

# HIV Status Disclosure Paradox: Implications of HIV Disclosure on Safer Sexual Practices among Women Living with HIV/AIDS

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Received date: January 14, 2019; Accepted date: February 05, 2019; Published date: February 12, 2019

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## Abstract

**Objective:** HIV status disclosure is typically encouraged because of its purported benefits. Unintended consequences of status disclosure to People Living with HIV/AIDS (PLHA) and their partners, however, rarely receive research attention. Understanding unintended consequences is essential to addressing the public health challenge of reducing HIV/AIDS incidence and re-infection. This study explores how status disclosure may impede rather than facilitate behavioral adherence.

**Methods:** Semi-structured interviews with 20 HIV positive women (mean age=27.9 (SD=8.2); 70% romantically involved), we explored why or why not these women adhere to sexual behavioral recommendations to protect against reinfection and transmission to partners. Interviews were transcribed, independently coded, and thematically analyzed. Participants understood condom use and ART adherence benefits. This did not always translate into adherence. Stigma concerns and partner willingness to risk transmission and reinfection influenced oscillations in behavioral adherence.

**Results:** We found evidence for the "HIV Status Disclosure Paradox," which includes four types. HIV status non-disclosure was related to greater behavioral adherence by (1) promoting abstinence and/ or singlehood, or (2) motivating infected women to insist on consistent condom use. Disclosure was related to (3) male partners' willingness to risk transmission or reinfection by insisting on unprotected sex and women's relinquishment of responsibility after disclosure, or (4) selecting partners accepting of HIV status or weeding out unaccepting partners.

**Conclusion:** These paradoxes coupled with suboptimal medical adherence suggest increased risk potential among PLHA and their partners. Disclosure counseling with patients and partners should incorporate information and messages to minimize unintended consequences that increase transmission or reinfection risk.

**Keywords:** HIV positive; Qualitative; Behavioral adherence; Status disclosure; Sexual behavior

## Introduction

Healthy behaviors such as medical adherence (routinely taking antiretroviral therapy (ART) according to the proscribed schedule) and sexual behavioral adherence (abiding by risk-reduction recommendations for safer sex or abstinence) are essential to optimize the quality of life for people living with HIV/AIDS (PLHA) and reduce transmission to others [1]. Inconsistent condom use remains a significant public health challenge among PLHA of all ages because of the risk of transmission between sero-discordant partners and reinfection between sero-concordant partners [2]. Youth living with HIV/AIDS are particularly vulnerable because they report a higher prevalence of risk behaviors compared to uninfected youth [1,3,4]. Furthermore, adolescents and young adults are less likely to engage in behavioral inhibition, planning, and rationale decision-making and more likely to act impulsively relative to adults with greater brain maturation in cognitive control regions [5-8].

Behavioral adherence to minimize HIV transmission or reinfection involves abstaining from or using barrier methods during any types of sexual activity. Several factors interact to influence sexual behavioral adherence levels among PLHA: basic need to create relationships – especially sexual relationships in young adulthood, immature brain development and coping (vulnerability particularly among young people), and stigma related to status disclosure. Belonging and social acceptance are fundamental human needs that motivate human behavior [9]. Forging intimate (sexual and non-sexual) relationships with others is a hallmark of young adulthood [10]. A lack of developmental maturity makes it difficult for HIV positive youth to appreciate the consequences of their daily behavior on future health outcomes [11,12]. Coupled with the fear of stigma with HIV status disclosure, these factors prime young PLHA for greater vulnerability to sexual behavioral non-adherence.

Stigma is a primary barrier to HIV disclosure to friends and sexual partners [13,14]. Young PLHA have reported feeling stigmatized, hopeless, angry, deny their illness, and have little sense of future prospects [15-21]. For example, to avoid peer ridicule and friendship loss, youth report they hide medication use or lie about the health

condition for which they are taking medication [18,19]. HIV status disclosure may increase risk or may promote the health of PLHA and their partners. Another way of framing it is that non-disclosure may serve as a risk-factor or protective factor. One hypothesis is that the threat of rejection by sexual partners upon HIV status disclosure or insistence of sexual abstinence without status disclosure will place both partners at greater risk. In other words, this threat of isolation may motivate youth-who have limited coping skills coupled with a developmentally appropriate prioritization for social relationships-to forgo protective behaviors (e.g., consistent condom use; sexual abstinence), placing them and their partners at greater risk exposure [22]. According to this hypothesis, non-disclosure increases risk. An alternative hypothesis is that non-disclosure will decrease risk because PLHA will avoid sexual relationships with partners whom they do not inform of their status or will insist on consistent condom-use to protect unknowing partners and minimize risk [23,24]. This study explores both potential hypotheses.

