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Complexities of HIV Disclosure in Patients Newly Entering HIV Care: A Qualitative Analysis

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Abstract

The role of HIV disclosure and its influence on engagement in HIV care after initial linkage to care is not well understood. We conducted 28 in-depth interviews with patients newly entering HIV care. Gaining access to social support was a key reason that many patients disclosed their HIV status. For some, HIV disclosure improved support networks related to engagement in care at the time of care entry, in the form of appointment reminders, emotional support, and confidence to disclose more widely. However, some participants cited anticipated stigma as a barrier to disclosure, as they feared rejection or further disclosure without their permission. Early access to social support and skill building related to stigma reduction and coping can be useful resources to help patients manage HIV, as they initiate care. In addition, incorporating support for smart

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disclosure decisions into interventions may improve access to social support, ultimately improving engagement in care.

Keywords

adherence; engagement in care; iENGAGE; new to care; social support; stigma

HIV continues to be a major public health concern in the United States, with approximately 40,000 new cases annually (Centers for Disease Control and Prevention [CDC], 2017; 2019b). New HIV cases in the United States remained stable from 2012 to 2016 with declines in some populations because of public health efforts to diagnose early, rapidly link to care, effectively treat, and prevent HIV using evidence-based strategies (CDC, 2019a). However, public health efforts have not been evenly distributed geographically across the country, with the Southeastern United States accounting for more than half of new HIV cases and nearly half of people living with HIV (PLWH; CDC, 2017; 2019a).

Newly diagnosed individuals contributed to the estimated 1.1 million individuals living with HIV in the United States; of which, approximately 14% were unaware of their HIV status, 75% were linked to HIV care in a timely manner (within 1 month of diagnosis), 57% were retained in continuous HIV care, and 58% were virally suppressed (CDC, 2016, 2019b). These data suggest that PLWH drop out at each step along the HIV care continuum from initial diagnosis to achieving the goal of viral suppression (U.S. Department of Health & Human Services, 2016). Retention in continuous HIV care is a prerequisite to the receipt of antiretroviral therapy (ART) and a predictor of survival; however, this stage along the HIV care continuum represents the largest proportion of drop-off (Mugavero et al., 2012). It is important that retention in HIV care has historically been suboptimal in patients newly entering HIV care, which has implications for disease transmission, receipt of ART, and survival (Horberg et al., 2013).

The first year after entry into HIV care is a critical time for patients to establish lifelong self-care behaviors, including attending regular health care visits and initiating lifelong ART, which have critical implications for survival. In addition, the first year can be mentally and emotionally overwhelming, as patients enter care, learn to cope with living with HIV, and develop strategies for managing psychosocial issues, such as HIV status disclosure. HIV disclosure has significant implications for HIV prevention, retention in HIV care, and ART adherence, as well as for gaining access to social support and reducing HIV-related stigma (Go et al., 2016; Greene, Derlega, Yep, & Petronio, 2003; Hightow-Weidman et al., 2013). HIV disclosure has been positively associated with enhanced social support networks (Go et al., 2016), retention in HIV care (Anderson et al., 2018; Colasanti, Stahl, Farber, Del Rio, & Armstrong, 2017), and ART adherence (Stirratt et al., 2006).

Although there are clear advantages to HIV disclosure, there are also disadvantages, such as HIV-related stigma. Reasons for and against disclosure have been widely reported by patients established in HIV care. Reasons for HIV disclosure have included gaining access to social support; reducing or relieving stress; telling those who needed to know, such as family members and close friends; and increasing awareness of HIV (Gaskins et al., 2011;

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Naigino et al., 2017; Siu, Bakeera-Kitaka, Kennedy, Dhabangi, & Kambugu, 2012). A study conducted in Uganda with pregnant women reported that women disclosed to female relatives (i.e., mothers, aunts, or sisters) to gain emotional and tangible support (Naigino et al., 2017). Similarly, Gaskins et al. (2011) explored reasons for HIV disclosure and nondisclosure in 40 African American men residing in the Southeastern United States and reported that participants disclosed to family members, close friends, and intimate partners to gain support, and that the act of disclosing not only increased access to social support but helped to reduce stress.

Access to social support from family members and intimate partners has been reported as a positive consequence of disclosure, but HIV-related stigma is commonly reported as a negative consequence of disclosure (Gaskins et al., 2011; Li, Chen, & Yu, 2016; Smith, Rossetto, & Peterson, 2008). In a sample of 297 participants, perceived HIV-related stigma was negatively associated with disclosure; at higher levels of perceived HIV-related stigma, disclosure decreased (Li et al., 2016). Similarly, in a sample of 40 African American men in the Southeastern United States, participants reported not disclosing their status to avoid stigma (Gaskins et al., 2011). On the other hand, a sample of health care workers living with HIV disclosed their HIV status to colleagues with the goal of reducing HIV stigma (Stutterheim et al., 2017). Other negative consequences of disclosure included rejection, blame, isolation, loss of financial support, mental distress, and violence (Gaskins et al., 2011; Naigino et al., 2017; Siu et al., 2012).

HIV disclosure can have positive or negative consequences for PLWH, and disclosure often happens when positive consequences overshadow negative consequences (Gaskins et al., 2011). Although HIV disclosure is widely known to be of concern for PLWH, most studies focus on patients already established in HIV care. Little is known about the role of disclosure in patients newly entering care (Elopre et al., 2016). Therefore, the purpose of our study was to qualitatively explore the role of HIV disclosure on engagement in HIV care in a sample of patients new to HIV care.

