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“The pleasure is better as I’ve gotten older”: Sexual Health, Sexuality, and Sexual Risk Behaviors among Older Women Living with HIV

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Abstract

There is limited research examining the sexual health and wellbeing of older women living with HIV (OWLH). Most studies focus on sexual dysfunction, leaving aside the richer context of sexuality and sexual health, including the effect of age-related psychosocial and interpersonal changes on sexual health behaviors. Guided by the integrative biopsychosocial model and the

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sexual health model, this study explored the importance of sex and sexuality among OWLH to identify their sexual health and HIV prevention needs for program planning. A purposive sample (n=50) of OWLH was selected from a parent study (n=2,052). We conducted 8 focus groups and 41 in-depth interviews with 50 African American and Latina OWLH aged 50–69 years old in three U.S. cities. The triangulation approach was used to synthesize the data. Six salient themes emerged: sexual pleasure changes due to age, sexual freedom as women age, the role of relationships in sexual pleasure, changes in sexual ability and sexual health needs, sexual risk behaviors, and ageist assumptions about older women's sexuality. We found that sexual pleasure and the need for intimacy continue to be important for OWLH, but that changing sexual abilities and sexual health needs, such as the reduction of sexual desire, as well as increased painful intercourse due to menopause-associated vaginal drying, were persistent barriers to sexual fulfillment and satisfaction. Particular interpersonal dynamics, including low perceptions of the risk of HIV transmission as related to gender, viral suppression and habitual condomless sex with long term partners without HIV transmission have resulted in abandoning safer sex practices with serodiscordant partners. These findings suggest that HIV prevention for OWLH should focus on how sexual function and satisfaction intersect with sexual risk. HIV prevention for OWLH should promote ways to maintain satisfying and safe sex lives among aging women.

Keywords

Sexuality; Sexual Health; Sexual Risk Behaviors; Aging; HIV

Introduction

With increased access to highly active antiretroviral therapy (HAART), people living with HIV (PLWH) are experiencing longer and healthier lives (Miller & Hodder, 2014; Samji et al., 2013; Wada et al., 2014); and many maintain the desire and ability to continue sexual activity into old age. Sexual health, sexuality, and sexual satisfaction among older PLWH are neglected areas of research, perhaps due to the assumption that older adults no longer engage in sexual activity. Sexuality in HIV research has almost exclusively been placed in the context of disease prevention rather than health promotion and wellbeing, with little attention paid to desire and pleasure. Studies on sexual health and HIV have focused primarily on the reproductive needs of younger PLWH to reduce mother-to-child transmission and promote safer conception, especially for serodiscordant couples (Chadwick et al., 2011; Matthews & Mukherjee, 2009; Schwartz et al., 2014; Taylor, Mantell, Nywagi, Cishe, & Cooper, 2013). However, little is known of the sexual health needs of older women living with HIV (OWLH).

According to the CDC (2014a), an estimated 91,492 women living with HIV in 2013 were aged 50 and older, the majority of whom were African American and Latina (CDC, 2014a). OWLH seek to sustain on-going relationships, as well as establish new relationships to maintain security, as well as the support and intimacy that partnered relationships provide (Keegan, Lambert, & Petrak, 2005; Lambert, Keegan, & Petrak, 2005). Examination of the sexual health and wellbeing of OWLH has primarily focused on sexual dysfunction, defined here as difficulty in sexual activity, including problems with desire, arousal and pleasure,

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which has been found to be common among women with HIV of all ages (Bell, Richardson, Wall, & Goldmeier, 2006; Denis & Sung-Mook, 2003; Goldmeier, Kocsis, & Wasserman, 2005; Siegel, Schrimshaw, & Lekas, 2006; Wilson et al., 2010). Denis and Sung-Mook (2013) found that women with HIV, in comparison to women without HIV, had significantly lower sexual functioning, including a diminished interest in sexual activity, sexual satisfaction, and fewer orgasms. Another study found that women with HIV reported greater sexual problems than those without HIV, and that lower sexual functioning was associated with low CD4 counts (Wilson et al., 2010). Importantly, Wilson et al. (2010) also found that for both women with and without HIV, lower sexual function is associated with menopausal status, depression, and not having a partner. However, very little is known about the changing sexual desires and sexual health needs of OWLH and how these factors may impact sexual risk behaviors.

Using data from the Women's Interagency HIV Study (WIHS) – the largest longitudinal cohort study of women with and without HIV in the US – we found that more than a quarter of the women with detectable (29 %) and undetectable (28 %) viral loads reported condomless sex (Taylor et al., 2014). Some data suggests that for OWLH, the acquisition of new partners is often accompanied by an increase in condomless sex and risk for acquiring sexually transmitted infections, since condom use (and its' negotiation) may be difficult for older male partners who may have issues with sexual function (Nunes, Azevedo, & Lisboa, 2015; Rich, 2001). Additionally, studies have found that certain psychosocial and interpersonal variables, such as partner trust, relationship power imbalance, traditional gender norms, and low condom negotiation self-efficacy can affect safe sex maintenance over time (Jarman, Walsh, & De Lacey, 2005; Stevens & Galvao, 2007).

Research suggest that maintaining sexual health and safer sex practices for some OWLH is further challenged by changing health, menopause, disability (Emlet, 2006; Gilbert & Linsk, 2004; Grov, Golub, Parsons, Brennan, & Karpiak, 2010; Shippy & Karpiak, 2005a, 2005b) and mental health problems, such as depression and anxiety (Brennan, Emlet, & Eady, 2011; Heckman et al., 2002; Heckman, Kochman, & Sikkema, 2004; Heckman et al., 2000; Kalichman, Heckman, Kochman, Sikkema, & Bergholte, 2014). Studies have found that changes in health and relationship status (from being married to being separated, divorced or widowed), social losses (the death of a spouse/partner, family or children moving away, and friends relocating as they retire) can result in diminished social support and increased psychological distress due to grief, isolation and concomitant loneliness, that can also adversely affect sexual health, sexual satisfaction and safer sex practices (Dykstra & Fokkema, 2007; Hemström, 1996; Lillard & Waite, 1995; Pearlin, 1980; Pinquart, 2003; Zick & Smith, 1991).

