

# Diminished Sexual Activity, Interest, and Feelings of Attractiveness Among HIV-Infected Women in Two Eras of the AIDS Epidemic

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**Abstract** Despite the high prevalence of sexual inactivity, decreased sexual desire, and poor sexual satisfaction documented among HIV-infected individuals, women's experiences of sexuality following HIV-infection and their reasons for these sexual changes remain little examined. Further, the potential effects of the availability of highly active antiretroviral therapy (HAART) medications on their sexuality have not been explored among women living with HIV/AIDS. To examine these issues, focused interviews were conducted with two samples of women living with HIV/AIDS: one before the advent of HAART and a second matched sample interviewed after HAART became widely available. Women in both the pre-HAART and HAART eras frequently discussed decreased sexual activity, a loss of sexual interest, and a diminished sense of sexual attractiveness following their HIV infection. In addition, they reported a number of reasons for why they had discontinued sexual activity or were no longer interested in sex, including anxiety about HIV transmission, a loss of freedom and spontaneity during sex, fears of emotional hurt, not wanting the hassle of sexual relationships, a loss of sexual interest, and a diminished sense of sexual attractiveness. However, the types of changes in their sexuality women described, nor the reasons offered for these changes, did not differ between women in the pre-HAART and HAART eras. The findings suggest that therapeutic intervention may be needed by some HIV-infected women to overcome difficulties in resuming healthy sexual relationships following their HIV diagnosis and offer insights into the potential content of such intervention efforts.

**Key words** Sexual dysfunction · Physical attractiveness · Libido · Abstinence · HIV-infection

## Introduction

Research on the sexuality of individuals living with HIV/AIDS has primarily focused on understanding the factors associated with unsafe sexual practices and evaluating the efficacy of interventions aimed at altering these behaviors. Given the public health orientation of most HIV-related research, this narrow focus is understandable. However, one consequence of it has been that comparatively little is known about the sexual experiences and adaptations of individuals living with HIV/AIDS (Schiltz & Sandfort, 2000). Yet, there is evidence that a diagnosis of HIV/AIDS may result in a subsequent loss of libido and cessation or reduction of sexual activity (e.g., Goggin, Engelson, Rabkin, & Kotler, 1998; Meyer-Bahlburg et al., 1991; Siegel & Schrimshaw, 2003). Learning that one is infected may also effect one's sexuality in other more subjective ways. For instance, it may alter one's sense of personal attractiveness or desirability as a sexual partner. In addition, the pleasure derived from even protected sex may be diminished greatly by anxiety related to the possibility of infecting others or becoming reinfected, as most recognize that condoms can break. When such changes occur, the pleasure of sexual intimacy will be greatly diminished and, as a result, there may also be a substantial decline in one's interest in sex. A greater understanding of how HIV-positive individuals feel about these changes is needed in order to promote and facilitate their adaptation to living with HIV/AIDS.

Although a number of studies have addressed the diminished sexual activity and interest among HIV-infected individuals, this work has been largely limited to

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HIV-infected men (Meyer-Bahlburg et al., 1991; Siegel & Raveis, 1993; Wagner, Rabkin, & Rabkin, 1997). Far less is known about the nature of such sexual changes among HIV-infected women. However, a small number of studies have documented that these women experience lower levels of sexual interest, pleasure, and satisfaction relative to HIV-negative individuals (Denis & Hong, 2003; Meyer-Bahlburg et al., 1993). For example, in a study of 75 women who had injected drugs (Meyer-Bahlburg et al., 1993), HIV-positive women reported less frequent sexual thoughts, were more likely to report no pleasure from sex, and to have “unpleasant, anxious, or tense feelings” during sex than HIV-negative women. Similarly, a recent study of 116 Canadian women found that HIV-positive women scored lower on 6 out of 7 measures of sexual functioning than HIV-negative women, including lower sexual interest, lower satisfaction, and lower overall sexual functioning (Denis & Hong, 2003).

A small number of studies have also documented a high prevalence of celibacy or sexual abstinence following women’s diagnosis with HIV/AIDS. In the only known study to compare HIV-positive men and women on sexual abstinence, Siegel and Schrimshaw (2003) reported that older HIV-positive women were significantly more likely to have become celibate following HIV-infection (78%) relative to older HIV-positive men (36%). This suggests that infected women’s sexuality may be more frequently impacted by an HIV diagnosis than men’s. Although lower than that found among older women, sexual abstinence following HIV diagnosis has also been found to be quite common among younger HIV-positive women. For example, studies have found that 32% of HIV-positive women in Canada were no longer sexually active following their HIV diagnosis (Hankins, Gendron, Tran, Lamping, & Lapointe, 1997), that 42% of HIV-positive women in New England reported not having had sex in the past month (Bova & Durante, 2003), and that 34% of HIV-positive women with a history of injecting drug use avoided sex due to their HIV infection (Meyer-Bahlburg et al., 1993).

Even more prevalent than sexual abstinence among HIV-positive women are reports of diminished libido, a lack of sexual interest, and lower sexual satisfaction. Using retrospective reports, Florence et al. (2004) found that HIV-positive women in Europe indicated they had significantly lower levels of sexual desire following their HIV diagnosis than before. Similarly, 43% of HIV-positive women in New York City were found to report decreased sexual desire since their HIV diagnosis (Goggin et al., 1998). Goggin et al. also noted that 39% of HIV-positive women met the diagnostic criteria for hypoactive sexual desire disorder (HSDD; Brown & Rundell, 1993), characterized by a persistent diminished sexual desire that causes distress for over a month. Further, there is some evidence that sexual interest following diagnosis may diminish over time. In a longitudinal study

of HIV-positive women in the military (Brown, Kendall, & Ledsky, 1995), 21% of women met the criteria for HSDD at the initial evaluation, but 50% met the criteria at both the second and third evaluations 6 to 18 months later. Among those who continued to engage in sexual activity, low levels of sexual satisfaction have been documented, with 32% of HIV-positive women in Canada reporting they were not satisfied or only a little satisfied with their sex lives (Hankins et al., 1997).

