Intimacy and Sexual Decision Making: Exploring the Perspective of HIV Positive Women Over 50

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Abstract

Due to advances made in HIV treatment, the population of individuals with HIV over the age of 50 is growing. Aging women face many developmental challenges and some of these challenges, including having or maintaining intimate partner relationships, may be particularly pronounced for aging women living with HIV. However, research exploring the psychosocial needs of aging women with HIV is limited. Thus, the aim of this study was to explore factors that impact intimate partner relationships for older women with HIV. Nineteen women (mean age = 56.79, SD = 4.63 years) referred from Boston-area community organizations and hospitals completed in-depth individual interviews. Forty-seven percent of participants identified themselves as Black/African American, and 37% as White/Caucasian. Average time since diagnosis was 16.32 years (SD = 5.70). Interviews continued until saturation of content was reached. Inclusion criteria included: biologically born female; aged 50 years or older; diagnosis of HIV/AIDS; and English speaking. Qualitative interviews were coded by two raters and content analyses were conducted using NVivo 9 software. The findings are described across the following three main themes: (1) stigma; (2) body image concerns; and (3) the disclosure dilemma. The themes and issues identified by this study may help guide sexual health-related interventions for older HIV-infected women.

ALTHOUGH ADVANCE IN HIV TREATMENT over the past 2 decades have vastly improved health outcomes and increased life expectancy for people living with HIV, the psychosocial needs of this aging population have not been well addressed.^{1,2} The CDC reports that approximately 24% percent of individuals living with HIV in the U.S. are over the age of 50.³ Women with HIV over the age of 50 comprise a diverse group, composed of long-term survivors, newly diagnosed, and undiagnosed women. This cohort of women commonly face challenges related to disclosure and risk of HIV transmission through unprotected heterosexual activity.⁴ Additionally, older HIV-infected women may be at risk for poor quality of life due to increased susceptibility to medication side effects, co-morbidity, and health complications linked to aging.⁵⁻⁸ Moreover, HIV-infected women are vulnerable to various types of stigma, including age-related and HIV-related discrimination—even within community organizations and health care settings.^{4,9}

The majority of research examining relationships and sexual behavior among older adults has been conducted with HIV negative samples.¹⁰ Given that HIV is largely a sexually transmitted disease, research examining sexual health among

HIV-infected individuals has focused primarily on HIV prevention. However, several recent studies have focused on sexual health of older HIV-infected individuals,¹¹⁻¹³ with two recent studies showing that approximately 38–50% of men and women over the age of 50 engaged in recent (within the past 3 months) sexual activity.^{11,13} Notable rates of unprotected or inconsistent safe sex—with approximately 20–33% of participants endorsing little or inconsistent condom use—have been documented; factors linked to unsafe sexual behavior included substance use, loneliness, negative affect, and HIV related stigma.¹¹⁻¹³ These studies suggest that older adults with HIV are engaging in sexual activity and, as with other populations of individuals with HIV, that a minority may be engaging in high-risk HIV transmission behavior.

Although the literature calls for continued research in this area, only a small number of studies exist that have examined how older HIV-infected women manage their sexual health needs.¹ While there is some evidence that older HIV-infected women are sexually active or may desire to be, more research is needed to understand the unique factors that impact decision-making related to sexual health for this group.^{1,14} For many older women, navigating intimate relationships is

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challenging. The period after menopause is associated with changes in body shape and changes in sexual functioning, such as vaginal dryness.^{15,16} For women who have ended a long-term relationship, there may be uncertainty about dating or concerns about the availability of new intimate partners. Managing a chronic illness that is primarily sexually transmitted and that remains highly stigmatized, such as HIV, may serve as an additional barrier to the developmental challenges that healthy HIV-negative women face.

Research specific to how older women with HIV think about intimate partner relationships may help healthcare providers better address the issues that are salient for this population, and in turn assist these women to engage in healthier relationships and sexual behavior. The following study used qualitative research methods to explore and understand how HIV positive women over 50 experience living with HIV. HIV and age-specific factors that impacted intimate partner relationships and sexuality emerged from a series of in-depth qualitative interviews, which were used in the analyses.

