

# The Significance of Sexuality and Intimacy in the Lives of Older African Americans With HIV/AIDS

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**Purpose of the Study:** Aging and HIV/AIDS research focuses primarily on standardized clinical, social, and behavioral measures, leaving unanswered questions about how this chronic and stigmatizing condition affects life course expectations and the meaning of aging with the disease. Utilizing Gaylene Becker's (1997) life course disruption theory, we explored older African Americans' experiences of living with HIV/AIDS.

**Design and Methods:** A purposive sample ( $N = 43$ ) of seropositive African Americans aged 50 and older was selected from a parent study. Thirteen participants completed one semi-structured in-depth interview on life course expectations and experiences of living with HIV/AIDS. Interview transcripts were analyzed using standard qualitative coding and thematic analysis.

**Results:** Responding to broad, open-ended questions about the impact of HIV on life course expectations, participants emphasized how HIV limited their ability to experience sexuality and intimacy. Two major themes emerged, *damaged sexuality* and *constrained intimacy*.

**Implications:** Older African Americans' discussions of living with HIV focused on the importance of and the challenges to sexuality and intimacy. Researchers and clinicians should be attentive to significant and ongoing HIV-related challenges to sexuality and intimacy facing older African Americans living with HIV/AIDS.

**Key words:** HIV/AIDS, African Americans, Sexuality, Life course, Qualitative research

Contrary to widespread cultural stereotypes of older adults as asexual (Taylor & Gosney, 2011), older adults maintain interest in and practice sex well into old age (Lindau et al., 2007). Older adults live longer than previous generations and are healthier, making ongoing engagement in sexual activity possible (Emanuel, 2014; Schick et al., 2010). Sexuality and intimacy are important life course

expectations and play a significant role in physiological, psychological, and social development and well-being (Field, 2010; Khaleque, 2004; Levy, 1994; Montagu, 1984; Scherrer, 2009; Traupmann, Eckels, & Hatfield, 1982). Older adults are at increased risk for HIV and other sexually transmitted diseases because they report less use of condoms (Emanuel, 2014; Schick et al., 2010). Factors

associated with advanced age including reduced pregnancy concerns and increased erectile dysfunction lead to decreased condom use. (Cove & Petrak, 2004; Schick et al., 2010; Zona et al., 2012). In addition to aging, HIV disease contributes to erectile dysfunction which, similarly, is related to various problems with condom use. (Cove & Petrak, 2004; Zona et al., 2012).

Gerontologists generally do not consider 50 years of age to be a marker of social and behavioral conditions associated with older age. However, in this study we followed the CDC convention of using age 50 as a marker of old age to be consistent with existing literature on HIV and aging and because people 50 and older are the fastest growing age group with HIV/AIDS in the United States (Emlet, 2006; Sankar, Nevedal, Neufeld, Berry, & Luborsky, 2011). The Centers for Disease Control and Prevention estimate older adults will comprise 50% of HIV/AIDS cases by 2015 and 70% by 2020 (Senate Special Committee on Aging, 2013). Older adults account for 17% of new cases of HIV/AIDS (Administration on Aging, 2014). Two epidemiological groups account for this increase: (1) people diagnosed at younger ages with HIV, "aging in", and (2) people diagnosed at older ages.

Despite the *graying* of the HIV/AIDS epidemic, ageism continues to obstruct attention to HIV risk among older adults. Beliefs that HIV is a younger person's disease create a false sense of protection among older adults and health professionals leading to reduced awareness of risk and late diagnosis (Brennan, Emlet, & Eady, 2011; Mack & Bland, 1999; NIA, 2014; Sankar et al., 2011; Ward, Disch, Schensul, & Levy, 2011). Older adults have been overlooked in HIV/AIDS prevention, research, surveillance, and testing (Davis & Zanjani, 2012; Orel, Wright, & Wagner, 2004). Increased late diagnosis of HIV among older adults results in poorer health outcomes because treatment is delayed and the damaged immune system is difficult to treat (Ford, Wallace, Newman, Lee, & Cunningham, 2013; Rickabaugh et al., 2011). As a result of late HIV detection, about 41.5% of older adults receive an AIDS classification at diagnosis and others rapidly progress from HIV to AIDS within 12 months after diagnosis (CDC, 2013). Older adults experience ageism, inequality in access to care and treatment, increased comorbidities, stigma, and financial burden from long-term treatment (CDC, 2013; Leland, 2013; NIA, 2014; Sankar, Nevedal et al., 2011).

