

Research Article

Study on HIV Status Disclosure and Treatment Adherence Amongst Support Group Members in Mushin Local Government Area (LGA), Lagos State

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Abstract

Human Immunodeficiency Virus (HIV) remains a significant global health concern, particularly in sub-Saharan Africa, where the burden of the epidemic is highest. Lagos State, in Southwest Nigeria, faces a significant challenge with HIV prevalence, particularly in the Mushin Local Government Area (LGA). This study investigates the relationship between HIV status disclosure and adherence to Antiretroviral Therapy (ART) medication among members of the God is Good Support Group in Mushin LGA, Lagos State, Nigeria. The study used a qualitative framework design and conducted semi-structured interviews with twenty members of the support group who were purposely selected due to the specific nature of the target population. Collected data was manually transcribed, while thematic analysis was used to analyze the interview data. The results showed that the majority of participants in the support group had disclosed their HIV status to their partners, and those who hadn't disclosed often confided in children or close relatives. Participants reported receiving strong support from their confidantes after disclosure. Participants believed that effective treatment adherence is crucial for achieving viral suppression, and a significant majority believed that disclosing their HIV status helped them achieve viral suppression. Most participants had positive experiences disclosing their status to partners, with nearly all reporting supportive partners. Only a small minority reported negative impacts on their sexual life, suggesting that disclosure may not necessarily harm relationships. Based on these findings, the study concludes that there is a high level of disclosure among support group members, and participants with good adherence were more likely to have disclosed their status. Disclosure was associated with achieving viral suppression, potentially due to the support received. The study suggests that strengthening support groups through funding from local, state, and international organizations could be beneficial in encouraging disclosure and improving health outcomes for individuals living with HIV.

Keywords

ART, Adherence, Disclosure, HIV, WLHIV, Support Group, Viral Suppression

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1. Introduction

Human Immunodeficiency Virus (HIV) remains a significant global health concern, particularly in sub-Saharan Africa, where the burden of the epidemic is highest. Nigeria, the most populous country in Africa, faces substantial challenges in addressing the impact of HIV within its borders. Lagos State, with its high population density, faces a particularly challenging HIV epidemic [1]. A study by Adebajo et al. (2018) highlights the concerning prevalence rates within the state, emphasizing the need for targeted interventions [1]. Lagos State, specifically, is known to have a high prevalence of HIV, with the Mushin Local Government (LGA) area being among the most affected [2].

In recent years, there has been increasing recognition of the importance of support groups in the management and care of individuals living with HIV. These groups provide a platform for sharing experiences, emotional support, and valuable information related to treatment adherence and the overall well-being of members. Support groups offer a valuable platform for People Living with HIV (PLHIV) to share experiences, access essential information, and receive emotional encouragement. Ogbonna et al. (2019) emphasize the significant influence these groups have on treatment adherence by fostering self-management and reducing stigma, both crucial factors for successful treatment [3]. Within the context of HIV support groups, two key factors emerge as critical for achieving positive health outcomes: HIV status disclosure and adherence to Antiretroviral Therapy (ART) [4].

HIV status disclosure refers to the process by which an individual living with HIV reveals their serostatus to either selected individuals or a broader social network. Disclosure has been associated with numerous benefits, including improved social support, reduced stigma, and increased access to healthcare services [5]. However, it is a complex and multifaceted decision, influenced by various factors such as cultural norms, fear of discrimination, and concerns about the potential negative consequences of disclosure. However, research suggests a positive association between disclosure and adherence to ART medication. As Adebayo et al. (2020) point out, disclosure can lead to increased social support and accountability, potentially improving adherence behavior [6].

Adherence to ART plays a vital role in managing HIV infection and preventing disease progression. ART medication effectively suppresses HIV replication, allowing the immune system to recover and preventing transmission. However, inconsistent adherence can have dire consequences. As highlighted by Okeke et al. (2023) in their research, missed doses can lead to viral load increase, drug resistance, and ultimately, treatment failure [7]. Consistent adherence to treatment regimens has been shown to improve immune function, reduce opportunistic infections, and prolong life expectancy. Support groups have the potential to enhance treatment adherence by providing a supportive environment, sharing strategies for

overcoming adherence challenges, and fostering a sense of accountability.