Despite a small but growing literature documenting diminished sexual activity, sexual interest, and sexual satisfaction among women living with HIV/AIDS, our understanding of the reasons for these changes (or whether women view these changes problems at all) is extremely limited. There is some evidence to suggest that psychosocial factors may play a more prominent role in sexual functioning among HIV-positive women than disease-related factors. For example, lower sexual functioning among HIV-infected women has been found to be associated with depression, irritability, and anxiety, but not with illness severity or CD4 count (Florence et al., 2004). Similarly, a diminished sexual desire among HIV-infected women has been found to be associated with both more depressive symptoms and lower life satisfaction, but to be unrelated to testosterone levels (Goggin et al., 1998). Sexual abstinence has also been found to be associated with psychological factors (e.g., quality of life), but not to disease related factors (e.g., CD4 cell counts, disease stage; Bova & Durante, 2003). Furthermore, some data suggest that women who were infected sexually by a male partner were significantly more likely to report low sexual desire than women who were not infected sexually (e.g., through injection drug use; Goggin et al., 1998).

Even less is known about how these women view their sexuality or their own understanding of why they have experienced a loss of sexual desire or discontinued sexual activity. However, a few such insights into this matter have been offered in the results of otherwise quantitative surveys. For example, in response to an open-ended question, Hankins et al. (1997) report that HIV-positive women described themselves as being afraid to be touched, feeling guilty, being less interested in sex, being worried about infecting others, and feeling a loss of spontaneity and freedom. Similarly, Goggin et al. (1998) reported that infected women’s beliefs about what may have caused HSDD “varied widely and included: fear of rejection, lack of a partner, fatigue, relationship problems and fear of infecting a partner” (p. 15). In the only known qualitative study of women’s discontinuation of sexual activity following HIV diagnosis (Siegel & Schrimshaw, 2003), found that older HIV-positive women (i.e., age  $\geq$  50) reported that fear of infecting others, a loss of interest in sex, anger and distrust of men, and a desire to focus on themselves rather than men were the primary reasons offered for discontinuing sexual activity.

The interesting, but limited, insights offered by the existing research suggest the need for further investigation of the psychosexual adaptations HIV-positive individuals make following their diagnosis. Although existing research has documented changes in sexuality following HIV diagnosis, women's views and experiences of these changes remain unexplored. Such research will offer insights into whether HIV-positive women view these changes positively or negatively, and suggest potential reasons for these sexual changes. Finally, this information can help to inform interventions which may be used to reduce sexuality-related distress and promote sexual satisfaction for women living with HIV/AIDS.

The current study explored how HIV disease affects women's interest in sex, the pleasure they derive from sex, and their feelings about their attractiveness as women and sexual partners. Further, it examined if these women's feelings and perceptions about these issues changed with the advent of highly active antiretroviral therapy (HAART) and the prospect of extended survival. Currently, little is known about whether the impact of being HIV-positive on sexuality has changed with the availability of HAART and the subsequent reconceptualization of HIV as a chronic disease rather than an acute life-threatening illness. HAART use has been linked to higher prevalence of sexual dysfunction among HIV-infected men (Collazos, Martinez, Mayo, & Ibarra, 2002; Colson et al., 2002; Lamba et al., 2004; Schrooten et al., 2001). Although the relationship between HAART and sexual functioning remains far less examined among HIV-positive women, the little research that has been done has found few differences. Comparisons of HIV-positive women who were antiviral treatment naive and those who had been treated found no difference on any domain of sexual functioning (including sexual desire and satisfaction; Florence et al., 2004). Similarly, Siegel, Karus, & Dean (2004) found that there was no significant difference in the psychosexual adjustment of HIV-infected women from the pre-HAART era and a matched sample of infected women from the HAART era. However, these reports examined only a limited aspect of sexuality as assessed by a quantitative measure. In the present article, we examined data from two time periods related to HIV-infected women's sexual adaptation to further investigate possible differences between the pre-HAART and HAART eras.

## Method

### Participants

This study employed data from two samples of women living with HIV/AIDS, collected in different eras in the HIV/AIDS epidemic. The first sample of women ( $N = 146$ ) was inter-

viewed between October 1994 and November 1996 prior to the advent of HAART regimens (which became available outside clinical trials in late 1996). The second sample ( $N = 138$ ) was interviewed between March 2000 and April 2003 following the widespread availability of HAART regimens.

The same eligibility criteria, except for age, were used for both samples. These were: (1) reported being HIV-infected; (2) lived in the New York City metropolitan area; (3) if African American or White to be native born and non-Hispanic, or if Latina, to be Puerto Rican and lived in the US mainland for at least four years; (4) completed an eighth grade education; and (5) had not used drugs by needle in the past six months. In the pre-HAART sample, women had to be between the age of 20 and 45. In the HAART era sample, women were allowed to be between age 20 and 50 (i.e., matched within a 5 year range).

Quota sampling was used when recruiting the pre-HAART era sample to ensure approximately equal numbers of African American, Puerto Rican, and White women as well as approximately equal numbers of women in each disease stage (i.e., asymptomatic, symptomatic, and AIDS) within each ethnic/racial group. In the HAART era sample, quota sampling was also used to achieve a similar distribution on race/ethnicity and disease stage. In addition, an attempt was made to find cases in that era that matched with cases in the pre-HAART sample on time since diagnosis, age, and history of injecting drug use.

In total, 158 women from the two samples (79 from each time period) were matched on age (within five years), race/ethnicity, disease stage, length of time since diagnosis (<2 years, 2–5 years, or >5 years), and injecting drug use history since 1977. The demographic characteristics of each sample and tests for potential differences between the two samples are provided in Table 1.

### Procedure

The same methods and sources of recruitment were used to obtain both samples. In order to protect participant confidentiality, recruitment relied on self-referrals. Women learned about the study through flyers placed in community-based organizations (CBO) that serve HIV-infected women in New York City, advertisements placed in local newspapers and in the newsletters of these HIV-related organizations and, in some cases, by word of mouth from other research participants. Staff within each CBO were asked to post the flyers or, when possible, to offer them directly to female clients. Flyers and advertisements described the nature of the study, the eligibility criteria, and provided a telephone number for women to call. Interested women who called about the study were screened for eligibility.