Research on aging with HIV/AIDS is well under way using biomedical markers and quantitative measures to understand biophysical health (disease progression, immune response, comorbidities), psychosocial concerns (stigma, isolation, social support, discrimination, disclosure, sexual identity), and self-management (adherence) (Emlet, 2014). What is less understood is the nature of

older individuals' experiences of living with HIV/AIDS in later life. Qualitative research exploring life course and lived experience will add to a more comprehensive understanding of aging with HIV (Rosenfeld, Bartlam, & Smith, 2012; Schoenberg, Miller, & Pruchno, 2011; Solomon, O'Brien, Wilkins, & Gervais, 2014).

African Americans represent half of HIV/AIDS cases among those 50 and older (CDC, 2014). They experience as follows:

- Increased morbidity and mortality compared with other ethnic groups and are underrepresented in research (Brooks, Buchacz, Gebo, & Mermin, 2012; George, Duran, & Norris, 2014; Linley, Prejean, An, Chen, & Hall, 2012).
- Increased HIV stigma in comparison to older whites or Latinos with HIV/AIDS (Foster & Gaskins, 2009).
- Increased poverty, comorbidities, and other factors contributing to health disparities (Bohnert & Latkin, 2009; Jain, Schwarcz, Katz, Gulati, & McFarland, 2006; Pound, Britten, & Morgan, 2005; Vyavaharkar et al., 2010).

Studying the subjective experiences of African Americans who are living with HIV/AIDS provides insight into the nature of disparities in health, socioeconomic status, and stigma associated with HIV/AIDS. Three studies to date have explored how older African Americans make sense of living with HIV/AIDS. Haile, Padilla, and Parker (2011) found older African American men-who-have-sex-with-men experience pervasive HIV-related social and structural stigma; however, Foster and Gaskins (2009) found older African Americans experience internalized shame and anticipated stigma rather than direct HIV stigma. Warren-Jeanpiere, Dillaway, Hamilton, Young, and Goparaju (2014) explained the importance of comorbidities in understanding HIV self-management among older African American women. We expand this literature by connecting the experiences of older African Americans with HIV/AIDS to core questions in gerontology and life course theory. The purpose of this article is to describe how HIV influenced the life course expectations of older African Americans and how HIV affected experiences of sexuality and intimacy, which participants identified as areas most affected by the disease.

## Theoretical Framework

Life course theory describes the roles of the individual, culture, and society in shaping how key phases, social roles, and expectations about life are understood and experienced (Fry, 2003). Building from life course theory, Becker (1997) developed the life course disruption theory to understand how people make sense of life when important expectations

are not met and to what extent people reorganize their lives after disruption. Becker used research on chronic and disabling conditions (e.g., infertility, stroke) to investigate how illness and disability affect individuals' culturally valued life course expectations such as parenthood or independence (Becker, 1997; Bletzer, 2007; Hinojosa, Boylstein, Rittman, Hinojosa, & Faircloth, 2008; Luborsky, 1994). Becker's life course disruption theory guided our research questions, data collection, and analysis. Our study began with the a priori question *How does living with HIV/AIDS disrupt the life course expectations of older African Americans?* As the study progressed and participants' perspectives were better understood, we revised our question to *How does an HIV diagnosis disrupt sexuality and intimacy?*

## Design and Methods

This study was conducted in 2009 and was an extension of a longitudinal study (2001–2006) of adherence to antiretroviral therapy among seropositive African Americans ( $N = 144$ ) (Sankar, Neufeld, Berry, & Luborsky 2011). Participants from the original study were recruited from two mid-western urban infectious disease clinics. The principal investigator of this extension study was part of the original study team and had prolonged engagement with participants.

## Study Participants

Demographic characteristics of the sample are shown in Table 1. Of the 144 in the original sample, 43 met the inclusion criteria of being seropositive, self-identified African American, and age 50 or older. Thirteen out of 43 eligible people participated in the study. Those who did not participate were deceased ( $n = 13$ ) or "lost-to-follow-up" ( $n = 17$ ). Telephone calls, clinic updates, and death record searches were used to locate "lost-to-follow-up" participants.