Methods

We conducted a descriptive qualitative study. Ethical approval was obtained from the institutional review boards of the University of Alabama at Birmingham and the University of Washington.

Participants

Study participants were recruited from participants enrolled in the Integrating ENGagement and Adherence Goals upon Entry (iENGAGE) trial at two US HIV clinics affiliated with academic health centers in Alabama and Washington (Modi et al., 2018). The iENGAGE study was a multisite randomized controlled trial with sites in Maryland, Alabama, Washington, and North Carolina. The purpose of the iENGAGE trial was to test an intervention for patients newly entering HIV care to enhance information, motivation, and skills for optimal HIV health care visits and ART adherence. Participants were randomized to the intervention arm or the control arm. The control arm received standard of care treatment, whereas participants in the intervention arm received four face-to-face counseling

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sessions focused on ART and health care visit adherence, scheduled and unscheduled contact including missed visit calls, and appointment reminders (Modi et al., 2018).

To maximize participant variation, we used purposive sampling to recruit participants from iENGAGE intervention and control arms, including participants who had and had not achieved HIV viral suppression at the conclusion of iENGAGE participation (48 weeks after study enrollment). Recruitment continued until data saturation was reached, which is the point of information redundancy. Potential participants were approached by a project coordinator during final iENGAGE study visits or through telephone, at which time screening ensured that they met the following inclusion criteria: enrolled in the iENGAGE study in Alabama or Washington; completed the 48-week study visit; living with HIV; 18 years of age and older; and able to speak and understand English. The Alabama and Washington sites of the trial were interested in participating in this substudy and had appropriately trained qualitative researchers on staff to conduct qualitative interviews. In addition, the Alabama and Washington sites had similar characteristics, including providing primary HIV care services only to PLWH.

Data Collection

In-depth interviews were conducted using a semi-structured interview guide, which was designed based on a review of HIV engagement in care and the adherence literature, as well as on a conceptual framework of the effects of stigma and disclosure on HIV-related behaviors and outcomes (Turan et al., 2017). Interviews began with an introduction of the interviewer and the purpose of the study. We then asked open-ended questions about participant communities, engagement in HIV care, disclosure and close relationships, and experiences of stigma and discrimination. Interviewers probed topics for examples, experiences, and context. Table 1 provides a sample of questions related to disclosure.

In-depth interviews were conducted in a private office between May 2015 and February 2016. Interviews were conducted by five interviewers with extensive qualitative training and interview experience who shared racial and gender demographics with the target population. Interviews were recorded with a digital voice recorder and transcribed verbatim by a professional transcriptionist, and notes were taken by interviewers during interviews to supplement audio recordings. Each interview lasted approximately 60 min. After completion of the interview session, each participant received a $30 incentive for their time and travel. This amount was approved by the institutional review boards, and the amount was consistent with similar studies conducted at the study sites.

Data Analysis

Data were coded and analyzed using Dedoose qualitative analytic software (version 7.6.21, 2017) by four coders. Each pair of coders independently coded the same two transcripts, and the transcripts were compared for similarities and differences in coding; any disagreements were discussed until the team reached consensus (Merriam & Tisdell, 2016). We used thematic analysis techniques to analyze and interpret patterns in the data (Braun & Clarke, 2006). Initial coding was based on major topics in the interview guide. Then, through an

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iterative process, the codebook was refined as new codes, and themes emerged from the data.

Data Rigor

We used several strategies to assure rigor and trustworthiness. We began by ensuring congruence between the design, purpose, and data collection method (Miles, Huberman, & Saldana, 2019). To ensure confirmability, we described the study methods and procedures, maintained the data, and created an audit trail so that it could be available for reanalysis. We enhanced the dependability and credibility by simultaneously collecting and analyzing data, and having four authors independently reviews and codes transcripts and discusses issues related to data divergence. Transferability was enhanced by the use of purposive sampling and by providing rich descriptions to allow the reader to assess transferability of findings to other settings and samples (Miles et al., 2019).

Results

Sample Characteristics

We interviewed 28 participants ranging from 21 to 56 years of age. The majority of participants (20/28; 71%) resided in Alabama. Fifteen participants (53%) self-identified as African American or Black, 1 (0.04%) self-identified as Hispanic, and 19 (68%) self-identified as male. Additional sample characteristics are provided in Table 2.

Four major themes related to disclosure emerged in the analysis as follows: the role of HIV disclosure on engagement in HIV care and ART adherence, reasons for HIV disclosure, negative consequences of HIV disclosure, and positive experiences after HIV disclosure. We did not identify any age, race, or gender differences related to disclosure.

Theme 1: The Role of HIV Disclosure on Engagement in HIV Care and Adherence

Participants said that members of their support networks encouraged them to adhere to ART and health care visits with appointment reminders, medication adherence reminders, and general social support. However, some participants described worry or fear about being seen by others while attending health care visits. In addition, participants reported that HIV disclosure improved social support networks in the initial year after linkage to care.

HIV care visit attendance.—One participant said that, after disclosure, her boyfriend encouraged her to keep her appointments despite competing demands: “Yeah, he be, he fuss at me when I don’t go [to the clinic], he fuss and I’m like, ‘Get out my face.’ And, ‘I had something else to do’” (26-year-old African American woman, control group [CG], Alabama [AL]). She continued to describe how she frequently spoke with her best friend and how that friend texted to remind her of upcoming health care appointments: “And, we’ll talk about some most everything, we talk, we talk, we talk. Like she text my phone last night, ‘Keep your appointment’ and all that, ‘Keep your head up, I’m praying for you,’ all that.”