**Table 1** Demographic comparisons of women living with HIV/AIDS in the pre-HAART and HAART eras

	Pre-HAART era: 1994–1996 ( <i>N</i> = 79)		HAART era: 2000–2003 ( <i>N</i> = 79)		<i>p</i>
	<i>N</i> (%)	<i>M</i> ( <i>SD</i> )	<i>N</i> (%)	<i>M</i> ( <i>SD</i> )	
Age <sup>a</sup>		36.3(5.35)		36.7(5.21)	<i>ns</i>
Range		23–45		23–46	
Race/ethnicity <sup>a</sup>					<i>ns</i>
African American	34(43)		34(43)		
Puerto Rican	22(28)		22(28)		
White	23(29)		23(29)		
Injecting drug use History <sup>a</sup>	35(44)		35(44)		<i>ns</i>
Disease stage <sup>a</sup>					<i>ns</i>
Asymptomatic	10(13)		10(13)		
Symptomatic	33(42)		33(42)		
AIDS	36(46)		36(46)		
Time since diagnosis <sup>a</sup>					<i>ns</i>
<2 Years	6(8)		6(8)		
2–5 Years	20(25)		20(25)		
5 Years or longer	53(67)		53(67)		
Education					<i>ns</i>
< High school	24(30)		25(32)		
High school, GED	25(32)		22(28)		
> High school	30(38)		32(41)		
Income \$20,000 or more	25(32)		19(24)		<i>ns</i>
Marital status					<i>ns</i>
Single, never married	37(47)		44(56)		
Divorced, separated, widow	28(35)		23(29)		
Married	14(18)		12(15)		
Relationship status (of the unmarried women)					
Has partner/boyfriend	43(54)		44(56)		<i>ns</i>
Lives with partner/boyfriend	13(17)		15(19)		<i>ns</i>
No of HIV-related symptoms		11.01(6.44)		11.14(6.21)	<i>ns</i>
Protease inhibitor use					<.001
Never used	79(100)		29(37)		
Previously used	0		26(33)		
Currently using	0		24(30)		

<sup>a</sup>Samples were demographically matched using these variables.

Eligible women met one or more times with a Master's-level female interviewer at the researchers' offices. Data collection took an average of 6 h in total to complete. While participants were offered the option of completing this data collection during three meetings on different days (within a one months period), many preferred to finish the data collection in a single day or two days (with breaks). Women were asked at points in the interview if they needed a break or wished to end the meeting for the day because of fatigue and schedule another time to return to complete the interview. Participants received \$75 for completing the study and were reimbursed for lunch, travel, and babysitting expenses (when necessary) at each meeting. In both time periods, the sponsoring Institutional Review Board approved the protocol.

After providing written informed consent, participants completed a set of psychosocial measures and an interviewer-

administered questionnaire that elicited demographic and medical history information. In subsequent meetings, women in both samples completed a focused interview (Merton, Fiske, & Kendall, 1990) about their experience of living with HIV/AIDS. Focused interviews use neutrally phrased questions so as to not display the assumption that sexual changes occurred or that these changes were inherently positive or negative. Thus for example, the participant would be asked, for example, "Have your relationships *changed* since your diagnosis?" If she responded she had, she would be asked, "How do you feel about these changes?" Interviewers use an interview guide which is a kind of conceptual roadmap of the topic areas to be covered, rather than a structured interview schedule. Interviewers were encouraged to use the associations the participant offered between topics to create a natural bridge from one topic to another, and to pursue topics raised that were not included in the interview guide.

One of the topic areas covered in the interview was sexual behavior and their sexual relationships with their partners. The qualitative data from these interviews are the focus of the present report.

### Data analysis

The transcribed interviews were analyzed through an iterative process of thematic content analysis developed by the authors and used extensively in their prior research. First, two research teams (each consisting of two researchers) working independently read a subset of the transcribed interviews. One team read 36 pre-HAART-era interviews (12 from each ethnic/racial group) and a second team read 36 HAART-era interviews, similarly selected. This division by teams enabled the immersion of researchers in data exclusively from one era of the epidemic, thereby avoiding any analytical contamination that could arise from the researchers' exposure to data from both eras. Within each team, the following steps were taken: (1) each researcher read independently the subset of interviews to begin identifying the various topics and concerns women discussed in relation to their living with HIV/AIDS; (2) the researchers shared and discussed the topics identified and collaboratively constructed a list of preliminary codes after reconciling any interpretive differences; (3) each researcher independently tested these provisional codes on the same 36 interviews and defined subcodes; (4) team members met and constructed an updated coding scheme for that time period. Next, the two teams met and compared the era-specific coding schemes. A common comprehensive coding scheme was then developed which included the codes from both time periods. This scheme was tested by each researcher on a common set of 30 additional interviews (15 from each era) to ensure it adequately captured and labeled all relevant text data. The coding scheme was further refined based on the reconciliation of any analytical issues that emerged from the application of the coding scheme on these additional data.

Next, two new researchers applied the final coding scheme to the full set of interviews from both eras using a qualitative data analysis software program, ATLAS.ti (Muh, 1997). Approximately equal numbers of pre-HAART and HAART era interviews were coded by each researcher to ensure that any era-specific differences observed emerged from the data, instead of individual differences in the coding process. Similarly, coders were assigned approximately equal numbers of interviews from each racial/ethnic group. These researchers were trained on the definitions and application of the coding scheme and were supervised throughout the coding process to ensure fidelity in the application of the scheme. Training also emphasized the need to code every mention of each theme, not just those in response to a direct question. To examine the reliability in coding, a subset of interviews coded

by both researchers were compared. The two researchers has an inter-coder agreement of 80.5% (including what blocks of text were coded and what core code or subcodes were assigned to the text).

For the present analyses, all the data assigned the codes "sexual relationships," "partner relationships," and "sexual behavior" were extracted by the authors to identify specific aspects of the women's behavior, perceptions, and experiences with regard to sex. Time period (i.e., pre-HAART vs. HAART eras) and racial/ethnic comparisons were explicitly examined. The material from the historical (pre-HAART) period for the African American participants was analyzed first, followed by an analysis of the contemporary (HAART-era) data for that race/ethnic group. The same was then done for the other two ethnic groups. This procedure of alternating the analysis between time periods allowed for the examination of potential era differences within each ethnic/racial group. Extracted material was analyzed to identify the principal themes related to the issues of women's sexual behavior and experiences.