## Data Collection

The Institutional Review Board at the respective institution approved this study and participants were consented. Pseudonyms were used for anonymity. A. Nevedal conducted the interviews and has extensive training in qualitative research. Thirteen participants completed one audio-recorded, semi-structured, face-to-face interview at home or campus. Participants received \$25. The semi-structured interview guide (Supplementary Appendix) included (1) open-ended questions about living with HIV, life course expectations, disruptions, and reorganization since HIV diagnosis (2) follow-up probes. Interviews lasted from 61 to 175 minutes ( $M = 101$ ).

**Table 1.** Participant Characteristics

Older African Americans With HIV/AIDS	Men ( $n = 8$ )	Women ( $n = 5$ )
Age range (51–78 years, $M = 58$ , $SD = 7.4$ )		
50–59	6	3
60–69	1	2
70–79	1	0
Marital status		
Single	3	0
Married/domestic partnership	1	1
Divorced/separated	4	4
Education		
High school	4	3
2-Year college	2	2
Graduate school	1	0
Unknown	1	0
Employment status		
Employed	1	0
Unemployed	5	5
Retired	2	0
Home		
Rent	6	4
Own	2	1
Own car		
Yes	4	0
No	4	5
Income since HIV diagnosis		
Very comfortable	2	0
Somewhat comfortable	3	2
Just got by	1	2
Hardly got by	1	1
Unknown	1	0
HIV exposure		
Men who have sex with men	5	0
Heterosexual sex	2	4
Injection drug use and heterosexual sex	1	1
Age at HIV diagnosis		
50 years and older	3	2
49 years and younger	5	3
Time since diagnosis (6–24 years, $M = 11.1$ , $SD = 5.8$ )		
6–10	5	4
11–15	1	0
16–20	1	0
21–25	1	1

## Analysis

Interviews were transcribed verbatim and transcripts were imported into ATLAS.ti, a qualitative data management program. We used a systematic, multiphased coding, and thematic analysis process adapted from Bernard and Ryan (2010). Four experts in aging, HIV/AIDS, and qualitative methods provided guidance throughout the study to improve trustworthiness. We began our analysis by focusing

on data addressing our primary research question: *How does living with HIV/AIDS disrupt the life course expectations of older African Americans?* A preliminary review of the data shifted our attention to an emergent research question: *How does an HIV diagnosis disrupt sexuality and intimacy?*

### Phase 1—Preliminary Analysis

To address the primary research question, participants were asked questions including *How has HIV affected your life?* and *Would you consider HIV a disruption?* These intentionally broad questions allowed participants to describe in their own words their experiences of living with HIV. We reviewed participants' responses to the questions referenced earlier to identify, compare, and discuss whether to apply closed codes (a priori) or create open codes (a posteriori). Closed codes were derived from the literature (Becker 1997) and included topics such as disruption, reorganization, continuity, sickness, and pill taking. Although sickness and pill taking were coded for, they appeared infrequently. We created an open code for sexuality and intimacy because it was the only topic discussed by all participants.

The following examples illustrate participants' focus on sexuality and intimacy when asked broader questions about the impact on or disruption to their lives from HIV. Alvin, a 78-year-old man living with HIV for 6 years, was also a cancer survivor. He described himself as a financially secure retired mechanic and reported having sex with men. He responded to the question, *How has HIV affected your life?*, by describing how his sex life stopped after his diagnosis.

Things I used to do, I don't do them no more. My ship just stalled in the water; I stopped it right there. It don't go no farther than me. I'm not gonna run out and give it to somebody.

Mildred, a 56-year-old woman was seropositive for 7 years. She was concerned about managing diabetes and experienced recent vision loss. Mildred was unemployed and described frustration with few job opportunities. She replied to the question, *Would you consider HIV a disruption to your life?* stating:

Being intimate or close to someone that's the only problem. Other than that I live like a normal person.

The participants' universal focus on sexuality and intimacy led us to shift our analyses to these topics.

