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“Keep it to Yourself”: A Qualitative Study of HIV Disclosure Perspectives among Older Adults Living with HIV who are Childhood Sexual Abuse Survivors in South Carolina

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Abstract

HIV disclosure is an important consideration for people living with HIV. The prevalence of childhood sexual abuse (CSA) may range from 16–22% among older adults living with HIV. There is a dearth of research on HIV disclosure among older CSA survivors. Therefore, the aim of this study was to qualitatively examine HIV disclosure among older CSA survivors living with HIV. Twenty-four CSA survivors living with HIV (aged 50–67 years) participated in in-depth, semi-structured interviews. Data were analyzed thematically, and the iterative coding and analytic process included discussion of initial thoughts and key concepts, identification and reconciliation

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of codes, and naming of emergent themes. Four themes emerged: 1) secrecy/not planning to disclose HIV; 2) disclose HIV regardless; 3) disclose HIV depending on the person; and 4) disclose HIV depending on the circumstance. Lack of disclosure may be due to HIV-related stigma. HIV disclosure intervention programs may be beneficial for this population.

Keywords

HIV disclosure; older adults; qualitative; trauma

Introduction

Due to notable improvements in HIV care and treatment, people are living longer with HIV (Centers for Disease Control and Prevention (CDC), 2020). In 2018 in the United States (US), approximately 20% of new diagnoses and half of people living with HIV were aged 50 and older (CDC, 2020). It is important that research on older adults living with HIV continue to explore how HIV may impact their health outcomes and quality of life.

HIV disclosure (telling others about one's own HIV serostatus) is a key consideration for people living with HIV and has been linked to a reduction in the risk of HIV transmission (O'Connell et al., 2015). One theory that may help in the understanding of HIV disclosure is the Consequences Theory of HIV Disclosure, which states that if the benefits of disclosing outweigh the costs, then people are more likely to disclose their HIV status (Serovich, 2001). In light of this theory, benefits of HIV disclosure may include social support (Zhang et al., 2021), better HIV treatment adherence (Mi et al., 2020) and opportunities to talk about HIV risk reduction with sexual partners (Dessalegn et al., 2019). Costs may include blame, stigmatization, (Dessalegn et al., 2019) and/or intimate partner violence (Brown et al., 2016). A seminal study found that disclosure of HIV status tends to be more common among women, White and Latinx, and younger populations compared to men, Black, and older populations (Mayfield Arnold et al., 2008). Specifically, older persons are likely to disclose their HIV status to fewer persons and are less likely to disclose to family, friends, and health care providers due to stigma, protecting and maintaining their status and privacy (Hlongwane & Madiba, 2020).

One group of older adults living with HIV that is understudied are those who have survived childhood sexual trauma. A link has been established between childhood sexual abuse (CSA) and risk of HIV infection, where CSA survivors were more likely to report working as sex workers (Zierler et al., 1991). In their seminal study, Zierler et al (1991) found that women CSA survivors were more likely to report becoming pregnant before age 18 and men CSA survivors were twice as likely to have HIV compared to those who did not report CSA (Zierler et al., 1991). Indeed, rates of childhood sexual abuse (CSA) among people living with HIV are two to four times those seen in the general population (Schafer et al., 2013). Prevalence estimates among older adults living with HIV may range from 16–22% given that among older adults living without HIV, the prevalence of CSA ranges from 8–11% (Choi et al., 2017; Chou, 2012). While this sexual trauma may have occurred in childhood, its effect can continue to negatively impact their lives in adulthood and may manifest as depression and posttraumatic stress disorder (PTSD) (Danese & Lewis, 2017), and may exacerbate the relationship between disease burden and inflammation among older adults living with HIV (Derry et al., 2021). Therefore, it is important that research examines older adults living with HIV who are CSA survivors to determine factors that may improve their overall quality of life.