### Results

An analysis of the interviews identified three major areas of sexual change among HIV-infected women both in the pre-HAART and HAART eras: (1) diminished pleasure in sex; (2) diminished participation in sex; and (3) diminished sense of sexual attractiveness. In all, approximately one third (33%) of women discussed one or more of these sexual changes.<sup>1</sup> The content of these themes was very similar in each of the two time periods and across the three ethnic groups. Below, women's perceptions of their sexuality are described, including the principal forms of sexual changes described by the women, as well as their own reasons used to explain their sexual changes. Instances where racial/ethnic differences were identified are noted.

#### Diminished pleasure

##### *Anxiety associated with sex*

Many women (regardless of age, race/ethnicity, or relationship status) reported that they found sex less pleasurable or satisfying since their diagnosis. The principal explanation they offered for this was the apprehension and anxiety they

<sup>1</sup> Because of the unstructured nature of the interviews, this prevalence represents a conservative estimate based on those who *spontaneously* discussed this issue within the larger context of their conversations about their psychosocial adaptation to their illness, and should not be construed as a reliable estimate of the true prevalence of these changes in the population of HIV-infected women.

experienced during sexual encounters due to their fear of transmitting the virus to partners or becoming reinfected. Even when protection was used, women worried throughout the act that the condom would break, a fear that made them “uptight” or “uncomfortable” during sex. For example, a 36-year-old African American woman from the pre-HAART era who was currently single and abstinent by choice said:

Through this whole thing [being HIV+], the only part that disturbs me sometimes is my uh my sexual life. You know I don't have one. It's mainly my choice you know, because I could meet a man and don't tell him my status and go for it. But it's got a lot to do with me not wanting to get anything, also from somebody breaking a condom, going to find out they got syphilis or, you know, anything . . .

A 41-year-old White woman from the pre-HAART era who said that she had a loss of sexual desire which caused conflict with her live-in boyfriend. She spoke of the anxiety associated with sex since her diagnosis and of the loss of freedom and spontaneity she felt during sex as a result of her HIV disease. She commented:

Ah, it's just always in the bedroom, HIV. It's always there. There's a loss of freedom . . . Ah, there's always the fear that you're gonna infect your partner, even if you use something. It's always a fear it's gonna break. It's always a fear of getting blood somewhere, you know, whether your tooth bleeds . . . And don't go down on me. And God forbid, I go down on you. And I get, I get a sore in my—you know, it's just like so much.

Another 35-year-old White woman from the HAART era spoke of the many things that can run through an infected woman's mind in the “heat of the moment,” preventing her from enjoying the pleasure of the intimacy with her current boyfriend and instead preoccupying her with worry. She said:

It's [HIV] depressed my sexuality. And it made me feel shame. And it was very hard for me to be very open. It took a lot of inner work on myself to get to the point where I am now. And it's still not comfortable, because if you're in the heat of the moment, and the person wants to perform oral sex on the woman, and there is a risk there, but you don't know how much. Like is there virus in vaginal secretion? Yes. But is that like when a woman is likely to have, like men have pre-cum. But, when the women have, it's not called pre-cum, but when a woman is wet, is there vaginal, is there a virus in that? And how much, you know, is, you know, how can I say it? Like if the condom breaks, or what is, you know, what is the, what when the condom comes off, when the man is pulling it out. And is there any fear of him getting the virus. Or, if you cut yourself shaving, and you got blood on you and someone touches.

Like just all these things that basically I know, as a health educator, but other people don't, like because these things happen. Like you have sex, the condom breaks. The guy wants to go down on you. Then you let him. And then you're thinking all these terrible things like in your head, or the condom comes off as it's coming out, and how that makes the woman feel. . .

Another 40-year-old White woman, also from the HAART era sample, reported that she was not in a relationship and had become celibate since her diagnosis. Sex, even safer sex, was too anxiety producing, she explained, due to her fear of inadvertently infecting a partner. She related what happened with her last partner who she explained she cared about too much to be willing to risk infecting him even with the added precaution of using two condoms. She explained:

It [using protection] was a, uh, it was something that was, uh important because, you know, uh, he didn't want to get it; I didn't want to give it to him, you know. So we, we tried to have sex once and that was disastrous cause, uh, he had like two condoms on and I still felt uncomfortable and I couldn't do it. And I just—so it was just, uh, it just didn't work. You know, so. And, uh, I had a lot of feelings for him, strong feelings to, that a woman would have for a man. But that was like one of the reasons why I couldn't get close to him. I couldn't let anything happen 'cause I was afraid of him gettin' sick.

When asked what had changed in her life since being diagnosed with HIV a 45-year-old African American woman in the HAART era who was not currently in a relationship said:

The first thing that comes to mind is sex. That's changed. [LAUGHTER] . . . i'm always very concerned about the partner. I stay away from positive men. For some reason, they turn me off completely. I don't want to be reinfected, at no cost. With the negative, I'm extra careful and really uptight with them. It's just with myself, I can't really relax and be sexual and at ease with a man.

#### *Loss of freedom and spontaneity*

Some women emphasized how the need to plan sex to ensure its safety diminished their pleasure by precluding the spontaneity and abandon they used to enjoy in their sexual experiences before their diagnosis. The need now to place so much attention on the safety of their sexual encounters and to use barriers (i.e., condoms or dental dams) seemed to some women to transform sex from an act of intimacy and love into a chore. Reports of a loss of spontaneity did not appreciably differ by age, race/ethnicity, or current relationship status.

A 44-year-old African American woman from the pre-HAART era, when asked what was the most difficult thing to cope with related to her HIV, described how safe sex with her boyfriend had resulted in a loss of sexual freedom:

It's not being able to party. I mean, you know, when I say party, I don't mean go out there listen to, to the disco music. I'm talking about, you know, just have fun with the with the young ladies. Because they—it's like, you have to be careful because they say you can be a—do—you know, uh, uh transmission through bodily fluids, like – You understand? So that makes you—you can't—I can't just, you know, get loose like I used to . . . I got to be careful; I can't do this here, I can't do that there. Can't let them do this here, can't let them do that. You know. It's like well, get the barriers. You know?