### Phase 2—Sexuality/Intimacy Coding

In Phase 2, we expanded the sexuality/intimacy coding to identify references throughout the entire transcript. A. Nevedal and A. Sankar independently coded several transcripts to refine code definitions. Coded transcripts were

compared to discuss discrepancies until reaching consensus. *Sexuality/intimacy* referred to all physical, emotional, and social topics related to sexuality and any discussions of intimate relationships affected by the HIV diagnosis. *Sexuality* included mentions of sexual behavior, practices, desires, orientation, relationships, and concerns about viral transmission. *Intimacy* referred to talk about HIV's influence on the individual's ability to emotionally engage in sexual relationships. Intimate kin relations such as ties to grandchildren were excluded from this code. A. Nevedal coded the remaining transcripts for talk featuring sexuality/intimacy using text-based keyword searches (e.g., love, sex, dating, and condoms) and by multiple readings of the transcripts to identify subtle discussions of sexuality/intimacy such as "my ship stalled in the water." A. Sankar reviewed the transcripts to ensure coding was appropriate and consistent.

### Phase 3—Sexuality/Intimacy Themes

We reviewed the coded references to sexuality and intimacy identified during Phases 1 and 2. We compared and contrasted each reference to identify the sexuality and intimacy themes. Consistent with rigorous applications of thematic data analysis (Braun & Clarke, 2006), several rounds of coding and comparisons were conducted until we reached agreement on the final themes of *damaged sexuality* and *constrained intimacy*. These themes appeared in some form in each participant's interview. We followed a similar process to identify variation within each theme.

## Results

### Damaged Sexuality

All participants said that they experienced what we call damaged sexuality after their HIV diagnosis. This term comes from a study participant who, in discussing his sexuality, declared that he was "a damaged piece of goods." Damaged sexuality was a theme reflected in discussions about reduced sexual activity, challenges to finding suitable partners, and transmission concerns. Participants experienced varying degrees of damaged sexuality from refusing sexual contact with another person to a heightened awareness of HIV stigma and fear of rejection in sexual encounters. We identified three types of damaged sexuality.

### Eliminate Sexual Contact

Six participants refused any involvement in sexual relationships fearing HIV transmission and anticipating HIV stigma. This group expressed frustration and anger about stopping sexual activity after their HIV diagnosis. Marion, a 62-year-old woman, seropositive 10 years, stated that, apart from weight loss, she was healthy and able to care for neighbors. She emphasized losses to sexuality when describing HIV's impact:

I get angry about it a lot because I'm not having sexual relationships. Damned if I do, damned if I don't.

William, a 53-year-old self-identified gay man, struggled financially and worked as a health aide before his HIV diagnosis 18 years ago. Although William yearned for romance and sexual contact, shame from HIV and concerns about transmission stopped his sexual activity.

[HIV] was an abomination for me. I turned into a tahila-monster. I'm alone and it hurts me. I will never have a person I can walk down the street and say I love. That's a horrible thing to have to deal with...I can't get close to anybody other than just talking. It's like fear. I don't want to give it to no one.

He continued explaining how masturbation and fantasies helped him deal with sexual losses.

I think about it [sex] every day. That's what keeps me going. Ain't nothing wrong with wishful thinking. I fantasize.

Alvin, introduced earlier, emphasized he was no longer the sexual person he once was.

I was [sexually] active. Since then [HIV diagnosis] I'm not. It scared the hell out of me. The sexual part. I don't mean I don't want that. I know better to leave it alone. I make myself not want it. That's about the only way that I can say that it [HIV] has impacted my life.

Alvin was concerned about transmission and anticipated HIV stigma after disclosure.

Things I used to do I don't do them no more. I'm not gonna run out there and give it to somebody. I stopped being sexually active. I know there are ways to be, but it's a stigma; I don't want to see no disdain in nobody's eyes.

Leonard was of age 56, seropositive 7 years, and bisexual. In contrast to other participants, he experienced major medication side effects and symptoms from HIV. Leonard avoided sexual activity because of his poor body image and hid muscle atrophy with clothing:

I'm very self-conscious about physical changes that have taken place since I've been sick. Since I don't look how I used to look, I've lost a lot of self-confidence.

Low self-esteem and fear of transmission influenced Leonard's avoidance of sexual relationships.

I would love to have [a sex life]. I still get flirted with but think of myself less than I am. If I wanted to be in a relationship, I could be in one easily. It's by choice. I won't bring anybody in to this. I was in a relationship with someone but I didn't see being able to offer her anything.