In addition, the dual stigma of AIDS and ageism, coupled with fewer supportive social networks (Emlet, 2006; Shippy & Karpiak, 2005a, 2005b) and a desire to remain self-sufficient, makes some OWLH more reluctant to disclose their HIV status (Emlet, 2006b, 2007; Emlet, Tangenberg, & Siverson, 2002; Gott, 1999; Grant & Ragsdale, 2008; Grodensky et al., 2015; Idso, 2009; Rich, 2001). One study among women living with HIV found that fear of stigma, discrimination and disclosure resulted in some self-imposing restrictions on expressions of sexuality and sexual desire (Gurevich, Mathieson, Bower, &

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Dhayanandhan, 2007). Similarly, Nevedal, and Sankar (2015) found that living with HIV limited older African American women's ability to experience sexuality and intimacy, resulting in perceptions of "damaged sexuality" and "constrained intimacy" due to stigma and fears of rejection and violence with HIV disclosure (Nevedal & Sankar, 2015).

Guided by the integrative biopsychosocial framework (Hillman, 2011; Lindau, Laumann, Levinson, & Waite, 2003) and Sexual Health Model (Robinson, Bockting, Rosser, Miner, & Coleman, 2002), the present study explores the changing sexual needs and desires of OWLH, as well as sexual behaviors, including pleasure, sexual satisfaction and safer sex practices among OWLH. The integrative biopsychosocial model provides a holistic approach for examining the interactions and interrelations between biological, psychological, and social factors that contribute to overall sexual health and wellbeing (Lindau et al., 2003).

The Sexual Health Model is a theoretical framework for improving people's overall sexual health and wellbeing. Derived from a sexological approach to education (Edwards & Coleman, 2004; Rosser et al., 1995; Sitron & Dyson, 2009), this model targets key components of "healthy" human sexuality that include (but are not limited to): a basic knowledge and understanding of sexual functioning; a recognition of how certain life challenges can impede sexual health; and the need for intimacy and sexual aspects of relationships (e.g., desire, arousal, and pleasure); and the promotion of sexual health care that includes safer sex practices. Proponents of the model argue that sexual literacy allows individuals to create strategies to reduce risk in their relationships and sex practices (Robinson et al., 2002). Using both frameworks provides a comprehensive approach for improving OWLH's overall sexual health and wellbeing.

Building on these models, we hypothesized that sexual health, sexuality and sexual satisfaction among OWLH are further impacted by concomitant health and non-medical challenges, such as ageism, HIV stigma, non-disclosure, body image, disability, menopausal symptoms, comorbidities, desire for pleasure and intimacy, relationship characteristics, partner's sexual dysfunction, and increasing social isolation and loneliness. This study, which is based on qualitative data collected in the in-depth interviews and focus group discussions, sought to elicit deeply personal and extremely sensitive information on how aging impacts sexual pleasure and satisfaction, as well as safer sex practices among older women with HIV. Given that 70% of all PLWH linked to care are aged 55 years and older and that 25% of PLWH are Black/African American or Latina women (CDC, 2008, 2014b), it is important to understand the biopsychosocial factors that impact sexual behaviors for this understudied population. Focusing on the sexual health and wellbeing of OWLH will enable the development of effective HIV programs that are gendered and generationally tailored to meet their specific needs and ensure that risk reduction messages relevant to this population are developed.

Design and Methods

Participants

Data from this study were collected in 2012 as part of a larger mixed method study to identify the sexual health and prevention needs of OWLH. Participants were drawn from two

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sources. The first included women enrolled at three of six WIHS sites (Brooklyn NY, Bronx, NY, and Chicago IL). The WIHS is a multicenter, prospective study, established in 1993, to investigate HIV disease progression in women in the United States. WIHS study recruitment and protocols have previously been described (Bacon et al., 2005; Barkan et al., 1998). Participants were also drawn from patients receiving HIV outpatient care at the Special Treatment and Research (STAR) Health Center at SUNY Downstate Medical Center. Participants were eligible to participate in the study if they were: (1) assigned female at birth, (2) age 50 or older, (3) had a diagnosis of HIV/AIDS, and (4) English speaking. In order to capture variability in sexual activity and behaviors, we did not limit recruitment according to sexual orientation or level of sexual activity.

Recruitment

Staff identified eligible women according to the aforementioned eligibility criteria and contacted participants on the telephone to assess if they were interested in participating in the study. Contact information for all interested STAR clients and WIHS participants was given to the PI (lead author), who then scheduled individual interviews or focus group appointments, depending on the preference and/or availability of the participant. Informed consent was obtained by the PI in English, after explaining study procedures, risks and benefits of participation, and answering any questions that participants may have.

Procedures

Following approval from the Institutional Review Boards at participating sites, we recruited 50 participants and conducted 41 semi-structured interviews and 8 focus groups (two at each site). In-depth interviews were conducted first and followed by focus group discussions. Of the 50 participants, 41 completed in-depth interviews; 39 of the 50 participants were also invited to participate in a focus group discussion; 30 completed both the in-depth interviews and focus groups; eleven completed the in-depth interview only; and nine participated in the focus groups only. In instances where there were unavoidable practical time constraints or a participant made it clear at the outset of recruitment that she would only participate in a face-to-face interview (n=1 participant at the STAR site), participants were invited to complete both the in-depth interviews and focus groups.