Still another woman from the pre-HAART sample, a 30-year-old African American, spoke of the loss of spontaneity she experienced in sexual encounters with her live-in boyfriend since her diagnosis. She lamented:

It's like you have to be more conscious now, you know. You, you have to look at the condoms and make sure it doesn't have a hole in it, you know, and it's, it's, it's—it's kind of frustrating. You just can't do whatever, you know, have sex or make love at the spur of the moment. You got to stop, get the condoms, you know.

A 40-year-old White woman from the pre-HAART era who was divorced and not in a relationship complained that safe sex was just not as pleasurable. When asked if this was because of the need to use condoms, she replied:

Well, using condoms is a small factor. The, the lack of oral sex is the main issue for me. It was my favorite thing. So, uh, you know, and I, and I don't orgasm easily, uh, any other way. So. That's the way it goes.

Another 37-year-old African American woman, also from the pre-HAART era sample, reported that despite having a boyfriend, she “can't enjoy herself with the opposite sex anymore.” When asked if she meant she was no longer sexually active, she replied:

Um um. No, no. I didn't mean it like that. Oh that, that, I haven't stopped that. I mean it hasn't got that bad that I don't have that feeling. But it's like I can't like party like I want to. Just, just let me go. Just enjoy it. I can't do it anymore. I can't drink like I used to. I can't, I can't do it anymore. I can't have sexual relationships, sex without a condom. And that has fault—that has taken a lot from me right there. So there you go!

A 33-year-old White woman from the HAART era who was not in a relationship said of safer sex: “It takes a lot of

the intimacy out of it [sex]; the spontaneity. That's what it takes out of it.”

Another 30-year-old White woman from the same era also spoke of the changes in her sexual behavior with her boyfriend that were necessitated by her diagnosis that diminished her pleasure and made her envious of those who were uninfected. She commented:

It's hard, it's—a sexual relationship—is hard when so many precautions have to be taken . . . Hard in that you are missing out on things that other people have. You know, in regards to oral sex or sensations. Or they don't have to worry about fluids and other things . . .

#### Diminished participation in sex

Some women had made a conscious choice to become celibate at some point following their diagnosis. Others, although not deliberately planning to abstain from sex, reported that they had so little interest in sex that they had not sought it out or been receptive to advances in recent months. These women were very inactive if not celibate. Although women of all ages and all three racial/ethnic groups reported a diminished participation in sexual activity, ethnic differences were noted in the reasons offered (see below). In addition, women who reported diminished sexual participation frequently, though not exclusively, reported not currently being in a relationship (sexual or otherwise), reflecting many women's decisions to become celibate or sexually inactive.

#### *Fear of emotional hurt*

The choice to be celibate or inactive seemed in many cases to occur because the women felt obligated to reveal their diagnosis to prospective partners, but feared certain rejection if they did. To avoid the stress, humiliation, and emotional hurt they expected rejection would involve, they chose instead to be celibate or to simply keep avoiding becoming close to someone, which would necessitate disclosing their status. These women were primarily Puerto Rican and from the pre-HAART era. Many of these women already had suffered profound emotional hurt as a result of the actions of partners when they had revealed their diagnosis. They seemed in some cases to have not recovered from the pain of those experiences and were too frightened to risk exposing themselves again. When asked whether being HIV-positive had changed her life in terms of her sexuality, a 43-year-old Puerto Rican woman from the pre-HAART era sample spoke of the hurt she had experienced in the past from partners. She saw her decision to not have a relationship and to be celibate as protecting her both from experiencing that kind of hurt again, as well as from reinfection. She remarked:

... I just had a pattern of having to always have one sex partner after the other. And after this—after this last encounter I had with this man after I came out of jail, um, for no particular reason he just stopped seeing me and married somebody else who lives in the same place where I live at. I decided that no, I'm not going to go find another one. And I'd rather keep to myself. Stay celibacy for me . . . . Because I don't like to—I don't like my feelings hurt. And I'm very, you know, I've had my feelings hurt so many times and I destroy myself because my feelings get hurt. So I am more afraid of me than what I am of a partner. So I keep, you know, I try to enjoy everything and if I have to stay celibate, you know, I've been like this for over a year and a half now. I'll stay celibate. It doesn't bother me. But ah, if I have to function sexually, yeah I can function sexually.

This same woman admitted that she felt embarrassed about her disease with some people. When asked who these people were, she replied:

People, you know, especially men. It's a big thing with the men. I'm into celibacy now going on nineteen months. I don't feel adequate with a male person. I don't even think about what I'm going to say because I don't feel comfortable with them. Um, you know, I can't—I can't see myself um, I don't know, after this man. Okay, he was HIV positive but for me, I, you know to go back through it again to tell another man that I'm HIV positive and we've got to wear condoms, I—it's—I don't know—I feel so different, so uncomfortable . . . . And not that I've been getting anxious because, you know, all of a sudden, someone being hot, I'm not getting any urges. It's just like I don't need no more . . . . I do have a lot of problems, which, you know, I am ashamed to tell the guys, yeah, I'm HIV positive. Then you have to tell them you have AIDS. And then, you know, then they look at you, yeah, you're big and you got AIDS. No, I can't go through that. I don't want to do no explaining.

Another 32-year-old Puerto Rican woman from the pre-HAART era who was separated from her husband similarly spoke of the emotional hurt she feared she would experience if she became close to a man and had to reveal her HIV-positive status. She, like others in both periods, expressed apprehension about allowing herself to care for anyone because the prospect of revealing her status and dealing with a potential partner's reaction was overwhelming to her. She said:

I have a fear of—I don't know. I'm like afraid. I don't want to get like—when it comes to the male issue, I don't want to like socialize too much because I'm afraid, if I do become close with someone, I'm—I don't know—you know, I'm tired of pain and I'm tired of emotional hurt. I

don't know if I'm going to be able to handle revealing my status to anyone. And if they were to know, I don't know how they're going to take it. So it's like something that I really don't look forward to until I try like to avoid it. I like—like I mentioned before, I might say a lot of things about the guys being attractive. But that's like as far as I would want to go. I don't want to get close to nobody.