### Limited Sexual Opportunities

Four participants were dating or in a relationship and experienced HIV-related challenges to forming sexual relationships and engaging in sexual behaviors. James was of age 54 and seropositive 24 years. He sought seropositive women through HIV dating sites and Narcotics Anonymous support groups. Although James was interested in dating, he described himself as "old, lonely, depressed" because he could not find a suitable seroconcordant woman.

The ones I've met that have HIV, I don't want. My friends say, "Your standards are too high." I just want someone nice to look at. I met some real scruffies, they wasn't for me. It's depressing. I had this lady come from Illinois. I talked to her online. She didn't look that bad. Then she drove here. That was one depressing day. 'Cause my hopes was up so high.

In comparison to other participants, Donald described his sexuality as slightly damaged. Donald was 60 years old, seropositive 8 years, and self-identified as gay. He retired after his diagnosis and was financially secure from a career in finance. When talking about how HIV affected his life, he discussed changes to sexual activity in his long-term, serodiscordant relationship:

Besides the sexual behavior [our relationship] hasn't changed at all. It's changed the way we do some things, but it hasn't been a major obstacle. Before being diagnosed, maybe we were a little wilder.

### Damaged Then Repaired Sexuality

Three participants described initial damaged sexuality before establishing serodiscordant relationships. The theme for this group centers on repairing damaged sexual identity. People described the repair process as a gradual acceptance of their HIV diagnosis that led to increased self-esteem and the pursuit of sexual relationships. A key feature of this group was finding supportive serodiscordant partners, who were willing to be involved in a sexual relationship with them despite their seropositive status. Although concerns about HIV transmission were ongoing, these people reported using condoms to prevent HIV transmission.

Patrice was a 51-year-old woman and former substance user who, prior to her diagnosis 8 years ago, was a caregiver for seniors. Patrice described healing her damaged sexuality through stages of grief, moving from anger to acceptance until establishing a serodiscordant sexual relationship.

I'm in the acceptance part of it now. I'm not in the angry part of it; I'm not in the denial part of it. I was very angry. Somebody chose to give it [HIV] to me and chose not to tell me. Now I just accept it. I chose to move on. I don't want to linger on it.

In the early years of living with HIV, Patrice was angry at her partner for infecting her with HIV. She felt like a leper; however, she remained with her partner and cared for him until his AIDS-related death a few years before our interview. Patrice was worried about spending life alone because of her serostatus.

I was lonesome but I would shy away from men. I wasn't worthy. I had something I didn't want to give anyone. I had some guys that were interested in me but I let them go. They wanted to have sex but I couldn't do it. I used to walk around like I was a leper.

Patrice mentioned how shifts in social attitudes about HIV helped her to become more accepting of her status.

More people are infected with HIV. I told the doctor I was HIV-positive. He said "I ain't sweating that. You would be surprised how many people are HIV-positive. That's the norm." It made me feel like I was not a leper. I don't feel that way anymore. So many people have HIV now, it's not abnormal anymore. Years ago it was not accepted, it's still not an acceptable disease but it's more acceptable through the commercials, walks, awareness. It's [HIV] not so much what you call a terminal illness anymore.

Patrice's acceptance of HIV helped to repair her damaged sexuality.

Time has made me not mad at it [HIV] anymore. I have to learned how to live my life with it. I had to learn how to accept for myself, so they could accept it.

Patrice mentioned she was in a new, serodiscordant sexual relationship with a man who accepted her HIV status and took measures to prevent HIV transmission.

We do it [sex], but we do it with safety. He gets checked. He's ok. So that makes me feel good.

In this section, we can see the various ways in which an HIV diagnosis affected the sexual lives of older African Americans. Except for Donald, the loss of or diminished access to sexuality were deemed to be significant impacts on people's lives.

### Constrained Intimacy

Older African Americans living with HIV described constrained intimacy as a major concern when forming sexual relationships. Participants experienced dilemmas as they sought emotional intimacy but feared rejection from potential sexual partners after HIV disclosure. Four different types of constrained intimacy emerged.

