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Addressing Sexual Problems in HIV Primary Care: Experiences from Patients

Theo G. M. Sandfort¹, Kate L. Collier¹, and Robert Grossberg²

Theo G. M. Sandfort: tgs2001@columbia.edu

¹HIV Center for Clinical and Behavioral Studies, New York State Psychiatric Institute and Columbia University, 1051 Riverside Drive, Unit 15, New York, NY 10032, USA

²Department of Medicine (Infectious Diseases), Albert Einstein College of Medicine, Bronx, NY, USA

Abstract

Evidence suggests that sexual problems are common among people living with HIV and may be related to sexual risk taking and treatment adherence. This study explored the extent to which sexual problems experienced by people with HIV are addressed in primary care as well as how primary care responses to sexual problems are experienced by patients. Structured interviews were conducted with 60 patients at an urban HIV clinic. The average age of the participants (37 male, 23 female) was 45.8 years ($SD = 7.9$). Sexual problems were common. The most common sexual problem experienced in the past year was a lack of interest in sex (53.3 % reported) and the least common problem was painful intercourse (reported by 20 %). There were no gender differences in reports of sexual problems, except that painful intercourse was more frequently reported by women than men. Relatively few individuals who experienced sexual problems had discussed them with their provider, but these individuals were generally pleased with the counseling they had received and could identify several factors that facilitated a positive patient-provider interaction. Those who offer primary care services to people with HIV should be aware of sexual problems their patients may be experiencing and should feel confident in their ability to successfully address these problems. Providers may need additional training in order to adequately address sexual problems among people with HIV in primary care settings.

Keywords

Sexual dysfunction; HIV; patient-provider communication

INTRODUCTION

While sexuality continues to be a source of gratification and fulfillment for people living with HIV (Bova & Durante, 2003), it may also conflict. First of all, sexual contact is also the means by which many were infected with HIV. People living with HIV bear a burden that others do not, being that they are capable of transmitting HIV to their sexual partners. Medications to address HIV and HIV treatment side effects may also impede sexual functioning (Bouhnik et al., 2008; Collazos, Martinez, Mayo, & Ibarra, 2002). While various studies have documented the presence of sexual problems in people with HIV, there has been less attention focused on how such problems are addressed by HIV care providers. In this study, we explored the extent to which sexual problems experienced by people with HIV are addressed in primary care and how the primary care response is experienced by the patient.

Until new treatment regimes that prolonged the lives of HIV-positive people became available in the mid-1990s, “the sex life of those infected...seemed to be a minor issue if not completely inconceivable” (Schiltz & Sandfort, 2000, p. 1573). Prolonged life implied prolonged sexual life and it is well documented that many people with HIV remain sexually active after receiving their diagnosis (Crepaz et al., 2009; McGowan et al., 2004; Weinhardt et al., 2004). Prolonged life, coupled with effective strategies to prevent mother-to-child transmission, also changed the nature of childbearing decisions for many people living with HIV (Gruskin, Firestone, MacCarthy, & Ferguson, 2008). Indeed, the array of sexual health concerns that people living with HIV now face is broad, encompassing reproductive health decisions, screening and treatment for sexually transmitted infections (STIs), HIV reinfection, and sexual difficulties (Shapiro & Ray, 2007).

Problems of sexual functioning are common in the general population: a study using a probability sample of U.S. men and women aged 18 to 59 found that sexual problems were reported by 31 % of men and 43 % of women (Laumann, Paik, & Rosen, 1999). In women, low sexual desire was the most common problem whereas, for men, it was premature ejaculation. A global study of men and women between the ages of 40 and 80 years produced similar findings (Nicolosi et al., 2004).

There is evidence to suggest that people with HIV may be disproportionately affected by sexual problems. Low libido and erectile dysfunction have been found to be more prevalent in HIV-positive men who have sex with men (MSM) than in HIV-negative MSM (Hirschfield et al., 2010; Lamba, Goldmeier, Mackie, & Scullard, 2004). As compared to HIV-negative women, HIV-positive women have been found to have lower sexual interest and satisfaction, less sexual activity, poorer sexual relationships, and more sexual problems (Denis & Hong, 2003; Wilson et al., 2010). However, research on sexual problems in people with HIV has rarely used a comparison group, and has mainly used samples of one gender (Bova & Durante, 2003; Collazos et al., 2002; Colson et al., 2002; Cove & Petrak, 2004; Florence et al., 2004; Guaraldi et al., 2007; Richardson, Lamba, Goldmeier, Nalabanda, & Harris, 2006). This body of literature is also limited by the fact that the assessment of sexual problems has not been uniform, i.e., sometimes study participants are asked only about specific problems (such as erectile dysfunction) while in other studies sexual difficulties have been assessed with one general question (Bouhnik et al., 2008).