Still another 39-year-old Puerto Rican woman from the pre-HAART era reported that recently she had had only one partner, a female, with whom she had not had sex with in two months. When asked if she was thinking of starting to date again, she revealed that while she would, the worry she had about how a potential partner might react to her disclosure of her status made it hard for her to seek a relationship. She said:

I would love to start dating. I'm scared. I'm really scared. I'll have to go through the, you know, the same thing. I'd rather just make friends. Maybe date, you know, date, you know? But then, you know, comes to the intimacy and all that, you know, and I don't want to be disappointed, and I don't want to disappoint anybody, you know? Because to look at me is not to see HIV or AIDS, you know? I would have to disclose that, you know, because I know I'm going to keep it to myself, you know. If you want to get intimate with a person, or whatever, it's hard. Either way it's going to be an emotional stress—stressful situation. Too much.

When asked if she would consider having sex if she felt attractive and someone was interested in her, she said:

No. HmMm. I felt that—you know, I feel that's why I'm, you know, sick now. So, you know, I'm trying to stay away from even thinking about having sex.

#### *Relationships are a hassle*

A number of women who had chosen celibacy indicated that they did so because being in a relationship usually involved hassles or stresses with which they currently were not willing to contend. They seemed to feel the need to preserve their sparse emotional resources to deal with the illness-related demands they faced rather than expending them on relationships that they often saw as difficult and too much “bother.” Some women, for instance, did not want to deal with the pressure men put on them to have sex or their resistance to using protection. For them, it was easier and less stressful to just avoid sex entirely. Again, these women were mostly Puerto Rican, but this time from the HAART era. For example, a 37-year-old Puerto Rican woman in the HAART era refused to have unprotected sex with her HIV-positive boyfriend, who would not use a condom. He contended that since they were both seropositive, protection served no purpose. She reported that his sexual desire was quite strong



while her's had diminished considerably and expressed how she felt about his pressure to have unprotected sex:

Um, just last night we were talking about it. And I tell him, you know what, I don't need to have you around me anyway. So, don't call me no more. So I hang up on him. And then he called me back and he was like, it's so easy for you. It's not easy for me, it's hard for me, but why hurting, why hurt myself more? I just got to be honest and I was honest. And that's how I feel. I don't want to be bothered.

Similarly, another 34-year-old Puerto Rican woman from the HAART era explained that she was not in a relationship because dealing with partners and their reactions to the situation was simply too taxing. She said:

I don't want to bother through all that emotional stuff. The fighting and arguing or "Who were you with?" Fighting that they don't want to wear a condom. I don't need it. I have enough just trying, just waking up in the morning is hard for me sometimes, just to be dealing with a man.

A few women seemed to find being in a relationship too much of a "bother." A 42-year-old African American woman from the HAART era, who was not in a relationship or sexually active because she felt betrayed by a former partner who she reported had cheated on her, when asked if she would be open to the possibility of being involved with somebody in the future said:

I have a lot of female, I mean men friends. Mostly all my friends [Inaudible] back in the old days was male. Because I didn't want to hang out with a bunch of females because they like to gossip a lot. So when one of them want to talk to me or come get close to me or want to touch me, I don't want to be bothered. I push them away. I gets mad and everything. It's like I don't want no mens touching me no more.

Another 40-year-old Puerto Rican woman from the HAART era spoke of how she was not in a relationship and was now largely sexually inactive. When asked if, as a result, she felt something was missing in her life and, if so, how she compensated if she did, she replied:

Keep myself busy. You know, people say I run around too much. You know, I stress myself out too much. But it just feels easier for me to when I come in the house I don't want to be bothered by nobody. And I take a shower and I'm ready to go to bed. Because I'm gone from 8:00 to 7:00 or 8:00 that night.

This woman explained that she tells men she meets that, "This is just going to be a friendship" and that "we can hang out now and then. . .but I'm not looking for no affair."

### *Loss of interest in sex*

Among the women who had not made a conscious decision to be celibate, but rather seemed to have drifted into inactivity, the most common reason was an apparent loss of interest in sex. Most of these women claimed to think very little about sex, to have little sexual desire, and claimed to not miss it.

For example, a 31-year-old White woman from the pre-HAART era who had recently married reported that her diminished interest in sex was causing some conflict between her and her new husband. She said that she had "less, really, really less interest [in sex]. Like I could care less about it, you know what I mean." Similarly, when asked if her attitude or behavior toward sexual partners had changed since her diagnosis, a 37-year-old White woman from the pre-HAART era sample who was not in a current relationship said:

Yeah, so my relationships have changed. I don't really—I don't really have any problem with men. Even in my program, guys are always asking me for dates, and I'm really just not interested, you know? Sexually or, or anything. I'm just not interested.

A 28-year-old African American woman from the pre-HAART era who was currently not in a relationship and choosing to be abstinent said:

I don't wish to be in no relationship with no one. I'd rather just—you know, there's nothing wrong—I would like to have someone I can call and, you know, talk to, or maybe go out sometime, but, I don't know. Either I don't want to have no relationship as far as, you know, physical relationship . . . Um, all I been through, since I found out my situation. That's, you know, and I don't feel that I'm attractive anymore, so, but I still—I mean, even if I felt I was, I mean, I wouldn't mind somebody, you know, trying to talk to me, but as far, as far as a relationship, I wouldn't let it get that far. I don't need nobody, you know . . .

Another 40-year-old White woman from the HAART era who was not in a relationship and currently abstinent said:

And the desire to have sex, I have none whatsoever anymore. I don't know if it has a lot to do with mentally or the medications or both. I don't know, you know. But the fact is with the virus, you know, it's—I don't want to just be with somebody that has the virus. I haven't met anybody that I feel compatible with. And am I going to go out and hurt another human being, you know, just because, you know, I want to be with somebody out of loneliness?

Some women expressed surprise at their complete loss of interest in sex. A 46-year-old White woman from the HAART era sample who was not in a relationship and described her sex drive as currently "non-existent" said:

Actually, you know. I have a lot of opportunities [for sex], but I just don't, I wouldn't—Geez, I just don't feel like it. So I don't really have any sex . . . I don't even masturbate. It's like it doesn't even exist. And it's funny because sometimes people are trying to talk to me about sex and I missed the clue.