Despite the potential benefits of support groups, there is limited research focused specifically on the relationship between HIV status disclosure, adherence to ART, and the experiences of support group members in Nigeria, particularly within the Mushin Local Government area of Lagos State. Understanding the dynamics surrounding disclosure and adherence among support group members in this context is crucial for developing targeted interventions to improve health outcomes and reduce the burden of HIV within the community.

Therefore, this research investigated the relationship between HIV status disclosure and adherence to ART medication amongst members of God is Good Support Group in Mushin LGA of Lagos State, Nigeria. The specific objectives of this research include 1) To know the extent of HIV status disclosure amongst women in God is Good Support Group, 2) To know how disclosure of HIV status has helped with adherence to ART among married women in the support group, and 3) To assess the post-disclosure changes in the sexual relationship between members of the God is Good Support and their partner. Understanding this association offers valuable insights for developing targeted contextually appropriate strategies and interventions that can promote optimal HIV management, and support system strengthening, and ultimately contribute to the global efforts to combat the HIV epidemic.

2. Materials and Methods

2.1. Study Design

This research employed a qualitative approach to explore the disclosure practices of HIV-positive women within the God is Good Support Group in Mushin LGA. The design utilized a semi-structured interview guide tailored to the study's objectives: understanding disclosure prevalence within the group, adherence levels to ART medication, and the impact of disclosure on their relationships. This qualitative approach allows for an in-depth examination of the lived experiences of these women, offering valuable insights into the complexities of disclosure in this specific support group setting.

2.2. Study Population

The study participants were recruited from the God is Good Support Group, a Community-Based Organization (CBO) located in Mushin LGA. This group was purposively selected due to its unique composition: it consists solely of Women Living with HIV (WLHIV) who have demonstrably maintained good adherence to ART as evidenced by their

clinic visit records and reported medication intake. The group comprises twenty women residing in and around Mushin.

2.3. Sample Size and Sampling Technique

The researchers employed purposive sampling to select the God is Good Support Group, a support group for PLHIV located in Mushin LGA. Their prior experience working with PLHIV as social workers facilitated their existing connection with the group. The group comprises twenty members who attend monthly meetings. The researcher got permission from the management of the support group to conduct interviews with all twenty women during one of their regular meetings. To remove bias, the researchers personally interviewed them in a confidential setting.

2.4. Instrument for Data Collection

Data collection for this research utilized a semi-structured interview guide. The guide was developed to align with the study's research questions and comprised three distinct sections. Each section addressed a specific theme: disclosure practices, adherence to ART medication, and the impact of disclosure on relationships within the support group. Each section incorporated a range of 2-5 sub-questions to delve deeper into these themes.

2.5. Data Collection

The interviews were conducted by the researchers within the familiar and comfortable environment of the CBO office. To ensure accurate data capture, the researcher utilized a combination of tools alongside the interview guide, including a digital recorder for audio recording, pens for notetaking, and potentially, diaries if participants opted to record their experiences beforehand. Respondents were assigned alphabets A-T, for identification purposes.

2.6. Data Analysis

Following data collection, all interview recordings were carefully transcribed manually. The choice of manual transcription involved the researchers listening to the recording and typing out the conversation. Although this method was time-consuming, it was selected to give a much higher level of accuracy and deeper immersion in the data. A thematic analysis approach was then employed to analyze the transcribed data. This involved a meticulous process of reading and re-reading the transcripts to identify recurring themes and patterns within the participants' responses. An inductive approach was utilized, meaning themes emerged directly from the data itself, rather than being imposed by pre-existing frameworks.

To ensure rigor and minimize bias, discourse analysis techniques were also employed. This involved examining the

language used by participants and the context of their responses. Annotations were made on the transcripts to capture key points and emerging themes. Ultimately, this process aimed to develop a comprehensive understanding of the participants' experiences and perspectives.

2.7. Ethical Clearance/Informed Consent

Ethical clearance was obtained from the Ethics Committee of the Post Graduate School, Lagos State University, Ojo, before commencing the investigation. An informed consent was obtained from all the respondents who participated in the study. The purpose of the research was explained to each respondent and verbal informed consent was obtained from them before inclusion into the study. Also, the anonymity of the respondents was assured and ensured.