The factors that contribute to sexual problems in people with HIV vary and may be psychological, organic, or both (Bell, Richardson, Wall, & Goldmeier, 2006; Catalan & Meadows, 2000; Cove & Petrak, 2004; Goldmeier, Kocsis, & Wasserman, 2005; Richardson et al., 2006; Siegel, Schrimshaw, & Lekas, 2006; Trotta, Ammassari, Murri, Monforte, & Antinori, 2007). In HIV-positive men, peripheral neuropathy has been associated with impaired ejaculation (Richardson et al., 2006). Another study with HIV-positive men demonstrated that increased body mass index was associated with erectile dysfunction; better mental health status was associated with higher scores on sexual desire, orgasmic function, and overall sexual satisfaction measures; and higher intercourse satisfaction was associated with lower interference of body changes with habits, social life, and attitude (Guaraldi et al., 2007). While some studies with HIV-positive men have found links between either HAART and hormonal disturbances (Lamba et al., 2004) or HAART and specific sexual problems (Collazos et al., 2002; Colson et al., 2002; Lamba, et al., 2004), other studies have not supported these associations (Collazos et al., 2002; Guaraldi et al., 2007).

In women with HIV, three major areas of sexual change after diagnosis have been identified: diminished pleasure in sex, diminished sense of sexual attractiveness, and diminished participation in sex (Siegel et al., 2006). HIV-positive women have reported diminished

sexual functioning since the time of their HIV diagnosis but not since the time they started antiretroviral treatment (Florence et al., 2004). Better sexual functioning has been associated with better mental health, a more positive meaning associated with HIV infection, and less severe HIV symptoms (Bova & Durante, 2003), whereas depression, irritability, and anxiety were associated with increased sexual dysfunction (Florence et al., 2004). In a large survey of both men and women with HIV in France, several psychosocial correlates of self-reported sexual difficulties (in the previous 4 weeks) were identified: they included perceiving treatment side effects as disturbing, experiencing lipodystrophy-related symptoms, knowing more than four people with HIV, and experiencing greater HIV-related discrimination (Bouhnik et al., 2008).

Just as causes and correlates of sexual problems may differ on an individual basis, reactions to and experiences of such problems also vary. People with HIV who report a lower frequency of sexual intercourse more commonly report sexual difficulties, but difficulties are more common in those who report one to five sexual experiences in the prior month as opposed to those who report no intercourse at all (Bouhnik et al., 2008). Past experience with sexual problems was one rationale offered by HIV-positive men for actively adopting celibacy (Siegel & Schrimshaw, 2003). Alternatively, men with erectile dysfunction may self-medicate without having received a prescription from a medical provider, which raises the likelihood of drug interactions and jeopardizes their health (Trotta et al., 2007).

Other research findings suggest that addressing problems of sexual functioning within the context of HIV primary care may be an opportunity to improve treatment adherence and prevent HIV transmission to sexual partners. Erectile dysfunction has been associated with inconsistent condom use among HIV-positive gay men (Cove & Petrak, 2004). The authors of that study suggest that untreated sexual problems could produce sexual risk taking, when, for example, men experiencing erectile dysfunction believe the solution is to have sex without a condom, attempt intercourse without a full erection, or take on the receptive role in anal intercourse (Cove & Petrak, 2004). Sexual dysfunction has been associated with poor antiretroviral adherence (Trotta et al., 2008) and the experience of therapy-related side effects (including sexual dysfunction) has been associated with intentional non-adherence to antiretroviral therapy (Heath, Singer, O'Shaughnessy, Montaner, & Hogg, 2002).

But while strategies for diagnosing and medically managing sexual problems in people with HIV have been described (Hijazi, Nandwani, & Kell, 2002), there have been few reports of how such issues are actually addressed in practice. In a study of 34 gay/bisexual HIV-positive men who presented with sexual problems, 76 % of participants reported resolution and 14 % reported improvement at follow-up (Catalan & Meadows, 2000). The study participants presented with a mix of problems that were either primarily psychogenic, primarily organic, or both; psychological and physical methods of treatment were offered accordingly.