In summary, few studies have examined the perspectives of HIV disclosure of older adults living with HIV using a qualitative approach. To our knowledge, no study has examined HIV disclosure perspectives of older adults living with HIV who have survived CSA. The philosophical underpinnings of the current research are that the perspectives on HIV disclosure from older CSA survivors living with HIV may differ from older populations living with HIV who have not undergone that trauma, which could be viewed as interpretivism (i.e., subjective views of participants about issues that affect them within a social context) (O'Reilly, 2009). For example, having a CSA history may influence the likelihood of HIV disclosure. As a result, a qualitative approach was warranted to explore HIV disclosure perspectives among this population. As older adults are less likely to disclose their HIV status compared to younger populations, the aim of this study was to explore the views on HIV disclosure among older adults living with HIV who are also survivors of childhood sexual trauma.

Methods

Setting and Participants

The study was conducted in South Carolina – a state designed as a high-priority HIV area (CDC, 2018). To be eligible, participants had to be living with HIV, 50 years of age or older, and had experienced (self-report) CSA before age 18. After obtaining approval from the University of South Carolina Institutional Review Board (Pro00084536), we recruited a purposive sample of older CSA survivors living with HIV from an immunology clinic in South Carolina through fliers and clinic staff approaching potential participants. Fifty-five participants expressed interest in participation but 30 were ineligible due to not experiencing CSA and/or being younger than 50 years old. Therefore, 25 participants were recruited for the study and one potential participant did not show for their appointment. Following informed consent, 24 participants were interviewed. The interviews were conducted in English in a quiet place and were scheduled to last approximately an hour. Twelve participants identified as cisgender male, 11 as cisgender female and one as transgender female. More than half (n=16) of the participants identified as Black, and a quarter (n=6) identified as White. Four percent (n=1) of the participants identified as Native Hawaiian/Pacific Islander, and the same proportion (4%) identified as American Indian/Alaskan Native and Latinx/Hispanic (Brown et al., 2021a). The Latinx/Hispanic participant also identified as Black.

Instruments

Interview questions were collaboratively developed by a multidisciplinary team with expertise in public health, sociology, HIV, and epidemiology. The development of the interview questions was informed by experiences working with older adults living with

HIV, HIV interventions, as well as experiences in researching childhood sexual trauma. The questions for the participants focused on their general/overall health, experiences with aging with HIV, coping strategies, support systems, barriers and facilitators of ART adherence, their experience with childhood sexual trauma and its potential impact on aging with HIV, and their views on “U=U” (Undetectable=Untransmissible).

Data Collection

The clinic staff helped recruit participants by informing potential participants about the study’s eligibility criteria and study team contact information. If potential participants were interested, research team members scheduled an appointment to determine eligibility through screening, obtaining informed consent, and conducting the interview. Interviews were in-person and were audio-recorded. Interviews lasted from 16 to 62 minutes with the mean time of interviews being 31 minutes (Brown et al., 2021b). Interviews were conducted by TJ or AK, who were trained in qualitative interviewing techniques. The interviews were conducted in a private room at the clinic or on campus. To ensure confidentiality, each participant was assigned an ID number. We used a semi-structured interview guide to explore the potential link between childhood sexual trauma and aging with HIV. Interviewers used probe questions such as “tell me more about that” and encouraged participants to add more detail to their answers via repetition of the participant’s last few words (Brown et al., 2021). Questions on HIV disclosure asked participants if everyone in their support system knew they were living with HIV with the following probes: “Who does and who doesn’t? Please explain,” and “If not everyone knows, are you planning to disclose your status to anyone else? Please explain.” Data were collected from October 2019 to February 2020.