3. Results

3.1. Objective 1: The Extent of Disclosure Among WLHIV in God Is Good Support Group

A vast majority (90%, or 18 respondents) reported full disclosure of their status. Disclosure primarily targeted sexual partners, with 72% (13 respondents) choosing this route. A smaller group (28%, or 5 respondents) disclosed to biological relatives (siblings, children) and other relationships (in-laws, friends). Interestingly, 35% (7) received assistance with disclosure, while 65% disclosed independently. It is important to note that at least one respondent reported a partial disclosure, likely to their partner.

"It was my brother's wife who did the disclosure for me, and since then my husband has been encouraging me to use my drugs. Aside from her family, my family members know all of them". - Respondent E

"oko mi ko mo rara rara idi ti mo fi n logun, Oko mi mo pe mi ki se onise ku se, won si gba eri mi je. Ni igba ti mo baa ma so fun won, ma ni doctor so fun mi wipe mo ni infection sugbon mi ko ni so ekurrere ohun to je fun"

My husband partially knows but does not have a full understanding of my status. He understands I am not an unfaithful person, and if I decide to disclose, I will tell him the doctor said I have an infection". - Respondent C

"I do not live with my husband, it is a family issue that separated us, I disclosed this to my brother and planning to tell my son who is 20 years plus, though I feel somehow disclosing it to my son." - Respondent A

Interestingly, some respondents didn't need to disclose their status because their partners were already HIV-positive. There were two main ways respondents learned their partners status: through couple testing with their partner or by finding out from their partner's family member.

"Awa mejeji lan loogun yii sugbo emi ni mo koko bere si lo

ki okomi to ko arun naa, won de mo si ipo ti wa”.

“We are both using the drugs. I was the first person that was using it before my husband got infected, and he knew my status”. – Respondent D

“Yes, we went together to get tested, and the result came out and we both had it and we feel comfortable disclosing to our children and do not feel comfortable disclosing to anyone else because they may not be able to handle it”. – Respondent I

“My partner got infected before I got infected. My husband got sick and tested HIV positive but did not tell me before the marriage. It was a member of his family that told me his father was also HIV positive. I confronted him and asked why he never disclosed it to me in the first place. I have disclosed this to my younger brother and sister”. – Respondent H

“Nigba ti ara won ko yaa a gbe won wa si Ejigbo fun itoju, ni doctor wa beere pe se okomi so oun to n se won fun mi, mo ni rara ooo ni doctor wa so pe aisan k gbo ogun ni won ni. Pe ati gba ti won ti se ayewo fun won ni won ti saloo ti won o pada wa gba ogun. Nigba to okomi ku, doctor ni ki npada wa si hospital lati se ayewo, ni won fi ni ki nma bo ni Mushin General Hospital fun ayewo mi ati ogun gbigba...”

“When my husband was severely sick and was taken to Ejigbo for treatment at his doctor’s hospital, the doctor asked me if he told me what was wrong with him, but I responded that he did not. The doctor then informed me that he tested positive some time ago and advised him to start treatment, but he never returned. After his death, the doctor asked me to come back for some tests, and after the tests, he referred me to Mushin General Hospital for further testing and treatment.” – Respondent O

Many respondents (61%, or 11 people) chose to disclose their status to their partners. However, a significant number (39%, or 7 people) disclosed due to external factors. It is important to note that one respondent did not disclose her status to anyone.

“Well, when my partner asked me out, I was hiding all those things. So, I made up my mind that I must tell him all these things, if he can go on fine, and if cannot go on let me just live my life. He proposed to me in church, and I disclosed my status to him in the church. I told him it should be between both of us”. – Respondent F

“I was sick and was taken to the hospital. Our family doctor had to disclose the nature of my sickness to my husband. My family does not know about it, because whatever you tell one can be used as an insult to one tomorrow.” – Respondent Q

“Let us forget that one for now because I do not know how to tell him. Though he was trying to find out what drugs I was taking, he read through the container but did not see anything related to HIV. I only told him it was my antenatal drugs. I am lucky my husband does not use a big phone reason my secret is still covered.” – Respondent R

3.2. Objective 2: How Disclosure Has Helped to Improve Adherence to ART Among WLHIV in God Is Good Support Group

Following disclosure, all respondents reported experiencing strong support from those they confided in. This support included financial assistance, emotional encouragement, medication reminders, and even help obtaining medications from the hospital. This comprehensive support, in turn, contributed to good adherence for all respondents.