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Participants also stated that fear of being seen attending health care visits by individuals who were unaware of their HIV status had the potential of leading to unwanted disclosure, which could negatively affect health care visit adherence. A 24-year-old White man stated, “There is always the fear—not fear, but worries that when I do go to the doctor, will there be people in the parking lot or in the office that I know that do not know?” He described situations in which he saw people who were aware of his HIV status, thereby making the situation more comfortable, less awkward, and less of an obstacle to attending appointments. Another male participant expressed how he tried to ease the awkward situation of seeing someone at the clinic who was unaware of his status: “I just walked in. He looked at me like he saw a ghost. He was like, ‘What you doing here?’ I said, ‘The same reason you’re here. I’m here to get some medicine’” (21-year-old African American man, CG, AL).

Antiretroviral therapy adherence.—A female participant described how, after she disclosed to her mother, her mother encouraged her by frequently inquiring about her ART adherence:

> I guess especially with the medication, like my mom, she knows about the medication so I think that would make me feel a little bit better to know I probably have someone like, “Did you take your medicine?”
>
> (38-year-old African American woman, intervention group [IG], AL)

Another participant said his mother encouraged him to take ART to prevent mortality:

> She told me how her best friend had HIV. He was gay. He didn’t take his medicine. He died. She said she didn’t want her son to be in the same boat that her best friend was. I got put on medicine and all that good stuff.
>
> (21-year-old African American man, CG, AL)

HIV disclosure made ART adherence easier for one participant because he did not have to hide taking his medication. He stated, “It [disclosure] does make it easier. I don’t mind pulling out my bottle. I don’t mind popping a pill in front of people” (50-year-old White man, IG, Washington [WA]). On the other hand, some participants described how fear of disclosure interfered with ART adherence. One woman hid her medication to prevent unintentional disclosure: “When I stayed down at my daughter’s, I keep my medication out in my car and I sneak out there” (45-year-old White woman, CG, WA).

Others did not feel that disclosure played a role in ART adherence. When asked if disclosure influenced ART adherence, many participants simply stated, “No.” Other participants were more expressive: “I don’t care who sees me taking any medicine. I don’t care anything about that, you know what I’m saying?” (37-year-old African American man, IG, AL).

Another participant stated, “[ART] are just expensive little pills. I am not taking them for other people generally. I am taking them for me” (24-year-old White man, IG, AL).

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Theme 2: Reasons for HIV Disclosure

Participants reported reasons for disclosing their HIV status to friends, families, and others, including disclosure on a "need to know" basis and to have a sense of peace, increase HIV awareness, gain social support, and combat HIV-related stigma.

Need to know basis.—Participants used the term "need to know" to refer to restricting information about personal HIV status to individuals who needed the information to help prevent or treat HIV and for reasons, such as disclosure to potential sex partners before intimacy. In addition, need to know was used to refer to disclosing to friends or family members who might serve as caregivers in times of need or simply to inform friends or family members as to why they went to the clinic. A participant described disclosing before intimacy:

> It was easy because, like I said, the more I disclose to my friends, the more comfortable I am with telling whoever about it. And so, we were just talking and I felt like it was getting to that point [for intimacy], I felt the need to let him know up front before anything really happened.
>
> (28-year-old African American man, CG, AL)

Another participant disclosed to inform those who needed to know why he attended the clinic:

> … letting people know that need to know is good so that way they understand like … why I am coming here [the HIV clinic]. … I mean there is no benefit to telling someone. It is just to let them know why I am here. I don't get a pass because I have HIV, right?
>
> (21-year-old White man, CG, WA)

On the other hand, one participant wanted people close to her to know in the event she got sick, but she was afraid of the reactions: "In a way I want them to know, but in a way I don't want them to know because I don't know how they're gonna react" (37-year-old African American woman, CG, AL).

Peace of mind.—Participants also described how disclosing their HIV status gave them peace of mind. One participant described early disclosure of his HIV status as a way of protecting himself from sudden and unwanted reactions:

> … because it messed with my mind so much to the point where I almost told them. I said, "Because I would rather face it head on than have it pop up and if this [HIV] bothers you, then I would rather already know so we can just go ahead and get this out of the way." It might be my way of protecting myself.
>
> (29-year-old African American man, IG, AL)

Another participant described disclosure as being therapeutic: "…I would say it is almost therapeutic to be able to say I am open to talking about it. If 'you have questions, let me know and I will tell you…'" (24-year-old White man, IG, AL).

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Disclosing to increase awareness.—Several participants disclosed to dispel myths about HIV in the community. For example, a 39-year-old African American man said he disclosed to change negative perceptions about the appearance of someone living with HIV, such as unintentional weight loss, ill appearance, and dermatologic abnormalities:

> … It helps the person to see a living person that somebody that is living with the disease and it is not the idea that they have in their head. Like when you think of a drunk, you think of the guy, one of the wino's laying outside the building, whatever. They think about an HIV person … as someone that's emaciated and sick and sores and lesions and stuff open, but I'm a healthy man. So, it helps.
>
> (39-year-old African American man, IG, AL)

Another participant wanted to increase HIV awareness in the community to help people take action to prevent HIV. He said:

> Maybe they won't make the same mistakes that I made. I tend to talk to my cousins, my friends, the people that are younger than me. I tend to explain to them the risk of having unprotected sex. The things that you can get from doing these things so maybe I can help somebody from contracting HIV.
>
> (33-year-old African American man, CG, AL)

Disclosure to gain social support.—Participants commonly reported disclosing their HIV status to gain social support. One participant discussed the importance of disclosing to a potential sex partner before intimacy to gain emotional support.