Methods

Participants

We purposively sampled older women who were HIV positive (homogeneous sampling) to participate in semi-structured qualitative interviews. The inclusion criteria were: (1) biologically born female; (2) aged 50 or older; (3) diagnosis of HIV/AIDS; and (4) English speaking. The only exclusion criterion was being unable or unwilling to provide informed consent. The primary means of recruitment was the use of flyers posted in Boston-area community HIV/AIDS organizations and referrals of eligible women by health care providers in the Infectious Disease Clinic at Massachusetts General Hospital (MGH). Participants were also recruited from the screening efforts of an on-going randomized controlled trial conducted at MGH that tested cognitive behavioral therapy for adherence to HIV medications and depression in HIV care settings. Women who were screened for the randomized controlled trial who appeared to meet criteria for the current study were provided with information and invited to participate. IRB approval from MGH/Partners HealthCare was obtained. Interviews were conducted between June 2009 and February 2010.

Measures

A semi-structured interview guide, developed using guidelines articulated by Huberman and Miles, was used to collect qualitative data.¹⁷ The interview guide was first piloted with the first four participants to assess its clarity and content, and revised to include questions on novel topics that emerged from the pilot interviews. The questions were designed to capture women's experiences with HIV as they age. Interviews began with a free-list activity whereby participants were asked to list the challenges faced by women over the age of 50 living with HIV. This was followed by questions exploring the issues raised by the interviewee during the free-list activity, as well as the following topic areas, which were selected after a review of the literature to identify areas important to those living with HIV, older women, or both: (1) mental health concerns/cognitive functioning, (2) sexual

functioning, (3) menopause, (4) quality of life, (5) social support, and (6) management of multiple health conditions/adherence to care. Questions were open-ended in order to minimize the risk of biasing participants' responses and to allow for novel themes to emerge. Participants were paid \$25 for their time participating in the single 1–1.5 h interview; a single interview was utilized in order to minimize participant burden. Interviews were administered by the first author (CP). Data presented here are related to the themes that emerged related to questions about sexual health.

Analyses

The qualitative interviews were audio-taped and transcribed. Using a grounded theory approach,¹⁸ content analyses were conducted using NVivo 9 software¹⁹ to uncover themes related to HIV and aging. This entailed an iterative multi-step process performed by the authors (CP and JB) using the techniques described by Miles and Huberman.²⁰ We first identified major themes. Coding was then performed to structure data into categories and to create groups. Themes were then reexamined, and major and minor themes within each content area were identified; messages were extracted and highlighted. Data were coded for frequency (how often a theme came up), intensity (how strongly a theme or topic was described), and duration (how long a topic was discussed). To ensure reliability, two coders (CP and JB) analyzed the data independently. To check for validity, at each phase of the analyses, the authors (CP, JB, and ERP) discussed their findings to assure that the interpretation of data was not being influenced by preconceived theories. Additionally, results from each phase of analyses were compared, and discrepancies were discussed between the coders until a resolution was reached. An audit trail of coding templates and discussions about the data and computerized coding was kept. We referred to this audit trail to resolve discrepancies, and compared computerized coding to raw data. To check reliability of coding in the final phase of coding, a Kappa was generated in NVivo 9, comparing the coders' results. The final weighted kappa was 0.89. Expert review of the qualitative process was provided by EP, while expert review of HIV-related content was provided by GR and SAS.

Results

Sociodemographic data on the 19 participants are presented in Table 1. The mean age was 56.79 (SD=4.63 years). Forty-seven percent of participants identified themselves as Black/African American, and 37% as White/Caucasian. The average time since diagnosis was 16.32 (SD=5.70 years), and 84.2% of the sample identified as being without a current intimate partner. Data from the 19 qualitative interviews were distilled into three themes that emerged as influencing how older women with HIV think about intimate partner relationships.

