV serostatus disclosure among people living with HIV/AIDS in Mwanza, Tanzania. AIDS Res Ther. 2014;11(1):5. doi:10.1186/1742-6405-11-5
- 19. Stanton AM, Bwana M, Owembabazi M, et al. Sexual and relationship benefits of a safer conception intervention among men with HIV who seek to have children with serodifferent partners in Uganda.. *AIDS Behav.* 2022;26(6):1841–1852. doi:10.1007/s10461-021-03533-0
- 20. Ngure K, Vusha S, Mugo N, et al. "I never thought that it would happen ... " Experiences of HIV seroconverters among HIV-discordant partnerships in a prospective HIV prevention study in Kenya. *AIDS Care*. 2016;28(12):1586–1589. doi:10.1080/09540121.2016.1191610
- 21. Sendo EG, Cherie A, Erku TA. Disclosure experience to partner and its effect on intention to utilize prevention of mother to child transmission service among HIV positive pregnant women attending antenatal care in Addis Ababa, Ethiopia. BMC Public Health. 2013;13:765. doi:10.1186/ 1471-2458-13-765
- 22. Saleem HT, Narasimhan M, Denison JA, Kennedy CE. Achieving pregnancy safely for HIV-serodiscordant couples: a social ecological approach. *J Int AIDS Soc.* 2017;20(Suppl 1):21331. doi:10.7448/IAS.20.2.21331
- Rispel LC, Metcalf CA, Moody K, Cloete A, Caswell G. Sexual relations and childbearing decisions of HIV-discordant couples: an exploratory study in South Africa and Tanzania. *Reprod Health Matters*. 2011;19(37):184–193. doi:10.1016/S0968-8080(11)37552-0
- 24. Beyeza-Kashesya J, Ekstrom AM, Kaharuza F, Mirembe F, Neema S, Kulane A. My partner wants a child: a cross-sectional study of the determinants of the desire for children among mutually disclosed sero-discordant couples receiving care in Uganda. *BMC Public Health*. 2010;10:247. doi:10.1186/1471-2458-10-247
- 25. King R, Kim J, Nanfuka M, et al. "I do not take my medicine while hiding" A longitudinal qualitative assessment of HIV discordant couples' beliefs in discordance and ART as prevention in Uganda. PLoS One. 2017;12(1):e0169088. doi:10.1371/journal.pone.0169088
- Pintye J, Ngure K, Curran K, et al. Fertility decision-making among Kenyan HIV-serodiscordant couples who recently conceived: implications for safer conception planning. AIDS Patient Care STDS. 2015;29(9):510–516. doi:10.1089/apc.2015.0063
- Rosenberg NE, Pettifor AE, De Bruyn G, et al. HIV testing and counseling leads to immediate consistent condom use among South African stable HIV-discordant couples. J Acquir Immune Defic Syndr. 2013;62(2):226–233. doi:10.1097/QAI.0b013e31827971ca
- Rujumba J, Neema S, Byamugisha R, Tylleskar T, Tumwine JK, Heggenhougen HK. "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. *J Int AIDS Soc.* 2012;15(2):17429. doi:10.7448/IAS.15.2.17429
- 29. Rispel LC, Cloete A, Metcalf CA. 'We keep her status to ourselves': experiences of stigma and discrimination among HIV-discordant couples in South Africa, Tanzania and Ukraine. SAHARA J. 2015;12:10–17. doi:10.1080/17290376.2015.1014403
- 30. Ngure K, Heffron R, Curran K, et al. I Knew I would be safer. Experiences of Kenyan HIV serodiscordant couples soon after Pre-Exposure Prophylaxis (PrEP) Initiation. *AIDS Patient Care STDS*. 2016;30(2):78–83. doi:10.1089/apc.2015.0259
- 31. Hailemariam TG, Kassie GM, Sisay MM. Sexual life and fertility desire in long-term HIV serodiscordant couples in Addis Ababa, Ethiopia: a grounded theory study. *BMC Public Health*. 2012;12:900. doi:10.1186/1471-2458-12-900
- 32. Watt MH, Knippler ET, Knettel BA, et al. HIV disclosure among pregnant women initiating ART in Cape Town, South Africa: qualitative perspectives during the pregnancy and postpartum periods. *AIDS Behav.* 2018;22(12):3945–3956. doi:10.1007/s10461-018-2272-5
- 33. Reed DM, Esber AL, Crowell TA, et al. Persons living with HIV in sero-discordant partnerships experience improved HIV care engagement compared with persons living with HIV in sero-concordant partnerships: a cross-sectional analysis of four African countries. *AIDS Res Ther.* 2021;18(1):43. doi:10.1186/s12981-021-00363-x
- 34. Colombini M, James C, Ndwiga C, t I, Mayhew SH. The risks of partner violence following HIV status disclosure, and health service responses: narratives of women attending reproductive health services in Kenya. J Int AIDS Soc. 2016;19(1):20766. doi:10.7448/IAS.19.1.20766