> … I just feel like, obviously, if you are going to date someone, they are going to need to know. And having their support is just as important as having a friend or a family member's support. I think that is more of an emotional investment than it is just typically a physical one, if that makes sense.
>
> (20-year-old White man, IG, AL)

Another participant disclosed to her best friend in the event that she needed tangible support, such as transportation to a clinic visit or assistance with activities of daily living if she was too ill, "… My best friend, I just told her just…you know, just because she's my best friend, just in case I might need her or something like that. Some kind of care or something. I told her, too" (37-year-old African American woman, CG, AL).

Peer support.—A few participants highlighted the importance of disclosing to other PLWH to gain peer support because peers understood. Peers were more likely to know potential side effects of ART and the meaning of laboratory tests.

> It was nice to disclose to somebody who is also HIV-positive because they understand generally. They know what going to a doctor is like, having all the blood taken. They know about the medications. Then you can ask, "What is your viral load?" They will know what that means or what your CD4 is. It is a way to relate with people.
>
> (24-year-old White man, IG, AL)

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Disclosing to combat stigma.—Participants combatted HIV-related stigma by disclosing. One participant explained that he was the voice of reason during negative conversations about HIV, which allowed him to fight stigma.

> … I've always been honest about—I mean I don't run around and prance and tell everybody that I'm HIV positive—but if it comes up in conversation or, obviously, for the people I'm closest to. … And there have been a few times where I had to be the voice of reason. Well that's a stigma. Look at me. I'm HIV positive and none of that pertains to me. So yeah … I will disclose to fight the stigma.
>
> (37-year-old Latino man, CG, WA)

Theme 3: Negative Consequences of HIV Disclosure

Although many participants enhanced social networks through disclosure, others reported that they avoided disclosure because they feared it would result in rejection, unauthorized disclosure to others, and stigma. Others had actual negative experiences with people after disclosure, including loss of relationships and unwanted disclosure to others.

Rejection.—One participant discussed her disclosure experience with her best friend who initially said that she would be supportive: "Well at first she was like 'Well, I'll be there for you,' and 'If you need anything just let me know' or whatever." However, the friend withdrew from the relationship:

> Now it's like we're kind of distant. She just got married and got a baby and all this stuff. But I don't get to talk to her as much as I used to. I don't know. My husband thinks it because of my status.
>
> (37-year-old African American woman, CG, AL)

Some participants felt that rejection by family members could be more devastating than rejection by friends. One participant said that she only disclosed to people who she perceived would not reject her. For example, she feared being rejected by her daughter if she disclosed her HIV status: "The ones that I feel would reject me, like my daughter, it's just her personality, who she is. She is very quick to judge somebody and push them away…" (45-year-old White woman, CG, WA). One participant was rejected by his family when he disclosed. He felt he was rejected because of the religious beliefs of his family members: "I told my family, and they told me that I was toxic and not to speak to them again. They're Jehovah Witnesses, so whatever. So I just left that alone. I didn't message them back or anything" (29-year-old White man, IG, WA).

Unintentional disclosure to others.—Participants described their experiences with unintentional disclosures of their HIV status. One man noted that he disclosed to someone who he considered a friend in whom he could confide, but the person disclosed his status to others without his permission: "I really only told one friend. We're not friends anymore because he went around telling people" (21-year-old African American man, CG, AL). Another man had a similar experience:

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> I had someone, a couple of months ago text me and ask if it was true. I was like, "Well, who told you?" … they would not tell me. I just had to put it out of my mind because I am not going to beg you to tell me who told you.

He continued to say that he was disappointed that someone would betray his trust and disclose his status without permission. He indicated that this experience would influence future disclosures: "It was disappointing that somebody that I had previously told had done that. … I had learned going forward what kind of criteria I would base disclosing that to" (24-year-old White man, IG, AL).

Stigma.—Many participants discussed experiencing stigma after disclosing their HIV status. Various types of stigma were discussed, including perceived community, enacted, anticipated, and internalized stigma. A woman experienced discriminatory behavior from her intimate partner after disclosing her HIV status. She described a situation when they were engaging in presexual acts:

> … And the last time we got together he wanted to be intimate and we got to where we were going to go and before we could do it, I was like, "No, I got to tell him. I can't do that." … So, I went on and told him and when I told him it was more like he was scared. The only thing I did was kiss him but he made it like, "Oh, am I gonna get it? I got it? You kissed me! I'm not going to get it am I?" I was like, "No, if I thought you could get it from a kiss, I would've told you … I'm telling you before we have sex because I want you to know."… he was making like he didn't want to touch it, you know what I'm saying? It was kind of hard. I think I cried. After that, I saw him …but it was more like, "Stay away from me."
>
> (38-year-old African American woman, IG, AL)

Another participant described disclosing to her family members, who were shocked, and her father's initial reaction:

> Papa called me stupid. That was the first thing he said. He said, "You're stupid. How could you be so stupid?" … they were really shocked because I'm such a clean freak. It was just like, "How could you be so stupid? How did that happen to you?"
>
> (21-year-old African American man, CG, AL)

Theme 4: Positive Experiences After HIV Disclosure

Many participants indicated that their relationships remained unchanged or improved after disclosure. For example, one participant reported that his relationships had improved, and he had been closer to his friends and family, "…in the majority of relationships and friendships, it's [disclosure] made it a little more solid, a little more real." He elaborated that he was relieved and happy that his friends accepted him, but he felt he burdened them with his diagnosis:

> … [disclosing] just made me cry because one, it felt so good that she didn't feed into their fear, and the other that she had to deal with it. This is my disease. Other people shouldn't have to deal with it. I know that it affects—it's got a domino