Impact of stigma on intimate partner relationships

HIV-related stigma was the most cogent barrier to the pursuit of intimate partner relationships. For many participants, this led to a sense of hopelessness about ever finding an intimate partner, namely due to the belief that no one would willingly enter a relationship with an older, HIV-positive

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF SAMPLE

Variable	Participant sample (N=19)	
	n	%
Age		
M=56.79	—	—
SD=4.63	—	—
Race/ethnicity*		
American Indian/Alaska native	2	10.5
Asian	1	5.3
Black or African American	9	47.4
White or Caucasian	7	36.8
Latina	1	5.3
Education		
Less than high school degree	5	26.4
High school graduate/GED	5	26.3
College/graduate school partial/degree	9	47.4
Employment		
Part-time	6	31.6
Disabled/retired	13	68.4
Income		
Under 15,000	14	73.7
Relationship status		
Single	6	31.6
Married/partnered	3	15.8
Separated/divorced/widowed	10	52.6
Years since diagnosis		
M=16.32		
SD=5.70		
HIV risk factors ^a		
Sex with men only	18	97.7
IV drug use	11	57.9
Blood transfusion	2	10.5
Current antiretroviral treatment	14	87.5

^aCategories not mutually exclusive.

woman, as illustrated by the following participant when describing the end of a long-term relationship:

When we broke up, I had all kinds of hopes about meeting somebody. I didn't realize how much HIV was going to be a problem. I really didn't. 'Cause you know, I lived for almost 20 years with the virus with my ex and it had not been a big issue. And that's when I think it really slapped me in the face is when I started wanting to date and wanted to build a new life and I realized more likely than not it's not going to happen. Not that I've given up but I'm not as hopeful as I used to be.

Several individual elements of stigma emerged. The first was related to a potential partner's perception of HIV and assumptions that are made about women who have HIV. Specifically, participants felt that they would be judged by potential partners as being "dirty" or having engaged in a series of undesirable behaviors, such as sex work or drug use. One participant noted the following:

I think, you know, like my mom always wanted me to marry a doctor or a lawyer, you know? And you know, it's just not easy when you're living with the virus. People look at people with the virus as drug addicts, alcoholics, low-lives, homeless. And it's really not the case, you know, it's really not the case at all. I've really done a lot since I've had the virus.

Another element of stigma involved perceptions of potential partners' assumptions around cost and management of HIV. For example, another participant described how potential partners may view her diagnosis as a health liability, "Opportunities for marriage have been limited because of it [HIV]. People, I think, fear that being with a woman with HIV is going to have an expensive impact on them."

Women described issues with dating HIV-positive men and HIV-negative men. Participants reported feeling like a "second class citizen" because of HIV, and described the sentiment that they should be grateful anyone wanted to be in a relationship with them at all. Some felt they could never be an equal in a relationship with an HIV-negative man, as serodiscordance created a power differential. Interestingly, while participants felt stigmatized as a result of their HIV, their perception of available partners also contained elements of stigma. Because of their age and diagnosis, participants' perceptions of the type of men that were available for them to date was negative; participants felt that they were only considered "datable" to men who made unsavory life choices, like engaging in drugs or crime,

So I had to get me together. I got me together, and it does have to do with HIV, not because I feel unattractive or anything; because I want me together, and it always plays into—on drugs or something. And I can't go there anymore. I've got to think about me, and only me.

Because of the considerable stress associated with stigma and dating, participants often decided to "focus on themselves", as illustrated by the following quote,

It's why I'm not in a relationship. My attention to, you know, my tolerant level is very low. Any kind of chaos. I don't want anyone else playing with it. So I worked real hard to stay healthy emotionally, physically, mentally. And it's work, believe me. So you know, it's very important to me that I keep myself safe.

While some participants felt comfortable with this decision to abstain from relationships, others mourned this as a loss and described feelings of loneliness resulting from the absence of an intimate partner, particularly at this stage of life. Several participants noted that this could be an ideal time of life during which to focus on intimate relationships, mainly because children were grown and they were working outside of the home less than they were younger, resulting in more free time. For example, one participant noted,

I think a lot of women our age don't have a significant other, whereas in your 20's and 30's you probably do, or because of your age and stuff, you can date. A lot of us are alone, our kids are older, so we're basically on our own.

Some participants felt robbed of the opportunity to have this experience because of their diagnosis and resulting stigma, as illustrated by the following participant, "It's [HIV] taken that away from me in my middle age. You know, having that companionship." The fear of growing old alone was also prominent, as illustrated by the following participant, "I don't feel like I'll be supported as I age. There's nowhere to go. I want to grow old with someone, you know?"