“Well disclosure has helped me because sometimes I sleep before my drug time and once my alarm buzzes, my children will come and wake me up and tell me to use my drugs and I am virally suppressed with 20 copies/ml.” – Respondent H

“My son advised me to tear off the drug labels so people will not know, and he tells me not to think.” – Respondent G

“Haha, my husband is trying. At times when I am sick, he would help me go pick and when I just started treatment he would remind me of my drugs.” – Respondent Q

All respondents acknowledged that effective treatment adherence is crucial for achieving viral suppression. Nearly everyone (all but 3) reported being aware of their current viral load. A significant majority (17 out of 20, or 90%) of respondents believed disclosing their status helped them achieve viral suppression. A small minority (2) indicated that disclosure did not influence their viral load status.

“My sister and fiancé remind me of using my drugs, during my days as an undergraduate my sister was helping me pick my drugs and send them to me. My fiancé will wake me up and ask me to use my drugs when it is time. I am also virally suppressed.” – Respondent F

“My husband helps me by going to the hospital to collect my medication and he does remind me of my drugs and ask for my health at times. In terms of suppression very well I am virally suppressed.” – Respondent B

“My friend go call me for night just remind me of my drugs, she go talk say I say make I remind you of your drugs. I go laugh and I dey virally suppressed with 20 copies/ml.”

“My friend calls me every night to remind me of my drugs. She will just say ‘I called to remind you to use your drugs’. I will laugh and I am virally suppressed with 20 copies/ml.” – Respondent S

“I know that my blood sample is taken for viral load, but I do not know the result for now.” – Respondent L

“My viral load is ok, even though I do not know the number.” – Respondent I

Interestingly, one respondent believed that their partner’s current level of support wouldn’t change even if they didn’t disclose their status.

“My husband who does not know anything about the drugs is the one monitoring me, even though I forget because I told him the time I always take. Once it is that time, he will remind me, though I am not suppressed I am working on achieving viral suppression.” – Respondent R

3.3. Objective 3: Assessment of Post-Disclosure Changes in the Sexual Relationship Between Members and Their Partner

Most respondents reported positive experiences disclosing their status to their partners. Nearly all (79%) of those who disclosed said their partners were supportive. Only a small minority (21%) reported negative effects on their sexual life.

“Before, when I was sick my husband was very strict with me, and he would not want me to share anything with him. But after I disclosed to him and he understands better now, I am feeling much better as he does not say or tell me to separate my things.” – Respondent E

“I disclosed my status in the year 2019 when I traveled out to Dubai and got a job. I was asked to do an HIV test then I tested HIV positive and got deported back to Nigeria. This prompted me to disclose to my husband so he would know why I was deported after spending so much on me. This experience affected my sexual life negatively.” – Respondent L

“I was sick and was taken to the hospital. Our family doctor had to disclose the nature of my sickness to my partner”. This disclosure affected my sexual life negatively.” “O affect mi o. Omo meji nii mo ni nigba ti mo discover. nigba ti mo ni mo fe bi omo si, won accept.”

“I was affected o. I had two children when I discovered my HIV status. When I wanted more children, my husband did not accept. It could have possibly been because of my status disclosure.” - Respondent Q

4. Discussion

This study found a 78% disclosure rate among WLHIV in the God is Good Support Group. While this is a significant proportion, it's slightly lower compared to previous research conducted in other African countries: Nigeria (88%) – [8], Northwest Ethiopia (89.7%) – [9], Dire Dawa, Ethiopia (86.5%) – [10], Uganda (85.4%) – [11] and Kenya (80%) – [12]. Encouragingly, the study also revealed a high overall disclosure rate (90%) when considering those who disclosed to at least one person, including a sexual partner or someone else. This aligns with findings from other studies by [13, 14]. The high disclosure rates observed in the God is Good Support Group suggest a potential link between support group membership and increased disclosure. This environment likely provides easier access to information and treatment opportunities, making disclosure a more feasible step. This aligns with research by Fitriyani RA et al. which found a "significant correlation between peer support and HIV serostatus disclosure" [15]. Furthermore, the study's findings echo those of Alema et al. who suggested that membership in an HIV/AIDS association increased disclosure likelihood [16]. Similarly, research in Kemissie District [17] indicated that support group members have frequent discussions about HIV and are more

likely to initiate behavioral changes. This supportive environment can help overcome feelings of shame, ultimately facilitating disclosure of HIV-positive status.