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> effect. But I mean this is—she shouldn't have to deal with me having HIV. Her son shouldn't have to deal with me having HIV. They shouldn't have to deal with that.
>
> (37-year-old Latino man, CG group, WA)

Another participant was surprised that his relationship with his friend and her daughter did not change after he disclosed his HIV status. He was afraid that he would not be able to have contact with his friend and her daughter because of fear of contracting HIV:

> Even my friend and stuff, she's got her 2-year-old daughter, well she's almost 4 now, but at the time she was a little girl, and nothing changed. I could still go over; she would still want me to pick her up and hold her. Like there was no feeling, there was no vibe or anything. In my mind I was like, "What if my friend, like what if she's different? What if she won't let me touch her daughter or something?" But it wasn't like that or anything. You know, you didn't get that vibe. It was amazing.
>
> (26-year-old White man, IG, WA)

Another participant reported that her family treated her the same and did not give her preferential or special treatment because of her HIV status:

> There's no change, and that's why they're the ones in whom I confided because there is no change. … They know the seriousness of it, but they feel like, "Okay, you are still who you were before you had HIV, so what am I going to treat you different for? I'm not. You get no special treatment."
>
> (34-year-old African American woman, CG, AL)

Discussion

Initial entry into care after a new HIV diagnosis can be a critical and overwhelming time. Failure to engage in HIV care has been associated with poor health outcomes, including mortality and risk of HIV transmission. HIV disclosure is an important factor in HIV management, and it often leads to increased access to social support, use of risk reduction strategies, engagement in HIV care, and reduction in perceptions of HIV-related stigma (Go et al., 2016; Greene et al., 2003; Stirratt et al., 2006). However, members of the HIV care team must understand the complex nature of HIV disclosure for individuals new to HIV care, the task of deciding to disclose one's HIV status, individual appraisals of to whom to disclose, and when and why patients newly entering HIV care decide to disclose or not to disclose.

The stories told by participants in our study highlighted the interplay between HIV disclosure, HIV-related stigma, social support, and engagement in HIV care. Four major themes were related to disclosure, and the themes were not mutually exclusive, often intersecting to tell a story. Participants described experiencing fear and worry about HIV disclosure, which influenced engagement in care. For many participants, fears were overcome by the need for social support and the desire to inform those who "needed to know."

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When asked if disclosing one's HIV status affected ART adherence, responses varied. For some participants, HIV disclosure did not affect the ability to adhere to ART; for others, HIV disclosure positively affected ART adherence, and for one participant, HIV nondisclosure interfered with her ability to adhere to ART (e.g., hiding medication in her car to prevent unintentional disclosure). In our study, participants who described positive experiences with disclosure indicated that disclosing helped them with positive health behaviors such as ART adherence and engagement in HIV care. These findings were consistent with other findings suggesting that HIV disclosure has often been linked to positive outcomes (Calabrese et al., 2012; Siu et al., 2012). In one study, HIV disclosure resulted in medication reminders, transportation to clinic visits, and increased access to social support (Siu et al., 2012). Furthermore, HIV disclosure has been associated with less medication hiding and better immune function (Calabrese et al., 2012), but Rotzinger et al. (2016) found that not disclosing resulted in improved ART adherence. One explanation for these contradictory findings was that people who failed to disclose their HIV status must depend on internal motivation for optimal adherence (Rotzinger et al., 2016).

Interventions to improve ART adherence and engagement in HIV care for patients newly entering HIV care could be more effective if they included strategies for smart disclosure, which we defined as strategies to help PLWH make better informed decisions about who, when, and where to disclose an HIV status. We posit that negative and adverse effects experienced after disclosing HIV status were not a result of the disclosure itself but of disclosing to the wrong individuals or using ineffective disclosure strategies. This was evident in Project ACCEPT, a gender-specific, group-based intervention for patients newly entering HIV care, that incorporated disclosure strategies, such as role playing and mapping steps to disclosure. Participants in the IG had better ART adherence compared with a time- and attention-matched CG (Hosek et al., 2018). Thus, HIV providers and researchers should consider integrating smart disclosure strategies into new patient orientation and when developing interventions to improve access to social support, ART adherence, and engagement in HIV care.

We reported reasons for disclosing HIV status, including disclosing to those who "need to know," for peace of mind, to increase awareness of HIV, to gain social and peer support, and to combat HIV-related stigma, which have been reported by other authors (Gaskins et al., 2011; Naigino et al., 2017; Stutterheim et al., 2017; Watt et al., 2018). Gaskins et al. (2011) reported that participants in their study disclosed their HIV status to relieve stress or have peace of mind, to inform individuals who needed to know, and as an HIV prevention strategy. Similar to our findings, Stutterheim et al. (2017) reported that a sample of health care workers living with HIV disclosed HIV status in an attempt to reduce stigma. However, we do not know the length of time after HIV diagnosis for that sample compared with ours, which is important to know because researchers have suggested that a recent diagnosis was associated with HIV nondisclosure (Daskalopoulou et al., 2017). We have extended the literature by increasing awareness that patients newly entering HIV care use disclosure as a stigma-reduction strategy. Understanding reasons for disclosure can help better tailor interventions for patients newly entering HIV care.