Data Analysis

Otter.ai (Los Altos, CA) was used to transcribe interviews. The thematic analysis approach (with constant comparative analysis) was used for data analysis (Saldana, 2015). We also used a phenomenological approach. Data analysis commenced with reviewing the transcripts. This review was conducted to ensure accurate representation of participants’ statements (Brown et al., 2021a). Two authors (TJ and AK) independently determined transcripts’ accuracy by reviewing transcripts and listening to audios of interviews. Four authors (MJB, CAN, TJ, and AK) then independently used line by line coding to code the interviews. During the coding process, team members (MJB, CAN, TJ, and AK) met weekly to resolve differences among codes that were identified. This occurred via discussion of thoughts, assumptions, and understandings of fundamental concepts. The four team members independently collapsed the codes into themes and subthemes; met to resolve any discrepancies among identified themes and subthemes; and discussed the relationships between themes and subthemes (Brown et al., 2021a), and how well the themes reflect the participant’s perspective of HIV disclosure. Our previous work with these data examined intervention program needs for older adults living with HIV who have a history of CSA (Brown et al., 2021a), explored CSA perspectives among older adults living with HIV (Brown et al., 2021b), and assessed psychosocial challenges among the study population (Hart et al., 2022). The reporting of the current study was guided by the Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007) and focused on HIV disclosure. Saturation was assessed using code frequency counts and code meaning (Hennink & Kaiser, 2022). Data saturation often occurs within 9–17 interviews using empirical data (Hennink & Kaiser, 2022).

Four concepts are usually used to address rigor in qualitative studies: credibility, transferability, dependability, and confirmability (Lincoln, & Guba, 1985). Credibility was attained by garnering data on participants' lived experiences by interviewing the participants. Transferability was obtained by using the purposive sampling method, providing a rich description of the data, and continuously returning to the transcriptions (Cypress, 2017). Dependability was enhanced by reviewing the transcribed text to validate the themes and subthemes. Confirmability was attained by using an audit trail (Cypress, 2017), by describing how we attained themes from codes and rationalizing what codes were aggregated to form the foundation of themes (Statistics Solutions, 2022).

Results

The following key themes emerged from the data: 1) secrecy/not planning to disclose HIV; 2) disclose HIV regardless; 3) disclose HIV depending on the person; and 4) disclose HIV depending on the circumstance. They are briefly discussed below under sub-sections:

Secrecy/Not Planning to Disclose

Most participants reported that they were not planning to disclose their HIV status mainly due to fear of stigmatization. They would rather keep it as a *'secret'* than to be stigmatized after disclosure. When asked about who in their social networks knew about their HIV status and if they were planning to disclose to anyone else, a 50-year-old Black woman stated:

> "No. Because…that's when people start treating you funny when they know stuff about you. You know, so to keep that humiliation down. I just…they don't need to know."

Another 52-year-old Black woman also shared her views:

> "My views on HIV disclosure, keep it to yourself because people tend to not be nice. Keep it to yourself."

It is evident from above that the fear of stigmatization impacted some participants' decision not to disclose their HIV status.

Disclose Regardless

It seems some participants had transcended health-related stigma, because they were open about their HIV status. They thought it was necessary regardless of the situation. A 51-year-old White woman sharing her experience reported:

> "I am very open and honest. Because if you don't accept HIV and a discussion about it, I don't need nothing to have to do with you."

Another woman shared the same sentiment, and she believes it is criminal for anyone not to disclose their HIV status, especially to their sexual partner:

> *"It's necessary. If you know, criminalization is big. If you don't want to go to jail, tell your status. Must disclose, especially disclose to your partner who you plan on having sex with, whether it's protected or unprotected.* (50 years, Female, Black)

From this, one could deduce that HIV disclosure depends on how an individual perceives it. Some participants felt that HIV disclosure was both morally and legally required to protect others, especially sexual partners.

Disclose Depending on the Person

Some participants reported having to be selective about whom they wanted to disclose to. Some felt the target's knowledge about HIV is key to their disclosure. For example, a 53-year-old Black male maintained that:

> "I don't think it's something you can just talk to any and anybody about openly because they don't, you know, like I say they are uneducated. I believe if people had the education now you could probably talk to them about it."

Some were more comfortable sharing their status with someone who was also living with HIV because they believe the person will understand them better.