Given that HIV status disclosure is encouraged by physicians and assumed to be a best practice without much empirical evidence related to sexual behaviors, this study explores whether and in what contexts disclosure and non-disclosure promote health or place PLHA and their partners at risk. In this study, we qualitatively explore why women living with HIV, particularly adolescent and young adult women, adhere or do not adhere to behavioral recommendations intended to optimize their health status and protect against infecting partners or re-infecting themselves or their sero-concordant partners.

## Methods

### Participant selection

Semi-structured in-depth interviews were conducted with 20 HIV-positive women currently receiving clinical care for HIV. These women reside in an urban setting known for its high prevalence of HIV and unplanned pregnancy. Women were recruited from one of two clinics: 8 women were recruited from an adult HIV clinic and 12 women were recruited from an adolescent clinic serving HIV-positive youth up to age 24. Women were sampled to cover a diverse age range (mean age=27.9; range: 18-40). Almost all women identified as African American (95%), half (50%) reported they were currently prescribed ART, and 70% reported having a current romantic partner.

### Procedures

Oral informed consent was obtained and interviews were conducted in a private clinic room. Interviews averaged 50 minutes in length and participants were compensated with a \$ 20 gift card. Although, the interview guide specified key topics including experiences living with HIV, future goals, romantic partner expectations, barriers to adherence, and childbearing intentions, participants were allowed to deviate and share additional information. This paper focuses on data related to medical and behavioral adherence including roles of partners, peers, and family. Given our interest in young PLHA adherence, discussion for women ages 18-29 will be emphasized; sample demographic characteristics are reported in Table 1.

Variables	N	%	Mean	SD	Range
Exact age	20	-	27.9	8.57	18-42
Race	Black/African American	29	95	-	-
	White	1	5		
Perinatal infection	Yes	5	25		
Currently romantically partnered	Yes	14	70		
	No	6	30		
Partner status (of 14)	Sero-discordant	6	42.9		
	Sero-concordant	3	21.4		
	Unknown	5	35.7		

**Table 1:** Sample demographic characteristics.

### Analytic strategy

After interviews were transcribed, two study team members independently coded the data, using thematic analysis, before reaching consensus on emergent themes. The larger study team then reviewed and refined themes.

As part of a larger parent study, nearly all participants (19 of 20) also completed a quantitative survey targeting childbearing intentions as well as provider-patient interactions and romantic relationships. Results from this survey are not discussed in this paper but have been published elsewhere [25-27].

### Results

Behavioral adherence includes safer sexual practices such as consistent condom use with sexual partners or sexual abstinence. Excluding a desire to conceive and bear biological children, the two most salient emergent themes pertained to disclosure of HIV status:

- The fear of stigma from disclosing HIV status to current or potential romantic partners that would negatively impact relationships (e.g., break-up, singlehood, abstinence)
- How disclosure of status affects condom use behaviors. Non-disclosure was related to consistent condom use or abstinence whereas disclosure may result in vulnerability to partner pressure to take the risk of unprotected sex.

We call this the “HIV Status Disclosure Paradox.” Four paradoxes emerged from the data.