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Furthermore, initial disclosure was frequently to a family member, close friend, or intimate partner. These findings were consistent with studies that suggested patients were more likely to disclose to family, friends, or a significant other (Elopre et al., 2016; Go et al., 2016; Maman, van Rooyen, & Groves, 2014). Many participants felt that disclosure was essential to access social support networks and often described disclosing to close friends, family members, and intimate partners to gain access to needed social support. Research has highlighted the importance of existing social networks to facilitate disclosure with the goal of sustaining those networks after disclosure (Go et al., 2016). Inadequate social support has been directly and indirectly associated with engagement in HIV care and ART adherence (Kempf et al., 2010). Our findings suggest that participants also disclosed to gain tangible support in the form of reminders and transportation to medical visits. Therefore, integrating strategies to facilitate social support interventions to improve engagement in HIV care has the potential to improve engagement in HIV care and ART adherence, ultimately improving survival.

Participants in our study reported fear of rejection, stigma, and unauthorized disclosure. HIV-related stigma is well documented and associated with nondisclosure, suboptimal ART adherence, and lack of retention in HIV care in those who had been engaged in HIV care. Our data suggest that patients newly entering HIV care anticipate and experience stigma, including rejection from family, friends, and significant others because of fears of contracting HIV through casual contact, perceptions regarding the type of people who contract HIV, and the physical characteristics of PLWH, thus interfering with ART adherence and engagement in care (McDoom, Bokhour, Sullivan, & Drainoni, 2015; Smith et al., 2008). For example, a cohort of older Black women reported that stigma interfered with engagement in HIV care from initial engagement to ongoing engagement (McDoom et al., 2015). Similar to HIV disclosure and ART adherence, perceived, internalized, and experienced HIV-related stigma can influence ART adherence (Rice et al., 2017). In our study, a participant discussed hiding medication in her car because she feared disclosure of her HIV status and being subjected to stigma. Furthermore, patients were reluctant to be seen at clinics that provided PLWH services because they feared unintentional disclosure, which could result in experienced HIV-related stigma. Similar findings were reported in a sample of women seeking prenatal/postnatal care who reported missing appointments and hiding or discarding ART (Spangler et al., 2018). Thus, interventions to address HIV-related stigma and smart disclosure in patients newly entering HIV care could positively influence engagement in HIV care and ART adherence. Addressing stigma early is critical because experiencing stigma over time may reduce support-seeking behavior and contribute to chronic stress (Smith et al., 2008), which have important implications for engagement in HIV care and ART adherence.

Limitations

The findings of our qualitative study should be understood within the context of study limitations. Selection bias is a potential limitation. Participants were recruited from comprehensive HIV ambulatory clinics in the United States. We relied on individuals who were in care, enrolled in a study about engagement in HIV care, and willing to participate in face-to-face interviews, and we may not have elicited concerns of PLWH with significant

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barriers, such as transportation, fear of stigma, and other multilevel barriers related to participating in research and face-to-face interviews. In addition, there was an overrepresentation of participants from Alabama and those who achieved HIV viral load (VL) suppression. Attempts were made to recruit more participants who had not achieved VL suppression, but more than 80% of iENGAGE participants had achieved VL suppression (Table 2). Attempts were also made to recruit equal numbers of participants from Alabama and Washington for in-depth interviews. However, recruitment at the Washington site was slower than expected, so the researchers increased recruitment in Alabama. As such, information presented may not reflect the views of participants who are not engaged in HIV care, thus limiting transferability of the findings.

Conclusion

For patients newly entering HIV care, HIV disclosure, social support, and HIV-related stigma have important implications for engagement in HIV care and ART adherence. Entry into HIV care is a pivotal time, and failure to engage in care has the potential to influence health outcomes, including survival. HIV disclosure can improve access to social support, potentially enhancing engagement in care and ART adherence at the pivotal time of entry into HIV care. On the other hand, some patients newly entering HIV care experience HIV-related stigma and other negative consequences of disclosure, so disclosure needs to be handled early and carefully. Interventions to improve engagement in HIV care and ART adherence should incorporate information and skill building with the goals of improving access to social support and developing smart disclosure strategies and strategies to reduce and cope with HIV-related stigma.

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References

Anderson K, Biello K, Rosenberger JG, Novak D, Mayer K, Carey K, & Mimiaga MJ (2018). The impact of social support and partner relationship dynamics on engagement in HIV care and antiretroviral treatment adherence among MSM in Latin America. AIDS Care, 1–7. doi:10.1080/09540121.2018.1456641

Braun V, & Clarke V (2006). Using thematic analysis in psychology. Qualitiative Research in Psychology, 3(2), 77–101. doi:10.1191/14788706qp063oa

Calabrese SK, Martin S, Wolters PL, Toledo-Tamula MA, Brennan TL, & Wood LV (2012). Diagnosis disclosure, medication hiding, and medical functioning among perinatally infected, HIV-positive children and adolescents. AIDS Care, 24(9), 1092–1096. doi:10.1080/09540121.2012.699670 [PubMed: 22799616]

Centers for Disease Control and Prevention. (2019a). CDC data confirm: Progress in HIV prevention has stalled Retrieved from https://www.cdc.gov/media/releases/2019/0227-hiv-prevention-stalled.html

Centers for Disease Control and Prevention. (2019b). HIV in the United States and dependent areas Retrieved from https://www.cdc.gov/hiv/statistics/overview/ataglance.html

Centers for Disease Control and Prevention. (2017). HIV surveillance report: Diagnosis of HIV infection in the United States and dependents areas, 2016 Retrieved from https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2016-vol-28.pdf

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Centers for Disease Control and Prevention. (2016). Selected national HIV prevention and care outcomes Retrieved from http://www.cdc.gov/hiv/pdf/library/slidesets/cdc-hiv-prevention-and-care-outcomes.pdf