#### Constrained Intimacy and Sexuality

Seven participants saw HIV as limiting access to emotionally intimate relationships due to fear of rejection after disclosure of their diagnosis. Six decided against seeking

emotional intimacy and sexual intercourse. One participant did not experience constraints on intimacy and sexuality but was aware of this problem. Participants emphasized the emotional and social risks they faced if they disclosed their diagnosis to potential sexual partners. Eschewing sexual relationships was a strategy to avoid HIV disclosure and the risks it entailed. Although loss of sexuality was discussed, people with this theme privileged their concerns about rejection due to HIV stigma over the pain they experienced from the loss of emotional intimacy (e.g., companionship, love) from a romantic partner. For these participants, disclosing their status was seen as essential for establishing emotional intimacy and morally responsible behavior before forming sexual relationships. As a result, they preferred to avoid intimacy and sexuality rather than face potential rejection.

William, previously introduced, described how his serostatus constrained his intimacy:

When you get close to someone and you tell them [your serostatus] they're gonna reject you. HIV has a lot of effect on me on that particular part. I cannot be intimate and openly with someone because of fear of being rejected. I just pretend and don't get close to anybody, which devastates me.

To prevent HIV stigma, Alvin, introduced earlier, was adamant about avoiding the emotional intimacy required to disclose his status to sexual partners.

I'm not sexually active right now, so I don't have to be telling nobody. If I were, I'd have to tell somebody. Kill two or three birds with one stone, I don't do it, so I don't have to tell nobody...[HIV] my little secret. Only one of my friends knows. Just one. My family don't know.

Mildred, introduced previously, desired romantic love but avoided intimacy because of anticipated rejection from HIV disclosure.

For the past years, I have not [had a relationship], I don't want to be bothered. I want someone to love me but once you tell it's gonna make them go away from you. They're not open minded. I don't let no one get that close.

#### Constrained Intimacy not Sexuality

Two participants described how HIV constrained the emotional intimacy they had with sexual partners because they either avoided or delayed disclosing their status. Sheila, 53 years old, lived with HIV for 22 years along with other disabling conditions including vision loss and arthritis. A former intravenous drug user, she took pride in being a housewife and completing a counseling certificate. Sheila described the close relationship with her (serodiscordant) husband except he was unaware of her serostatus during the early years of their marriage. Although she eventually

disclosed her status, she told her husband she was *newly* diagnosed to prevent anticipated rejection.

This is the part that my husband don't know. In '87 I went into the hospital and I found out I was HIV-positive. I got with my husband in '98 but didn't tell him at that time. He found out in 2004. I shouldn't have done it. I've asked for forgiveness for it. The Lord has forgiven me because he don't have anything.

Melvin, a 59-year-old man, seropositive 6 years, was a factory worker prior to a traumatic accident and brain injury. Melvin emphasized that the ultimate goal in his life was to achieve a long-term emotionally intimate sexual relationship.

As far as I'm concerned falling madly in love with a person is the ultimate goal. To find that one someone that you can share everything in your life with. Loving them no matter what. That's what everybody be trying to get.

Although Melvin desired emotional intimacy, he was concerned his girlfriend (serodiscordant) of 20 years would reject him if she found out about his serostatus. He did not disclose to her despite calling her "the closest thing to me, almost a wife."

### Reducing Constrained Intimacy

Two participants described pursuing or remaining in a seroconcordant sexual relationship in order to reduce constrained intimacy. For example, James, introduced earlier, described himself as conscientious about disclosing his status and dated women who were also seropositive to avoid stigma or rejection.

I try to date women who have the virus. 'Cause I can talk to them about it. I'm not a bad-looking guy. I can get women sometimes that don't have the virus. But I shy [away]. They might think I'm gay. I play past the sex thing because I don't want to have to tell them. Even though I can put on a condom you're still supposed to tell them.

Gerard was a 56-year-old self-identified gay man who was a financially secure social worker and seropositive for 8 years. In contrast to the other participants, Gerard was in a long-term, but unhappy seroconcordant domestic partnership. Fearing rejection as an older gay seropositive man, he remained in the relationship.

If I had to re-enter the dating scene, that would be a real burden. Aside from my age, I've got this health thing that limits the number of people that would date me. Because you'd have to discuss it [HIV] with strangers, that would be very uncomfortable for me. That's one reason why I stick in [relationship] because it's not ideal. Both of us are positive.