### **Paradox 1: Non-disclosure, staying single and abstinent**

Several participants voiced concerns about disclosing their HIV positive status to potential dating partners. They fear stigma associated with their status, most notably rejection and being perceived as different. For some participants this fear of disclosure prevented them from pursuing intimate or sexual relationships at all, thereby promoting singlehood and sexual abstinence. A 23 year old woman explained that although she wants to date men and have children, she stays single due to her fear of disclosing her status. A 20 year old participant lamented that her status precludes her from engaging in sexual relationships. A 24 year old participant reported that she avoids talking to people who are interested in her or pursuing relationships with people whom interest her. Another woman described just how difficult it is to verbalize that she is HIV positive to anyone, especially a potential partner:

*“It affects my life a lot. Um...it makes me skeptical about talking to someone or pursuing someone that I'm interested in. It makes me skeptical about giving my phone number to someone that wants to talk to me... (ID 3, age 22).”*

The first paradox is that non-disclosure may protect against transmission and reinfection by resulting in sexual abstinence *via* non-coupling. Although, avoidance of intimate and romantic relationships promotes abstinence and, in turn, prevents HIV transmission and reinfection, this forced singlehood and/or abstinence is not developmentally appropriate and has unintended psychological consequences of social isolation. It is not a sustainable coping strategy because humans are social beings and part of adolescent and young adult development is the formation of intimacy and intimate relationships.

### **Paradox 2: Non-disclosure and consistent condom use**

There are safe ways of engaging in intimate and sexual relationships for young PLHA that fulfill their needs and those of their partners, such as insisting on consistent condom use and PrEP. Some participants, however, rationalized the choice not to disclose their HIV status to their sexual partner because they perceived they were keeping their partners safe by insisting on condom use during each sexual act. This plan fails when relationships transition from new to longer term and partners perceive condom nonuse as a symbol of trust and insist on having unprotected sex. Some participants chose to end relationships when this occurred because the stigma of revealing their HIV positive status was worse than being single. As one young woman who insisted on consistent condom use explained, she was concerned about a past relationship with boyfriend that would eventually become serious when he would encourage her to have unprotected sex

*“No. It wasn't like that. But I knew at one point it would probably get to that point...that place. So that's why I just said ‘Well, you know, I'm going to cut it here’” (ID 17, age 20).*

The second paradox is that non-disclosure among HIV positive females may serve as protective factor within sexual relationships because it promotes insistence on consistent condom use by the infected partner. Many participants, however, disclosed their status to partners with whom they were intimate which results in the third paradox.

### **Paradox 3: Disclosure and inconsistent condom use**

Reasons for inconsistent condom use varied including a lack of perceived susceptibility to contracting HIV by sero-discordant partners as well as a perception of great caring and intimacy in the relationship. Male partners sometimes would ask to go without condoms, knowing their female partners are HIV positive. For example, one young woman explained how difficult it was to get her boyfriend to consistently use condoms because he did not believe he was at risk of becoming HIV positive:

*“Like my last boyfriend...I think when I told him (about her status) it went in but I think he blocked out the HIV point because with him I be like ‘we need to use the condom.’ He be like ‘no, for what?’ And I think I overeducated him because it's like ... he be more concerned like every time I get tested he'd be like ‘so where was it (her viral load)’ and I would tell him and he be like ‘alright...we don't need to use condoms...’ I was like ‘if anything happen, you cannot blame me for this cause I told you from the beginning’” (ID 18, 23 years).*

It was evident that the participant's boyfriend's low sense of perceived susceptibility to and severity of HIV led him to feel a false sense of security. He did, however, understand he was at risk as he reportedly went to get tested every time she [participant] went for a checkup. She described him as “*playing Russian roulette*” with his life. It was also clear, however, that the participant felt that by disclosing her status, she was no longer responsible for his decisions. She reported that the same situation was occurring with her current boyfriend. This low sense of risk also speaks to the sense of invincibility typical of adolescents and young adults.

Another participant (ID 4) shared that she and her partner were having unprotected sex even though he was aware of her status. She believed that this occurred because of the caring nature of their relationship. Their intimacy transcended her HIV status. In other words, by having unprotected sex, her male partner was conveying to her that he saw beyond her HIV status and wanted to be intimate with her because of his love for who she was as a person.