Body image concerns as barriers to intimate relationships

Participants were acutely aware of the way their bodies looked, and several participants commented on body image concerns that impacted negatively on intimate partner

relationships. Participants described significant body dissatisfaction, some of which was perceived to be the result of long-term use of antiretrovirals (e.g., lipodystrophy), being post-menopausal, or due to a combined impact resulting from both factors. Body dissatisfaction precluded some participants from seeking out intimate partners, as described by this participant,

I'd like to meet somebody, but I don't really date that much right now. I think for me, my biggest issue is body image. I think partly, probably, being 55 is post-menopause, but I do believe that I have some of the side effects of either the HIV meds or having HIV, which is very difficult because it changes your body image. I've been working very hard, I joined a gym, and it doesn't—I feel better, but as far as changing my body image, it hasn't done anything. It's really like an upstream battle. That's a big thing for me.

Another participant described how her long-term partner ended their relationship; she perceived this to be the result of changes in her body that were the result of antiretroviral use that left her no longer desirable, “My long term lover—we broke up five years ago. And that was the reason why he left. He says he didn't find me sexually attractive anymore.” Participants felt that their body changes were beyond what an HIV-negative woman over 50 may experience, as illustrated by the following quotes,

I see the difference when someone that doesn't have the virus that's my age. I could see the physical differences in a woman. The physical features are different.” This sentiment was reinforced by another participant, who noted, “I think age plays a lot because I look at myself when I was twenty five and it's a big difference. Physically how I look now. And I know a lot of it is because I'm a woman with HIV that is over 50.

The disclosure dilemma

Another barrier to pursuing relationships was what participants described a “disclosure dilemma.” This is characterized by a strong sense of obligation to disclose HIV status and feared reactions to disclosure. Participants described a heightened responsibility to disclose their HIV status to any potential sexual partners. For some participants, this was in an attempt to avoid harming another person, as they had been harmed. For example, one participant stated, “I said to myself when I first got sick that I would never ever do what was done to me to another person.” Others cited the legal burden of their diagnosis,

Where I moved from, on the table in the clinic was a brochure, a Xeroxed page reminding us that it's a felony—you can be arrested—if you, for example, have a sexual relationship and you do not disclose it. So yeah, there are lots of prohibitions. Lots of worries about abstinence. Or if you're not abstinent.

Disclosure fears often centered around negative experiences with disclosure in the past. For example one participant explained,

I believe I'll be judged. The stigma is out there. But a lot people don't know that I'm HIV and they have asked me to go out or whatever and I've mentioned that I was HIV and I can automatically see it. So I don't even bother.

Another participant noted,

It's a situation where you're asking for rejection. You truly are. I mean if you can get a guy to find you reasonably attractive...you tell him you got the virus and you might as well tell him you got leprosy.

Some participants felt this phenomenon was worse among men in their age group, making their disclosure experience potentially different for women with HIV who may date younger men as illustrated by the following quote,

With guys 50 or my age, or maybe even in their 40s, it's just, I don't know. I do think possibly there's more of a stigma with that age group. It probably would be different if I was younger, 20 or 30. Because people my age and age group, there's still that stigma.

For some women, the fear of disclosure reactions coupled with the pressure to disclose was “too much” and they chose to abstain from intimate relationships.

Discussion

The current study explored the way in which older, HIV infected women think about intimate partner relationships. Most participants expressed desire to have an intimate partner relationship, but described multiple challenges to pursuing these relationships. The results suggest that the challenges experienced by the participants may be even greater than what could be expected from same age, HIV-negative women. Overall, participants described a sense of hopelessness around being in an intimate partner relationship. This hopelessness seemed to be fueled by stigma, concerns about body image, and the dilemmas raised by disclosure.

While participants described a fear that potential partners would judge them poorly as a result of their diagnosis, paradoxically they also felt that because of their age and diagnosis, the pool of partners that was “left” would consist of people that were not relationship-worthy. While participants accepted that body changes were a part of normal aging, in many cases participants felt their body changes were worsened by HIV and long-term effects of antiretroviral therapy. Most participants identified heterosexual activity as the likely source of HIV infection, and discussed the importance of disclosure to avoid “harming another” as someone had harmed them by not disclosing. However, past attempts at disclosure had generally not gone well, and participants were not eager to try again. Disclosure was made harder for participants as they perceive men from their generation as having more negative beliefs about HIV and women who are HIV positive. Participants in the study often managed this by choosing to remain single and trying to “focus on themselves”, suggesting the belief that as an older HIV-positive woman well-being and intimate partner relationships could not coexist.