#### Diminished sense of sexual attractiveness

Another way in which HIV-infection impaired women's sexuality was to make them feel very insecure about their appeal and attractiveness to potential partners. These women saw no reason to "put themselves out there" so to speak because they assumed there would be no interest in them. While devaluing themselves as desirable partners, some did express a desire for the companionship or friendship of a man. Reports of diminished feelings of attractiveness did not notably differ by age, race/ethnicity, or current relationship status.

A 31-year-old White woman from the pre-HAART era spoke of the unwanted changes in her sex life with her husband that HIV had necessitated. When asked how these changes made her feel, she said:

Ugly! You know. Like I'm not a woman anymore. To him [her husband] anyway. You know, it's so hard. You know. I, I try to do things, you know, that I used to do that, you know, in a second would get him running. And it's like, you know it doesn't faze him anymore . . .

Still another 23-year-old White woman from the pre-HAART sample also spoke of how unattractive she felt because of her disease. She lamented:

. . . when a man asks me out, and I go out, maybe we go out for a couple dates. He's seeing me as, as an attractive woman that he's probably interested in, you know, unless for some reason he doesn't like me. But whatever, let's say it's in—you know, he likes me, and he's attracted to me, and the whole idea, the whole, the whole thought of HIV is totally contrary to all that's attractive. And, um, you know, in general, like, you just—I don't know how to explain it exactly, but it's like a man is looking at a woman and seeing how pretty she might be and how she laughs and how she smiles—there are all these little things that are so attractive and then you say the word HIV and it's like, um, you know, it just turns the whole thing maybe ugly, you know, all of a sudden, and I think—yeah—I don't know how else to explain it.

A 32-year-old married Puerto Rican woman from the pre-HAART era, said that the hardest thing about living with HIV was dealing with how the "sexual component" of her life changed. She said that since her diagnosis she felt like "I'm

a walking, friggin' germ." When asked about the diminished sense of attractiveness her comments seemed to suggest she had suffered since her diagnosis, she said:

Well, I do feel less attractive . . . And then I have like this thing also that I—so many people have been told about my status in my neighborhood that it's like—I feel that men look at me like, "Oh, look at her. She's got all the weight. She looks good. But I don't know what she's got, you know, that is infected." You know, so I feel like sometimes they look at me like I'm disgusting or something, you know. So I walk around a lot of times with a big friggin complex. Like, you know, yeah, I want to look attractive, but what the hell for? If they already know my status, they wouldn't want to have shit to do with me anyway.

Nearly parallel sentiments were echoed by a 32-year-old Puerto Rican woman from the HAART era who was not in a relationship. When asked if she ever felt shame or embarrassment about being HIV+ said:

Yeah . . . When it comes to being with my, if I'm having a relationship with somebody or I'm gonna have sex with a partner . . . I feel disgusting. I feel like I, I can't have sex if I want to.

Similarly, another 34-year-old Puerto Rican woman from the HAART era who despite having a boyfriend reported that she no longer felt attractive. When asked if learning she was HIV-positive had changed the way she felt about herself, said, "Yes, of course!" She elaborated:

. . . I used to dress up nice. And I mean, you know, I still do. But I used to, you know, I had, oh, I used to feel sexy and all of that. But I, I feel the opposite of everything that I just said. I don't feel . . . you know, why should I be all but I used to, you know . . . I used to walk with my head up high. And I used to feel sexy and pretty and all of that. But I, I feel the opposite of everything I just said. I don't feel, you know, why should I be all dressed up. Or why should I go and, and have a nice time. And why would someone, you know. I don't feel, I don't feel, I don't feel pretty, or, or . . . you know. I don't know. Why should I, you know.

Another 33-year-old White woman, from the HAART era, who was not in a relationship said:

I think being an HIV positive woman can make you feel less attractive, less wanted. You know, women have this, I don't know if all women do, but a lot of women have this, this urge to feel attractive and beautiful and sexy and wanted by a man or your husband or your boyfriend or any man, depending on who. And I feel that HIV, as a woman with HIV, makes you feel less attractive, less

wanted, less beautiful, sometimes. I mean, I don't really feel that way too much anymore. Early on in the disease, I felt very unattractive and very unwanted.

A 42-year-old single African American woman from the HAART era when asked if she would disclose her status if she met a man she really liked said:

... Like I said, once you tell people you have it, they don't want to be with you. It seem like they shy away.

## Discussion

The findings suggest that the diagnosis of HIV infection can have far-reaching implications for the women's sexual interest, the pleasure they derived from sex, and their sense of attractiveness or appeal as a sexual partner. Indeed, approximately a third of the women interviewed described changes in one or more of these domains. The picture that emerges is one of women who, due to the possibility of sexual transmission of their disease and/or reinfection by a partner, felt that sex had become too plagued with anxiety, worry, danger, and stress to still be pleasurable. Further diminishing their enjoyment of sex was the perception that because safer sex required so much planning and preparation, the spontaneity and abandon that were so much a part of the excitement of sex were no longer possible. In the view of many women, their disease had transformed sex from an intimate romantic act into a tedious chore and/or a dangerous pursuit. They also felt that their disease rendered them unappealing and devalued as potential sexual partners. They saw themselves as tainted and dirty and doubted that anyone could desire them again as a sexual partner. They felt alienated from their bodies and "defeminized" by their disease (Squire, 2003). The loss of their sense of themselves as desirable sexually attractive or enticing women was obviously very painful.

Most who were sexually inactive insisted that they had little or no desire for sex and did not miss it. Nevertheless, a few did express an openness to seeking the friendship and companionship of a man that they could talk to, but insisted that they wanted the relationship to stop there. Although many claimed a loss of an interest in sex, in some cases this posture seemed to be a defense against risking rejection. Even among those who remained interested in sex, the sense of shame they felt about their disease and their expectation that they would surely be rejected once they disclosed their diagnosis made them very reluctant to try to enter into new relationships. Most women who had previously suffered rejection still felt so hurt by those experiences that they were unwilling to risk putting themselves in a situation again where disclosure would be necessary. As a result, some made a choice to become celibate, while others drifted in to a "de facto" celibacy

by their avoidance of any relationships that might eventually become sexual ones.