This study aligns with previous research on the positive outcomes of disclosure. Similar to Sagay AS et al.'s findings, a high proportion of respondents who disclosed their HIV status received supportive responses from their partners (Sagay reported that 86.9% of partners of PLHIV were supportive after disclosure and 5.7% were indifferent) [18]. This is further exemplified by Respondents B, E, J, L, P, S, and Q who, like [18] findings, reported minimal negative consequences following disclosure. However, the study also acknowledges the potential for negative experiences. Respondent S's story, where she discovered her status during pre-marital testing and her husband remained supportive, reflects [19] research on positive consequences like partner support. Maeri I et al's study also highlights potential negative outcomes such as partnership dissolution and violence, which emphasizes the importance of considering both sides of disclosure [19].

The study identified different comfort levels with disclosure among respondents. Some, like Respondents B, L, and Q, felt comfortable disclosing only to their partners due to fear of future abuse if disclosed to others. This aligns with [20] finding that disclosure is more common with spouses/sexual partners than with extended family, friends, or colleagues. Conversely, Respondents A, G, K, M, and P preferred disclosing to trusted individuals (siblings or relatives) but not their partners. Maeri I et al's study on reasons for non-disclosure to partners resonates here, highlighting fears of abandonment during vulnerable times. Respondent K's fear of being thrown out by her partner echoes this concern. Similarly, Respondent M felt her husband wasn't receptive to disclosure, highlighting potential challenges within relationships. According to her, *“I have given him various tests which he keeps failing and when I put up documentaries about HIV, he always feels uncomfortable and keeps rejecting it for our family”* but I have disclosed this to my mum. The study also emphasizes the importance of trusted support systems. Respondent E's disclosure to her sister demonstrates the value of having someone who can provide informed support during illness. In her words, *“My sister is aware; she knows the drug to fish out for me when I am sick if she was not aware I could use drugs that will affect me the more”*.

The study revealed a concerning difference in how partners disclosed their HIV status. Female respondents were more likely to disclose their status than their male partners. This disparity can have serious consequences, as some female respondents reported having been infected with HIV by their partners who hadn't disclosed it. Several factors might contribute to this gender gap. As suggested by [21], Women's Focus on Partner Health. They may prioritize their partners' well-being or feel a sense of responsibility that motivates disclosure. However, [22] highlights that fear of stigma and discrimination can also lead individuals, regardless of gender,

to conceal their status. This finding underscores the need for further research into the complex factors influencing disclosure decisions. Research by [23, 24] suggests men are generally less likely to seek healthcare services, including HIV testing. This may translate to lower disclosure rates among male partners. Obermeyer CM et al's review observed similar trends, emphasizing the need for more research on gender dynamics and disclosure [25]. Targeted interventions to support open communication about HIV status within partnerships are crucial. However, further research is needed to understand the underlying gender-based reasons behind disclosure choices. Addressing these factors is key to promoting transparency and preventing infections.

The study identified several cases where couples were both taking ARV medications (antiretroviral drugs). However, the reasons for starting treatment differed. Respondents D and I reported open communication – they discovered their status together and began treatment as a couple. For Respondents H and O, the situation was different. Their partners did not initially disclose their HIV status, leading to delayed treatment for the women. This highlights the importance of open communication about HIV status within partnerships. These findings align with the [26] recommendations for serodiscordant couples (where one partner is HIV-positive, and the other is negative). WHO recommends that ART can significantly reduce the risk of transmission from the positive partner to the negative partner. Starting treatment when the Clusters of Differentiation 4 (CD4) count is high (above 350 cells/ μ L) can further decrease transmission risk. This study emphasizes the importance of open communication within couples regarding HIV status. Early disclosure allows for timely access to treatment for both partners, potentially preventing further transmission within the relationship.