### Initial Constrained Intimacy

Two participants described overcoming the barriers they envisioned when establishing an intimate relationship and revealing their HIV status. Walter was a 51-year-old grandfather, who enjoyed painting houses for extra money and was seropositive for 12 years. Although Walter initially delayed HIV disclosure, another person revealed his status to his girlfriend. Walter and his (serodiscordant) girlfriend worked through these challenges and established an emotionally intimate sexual relationship.

She's okay with it. She helped me a lot. She found out from somebody else and she said, "Walter, you know, you can just tell me. I'll be right there." I fell for her right there. It's been good ever since. She don't see me no different.

Walter went on to describe the importance of establishing intimacy:

I was used to having sex with people I didn't even know. Now I take time to really get to know people. That really changed my life. I'm with one person and with one person only.

Patrice, introduced previously, also hesitated to disclose her status when establishing a new relationship. She emphasized challenges to establishing emotional intimacy in serodiscordant dating. However, she overcame the fear of HIV disclosure and her serodiscordant partner accepted her.

My male friend knows, he accepted, but it was hard to tell him. I didn't want to. I thought I was gonna live life by myself, but God seemed fit to send me a companion. I was concerned about being lonely. The other one had [HIV] so we could deal with it better. When you have one that don't have it and one that do have it, it was hard to tell him. Then he wants to be sexually active. He thought I didn't like him but I was scared to tell him. I could have laid down and had sex with him but I didn't do that.

Although sexuality and intimacy are clearly linked, for many in this study, the loss of emotional intimacy associated with a sexual relationship was the greater burden from the disease. Some participants came to terms with their diagnosis and established intimate sexual relationships, whereas others chose to forgo this desired part of life rather than risk rejection and the humiliation of HIV stigma.

### Discussion

We used Becker's (1997) life course disruption theory to explore broad, open-ended questions about older African Americans' experiences of living with HIV/AIDS. Participants described the themes damaged sexuality and

constrained intimacy to discuss aspects of their lives most affected by an HIV diagnosis. Becker's (1997) life disruption theory suggests after an unexpected life event people experience disruption when they cannot fulfill culturally valued life course expectations. Emphasis on damaged sexuality and constrained intimacy after an HIV diagnosis provides evidence to support the life disruption theory. Even after living with HIV for 6–25 years, many participants described HIV as enduring disruption and restraint to one's sexuality and intimate relationships. We expand on Becker's research by exploring the ways in which the perceived limitations to sexual expression and intimacy associated with an HIV/AIDS diagnosis constitute life course disruptions. Our research on older African Americans' experiences of living with HIV/AIDS supports notions that sexuality and intimacy are important expectations throughout adulthood and key features of human development (Levy, 1994).

Life reorganization was an additional component of Becker's (1997) theory, which described the efforts people make to create continuity after experiencing disruption. Most participants experienced ongoing disruption to sexuality and intimacy; however, some participants described damaged then repaired sexuality or initial constrained intimacy, which support the reorganization aspects of Becker's theory. Although it is not the focus of this article, many participants described moving on with life despite disruptions from HIV. This supports research on reorganization and resilience in older chronically ill African Americans (Becker & Newsom, 2005).

Our findings suggest a need for studying how stigma and life course theories intersect and how life course expectations for sexuality and intimacy are affected by HIV stigma. We used Becker's (1997) life course disruption theory instead of stigma theory to better understand the experience of living with HIV as an older adult. Importantly, the focus on life course allowed spontaneous discussions about expectations for sexual and/or intimate relationships in older age and the painful consequences of an HIV diagnosis for these expectations. We argue for using a life course disruption theory to better understand the significance of this disease for older adults.

Damaged sexuality and constrained intimacy themes confirm previous research on the pervasiveness of HIV-related stigma in the lives of older African Americans with HIV (Emler, 2006, 2007; Foster & Gaskins, 2009; Haile et al., 2011; Vyavaharkar et al., 2010). We expand what is known about HIV stigma in older African Americans by describing the presence of anticipatory and social stigma in forming sexual and intimate relationships. Consistent with research on stigma among older African Americans with HIV (Foster & Gaskins, 2009), most participants described internal HIV-related stigma such as shame and

anticipated rejection after disclosure rather than having experienced external HIV-related stigma (Florum-Smith & De Santis, 2012). Anticipated rejection and shame were seen as barriers to forming sexual and emotionally intimate relationships.