Sexual problems cannot be managed unless there is patient-provider communication around the issue. Communication about sexual functioning can be problematic even in the non-HIV-positive population. A national probability survey conducted in Great Britain found that only 10.5 % of men and 21 % of women with sexual problems sought help (Mercer, 2003). People with persistent problems were more likely to seek help, and the majority of men (63.8 %) and women (74.3 %) who did so reported consulting their general practitioner (Mercer, 2003). Other studies also suggest that most people who experience sexual problems would like professional help, but few have received it (Dunn, Croft, & Hackett, 1998; Moreira et al., 2005). Nearly half of the people surveyed through the Global Study of Sexual Attitudes and Behaviors thought a doctor should routinely ask about their sexual functioning, but only 9 % reported being asked about sexual functioning during a routine

visit in the prior 3 years (Moreira et al., 2005). People endorsed various reasons for not seeking help on their own, and these were more commonly personal factors (e.g., don't think it's a medical problem, don't think it's serious) as opposed to provider-related factors (e.g., doctor is expensive, doctor is uneasy to talk about sex).

We identified one study that examined patient-provider communication about sexual problems specifically for people with HIV (Bell et al., 2006). Lead clinicians at 74 HIV clinics in the UK were surveyed; 61 % said they rarely or never ask their female HIV patients about sexual functioning. Sixty-three percent of the responding clinicians reported that they would refer such a problem to psychology and 31 % said they managed sexual problems themselves. Other studies have shown that HIV care providers in clinical settings are more likely to discuss safer sex than specific sexual activities (Morin et al., 2004), and that they are less likely to talk about sexual satisfaction during regular care visits than about sexual activity or safer sex (Myers et al., 2007).

Sexual problems clearly impact quality of life for people with HIV, and have the potential to produce high-risk sexual behaviors and/or poor treatment adherence. Treatments exist that can be implemented in primary care settings (Hijazi et al., 2002), although we know little about how this is done. The aims of this study were to (1) assess how often problems of sexual functioning were addressed in HIV primary care; and (2) assess participants' reactions to related counseling/care received from their primary care providers. The problems of sexual functioning on which we focused include lack of sexual desire, inability to orgasm, premature ejaculation, pain during intercourse, not finding sex pleasurable, anxiety about sexual performance, and difficulty achieving or maintaining lubrication or erection.

METHOD

Participants

Participants were 60 patients (37 men, 23 women) of a New York City HIV clinic that offers primary care and other health services (e.g. mental health, gynecological care, adherence counseling, pharmacy) to approximately 2,500 patients. Individuals were eligible to participate if they (1) were patients of the clinic; (2) were HIV-positive; (3) could read and speak in English; (4) were between the ages of 18 and 75; and (5) had received a comprehensive exam from their primary care provider in the previous 12 months. Such comprehensive exams are routine as the first exam for new patients of the clinic and are then repeated annually. More than 80 % of the clinic's patients receive an annual comprehensive exam with their designated primary care provider, who may be a doctor, nurse practitioner, physician's assistant, or a trainee/fellow.

Characteristics of the sample are shown in Table 1. Participants ranged in age from 26 to 65 years ($M = 45.8$, $SD = 7.9$) and were primarily non-Hispanic Black (46.7 %) and Hispanic (45 %). Fifteen men and six women reported same-sex sexual behavior in the past year (35 % of the total sample) although behavior and sexual orientation identity were not always concordant. The participants' mean time since HIV diagnosis was 14.4 years ($SD = 7.0$). All but one participant reported having public insurance.

Procedure

Participants were recruited into the study either by responding to a flyer that was distributed in the clinic waiting room and at the registration desk, or were referred directly to the available interviewer by one of the clinic's providers or staff members at the conclusion of their appointment. Quota sampling was used to obtain a roughly even mix of women, heterosexual men, and MSM in the sample. The interviewers worked in collaboration with

the clinic's medical director and nurse manager to alert the clinic's providers about recruitment priorities.

After verbally giving informed consent, participants were interviewed in private exam rooms at the clinic. Public health graduate students from Columbia University conducted the interviews after having received training. The interviewers were not employed by the clinic or involved in any way with patient care and this was made clear to the study participants. Interviews were audio-recorded and lasted approximately 30 minutes. Participants were interviewed using a structured interview guide that allowed for open-ended responses and elaboration in response to some questions. They were also asked to self-administer two brief paper questionnaires. Participants received \$15 as compensation for their time. Identifying information about the participants or about their providers was not collected. This study was approved by the Institutional Review Boards of both the hospital housing the HIV clinic and Columbia University Medical Center.

Measures

The interview and questionnaires covered a range of sexual health topics that might be addressed in primary care, such as HIV status disclosure, childbearing and contraception, and sexually transmitted infections.