All focus groups and in-depth interviews took place in private rooms at recruitment sites. Each interviews lasted approximately 90 minutes; each focus group discussion lasted two hours. Interviews were structured to elicit responses and experiences related to central research questions in the following domains: 1) women's thoughts and beliefs about sex and aging; 2) sexual health needs; 3) effect of comorbidities on one's sex life; 4) safer sex practices and disclosure; 5) social networks and degree of loneliness, as well as the impact of depression and relationships factors on safe (and unsafe) sex practices. Sample questions included: *In what ways, if any, has your sex life changed as you have gotten older? How is sex more or less pleasurable as you have gotten older? How important is sex is for older women? Has your ability to have sex changed or not as you have gotten older? How has menopause changed sex for you? How has getting older with HIV affected your ability to practice safer sex? How has condom use changed as you get older? What challenges do you face in using them?* We explored the same questions in the focus groups and asked the

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women to comment on the experiences of OWLH in general rather than their personal experiences. Demographic data, including participant age, race, ethnicity, marital status, sexual activity, employment and education were collected from all study participants. All interviews and focus groups were recorded and resulting audio-files were later transcribed by a professional transcription service to create verbatim transcripts for coding and analysis. A $30 incentive and transportation cards were provided to each participant (per in depth interview and focus group).

Individual interviews are the most appropriate method for eliciting personal and/or sensitive information that might not be comfortably revealed by some women within the context of a public focus group format, while focus groups are ideal for identifying group norms, attitudes and perceptions and to target normative beliefs pertaining to ageism, HIV stigma, body image issues, menopausal symptoms, and safer sex knowledge, as well as disclosure and nondisclosure practices (Krueger & Casey, 2009; Patton, 2002). Therefore, during individual interviews, attention was placed on eliciting information about participants' detailed sexual experiences, and descriptions of their sexual satisfaction and desires, as well as information on their partners' sexual behavior and dysfunction. One advantage of combining in-depth interviews and focus group discussions was that it provided women the opportunity to choose which interview format they would prefer. Although most women were encouraged to participate in both types of interviews, we hypothesized at the outset, given the sensitive nature of the study, some women would not agree to participate in a focus group interview (preferring the confidentiality and privacy of a face-to-face interview). Finally, information gained from the in-depth interviews helped to inform and refine focus group discussions throughout the study.

Data Analysis

Transcriptions of the focus groups and interviews were imported into NVivo (QSR, International, Pty, & Ltd, 2010) for data management and analyses. A thorough assessment of the quality and completeness of the data was conducted. Structural coding was used to mark responses to questions in the interview guide (MacQueen & al, 1998). Following a review of the *a priori* themes, we used thematic analysis to identify salient themes and relationships. Once the codebook was finalized, a minimum of three researchers independently coded each transcript, and two researchers coded all transcripts. We calculated the inter-rater agreement with 95% confidence intervals for all interviews, comparing the first author's coded text to those of each member of the coding team. For the purpose of this paper, we report the Kappa coefficients for only 5 codes that correspond with the five of the seven themes discussed: aging with HIV (89–95%), pleasure (89–95%), ageism (89–94%), changing sex abilities (89–97%), and sexual risk (89–98%). Unless otherwise noted, quotes used throughout this paper reflect participants' typical comments that addressed primary themes. Methodological triangulation, or using multiple methods, is highly effective when drawing common themes from data sets (Bekhet & Zauszniewski, 2012). Themes from the qualitative focus groups clarified findings from the in-depth interviews, and further reflected on the sexual behavior and experiences of OWLH.

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Results

Table 1 provides information on the demographic characteristics of this sample. The majority of participants identified as Black or African-American (90%), had more than a high school level of education (48%), were single, divorced, widowed or separated (68%), un-employed (88%), and reported sexual activity (i.e., anal or vaginal intercourse in the last 3 months) (82%). We did not collect information on sexual orientation; however, all of the sexually active women (82%) reported having a male sexual partner and only one participant mentioned having had a female sexual partner in the past. All of the participants who reported no sexual activity did not have an available sexual partner and stated that they were no longer interested in sex, feared HIV transmission, or did not want the aggravation of sexual relationships.

Six themes emerged from data analysis of both the in-depth interviews and focus group discussions regarding the sexual behaviors and experiences of OWLH: 1) "*The pleasure is better…as I've gotten older*"(sexual pleasure increases with age); 2) sexual freedom (from the fear of pregnancy and traditional gender norms); 3) "*It's a little less pleasurable because of my relationship"* (due to partner and relationship characteristics); 4) "*I can't hold my leg up for hour[s] no more like I used to"* (changes in sexual abilities); 5) *"We do unsafe sex"* (sexual risk behaviors); and 6) *"You all too old!"* and *"She ain't got HIV"* (ageist assumptions about their sex lives and serostatus).

1) "The pleasure is better…as I've gotten older"

Sexual pleasure and satisfaction emerged as a salient theme from this sample of participants. Many reported that sex became more pleasurable after the age of 50. One participant equated this increasing pleasure with age as achieving a "sexual peak" that is enhanced through sexual experimentation:

> *I don't feel like I'm 50. I feel like I'm at my peak. I'm in the prime of my life… that I want to be sexually aroused. I want my husband to make love to me because I feel that as I was growing up I didn't really care about sex.* [But] *now, we're alone, we're married, and this is what you look for in a marriage; you look to have fun, to enlighten your horizon, try new things, experiment* (African American, 52, Brooklyn).

Another participant, a 58-year-old African-American woman from the Bronx, added that sexual pleasure increased because, in growing older, she became increasingly self-aware and knowledgeable about what she finds personably pleasurable.