Intimate partner relationships are widely viewed as important determinants of quality of life. The results of this study suggest that older, HIV-positive women may benefit from support around negotiating the complexities of intimate partner relationships. Specifically, we hypothesize these women seem to struggle most with the management of perceived and actual stigma, managing disclosure, and addressing body image related concerns based on our findings. While findings from the current study are meant to be hypothesis generating and require replication, they may have implications for healthcare providers who work with HIV-positive individuals who would like to pursue an intimate partner relationship, but experience some of the barriers described in the current study. The literature has suggested that older women in general are less likely to speak with their physicians about

HIV risk and sexual health, although they do show an interest in talking with their providers about sexual health.^{21,22} At least one study has documented that a sample of healthcare workers identifying themselves as specialists in geriatric medicine lacked knowledge of issues specific to older adults with HIV,²³ though this may not apply among providers who identify as specializing in HIV. Little research has focused on patient–doctor communication and sexual health decision-making for older women with HIV.

It appears that perceived stigma can potentially be reduced by helping women identify ways of meeting potential partners and building a sense of community. Local HIV/AIDS organizations may be an ideal setting for this to occur, however, a series of online dating sites for HIV-positive persons have also emerged. Utilizing these venues increases the likelihood that women can identify similarly minded individuals and reduce the likelihood of stigmatization. As there are age-related differences in using the Internet as a health resource,²⁴ healthcare providers may serve as an important gateway to information for older women with HIV.

Fear of transmission to a negative partner was also prominent. Because HIV is a sexually transmitted disease, care must be taken when advising patients about sexual activity. HIV prevention strategies are rapidly evolving, and combination approaches such as treating the infected partner and pre-exposure prophylaxis (PrEP) may afford additional protection to negative partners,^{25–27} and can be prescribed in addition to condom use. Healthcare providers are in a unique position to counsel their patients and their partners about these options and to assuage unrealistic transmission fears.

Disclosure also posed a significant worry for participants. While disclosure is generally encouraged, women may need help evaluating when it is safe to disclose. The Consequence Theory of HIV disclosure has been studied in women, and posits that an individual will weigh the possible consequences of disclosure before making a decision to disclose their status.^{28,29} Some evidence suggests that women may tend to prioritize the needs of others over their own needs when evaluating the consequences of disclosure.²⁹ Brief interventions based in principles of cognitive behavioral therapy may be helpful in this context. Specifically, providers can help women identify fears around disclosure, identify the pros and cons of disclosure, and teach effective communication skills. Behavioral strategies such as rehearsal may ease the anxiety associated with such challenging conversations.

A number of prior studies have described the impact of body image concerns in women with HIV, including its relationship with lipodystrophy, sexual dysfunction, and medication adherence.^{30–34} However, the few studies that have tested interventions for HIV-related body image concerns have only involved all-male samples.^{35,36} Findings from the current study indicate that additional research is necessary to better address body image concerns among women aging with HIV. Interventions may involve acceptance of bodily changes, as well as nutrition counseling, exercise regimens, or surgery.^{37,38}

The current study has some limitations. The first is the small sample size, and the recruitment strategies may preclude findings from being generalizable to all populations of older, HIV-positive women. However, interviewing occurred until we reached thematic saturation. As a qualitative study, findings related to women's perceptions of attitudes towards

and barriers to intimate partner relationships should be interpreted as hypothesis-generating for future research, and need to be replicated using quantitative methodologies.

Despite the limitations, this work adds to our understanding of the psychosocial challenges experienced by women with HIV as they transition into middle and older adulthood, and generates hypothesis for additional work. Because HIV treatments have improved, most HIV-positive women can expect to experience the developmental milestones of aging, including negotiating intimate relationships as an older adult. Identifying interventions to support healthy aging and increased quality of life is one of the next important initiatives for HIV researchers and clinicians.

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