*“But you know when he thinks of me, he doesn't think of my HIV status. You know what I'm saying. He loves...well he cares about me because I am who I am, you know and the things I do and accomplish. But it (condom use) depends on where we are and stuff like that” (ID 4, age 21).*

In a similar vein, another participant provided an example of how the decision to forego condom use was seen as a gift, a sign of intimacy that the partners were comfortable with each other. Trust in monogamy was part of this comfort and decision to not use condoms:

*“On my birthday he stopped using condoms. I feel okay with it. I feel more comfortable with him wearing condoms. But it's strange that in the beginning of the relationship, he would wear condoms and now he doesn't want to wear no condoms... as long as he don't go nowhere else and I guess he feels comfortable as long as I don't go nowhere else” (ID 10, 32 years).*

Within sero-concordant relationships, knowledge of reinfection does not necessarily motivate consistent condom use. For one couple, the desire to have a biological child was worth the known health risks:

*“I wouldn't say that it (condom use) is not necessary, because I guess he can keep infecting me or I can infect (him)... But we also know that it can...one of us can also worsen; the other will keep giving the other the infection even more” (ID 19, 40 years).*

Even knowledge and awareness about condom nonuse leading to re-infection and greater compromised health does not deter partners from unsafe sexual practices.

Not all participants were comfortable with their male partners choosing not to use condoms after knowing her HIV status. One participant remarked about how she has difficulty negotiating condom use with her partner because she is concerned about her own risk even though he is not concerned with his own.

*"He may want to go naked (condom nonuse) every now and again... we had an altercation the other day when he did that. You know he went raw and I was like 'don't do that.' You know I was mad. I don't like that. That's putting me at risk. You know I feel it's just like he's raping me."* (ID 1, 29 years)

The third paradox is that disclosure of one's status may increase HIV/AIDS transmission and reinfection because partners' willingness and insistence on taking the risk *via* condom non-use. This speaks to the need for condom negotiation skills training for PLHA of all ages. And, the need to educate both partners not only about the relationship between viral load and the risk of transmission to others, but also their own risk of reinfection that can compromise their treatment options or other infections (e.g., Chlamydia, gonorrhea) resulting from unprotected sex.

Disclosure may be used by PLHA as a mechanism of selecting partners who truly care about them above and beyond HIV status or as a means of "weeding out" potential partners who are unaccepting of their status. For example, one woman had a healthy and confident outlook on disclosing her status. She reported that it is important to tell others about her status regardless of whether they are accepting or judgmental. For her, telling her status weeds out people with whom she does not want to interact:

*"Someone I'm just meeting and they ask my name if they can have my number. I tell them my situation and very few backs off or don't want anything to do with me. I'd rather tell the person...I can kind of feel who to tell and who not to tell...some will still be by my side and still be my friend and talk to me and the rest of them I know are more on a childish level and can't handle what I tell them.... I always tell them before I have sex with them... The person I'm with now he knew about it the first time I found out about it...we've been friends since '03" (ID 10, age 32).*

It is not clear to what extent this strategy is related to consistent condom use or not. One could hypothesize that partners who are accepting of a partner's HIV status may be less likely to insist on condom use and more willing to risk transmission and/ or reinfection. Future studies are needed to understand how disclosure may be used as a partner selection strategy and the extent to which it is related to increased transmission or re-infection risk. Both partners advocating for medical and sexual behavior adherence that minimizes the risk of transmission and/ or re-infection are necessary to promote the health of both partners.

## Discussion

Status non-disclosure was a protective factor, motivating infected women to insist on consistent condom use. Once status was disclosed, male partners who were willing to take the risk of transmission convinced female partners to not use condoms. We call this the "HIV Status Disclosure Paradox," which to our knowledge has not been previously empirically explored.

The fear of stigma and the possibility of physical and emotional isolation complicated entering into romantic and sexual relationships as well as HIV status disclosure and condom negotiation among PLHA who had sexual partners. Some women perceived the negative social ramifications of HIV status disclosure so grave that they would forgo establishing relationships to avoid the pressure to disclose their status (non-disclosure as a protective factor). Other women chose not to disclose their status and justified this choice because they were protecting their partners from transmission by insisting on consistent condom use (non-disclosure as a protective factor). Among women in longer-term relationships who disclosed their status, some partners (some of whose HIV status was not known by these women) would risk HIV transmission and/ or reinfection by insisting on condoms nonuse (disclosure as a risk factor).