Some women also noted that increasing sexual self-awareness with age made them reevaluate and appreciate sex, not just as something that is satisfied with frequency or sexy display, but as a more sensual or organic experience. One participant explained:

> *As you get older, you learn to appreciate it more and realize who you were…When I was younger, it was about being young, and being frisky, and being sexy. Now it's like it's more natural now. It's more like a come on thing, you know, for me* (African American, 63, Bronx).

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In addition, as women aged, understandings of sexual pleasure shifted to sensual pleasure and satisfaction, often achieved through embracing, hugging, touching, caressing, kissing, mutual stroking and/or masturbation and other non-penetrative aspects of intimacy and physical exploration. One woman noted that:

> *The pleasure is better…as I've gotten older. There's more touching and more feeling. There's more exploring, you know, like touching of the hair and the ears and the eyebrows. There's more exploring of the face* (African American, 63, Bronx).

Another added that touch and caressing are essential to enjoying penetrative sex:

> *If he can touch me… like, he may rub my breasts or feel on my breasts or something. And he'll know the way I respond to him whether or not I'm willing to, you know, take it to the next level* (African American, 51, Brooklyn).

Overall, regardless of their experiences or current situations, most of the participants described a strong desire to maintain sexual pleasure and intimacy as they aged because it was perceived as a fundamentally important aspect of what it means to them to be a woman.

> *I think sex is important, period! You know, for women…throughout the course of their whole adult womanhood…What I mean by that is especially as women age…I always considered myself to be a sexual individual. I know what it's like to be pleased. I know what it feels like to be pleased. I have enjoyed being pleased. You understand* (African American, 56, Brooklyn).

2) Sexual freedom

In addition to themes surrounding increased sexual pleasure, many participants expressed feelings of sexual freedom as a result of the onset of menopause coupled with liberation from the fear of pregnancy and sexual freedom from traditional gender norms (sex within committed partnerships).

> *When you're in the age of 50, one thing you don't really have to worry about…, is that you are not going to get pregnant. That used to be the big thing… to have sex, I have to use protection… 'cause I'm going to get pregnant… When you reach that age, it's like being more freer* [sic]. *That's one thing you don't have to concentrate so much on, you know* (African American, 59, Chicago).

Sexual freedom also included the ability to just have sex without the expectations of being in a committed relationship or needing financial support.

> *I'm highly sexual. If anything should happen to him* (her partner), *guess what, the next man I want, I want a booty call.*[a] *I don't want you to know where I live at. We go to a hotel, and that's all it's for. I need to satisfy this, and that's it. I don't want money, don't want nothing. You do you; I do me* (Bronx Focus Group #1).

[a]"Booty call": a person with whom one has sex at random times outside of a relationship; the act of calling said person; the term used to refer to said phone call.

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For another woman, the notion of freedom includes the ability to have more than one partner, and to have sex whenever she wants.

> *We're not restricted to this one* [type of experience] *because that falling in love stuff* (i.e., romantic beliefs), [such as] *he's my heart, and he's my 'all in all'*[b] *… no! All of them are my 'all in all.' You pick and choose. And if he don't come, then hey, maybe Jackie will come, or Jeffrey will come, or John Mark will come. You know, it's not one guy…Sure, that's how we feel about that. You don't just stop* (African American, 60, Brooklyn).

3) "It's a little less pleasurable because of my relationship"

Although many of the women described experiences of sexual pleasure and satisfaction as they aged, many also expressed dissatisfaction with their sex lives. Those dissatisfactions included their partners' inability to sexually perform, and unhappiness in their relationships. One participant described a synergistic relationship between her partner's impotence and her own decline in a desire for sex:

> *It's a little less pleasurable because of my relationship. He… is incompetent* [impotent] *…he been to his neurologist, taking the Viagra, the Cialis. He's tried every medication. And it worked for a minute, of course, and then later on it didn't work… he wasn't getting erect often…it was okay with me because…my sexual appetite started to decline…I still have feelings, you understand? I still have desires, you know, fantasies and stuff like that, that… I mean, it's still there, but it* [is]… [but it's] *Not as strong today* (African American, 55, Brooklyn).

For one woman, the sexual dissatisfaction was because of her partner's premature ejaculation, leaving her feeling sexually unfulfilled. To remedy this problem, she started to masturbate, thereby addressing her sexual needs:

> [Sexual satisfaction] *depends on your partner because sometimes they come too fast,*[c] *and you don't get no satisfaction.* [When] *he comes too fast, I go to the bathroom, and I take it on myself* (i.e., take care of my own sexual satisfaction, masturbate). *I don't want to stay* [sexually unsatisfied] *…because if you don't come, you gonna stay depressed. It's like a pressure, you know. So, if I have an urge, and I can't get it from him, I do it myself* (Latina, 54, Bronx).

Another participant described feeling trapped in a sexless marriage and dysfunctional relationship:

> *I'm missing sex. I want to have sex with somebody right now. But I'm 55, and right now, I don't get as wet*[d] *as I used to, right? …He urges me to go to my gynecologist to find out if that's the problem. But I don't want to do that because I don't want to get too wet for him because… After 19 years, I'm kind of almost done. And now the sex is really fucked up, excuse my language. The relationship has passed its expiration date* (Brooklyn Focus Group #2).

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[b]"All in all" the object of one's attention or interest (http://www.collinsdictionary.com/dictionary/english/all-in-all)
[c]"Come too fast": premature ejaculation (http://www.netdoctor.co.uk/sex_relationships/facts/prematureejaculation.htm)
[d]"Wet": when a women's vagina is fully lubricated and ready

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4) “I can’t hold my leg up for hour[s] no more like I used to”

Most of the participants in this study commented on their changing sexual abilities and sexual health needs, which include: new physical limitations, the increase or decline of sexual desire due to menopause; and painful intercourse due to ubiquitous vaginal drying among postmenopausal women.