A 54-year-old White female stated:

> "For me, it depends on who I would be with. If it was somebody else positive, I think that it would go over a lot better. If it was somebody that actually understood, it might work. But for most of the population, I think right now it's still 'Nope, you have HIV, I don't want to have anything to do with you'."

HIV-positive status and knowledge of the other person were key for some participants before they could disclose their HIV status.

Disclose Depending on the Circumstance

Some participants reported that HIV disclosure depends on the circumstances. They will divulge their HIV status if it is medically required or very important. For example, some reported that they can disclose to their doctors or sexual partner. A 58-year-old White male felt it was necessary to disclose his status to his sexual partner and doctor:

> "I still don't think anybody should have to disclose their status except where it is medically necessary to do so. Or if they have a sexual partner, I think it's important that they know upfront that you would have the disease, but you are on medication, and it is completely suppressed because that's the choice they need to make on how they want to deal with that."

Similarly, a 62-year-old Black female shared her experience:

> "Oh, if I have to I will. But if they don't ask, I'm not gonna tell you [at] all. I mean if it comes down to sex. Yeah, I'm gonna tell it but somebody come up and say are you HIV you know like in the street. No. I won't disclose that out there like that. No. To my doctors and whatever. Yeah."

Gender Differences and Similarities

Examining disclosure perspectives and plans by gender revealed some differences and similarities. For example, women were more likely to state that "everybody knows" or "most people know" compared to men who tended to say "some people know". This shows that women were more likely to reveal their HIV status than men. Early exposure to sexual and reproductive health services among women could impact their willingness to disclose their HIV status. A 50-year-old Black female, when asked if everyone in her support system knew that she was living with HIV, stated: "Yes…everybody knows", while a 53-year-old Black male stated that only his brother knew about his HIV status and he wasn't planning on disclosing to anyone else. Nevertheless, a 60-year-old Black female stated that her support system knew and she was not planning on disclosing to anyone else.

Overall, HIV disclosure depends on an individual's HIV status, knowledge, and different circumstances. While some participants will share their HIV status, depending on the situation, others will not because of fear of stigmatization. In fact, even among those who reported that they can disclose their HIV status, they still feared HIV-related stigma.

Discussion

Views on HIV disclosure varied among participants. Some participants were not planning to disclose, while some thought disclosure irrespective of the person or situation was important. Others thought that disclosure was dependent on the person or the circumstance. In considering the risks and benefits of disclosing based on the Consequences Theory of HIV Disclosure (Serovich, 2001), some participants may be hesitant to disclose their HIV status due to anticipated or enacted HIV-related stigma due to potential rejection or further disclosure without consent (Chapman Lambert et al., 2020). Previous quantitative research has found a correlation between lack of HIV disclosure and greater perceived HIV-related stigma (Yin et al., 2019).

Few studies have examined HIV disclosure among older adults living with HIV using a qualitative approach. Emlet (2008) found seven themes related to HIV disclosure among older adults living with HIV. These themes were "non-disclosure, protective silence, anticipatory disclosure, violations of confidentiality, unintentional disclosure, and intentional disclosure", including limited and open disclosure. The concept of forced disclosure, which was evident among Emlet's findings, was not a salient theme that was encountered in the interviews for the current study. Differences over time in how HIV is perceived could be an explanation. For example, though HIV stigma still exists, research has shown a decrease in enacted stigma (Hedge et al., 2021). However, the non-disclosure and protective silence themes from Emlet (2008) are most akin to the *secrecy/not planning to disclose* theme in the current study's findings, while the open disclosure theme is similar to the *disclose regardless* theme in the current study.