According to HIV Status Disclosure Paradox, status disclosure – typically recommended by providers and perceived as the best strategy in relationships ("honesty" as the best policy) – may be far more risky for all parties involved than status non-disclosure if non-disclosure is related to abstinence or consistent condom adherence, particularly among youth. These data suggest that an unintended consequence of disclosure is decreased condom use (risk factor) and an unintended consequence of nondisclosure is abstinence or consistent condom use (protective factor). Herein lies the paradox.

Fear of rejection and stigmatization resulting in intimate relationship avoidance and ultimately sexual abstinence is a protective factor for re-infection (unprotected sex with an HIV positive partner) and HIV transmission to a sero-discordant partner. Non-disclosure of HIV status within intimate relationships is similarly protective in that it resulted in women insisting on consistent condom use with male partners, second to abstinence in reducing transmission risk to sero-discordant partners and minimized re-infection with sero-concordant partners. If male partners insisted on not using condoms, a few of these women preferred to end the relationship rather than disclose their status. Disclosure to partners in intimate relationships, however, may confer greater risk relative to non-disclosure.

Women who disclosed their HIV status to partners reported condom non-use because their partners willingly and knowingly wanted to take the risk of unprotected sex with an HIV female partner. As one woman noted, educating her partner about the decreased risk of transmission when viral load is low and CD4 count is high further perpetuated his desire to forgo condom use. Although, HIV negative partners may be willing to take the risk, transmission is possible and does happen, as evinced by the 22 year old participant who transmitted HIV to her seven-year on-and-off boyfriend who insisted on condom nonuse.

The risks associated with condom non-use are compounded when the male partner has not disclosed an HIV positive status (several women noted they did not know their partner's status) or other sexually transmitted disease status to female partners. It is possible that positive male partners may be more willing to forgo condoms, increasing the risk of re-infection of both partners. And, risk is even further heightened when ART medication is not adhered to by one or both partners, CD4 counts are not high, and viral load is not monitored consistently to ensure it is sufficiently low to reduce risk of transmission. Based on the findings from this study, the following recommendations are offered.



## Recommendations

The HIV Status Disclosure Paradox, coupled with sub-optimal medication adherence, increases the risk of women living with HIV/AIDS being re-infected by sero-concordant partners or transmitting HIV to sero-discordant partners. This vulnerability is particularly worrisome among youth PLHA who report greater medical and behavioral non-adherence relative to their older peers.

The HIV Status Disclosure Paradox suggests that the disclosure process may benefit from discussions with providers (e.g., physicians, nurses, social workers, or peer mentors) to reinforce the need for consistent condom use even when partners want to forgo condoms. These conversations can occur with one or both partners. If both partners are present, providers may reinforce that consistent condom use is akin to loving and trusting a partner because it ensures both partners' optimal health. In the case of sero-discordant partners, the implications for infecting a partner need to be reinforced as well as the possibility of infecting the HIV positive partner with other sexually transmitted infections (STIs). Both partners are responsible for insisting on consistent condom use regardless of the risks one partner is willing to take. Providers can discuss the pros and cons of PrEP with sero-discordant couples in which the uninfected partner is at high-risk of infection. Again, making clear that PrEP is to be used in addition to consistent condom use and not mistaken as a replacement for condoms.

Swiss recommendations have moved to supporting condom non-use when viral loads are undetectable, Vernazza et al. [28] supported by interim analyses from the PARTNER study showing no transmissions among sero-concordant partners in 14 European cities when the infected partner had an undetectable viral load (<200 copies) [29] and findings from HPTN 052 [30]. Furthermore, the introduction and validation of pre-exposure prophylaxis (PrEP) has introduced an additional option for sero-discordant couples [31]. Routine medication administration continues to be essential, however, as the degree of protection provided to the uninfected partner is directly related to their level of daily PrEP adherence [32-35]. Implicit in these recommendations, however, is high adherence to ART to maintain undetectable viral load levels. This recommendation could be misinterpreted if PLHA and/or their partners pay attention only to the behavioral recommendation and not medical adherence. Understanding the decision-making process of placing oneself and one's partner at risk for transmission and/or reinfection is important. This study examines the barriers and facilitators of medical and behavioral adherence with special attention to young PLHA. Programs can be designed to (1) educate partners about the importance of medication and sexual behavioral adherence, and (2) develop advocacy skills among PLHA to promote their and their partners' optimal health.