Changing sexual abilities for many revolved around new physical limitations. One woman described how new physical limitations altered her sexual pleasure and satisfaction:

> *It feels good, but you can’t move, you can’t put your leg up, you can’t do this with the arthritis and stuff. It’s not the same no more. Oh man, it’s certain positions that like you can’t put your leg up, you out of business. You can’t do it no more* (African American, 54, Bronx).

For others, the recognition of these changes resulted in discussions or renegotiations with their partners. One woman described setting new boundaries with her partner in terms of what she was now willing to do sexually.

> *You got me in a position where my legs wrapped around my neck…No! I can’t do that! …So, I know how far my body can go now…But when I was younger, you would twist me up like a pretzel, and I couldn’t walk the next day. So, I’m not going to let you do that to me no more… With age, you get that. No, we’re not going to swing* (African American, 60, Brooklyn).

In the face of these challenges, some women found new ways to circumvent their physical limitations. One participant described how she made personal modifications to sidestep the changes in her sexual capabilities:

> *I can’t hold my leg up for hour*[s] *no more like I used to… I can’t do the things like I used …like the positions and all this stuff that like… if I’m on my knees for a long time, or holding my leg up for a long… I turn to the side or make it where I can be real comfortable to do stuff* (African American, 58, Bronx).

Although many women reported being physically challenged, these challenges did not always impact their ability to become aroused and experience an orgasm; overall, women described experiencing both positive and negative changes in their ability to have an orgasm. Several women described aging as a barrier to achieving a satisfying sexual climax.

> *I know that for myself the overall climax isn’t what it used to be. You know, it’s like a firecracker. It’s a dud* (African American, 54, Chicago).

> [Its] *hard for me to reach orgasm. You know, it got to the point where I would say, “Dang, I wish he’d hurry up”* (African American, 50, Chicago).

On the other hand, other women acknowledged how aging has improved their orgasm experience. One woman noted that:

> *It's more. It’s like before it was eh, but it’s easier for me to have an orgasm…In fact, it’s like some people only have one. I can have three. Years ago, I didn't have that. Now, I have it* (African American, 50, Chicago).

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For many, the experience of menopause profoundly changed their ability to have and enjoy sex. We found, however, that menopause impacted the sexual health of older women with HIV in different ways. For some, menopause hampered their desire and interest in sex. One participant explained:

> *Yeah, it changed because you don't feel the same. Your body change, your mind changes. You're going from a woman to an older woman…It's not easy. That medication* (treatment for menopausal symptoms), *I do everything. I just be in bed because I feel so weak, you know. So, it's not too much time thinking about sex. It's more time getting myself together, feeling good because sometimes you don't want to think about sex* (African American, 54, Bronx).

For another participant, menopause was akin to internal chaos, with the constant highs and lows of mood swings and hot flashes.

> *Sometimes you go through your highs and lows. And that's part of not having your menstruation, menopause, hot flashes, oh my God! All these things going on in this one body! The anxiety attacks! Oh, I get everything, the high blood pressure. Oh man, you don't know! Hot flashes, anxiety, depression, menopause! It's crazy! I didn't know how strong I was until I was going through all this in my body* (African American, 51, Bronx).

Almost all of the participants described the negative impact of vaginal dryness on their ability to enjoy sexual pleasure as they aged. While a participant experienced an increase in her sex drive, her constant vaginal dryness (even with the use of lubricants) resulted in extremely painful intercourse that negatively impacted her relationship with her husband:

> *Oh yes, I'm more horny* [sic] *than ever…* (but vaginal dryness) *…That is a problem …Staying dry…Too dry. It hurts sometime. So, I take the gels that they have out there…We tried to do it one time, and it hurt so bad! And I started crying. And he said "What's the matter?" I said, "You hurt me." He said, "How I hurt you?" I said, "Because it's like you tearing my thing apart. It feels like I was a virgin, you know… That kind of hurt." I said, "Oh, no, no, no, no, we can't do this! No!" …I want to have sex, but if it hurt, and if he hurt me, then I push him off…And I have to wait until later on, until I feel like I want him to touch me again because it hurts so bad down* (African American, 52, Brooklyn).

For other participants, having to use vaginal lubricants was a distracting and unwanted part of how they have sex. For one woman, the use of lubricants was a barrier to intercourse:

> *Even when we have sex, you know, you've got to stop and put the lube. You've got to make sure you have the lube because it's dry. You know, my vagina, it's not as moist as it used to be… he's never, you know, made me feel any differently. But myself, I feel differently down there. So, when you've got to stop and start the messing with this and that and the other thing, I just rather do without. And my husband, he don't push the issue, you know* (African American, 51, Brooklyn).

Finally, a small number of participants described how their changing sexual abilities, due to a combination of aging and HIV-related illnesses, created a barrier to sexual pleasure and intimacy. Battling a number of age-related comorbidities (diabetes, hypertension) and

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neuropathy, one woman described how the combination of all of her ailments has severely impacted her ability to have sex:

> *I really feel that the greatest issue in terms of change* [in my sex life] *has been my physical limitations…It's just that simple. My legs don't work anymore. You understand? I can't feel stuff, like I be numb. You understand? My legs, hands, and feet are numb almost all the time. You know, people think I be joking when I tell them I'm only hot from the neck up. My brain is ready…But my body is not!* (African American, 56, Brooklyn).

Importantly, living with these physical and interpersonal limitations has precipitated or exacerbated feelings of low self-esteem and depression for a number of the participants.

5) "We do unsafe sex"

In the in-depth interviews only, we asked participants to describe their safer sex practices and/or any challenges they may have experienced with their partners. Data analysis identified several preventive issues for older women with HIV; these include: 1) a perception that the risk of HIV transmission is low as related to gender and being virally suppressed; 2) years of condomless sex with HIV-negative partner is perceived as evidence that transmission risk is low; and 3) their partner refuses to wear condoms because they trust them not to infect them.