This study found a strong association between disclosure, social support, and positive health outcomes for PLHIV on ART. All respondents who disclosed their status (fully or partially) reported receiving strong support from their partners or confidantes. This aligns with research by [27] which highlights the importance of sexual partner support for treatment success. Membership in the support group likely fostered a sense of self-confidence and self-esteem, which may have empowered disclosure. This finding resonates with Luque-Fernandez MA et al's study on support groups as an effective model for improving treatment adherence and viral suppression [28]. Encouragingly, nearly all respondents achieved viral suppression, underscoring the potential benefits of disclosure. Hardon A et al suggest support groups can be valuable spaces to discuss the positive impact of treatment on both individual and partner health, potentially influencing disclosure decisions and adherence [29]. These findings emphasize the value of interventions that encourage PLHIV on ART to disclose their status to partners. Disclosure, as [30] highlights, can strengthen adherence and ultimately prevent HIV transmission. Increased viral suppression rates, as observed in this study, are crucial for achieving the [31] goal of

ending the AIDS epidemic by 2030.

The study investigated how disclosure affected respondents' sexual lives. Few respondents reported negative changes in their sexual relationships with their partners following disclosure. While many reported no significant changes, some experienced a shift towards safer practices. Respondent D, for example, described relying on condoms after disclosure. This aligns with research by [32, 33] suggesting disclosure can lead to couples adopting safer sex practices, potentially reducing transmission risks. Open communication allows for informed decisions about sexual health and prevention strategies. The research briefly touched on family planning for couples affected by HIV. One respondent (J) with a discordant partner (HIV-negative) reported having HIV-negative children. This finding, while based on a single case, resonates with the World Health Organization's (WHO) guidelines on integrating fertility care and HIV treatment. The WHO acknowledges the desire of some HIV-positive individuals with negative partners to have HIV-negative children through assisted reproductive technologies. This study provides valuable insights, but further research is needed to fully understand the long-term impact of disclosure on sexual relationships and family planning decisions among PLHIV and their partners.

The study also revealed some negative experiences associated with disclosure. Not all recipients of disclosure offered support. Respondent L reported an unsure response from her husband, who while guiding her, made the process challenging and Respondent O faced a divided reaction. One child offered unwavering support, while the other threatened to expose her status and even tampered with her medication. These experiences highlight the potential for disclosure to lead to conflict within families. This resonates with David H et al's findings on reasons for non-disclosure, such as fear of blame, disapproval based on tradition, and potential marital breakdown [34].

5. Conclusion

This study aimed to understand how the God is Good Support Group in Mushin LGA influences its members with HIV. The research examined how the support group facilitates disclosure of HIV status, adherence to ART, and achieving viral suppression. It also explored the potential impact of disclosure on relationships with partners. Key findings from the research show a high level of disclosure among support group members. There was a significant rate of viral suppression amongst those who disclosed. Members with good adherence were more likely to have disclosed their status. Interestingly, the study suggests that disclosure does not necessarily harm relationships. While some negative outcomes are possible, overall, disclosure appears to be manageable within supportive environments.

The research highlights the potential benefits of support groups. The sense of community, encouragement, and shared experiences within the God is Good Support Group likely

empowers members to overcome fear and stigma, leading to increased self-esteem and confidence when dealing with their HIV status.

6. Recommendations

The research provides the following recommendations:

- 1) Empower community-based organizations to provide valuable services and training in interpersonal communication for PLHIV at the community level.
- 2) Prioritize communication as an advocacy tool to raise awareness and educate about HIV/AIDS prevention and management.
- 3) Secure funding from the government, donor agencies, and implementing partners to support and increase membership in support groups, contributing to the 95-95-95 goal of HIV treatment and viral suppression.

One limitation of this study is the small sample size and the specific nature of the target population, which consists of members of the God is Good Support Group in Mushin LGA, Lagos State. The findings may not be generalizable to other support groups or individuals living with HIV in different locations. The results may be influenced by the specific characteristics and dynamics of the support group, such as trust and social support within the group, which may differ from other support groups. Hence there is a need for future research with larger and more diverse samples, including different types of support groups and control groups, and employing a mix of research methods, such as longitudinal studies and objective measures of treatment adherence, would enhance the validity and generalizability of the findings.

Abbreviations

ART: Antiretroviral Therapy
 CBO: Community-Based Organization
 CD4: Clusters of Differentiation 4
 HIV: Human Immunodeficiency Virus
 LGA: Local Government
 PLHIV: People Living with HIV
 WLHIV: Women Living with HIV
 WHO: World Health Organization's

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Author Contributions

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Conflicts of Interest

The authors declare no conflicts of interest.

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