On the other hand, it is important to acknowledge that avoiding all romantic and sexual relationships is not a healthy and sustainable lifestyle either. Thus, providers can communicate support and non-judgment for sexual relationships and coach patients on how to navigate the process in a caring and responsible way. The lack of direct communication between partners about their desire to have children is evident when participants talk about how they suspect or assume their partners want to get them pregnant. Fertility intention communication among couples is an area warranting future attention. Making childbearing discussions routine will also likely reduce the associated stigma, just as routine opt-out counseling and testing have been shown to reduce the stigma associated with HIV testing. Interventions need to

facilitate communication regarding future childbearing and referral to appropriate preconception services to ensure optimal health outcomes.

## Limitations

This study is limited by several factors. First, this study is limited to a small sample of women living with HIV/AIDS. Additional research is needed to understand the adherence and non-adherence patterns among men who are living with HIV/AIDS and the extent to which these themes are voiced by men as well as other emergent themes. Qualitative interviews with sero-discordant men in relationships with HIV positive women may provide insight into the reasons why some men insist on condom nonuse, willingly taking the risk of becoming HIV positive. Furthermore, interviews with partners may provide guidance about:

1. How they perceive their role (if any) in helping their partners adhere to medication and behavioral regimes
2. If they perceive a role, what resources and strategies would be most helpful in promoting adherence among their partners

Couple level data-particularly on communication and role expectations—is an area in need of future research, including interventions to promote communication and adherence. Specific to sero-discordant partners, further work is needed to establish their understanding and willingness to use PrEP. Second, the findings of this study are based on qualitative data only, however, results from a quantitative study among PLHA in the same setting showed that three-quarters of the 166 participants in a current sexual relationship used condoms, but only 28% reported consistent (100%) condom use [25]. Despite the small sample size of this study, these findings are consistent with and expand upon quantitative findings from a larger sample.

## Study Contributions

Despite these limitations, this study contributes to the field in several ways. Findings from these interviews reveal common themes that lend themselves to strategies and recommendations to enhance adherence. First, developmental tasks prioritize social approval and romantic and sexual relationship formation during adolescence and early adulthood. Adherence to sexual behavioral recommendations calls attention to HIV/AIDS status and stigmatization may interfere with these developmental tasks. Second, HIV positive women of all ages and particularly young women report challenges with medication and behavioral adherence. Third, behavioral adherence facilitators include non-disclosure to partners whereas disclosure undermines adherence when partners insist on risking transmission and/or reinfection *via* condom nonuse (the HIV Status Disclosure Paradox). These barriers, however, can be addressed for most PLHA. Taken together, these findings highlight the need for intensified efforts to support adherence and healthy decision-making among PLHA and their partners, with particular attention paid to young PLHA. This study examines unintended consequences of status disclosure to PLHA and their sexual partners and has implications for optimizing health status *via* educating PLHA and their partners about transmission and re-infection risk and the need to ensure low viral load and consistent medication adherence prior to considering unprotected sexual acts. A combination of strategies is needed to optimize the health of PLHA and their partners because both medical and sexual behavioral adherences are essential. Additional research is needed to understand the adherence and non-adherence patterns of PLHA and to further explore the HIV Status Disclosure Paradox in other samples.

## Compliance with Ethical Standards

Informed consent was obtained from all individual participants included in the study. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

## Author Disclosure

The authors declare that they have no conflict of interest.

## Acknowledgements

We are grateful to the Women's HIV Program for providing funds for participant remuneration and the University of Kansas Medical Center which provided funding for transcription. We acknowledge the contributions of the providers and staff at the two data collection sites, particularly Maria Trent, May Joyner and Mary Ann Knott-Grasso, and Jean Keller, and the valuable assistance with participant recruitment from Rosemary Ramroop, Jennifer Gaver, and Angela Williams. We sincerely thank the adolescent and adult women who participated in this study.

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