- 35. Baratedi WM, Thupayagale-Tshweneagae G, Ganga-Limando M. Experiences of the HIV serostatus disclosure in serodiscordant couples in three urban areas in Botswana. *Life Sci J.* 2014;11:961–965
- 36. Knettel BA, Minja L, Chumba LN, et al. Serostatus disclosure among a cohort of HIV-infected pregnant women enrolled in HIV care in Moshi, Tanzania: a mixed-methods study. SSM popul health. 2019;7:7. doi:10.1016/j.ssmph.2018.11.007
- Bulterys MA, Sharma M, Mugwanya K, et al. Correlates of HIV status nondisclosure by pregnant women living with HIV to their male partners in Uganda: a cross-sectional study. J Acquir Immune Defic Syndr. 2021;86(4):389–395. doi:10.1097/QAI.00000000002566
- 38. Bhatia DS, Harrison AD, Kubeka M, et al. The role of relationship dynamics and gender inequalities as barriers to HIV-serostatus disclosure: qualitative study among women and men living with HIV in Durban, South Africa. *Front Public Health*. 2017;5:188. doi:10.3389/ fpubh.2017.00188
- 39. Ismail N, Matillya N, Ratansi R, Mbekenga C. Barriers to timely disclosure of HIV serostatus: a qualitative study at care and treatment centers in Dar es Salaam, Tanzania. PLoS One. 2021;16(8):e0256537. doi:10.1371/journal.pone.0256537
- 40. Ajayi AI, Otukpa EO, Mwoka M, Kabiru CW, Ushie BA. Adolescent sexual and reproductive health research in sub-Saharan Africa: a scoping review of substantive focus, research volume, geographic distribution and Africa-led inquiry. *BMJ Global Health*. 2021;6(2):e004129. doi:10.1136/ bmjgh-2020-004129
- 41. Odiachi A, Erekaha S, Cornelius LJ, et al. HIV status disclosure to male partners among rural Nigerian women along the prevention of mother-tochild transmission of HIV cascade: a mixed methods study. *Reprod Health*. 2018;15(1):36. doi:10.1186/s12978-018-0474-y
- 42. Madi D, Gupta P, Achappa B, et al. HIV status disclosure among people living with HIV in the era of combination antiretroviral therapy (cART). J Clin Diagn Res. 2015;9(8):OC14–OC16. doi:10.7860/JCDR/2015/12511.6373

#### HIV/AIDS - Research and Palliative Care

#### **Dove**press

Publish your work in this journal

HIV/AIDS - Research and Palliative Care is an international, peer-reviewed open-access journal focusing on advances in research in HIV, its clinical progression and management options including antiviral treatment, palliative care and public healthcare policies to control viral spread. The manuscript management system is completely online and includes a very quick and fair peer-review system, which is all easy to use. Visit http://www.dovepress.com/testimonials.php to read real quotes from published authors.

Submit your manuscript here: https://www.dovepress.com/hivaids—research-and-palliative-care-journal