Colasanti J, Stahl N, Farber EW, Del Rio C, & Armstrong WS (2017). An exploratory study to assess individual and structural level barriers associated with poor retention and re-engagement in care among persons living with HIV/AIDS. Journal of Acquired Immune Deficiency Syndromes, 74(Suppl 2), S113–S120. doi:10.1097/QAI.0000000000001242 [PubMed: 28079721]

Daskalopoulou M, Lampe FC, Sherr L, Phillips AN, Johnson MA, Gilson R, … Rodger AJ (2017). Non-disclosure of HIV status and associations with psychological factors, art non-adherence, and viral load non-suppression among people living with HIV in the UK. AIDS and Behavior, 21(1), 184–195. doi:10.1007/s10461-016-1541-4 [PubMed: 27586375]

Elopre L, Westfall AO, Mugavero MJ, Zinski A, Burkholder G, Hook EW, & Van Wagoner N (2016). Predictors of HIV disclosure in infected persons presenting to establish care. AIDS and Behavior, 20(1), 147–154. doi:10.1007/s10461-015-1060-8 [PubMed: 25855046]

Gaskins S, Foster PP, Sowell R, Lewis T, Gardner A, & Parton J (2011). Reasons for HIV disclosure and non-disclosure: An exploratory study of rural African American men. Issues in Mental Health Nursing, 32(6), 367–373. doi:10.3109/01612840.2011.571807 [PubMed: 21692575]

Go VF, Latkin C, Le Minh N, Frangakis C, Ha TV, Sripaipan T, … Quan VM (2016). Variations in the role of social support on disclosure among newly diagnosed HIV-infected people who inject drugs in Vietnam. AIDS and Behavior, 20(1), 155–164. doi:10.1007/s10461-015-1063-5 [PubMed: 25972071]

Greene K, Derlega VJ, Yep GA, & Petronio S (2003). Privacy and disclosure of HIV in interpersonal relationships: A sourcebook for researchers and practitioners Mahwah, NJ: Lawrence Erlbaum Associations, Inc.

Hightow-Weidman LB, Phillips G II, Outlaw AY, Wohl AR, Fields S, Hildalgo J, & LeGrand S (2013). Patterns of HIV disclosure and condom use among HIV-infected young racial/ethnic minority men who have sex with men. AIDS and Behavior, 17(1), 360–368. doi:10.1007/s10461-012-0331-x [PubMed: 23054043]

Horberg MA, Hurley LB, Silverberg MJ, Klein DB, Quesenberry CP, & Mugavero MJ (2013). Missed office visits and risk of mortality among HIV-infected subjects in a large healthcare system in the United States. AIDS Patient Care and STDS, 27(8), 442–449. doi:10.1089/apc.2013.0073 [PubMed: 23869466]

Hosek SG, Harper GW, Lemos D, Burke-Miller J, Lee S, Friedman L, & Martinez J (2018). Project ACCEPT: Evaluation of a group-based intervention to improve engagement in care for youth newly diagnosed with HIV. AIDS and Behavior, 22(8), 2650–2661. doi:10.1007/s10461-018-2034-4 [PubMed: 29396633]

Kempf MC, McLeod J, Boehme AK, Walcott MW, Wright L, Seal P, … Moneyham L (2010). A qualitative study of the barriers and facilitators to retention-in-care among HIV-positive women in the rural southeastern United States: Implications for targeted interventions. AIDS Patient Care and STDS, 24(8), 515–520. doi:10.1089/apc.2010.0065 [PubMed: 20672971]

Li H, Chen X, & Yu B (2016). Disclosure appraisal mediating the association between perceived stigma and HIV disclosure to casual sex partners among HIV1 + MSM: A path model analysis. AIDS Care, 28(6), 722–725. doi:10.1080/09540121.2016.1140884 [PubMed: 27009408]

Maman S, van Rooyen H, & Groves AK (2014). HIV status disclosure to families for social support in South Africa (NIMH Project Accept/HPTN 043). AIDS Care, 26(2), 226–232. doi:10.1080/09540121.2013.819400 [PubMed: 23875539]

McDoom MM, Bokhour B, Sullivan M, & Drainoni ML (2015). How older Black women perceive the effects of stigma and social support on engagement in HIV care. AIDS Patient Care and STDS, 29(2), 95–101. doi:10.1089/apc.2014.0184 [PubMed: 25494607]

Merriam SB, & Tisdell EJ (2016). Qualitative research: A guide to design and implementation (4th ed.). San Francisco, CA: Jossey-Bass.

Miles MB, Huberman AM, & Saldana J, (2019). Qualitative data analysis: A methods sourcebook (4th ed.). Thousand Oaks, CA: SAGE Publications, Inc.

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Modi R, Amico KR, Knudson A, Westfall AO, Keruly J, Crane HM, … Mugavero MJ (2018). Assessing effects of behavioral intervention on treatment outcomes among patients initiating HIV care: Rationale and design of iENGAGE intervention trial. Contemporary Clinical Trials, 69, 48–54. doi:10.1016/j.cct.2018.03.003 [PubMed: 29526609]

Mugavero MJ, Amico KR, Westfall AO, Crane HM, Zinski A, Willig JH, … Saag MS (2012). Early retention in HIV care and viral load suppression: Implications for a test and treat approach to HIV prevention. Journal of Acquired Immune Deficiency Syndromes, 59(1), 86–93. doi:10.1097/QAI.0b013e318236f7d2 [PubMed: 21937921]

Naigino R, Makumbi F, Mukose A, Buregyeya E, Arinaitwe J, Musinguzi J, & Wanyenze RK (2017). HIV status disclosure and associated outcomes among pregnant women enrolled in antiretroviral therapy in Uganda: A mixed methods study. Reproductive Health, 14(1), 107. doi:10.1186/s12978-017-0367-5 [PubMed: 28854944]