A number of participants mentioned their belief that there is a decreased risk of HIV transmission from a woman to a man as a rationale for not using condoms, as exemplified by the following quotes:

> *It's hard for a man to catch it from a woman* (African American, 51, Bronx) *It's hard to give* [it to] *a man, unless there's lots of blood* (African American, 58, Bronx). *You know, women usually don't give men HIV* (African American, 50, Chicago). *It's very easy for a man to give a woman HIV, but it's not that easy for a woman to give a man HIV* (African American, 56, Chicago).

Some women were still aware that as women they were biologically more vulnerable to new sexually transmitted infections or ART resistant strains of HIV through condomless sex. One participant explained: *I mean, we can pass it to you, but we are more vulnerable to whatever you have faster than we can give it to you, you know* (African American, 53, Brooklyn).

Most of the participants were aware that if they maintained a low viral load the chance of transmitting the HIV virus to a sexual partner is lessened. Many also expressed that they chose to engage in condomless sex knowing that the risk is less:

> *I'm not saying that I'm 100% safer sex. …I'm like a non-progressor…so, me transmitting that is next to* [nothing]*…because* [my] *viral load is so low, you know"* (Bronx, 54, African American).

A 50-year-old African American woman from the Bronx voiced a similar explanation:

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> My doctor told me that …me being undetectable and stuff, it's much quicker for me to catch something from him than for me to give it to him. It's like I don't even have it 'cause I've been undetectable for so long.

The majority of women were in discordant relationships. Many also claimed that their HIV-uninfected partners encouraged condomless sex knowing that their partner was living with HIV. Furthermore, many reported that they have been engaging in condomless sex for many years but, despite repeated exposure, their partners never acquired HIV infection. One woman, who was also employed as a HIV peer educator, reported that her partner accepts the risk of HIV infection. Despite this acceptance, his cavalier attitude about acquiring HIV concerns her.

> *So, I preach it in my workshops* (to use condoms) *…but we don't* (use them) … *We've been together six years. I test him every six months; he's not positive. So, I don't use protection. Not by my choice. My choice, I prefer to use protection. But by his choice, he don't want to* [use condoms] … *But he is aware that he could become infected. And he keeps telling me, I don't care; I would die for you, whatever. I'm not looking for you to die for me. I'm not looking to give you what I got. If I could just not have it at all, it would have been perfect, but unfortunately, it's six years* (Latina, 54, Bronx).

Many women mentioned that one reason they did not consistently use condoms was that their partners were still HIV-negative after years of practicing inconsistent condom use.

> *Of course, we don't use them* (condoms) *all the time because he don't believe, in his heart, that I can pass it on to him. And it hasn't happened in 19 years. And that's a blessing only though God's grace… I know that I still could pass it on…I know that. But I don't worry too much …because …I talk to him constantly about condom use. …At one time, he used to say, it don't matter. What you have I'll have. No, honey, it don't work like that. That's not a sane thought. That's an insane thought. You don't want what I have. But as time went on, we use condoms, we don't use condoms…But most of the time we don't…I think it's because …we've been in a relationship for so long and he's* [still] *not positive…and he says that a lot…because he doesn't come up positive* (Bronx, 53, African-American).

For one woman, acquiescing to her partner's preference not to wear a condom became a hard habit to break, especially with her subsequent new sexual partner. This woman acknowledged that if given an opportunity not to use a condom she would not.

> *I have to confess; they know that I have the virus. My relationship for 12 years, me and him only use condoms sometime. We figured out a way where he didn't get none of my vagina juices. We was together 12 years, and he never caught anything. And he made me spoiled. So, the next relationships, I don't want them to use a condom because they* [also] *knew that I have the virus. And if they say not to use, they don't want to use a condom, I pretend that, no, no, no, put it on, put it on. Don't worry about it. And then I give in* (African American, 51, Brooklyn).

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Relationship dynamics were key factors for not maintaining safer sex practices with their HIV-uninfected partners. For one woman, the length of time of the relationship and her profound trust in her partner provided the rationale for not using condoms.

> *We do unsafe sex…I feel like if you with a partner for a long time, and you could trust your partner and talk, 'cause if you don't talk, I mean, you got to be able to talk. And your partner is being truthful to you and telling you that he's not out there messing around or whatever, then I feel that you don't have to wear a condom if you've been with that partner for a long time, and he's doing what he's supposed to do by taking his tests, and you staying on your diet and doing what you got to do… to keep yourself healthy. Then I feel you don't have to wear a condom* (African American, 50, Bronx).

6) "You all too old!" and "She ain't got HIV"

Finally, when we discussed women's thoughts about aging and sexuality we found several themes related to ageism. Some participants reported an awareness of the need to confront ageist assumption about older women's sexuality. These assumptions include the belief that older women should not be sexually active. Another assumption is that older women should not have HIV, which stems from younger men's perceptions that condomless sex with older women carries less sexual risk.

In response to the ageist belief that older women are too old for sexual intercourse, one respondent described what she thought were the beliefs held by many younger people:

> *They think that* [we're] *being freaky, old people… 'Cause my kids say, 'oooh, you nasty!' 'What is nasty? You need to sit down somewhere,' I told her. 'You need to stop having sex, too!' But that's how they look at it* (African American, 55, Brooklyn).

Another added:

> *My grandson, he just be 18…He said, 'nana, you know you and grandpa are not having sex.' I said, 'why not?' He said, 'you all too old!' So*, [that's] *younger people's state of mind when you reach a certain age you're not supposed to do things* (Brooklyn Focus Group).