Participants who described constrained intimacy not sexuality explain how maintaining sexual relationships is sometimes privileged at the expense of emotional intimacy and HIV disclosure. Further understanding of relationships that are sexual in nature but have constrained intimacy (e.g., due to lack of HIV disclosure) provides insight into the challenges that older African Americans living with HIV/AIDS face with respect to secondary transmission and prevention. This finding supports the arguments of Emanuel (2014) suggesting increased risks of sexually transmitted infections in older populations. Disclosure challenges and transmission risks may be heightened among older African Americans because of increased HIV stigma reported in this population (Vyavaharkar et al., 2010) compared with other populations of older adults with HIV.

We know sexuality, intimacy, and touch are valued and are needed for physiological, psychological, and social well-being throughout the life course (Field, 2010; Khaleque, 2004; Levy, 1994; Montagu, 1984; Scherrer, 2009; Traupmann et al., 1982). However, what happens to older adults' expectations for sexuality and intimacy after receiving an HIV/AIDS diagnosis? Our findings begin to address this question by explaining the importance of and meaning of sexuality and intimacy in the life course expectations of older African Americans living with HIV/AIDS. Findings support non-HIV research emphasizing older adults' continued desires for romantic partnerships and participation in sexual activity in later life (Brooks et al., 2012; Morgan & Kunkel, 2007; Schick et al., 2010; Taylor & Gosney, 2011). This may be even more evident for older African Americans with HIV/AIDS as both our study and a recent study describing concerns about loneliness and companionship among older African American women living with HIV/AIDS have demonstrated (Warren-Jeanpiere et al., 2014).

### Strengths and Limitations

An important strength of our study was prioritizing older African Americans' perspectives of living with HIV/AIDS because this population has been underrepresented in research (George et al., 2014). The sample was clinic based and approximately two thirds of the participants were "lost-to-follow-up" or deceased. Member checking was included in the original study but not feasible for this study due to the sensitive, emotional topics discussed in the interviews (Hallet, 2013). The small sample size limited

our ability to explore group differences (Guest, Bunce, & Johnson, 2006). Replicating this study in different populations with other stigmatized conditions (e.g., various mental health disorders) would help determine how findings from these interviews vary across social and study contexts.

## Implications

### Research Implications

Research on older adults with HIV/AIDS should incorporate gerontological and life course theories to better understand life-stage-specific issues posed by an HIV infection and how other normative social roles and expectations are affected by HIV/AIDS. Future researchers are encouraged to use larger and different samples of African Americans and other ethnic groups to explore how desires for sexual and intimate relationships are important to psychological, social, and physiological aspects of life and how HIV stigma limits access to this vital part of life for older people with HIV.

### Practice Implications

Findings from this study highlight a need for screenings, interventions, and sources of support for older African Americans with reduced well-being because of challenges and losses to sexuality and intimacy after an HIV diagnosis. Individual therapy may provide support and facilitate coping for people who self-report feeling lonely and depressed because of challenges to sexuality and intimacy. Interventions should address individual and psychosocial issues, such as low self-esteem and relationship fears and/or ambivalence, as well as behavioral interventions to encourage and facilitate social interaction.

We recommend these interventions for older African Americans with HIV/AIDS:

1. Clinicians should discuss sexuality and intimacy at the time of HIV diagnosis and throughout care because of changing relationships and enduring challenges that individuals face while living with the disease.
2. Internet-based or telephone support addressing HIV-related challenges to sexuality and intimacy are needed, especially for people who are concerned about privacy, are homebound, or without transportation.
3. In-person support groups may not be well received because of increased HIV-related stigma and concerns about HIV disclosure.
4. Discussions about HIV with health professionals may be more acceptable than with family or community members because of HIV stigma. Health professionals are an important resource for linking people to support services.

The study findings provide important insight into understanding the experiences of older African Americans who are aging with HIV/AIDS as well as the general importance of intimacy and sexuality in later life.

## Supplementary Material

Supplementary material can be found at: <http://gerontologist.oxfordjournals.org>.

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