Rice WS, Crockett KB, Mugavero MJ, Raper JL, Atkins GC, & Turan B (2017). Association between internalized HIV-related stigma and HIV care visit adherence. Journal of Acquired Immune Deficiency Syndromes, 76(5), 482–487. doi:10.1097/QAI. 0000000000001543 [PubMed: 28885270]

Rotzinger A, Locatelli I, Reymermier M, Amico S, Bugnon O, Cavassini M, & Schneider MP (2016). Association of disclosure of HIV status with medication adherence. Patient Education and Counseling, 99(8), 1413–1420. doi:10.1016/j.pec.2016.03.012 [PubMed: 27033978]

Siu GE, Bakeera-Kitaka S, Kennedy CE, Dhabangi A, & Kambugu A (2012). HIV serostatus disclosure and lived experiences of adolescents at the transition clinic of the infectious diseases clinic in Kampala, Uganda: A qualitative study. AIDS Care, 24(5), 606–611. doi:10.1080/09540121.2011.630346 [PubMed: 22081975]

Smith R, Rossetto K, & Peterson BL (2008). A meta-analysis of disclosure of one's HIV-positive status, stigma and social support. AIDS Care, 20(10), 1266–1275. doi:10.1080/09540120801926977 [PubMed: 18608080]

Spangler SA, Abuogi LL, Akama E, Bukusi EA, Helova A, Musoke P, … Turan JM (2018). From "half-dead" to being "free": Resistance to HIV stigma, self-disclosure and support for PMTCT/HIV care among couples living with HIV in Kenya. Culture, Health & Sexuality, 20(5), 489–503. doi:10.1080/13691058.2017.1359338

Stirratt MJ, Remien RH, Smith A, Copeland OQ, Dolezal C, & Krieger D (2006). The role of HIV serostatus disclosure in antiretroviral medication adherence. AIDS and Behavior, 10(5), 483–493. doi:10.1007/s10461-006-9106-6 [PubMed: 16721505]

Stutterheim SE, Brands R, Baas I, Lechner L, Kok G, & Bos AER (2017). HIV status disclosure in the workplace: Positive and stigmatizing experiences of health care workers living with HIV. Journal of the Association of Nurses in AIDS Care, 28(6), 923–937. doi:10.1016/j.jana.2017.06.014 [PubMed: 28751112]

Turan B, Hatcher AM, Weiser SD, Johnson MO, Rice WS, & Turan JM (2017). Framing mechanisms linking HIV-related stigma, adherence to treatment, and health outcomes. American Journal of Public Health, 107(6), 863–869. doi:10.2105/AJPH.2017.303744 [PubMed: 28426316]

U.S. Department of Health & Human Services. (2016). HIV/AIDS care continuum Retrieved from http://aids.gov/federal-resources/policies/care-continuum/

Watt MH, Knippler ET, Knettel BA, Sikkema KJ, Ciya N, Myer L, & Joska JA (2018). HIV disclosure among pregnant women initiating ART in Cape Town, South Africa: Qualitative perspectives during the pregnancy and postpartum periods. AIDS and Behavior, 22(12), 3945–3956. doi:10.1007/s10461-018-2272-5 [PubMed: 30196332]

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Key Considerations

- Engagement in HIV care is critical to ART initiation and ART adherence, which are significant determinants of HIV treatment success, including reduced morbidity and mortality.
- Entry into HIV care can be distressing, as individuals consider when and how to disclosure their HIV status to family and friends with the goal of enhancing and sustaining social support networks.
- Strategies for smart disclosure and enhancing social support networks should be incorporated into HIV care settings in general and on entry into HIV care more specifically.
- Integrating skill building related to smart disclosure, accessing social support networks, and reducing stigma on entry into HIV care are critical to enhancing engagement in HIV care and ART adherence.

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Table 1.

Sample Interview Questions Related to Disclosure

With whom have you disclosed your HIV status, if anyone? Can you tell me more about who you have disclosed to? Why did you decide to disclose to those persons? How did you tell them?
Can you tell me about any fears you have about how people will react if they learn about your HIV-positive status? People you know? People close to you? Strangers?
How does having HIV affect your relationships with the people closest to you?
Probes: Romantic partners? Friends? Family? Acquaintances? Strangers?
How do your relationships with the people closest to you affect attending your regular HIV care visits?
How do your relationships with the people closest to you affect your adherence to your HIV medications?
Did telling people about your HIV status affect your health in any way? If so, how?
Probes: What about your ability to take your medicines as prescribed? In what ways? What about your ability to attend your HIV visits? In what ways?
How do your relationships with the people closest to you affect attending your regular HIV care visits?
How do your relationships with the people closest to you affect your adherence to your HIV medications?

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Table 2.

Sample Characteristics ($N = 28$)

Characteristics	Alabama	Washington	Total
Interviews completed	20	8	28
Race			
African American	15	0	15
American Indian/Alaskan Native	0	1	1
Caucasian	5	6	11
Other	0	1	1
Ethnicity			
Hispanic	0	1	1
Non-Hispanic	20	7	27
Sex			
Female	8	1	9
Male	12	7	19
iENGAGE study arm			
Control	10	3	13
VL suppressed at 48 weeks	7	3	10
VL not suppressed at 48 weeks	3	0	3
Intervention	10	5	15
VL suppressed at 48 weeks	8	5	13
VL not suppressed at 48 weeks	2	0	2

Note. iENGAGE = Integrating ENGagement and Adherence Goals upon Entry; VL = viral load.