Despite these ageist assumptions, many of the older women with HIV in this study continued to embrace their needs for sexual pleasure and intimacy, fighting back against these ageist stereotypes. One participant explained:

> *Excuse me, I do not understand how the younger generation figured just because they having sex now that we don't have none. It doesn't not turn off just because we older. That's how you all got here. Okay? And we realized how much fun it was long before you got here. Hello, we still think it's' fun…First of all, this is* [my] *husband, come on. If you hear the bed knock in the night time, mind your business. Yes, we knocking boots,*[e] *okay? Yes, I'm flipping the switch*[f] *in the room, okay? That's not a problem, so please, please cut it out* (African American, 56, Chicago).

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A small number of participants commented on how some younger men perceive that sex with older women is lower risk behavior because they maintain the ageist assumption that older women do not have HIV or other sexually transmitted infections. Consequently, these younger men are pursuing sexual liaisons with older women with the expectation that they can engage in condomless sex with minimal risk. One participant explained:

> *They're not willing to use them. The younger generation is not ready to use it. With the older woman, they say, that's fresh meat. She don't have no HIV. That's how young kids look at it, young men look at it. Oh, she ain't got HIV. She can treat me to a few things, or she can give me a roof over my head. I can jump*[g] *her anytime I want* (African American, 69, Bronx).

Another participant added:

> *Okay, so the young guys are thinking that because she is an older woman that she's out of that risk group* (African American, 58 Bronx).

Related to condom use, this same participant elaborated: "*whereas they might put on a condom if they're going to have sex with someone their own age.*"

Discussion

In this sample of older women living with HIV (OWLH), most reported being involved in intimate and sexual relationships, a finding that is echoed in larger studies (Brennan et al., 2011; Grodensky et al., 2015; Nevedal & Sankar, 2015; Psaros et al., 2012). Furthermore, sexual pleasure and intimacy remain an important aspect of life for women with HIV as they age. Among the 50 women who participated in this qualitative research, most (82%) were sexually active and some reported a range of sexual behaviors that included oral and anal sex and concurrent partnerships. Reasons for no longer engaging in sexual activity (i.e., loss of interest, fear of HIV transmission, or did not want the aggravation of sexual relationships) that we found are consistent with previous research (Siegel et al., 2006). Participants described a range of changing sexual experiences as they aged that included either an increase or decline in sexual desire, pleasure, and satisfaction. Many women also reported changing sexual health or physical capabilities due to aging and menopausal symptoms, such as vaginal dryness. A few women reported a decline in their safer sex practices due to the perception that the risk of HIV transmission was low because of their gender, viral suppression, partner trust, or because their partners were still HIV-uninfected despite repeated exposure through condomless sex.

Our findings on condomless sex among OWLH support previous research that found that condomless sex was common among sexually active male and female older adults with HIV (Aidala, Lee, Garber, & Chiasson, 2006; Illa et al., 2008; Sormanti & Shibusawa, 2007). In the Research on Older Adults with HIV (ROAH) study, more than one-third of sexually active older adults with HIV reported engaging in condomless sex, and 18% reported

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[e] "Knocking boots": to have sexual intercourse (http://www.urbandictionary.com/define.php?term=knocking+boots)
[f] "Flip the switch": To have a change of heart or contrary approach. (http://www.urbandictionary.com/define.php?term=flip+the+switch).
[g] "Jump": to want to have sex with someone (http://www.urbandictionary.com/define.php?term=jump)

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condomless sex with a serodiscordant partner (Golub et al., 2011; Golub et al., 2010; Karpiak & Brennan, 2009). In a longitudinal analysis, using data also from the Women's Interagency HIV Study (WIHS), we found that 22–25% of women living with HIV, regardless of viral suppression, exhibited moderate to high levels of condomless sex after 13 years (Taylor et al., 2014). In the present study, participants mentioned that evidence of their minimal risk of transmitting HIV to their serodiscordant partners was that, despite repeated exposures to HIV with condomless sex, their partners never acquired HIV infection. We found, similar to other studies (Wilson et al., 2007; Wilson et al., 2004; Wilson & Minkoff, 2001) that OWLH abandoned their safer sex practices due to awareness that treatment adherence and low viral loads reduce the risk of HIV transmission and their understanding that it is harder for a woman to transmit HIV to a male partner (Gray et al., 2001; Quinn et al., 2000).

In regards to menopause and sexual risk behaviors, we found in our previous studies that although the odds of any condomless sex declined by 28% among women age 40–57 with a detectable viral load, 25% of these virally unsuppressed women in the sample reported condomless sex (Taylor et al., 2014). Condom use has been shown to decline with age (Allison-Ottey et al., 1999; Massad et al., 2007; Schable, Chu, & T, 1996); however, recent studies have found no association between menopause and condom use among women with HIV (Massad et al., 2007). Therefore, more research is needed to explore the role of menopause in sexuality and sexual risk among older women with HIV (Paparrigopoulos, Tzavellas, & Karaiskos, 2007; Pitkin, 2009; Rheaume & Mitty, 2008; Roughan, Kaiser, & Morley, 1993; Scott, 2002).

This qualitative study expands understanding of specific partner and interpersonal factors that influence older women who are infected with HIV and, in particular, why some may continue to engage in sexual risk behaviors. Specifically, perceived risk of HIV transmission is diminished when assessed according to gender and treatment adherence. The OWLH in this study understand that it is harder for women to transmit the virus. They also understand that viral suppression reduces the risk of HIV transmission. Similarly, other studies indicated that treatment optimism and safer sex burnout may play a role in increased risk behavior among couples in ongoing relationships (Chen, 2013; Hanif et al., 2014).