Another recurring theme was that sex was a dangerous pursuit because it can lead to disease, death, and emotional pain. It can also lead to pregnancy and infected children. Because sexual relationships can produce such feared outcomes, many women felt it was best to suppress their sexual desires and remain sexually inactive. They became fearful of their own sexual feelings which they saw as responsible for their current predicament – being sick with a life-threatening disease. Some expressed that relationships were just too stressful because partners, typically male partners, resisted or refused to use protection or because they were jealous and suspicious, creating conflict and tension in the relationship.

Of critical concern in the present study was whether the prospect of extended survival that the advent of HAART has afforded many HIV-positive women may have changed their experience of sexuality. Although HAART use has been linked to sexual functioning of HIV-positive men (e.g., Colson et al., 2002), the current study found that HIV-positive women described highly similar experiences of diminished sexual activity, a loss of sexual interest, and decreased feelings of attractiveness both before and after the advent of HAART. Relatedly, despite women often attributing various symptoms to side effects of antiviral medications, women described here did not attribute their diminished sexual interest or behavior to HAART. These findings further validate the quantitative findings from this study (Siegel et al., 2004), which found no differences between women in the pre-HAART and HAART eras regarding their psychosocial adjustment to their illness, including the sexual relationships domain (e.g., sexual conflict, loss of sexual interest, decreased sexual activity, decreased satisfaction).

The present study explicitly examined potential racial/ethnic differences in these women's reports of their sexuality. Although women in all race/ethnic groups and in both time periods reported experiencing less pleasure from sex, diminished interest in sex, and a loss of attractiveness, there were some differences in the reasons and factors behind these changes with the Puerto Rican women standing out as the most distinct. In the pre-HAART era, Puerto Rican women were most likely to adopt celibacy or drift into inactivity because they feared humiliation and rejection if they disclosed their status to a partner. By contrast, in the HAART-era they were most likely to say that they were celibate or largely inactive because they found relationships too stressful. Often this stress was linked to their partners' unwillingness to use a condom or to the pressure they put on the women to have sex when they didn't wish to do so. These women seemed unwilling to deal with the stress and conflict this created just to be in a relationship. Thus, for Puerto

Rican women, it seems that over time the reason for diminished sexual activity had shifted. The reasons why Puerto Rican women offered different reasons between the pre-HAART and HAART eras are unclear. While experiences of stigma and discrimination have decreased in the HAART era (Lekas, Siegel, & Schrimshaw, *In press*), it is unclear why this would differentially effect Puerto Rican women. However, these ethnic/racial differences may need to be considered when designing interventions for Puerto Rican women.

One must raise the question of the psychological costs to women of withdrawing from all sexual intimacy. While a few women were relieved to no longer have the burden of sexual relationships, disclosure, and negotiating safer sex and others seemingly did not miss this aspect of their lives, most felt differently. Most of the women described here were clearly upset or saddened by their experiences of diminished interest in sex, anxiety regarding sex, loss of the sexual freedom they felt before their diagnosis, feeling sexually unattractive and tainted, and fear of rejection by sexual partners. Many spoke of the slights and rebukes they had suffered from partners in the past that they attributed to their disease and the inability they felt to endure the pain of similar events again. Such unsupportive and rejecting responses, particularly from a sexual partner, have been found to be associated with depression among HIV-infected women (e.g., Schrimshaw, 2002; 2003). Yet, if the women avoided relationships out of a fear that there would eventually be an expectation of sexual involvement, they might also be depriving themselves of a potentially valuable source of social support (e.g., Haas, 2002). The benefits of social support from a sexual partner for the mental health of HIV-positive individuals are already widely recognized (e.g., Schrimshaw, 2002; Siegel, Raveis, & Karus, 1997).

The findings suggest that many HIV-infected women might benefit from counseling around their sexuality. While a certain amount of anxiety concerning infecting others or becoming reinfected can be adaptive if it motivates consistent condom use, too much anxiety may be maladaptive if it results in a fear of physical closeness and any kind of sexual intimacy, even acts that carry no risk of HIV transmission. Given the recognized association between aspects of emotional distress and low sexual desire among both HIV-positive and HIV-negative samples (e.g., Goggin et al., 1998; Laumann, Paik, & Rosen, 1999), HIV-infected women's mental health, already documented to be poor (e.g., Cook et al., 2004; Ickovics et al., 2001; Siegel et al., 2004), may in some cases be further compromised by their total withdrawal from sexual relationships and intimacy. The data further suggest that the women felt deeply discredited and profoundly tainted by their disease in ways that were very damaging to their self-esteem and identity as women and potential partners. We believe that this is a kind of HIV-

related suffering that has not been adequately studied or appreciated. These women need interventions to address these issues and to help them regain a sense of themselves as appealing, sensual women who can have gratifying, yet safe, relationships with both uninfected and infected partners. They would also likely benefit from guidance concerning how and in what circumstances to share their diagnosis with potential sexual partners to reduce the risks of painful rejection or to endure such rejection without personalizing it as much.

The limitations of the study must also be acknowledged. The most significant, and one that to a greater or less degree plagues all research on HIV-infected populations, is that the sample was one of convenience. Women had to be willing to self-identify as HIV-infected to self-refer into the study. As a result, those women who are most hidden and perhaps most ashamed of their disease may not be represented in the study samples. Second, because the women in both the pre-HAART and HAART era samples were interviewed about a broad range of adaptive challenges posed by their illness (e.g., stigma management, disclosure, treatment adherence, managing uncertainty), their sexual behavior and adaptational choices were not able to be as fully explored as would have been feasible had these issues been the exclusive focus of the research.

In conclusion, women's sexual adaptations to being HIV-positive has received only limited research attention exclusive of work on participation in unsafe sex and condom use. Only in the last few years has there been some attention to the sexual changes that occur subsequent to diagnosis and the distress this causes for women. We believe this an important area for future research as its may bear strongly on infected women's mental health and quality of life.

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