Nevertheless, previous studies have examined HIV disclosure among other populations living with HIV using qualitative methodology. For example, research has examined HIV disclosure among sexual minority men. The themes that arose from this study included: disclosure (passive or active); and non-disclosure (passive or active (concealment)) (Perlson et al., 2021). These themes are similar to the themes in the current study where concealment may be akin to *secrecy/not planning to disclose*; and the theme of disclosure (whether active or passive) is similar to disclose regardless. Perlson et al. also examined the disclosure of different identities such as sexual orientation and substance use, which did not arise in the current study. Lambert and colleagues also examined HIV disclosure among newly diagnosed patients. HIV disclosure was related to improved social support, and the confidence to disclose to additional individuals. However, stigma was a barrier to HIV disclosure as patients feared that they would not be accepted or that others would be told about their HIV status (Chapman Lambert et al., 2020). The findings on HIV stigma corroborate what was found for the *secrecy/not planning to disclose* theme in the current study, as patients had anticipated stigma and some had experienced stigma first-hand.

History or experience with CSA disclosure may also be related to HIV disclosure during older adulthood. Research has shown that women living with HIV with a history of CSA may experience challenges with disclosure of HIV serostatus to sexual partners (Clum et al., 2013). For example, disclosure of CSA was associated with self-blame (McElvaney & Culhane, 2017), fear of family breakdown and removal from family (Brazelton, 2015), revictimization, and retribution (Brazelton, 2015). These factors may result in avoidance, related to PTSD, which may lower the likelihood of HIV disclosure (Clum et al., 2009). Even though this theme was not evident in our study, it is possible that older adults' negative experiences with CSA disclosure such as disbelief and apathy can also contribute to hesitancy in disclosing their HIV status in later life. Similarly, positive experiences from CSA disclosure such as understanding, and sympathy may contribute to more openness in disclosing their HIV status and warrants further investigation among this population.

With respect to gender differences and similarities, some quantitative studies have not reported statistically significant differences in HIV disclosure by gender (Longinetti et al., 2014; Yin et al., 2019). Nevertheless, one study found that while there were no significant differences between heterosexual men and heterosexual women, these groups had a higher prevalence of HIV disclosure compared to men who have sex with men (Przybyla et al., 2013). In our current study, using a qualitative approach, we found that women were more likely to state full disclosure compared to men.

The findings of this study should be considered with limitations in mind. First, the study focuses on older adults living with HIV who had experienced CSA. Comparing the HIV disclosure perspectives of older adults with and without a CSA history would help to determine those factors that may be unique to the CSA history (Clum et al., 2013). It is also necessary to identify selection bias. The participants who were willing to report their CSA history may be more open in general and may have relatively more liberal views with respect to HIV disclosure compared to participants who are not willing to report a CSA history. In addition, these participants were receiving HIV care and their views may not be reflective of older CSA survivors living with HIV who may not be in care. The majority of participants were Black and views here may not represent the varying cultural aspects that may be related to HIV disclosure. Future research should aim to address potential differences in HIV disclosure among this population by race/ethnicity.

Conclusion

By examining HIV disclosure insights among older adults living with HIV with a history of childhood sexual trauma, this approach may help to inform trauma-informed interventions geared towards HIV disclosure decisions for this population. Future research should examine the feasibility of implementing HIV disclosure interventions among older CSA survivors. Indeed, disclosure interventions may increase social support and retention in HIV care (Chapman Lambert et al., 2020), which may improve HIV treatment outcomes and overall quality of life.

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Key Considerations

- The Southern US continues to be disproportionately affected by HIV/AIDS with higher prevalence and incidence estimates.
- Trauma, including childhood sexual abuse, is commonly reported among people living with HIV.
- As people living with HIV age, they may have unresolved trauma, especially sexual trauma from childhood.
- A history of childhood sexual abuse may impact HIV disclosure attitudes and perspectives among older adults living with HIV.
- In our qualitative interviews, we found that disclosure perspectives varied, and some participants suggested disclosing regardless while some were not planning to disclose. In addition, the decision to disclose was dependent on the person and the circumstance.
- Trauma-informed disclosure interventions for older adults living with HIV who are survivors of childhood sexual trauma are warranted.