The belief that there is a low risk is further supported by the fact that women reported a lack of HIV transmission after years of condomless sex with HIV-negative partners. Finally, partner refusal to wear condoms due to partner trust or gender inequality (which increases with the length of the relationship) drives engagement in risk behaviors among serodiscordant couples (Buchacz et al., 2001). As such, power dynamics are still barriers to condom negotiation among older women, and men continue to play the leading role in the condom use decision-making. This dynamic is exacerbated by the relationship between erectile dysfunction and a decreased desire to use condoms, especially in men over 50 (Schick et al., 2010). In addition, the acceptance of condoms by a primary partner is often the deciding factor in whether or not condoms use occurs in long-term relationships (Stevens & Galvao, 2007). For example, HIV positive women who engage in condomless sex are often distressed by their actions, but concede to a partner's wishes because of their gratitude for his acceptance (Stevens & Galvao, 2007). Data from women in this study suggests that

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their HIV-negative partners believe that acquiring HIV would not be that bad because there is effective treatment. Emerging data, however, suggest that older adults who acquire HIV might not have the same immunological response as younger adults (Nogueras et al., 2006).

Regardless of the perceptions of diminished risk of HIV transmission among OWLH, according to the CDC in 2013, an estimated 18% (8,575) of all new HIV diagnoses were among Americans aged 50 and older (CDC, 2013). The CDC found that 23% of new infections among men over 50 years of age were acquired through heterosexual sex (CDC, 2010). Importantly, OWLH are interested in maintaining safer sex practices, but many are unable to maintain these practices due to their partner's attitudes and beliefs, specifically those of not being at risk for HIV infection, negative attitudes towards condoms, and sexual dysfunction. Secondary prevention programs for OWLH should address the psychosocial and interpersonal challenges of maintaining a satisfying and safer sexual health with age.

Although, the use of sildenafil and other drugs marketed to treat erectile dysfunction have revitalized the sexual lives of many older men with HIV (Crum-Cianflone et al., 2007; Rabkin, Wagner, McElhiney, Rabkin, & Lin, 2004) there are few effective and safe treatments for sexual dysfunction for older women. Though many OWLH use vaginal lubricants, moisturizers, and dilators to help improve sexual health and pleasure, there does not appear to be widespread knowledge of lubricants' role in reducing HIV transmission. More attention is needed on the use of vaginal lubricants as a sexual safety method for OWLH. Still, there is new optimism for the treatment of hypoactive sexual desire disorders in women with the recent FDA approval of the drug flibanserin (Clayton, Dennerstein, Pyke, & Sand, 2010; Roehr, 2015). Finally, with the availability of new biomedical tools for serodiscordant couples, feasibility, acceptability, and efficacy studies are necessary to test prevention methods for older adults who are experiencing a decline in sexual function. High Impact Prevention (HIP, such as *Pre-Exposure Prophylaxis* (PrEP) and *Post-Exposure Prophylaxis* (PEP), along with *Treatment as Prevention* (TasP) are promising options for older serodiscordant couples, or older adults who have sexual dysfunctions that interfere with their ability to consistently use condoms. Providers should promote these new methods to help OWLH and/or their HIV-uninfected partners who are reluctant or inconsistent in their use of condoms.

Limitations

Our results should be interpreted within the context of the study's limitations. First, qualitative research is an inherently *subjective* exercise typically utilizing small samples. A convenience sampling method, instead of randomization, can produce a selection bias of either under-representation or over-representation of particular groups within the sample; similarly, we were not able to collect complete data on all the women who declined to participate in the study. Thus, these findings are not generalizable to a broader population. Additionally, it is important to note that 96% of the participants were monolingual English speakers and, therefore, we were not able to capture insights from more linguistically-marginalized older women with HIV. Finally, participants were recruited exclusively from urban clinics, so the applicability of our findings to non-urban and non-clinic populations is unknown. Through exploring a select number of key issues in-depth, qualitative research is

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not aimed at generalizability, but instead the trustworthiness, credibility and dependability of the data, which was achieved through data saturation.

Conclusions

Older women with HIV continue to engage in intimate and sexual relationships as they age. These findings suggest that as women age, they may need additional support for maintaining and expanding concepts of safer sex practices. These findings also suggest that information concerning sexual behavior of older women with HIV should focus more on how to maintain satisfying and safe sex lives as they age, and less on “risk.” While exploratory in nature, our findings stress the critical need for further research and guidance focused on identifying and addressing the prevention needs of older women with HIV, and older women at risk for HIV infection. Additional research is needed to understand how age-related physical, psychosocial and interpersonal factors affect sexual behaviors among aging women.

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Table 1

Sociodemographic Characteristics (N=50)

Characteristics M ± SD or n (%)	Bronx (n=12)	SHC (n=11)	Brooklyn (n=11)	Chicago (n=16)
Age	56.4 (5.09)	57.4 (5.66)	55.6 (3.47)	55.25 (5.05)
Race & Etnicity				
Black/African American, non-Hispanic	10 (83)	11(100)	10(91)	15 (93)
Hispanic/Latino, non- black	2 (17)	0	1(9)	1 (7)
Hispanic/Latino, and black	0	0		0
Marital Status				
Single	5 (42)	4(36)	1(9)	6 (38)
Married	2 (16)	2(18)	6(55)	6 (38)
Divorced	1 (10)	0	0	1 (6)
Separated	2 (16)	0	0	1 (6)
Widowed	2 (16)	5(46)	4(36)	2 (12)
Sexually Active				
Yes	12 (100)	9(82)	8(73)	12 (75)
No	0	2(18)	3(27)	4 (25)
Employment				
Yes	2 (17)	2(18)	2(18)	1 (7)
No	10 (83)	9(82)	9(82)	15 (93)
Education				
Less than high school	6 (50)	4(36)	1(9)	4 (25)
High school/GED	1 (8)	3(27)	5(45)	2 (13)
More than high school	5 (42)	4(36)	5(45)	10 (62)