Sexual health care inventory—To facilitate recall, participants first completed a 28-item checklist about sexual health issues they had discussed with their primary care provider in the past year. Response options were “yes,” “no,” and “not sure.” Seven of the 28 items were related to sexual functioning: sexual pleasure, lack of sexual desire, problems with sex, problems with sexual arousal (erections, lubrication), problems reaching an orgasm, how medications affected one's sex life (sexual side effects), and pain during sex.

Provision of counseling/care related to medication side effects—Participants were asked by the interviewer if their primary care provider had ever discussed “whether the medications that you are using might affect your sexual life.” The type of medication was left unspecified (so may include ART, but also pain medication, antidepressants, etc.). Those who responded affirmatively were asked to provide additional details about the conversation (e.g., what was discussed, whether the advice was general or person-specific). Participants who reported multiple conversations about this topic were asked to describe the most recent conversation.

Participants were then asked whether they had ever personally experienced sexual side effects from medication. Participants who reported having had a discussion about sexual side effects were asked to rate that discussion using three items: pleasantness (1 = *very unpleasant*, 6 = *very pleasant*), ease (1 = *very difficult*, 6 = *very easy*), and helpfulness (1 = *very unhelpful*, 5 = *very helpful*). Interviewers then asked the participants to explain the ratings assigned.

Provision of counseling/care related to other sexual problems—After discussing sexual side effects of medications, the interviewers asked participants if they had experienced any other problems with sexual functioning in the past year. If the participant reported experiencing a problem, the interviewer probed for further details and asked whether the participant had discussed the problem with his or her primary care provider. If so, the participant was asked to provide further details about the conversation, rate each conversation on the three scales (pleasantness, ease, and helpfulness), and explain the ratings assigned. If the participant had experienced a problem but had not brought it to the provider's attention, the participant was asked to elaborate on this decision.

Participants who had not recently experienced any problems with sexual functioning were asked whether they would seek help from their primary care provider should such problems arise. They were asked to rate how comfortable they expected to feel having that conversation (1 = *very uncomfortable*, 6 = *very comfortable*) and how easy it would be to have that type of conversation (1 = *very difficult*, 6 = *very easy*).

Sexual problems inventory—To obtain more standardized information from each participant, all were asked to self-administer a questionnaire, adapted from Laumann, Gagnon, Michael, and Michaels (1994), at the conclusion of the interview. Alternate versions of the questionnaire were administered to men and women, with only minor differences in language on the two versions. The prompt read as follows: “During the past 12 months has there ever been a period of several months or more when you...” Participants responded yes or no to the following items: (1) lacked interest in having sex; (2) were unable to come to a climax (experience orgasm/ejaculate); (3) came to a climax (ejaculated) too quickly; (4) experienced physical pain during intercourse; (5) did not find sex pleasurable (even if was not painful); (6) felt anxious just before having sex about your ability to perform sexually; (7) had trouble lubricating/achieving or maintaining an erection. Participants were also asked to indicate if, in the previous 12 months, they had ever avoided sex because of the problem(s) they reported.

Analysis

Responses to close-ended survey questions were analyzed using SPSS Version 18. Descriptive statistics were computed for the sample as a whole and for sample sub-groups. We compared those who did and did not experience sexual problems in terms of personal characteristics and sexual history information (i.e., age, gender, past-year STD diagnoses, past-year sexual activity, time since HIV diagnosis, and past-year number of sexual partners); see Table 1. Within the sample of participants who had experienced sexual problems ($N = 48$), we compared the prevalence of specific sexual problems among those who did and did not discuss their problem(s) with their provider. Chi-square tests with Yates’ correction for continuity or Fisher’s exact tests were used to assess differences between the subgroups on categorical variables and independent samples t -tests were used to test for differences on continuous variables. We used chi-square tests with Yates’ correction for continuity to assess the association between specific sexual problems and avoidance of sex as a result of experiencing these problems.

Participants’ responses to open-ended questions were transcribed verbatim by research assistants. For purposes of this article, we focused on the sections of the transcripts related to sexual side effects and problems with sexual functioning. Text from these sections of the transcripts was organized by sub-group (i.e., those who had and had not discussed sexual problems with their primary provider) so that responses from all the participants within each sub-group could be reviewed together. Quotations that enhanced our understanding of the quantitative findings were selected for inclusion in the manuscript.

RESULTS

The only participant characteristic that was significantly related to discussion of sexual problems with one’s provider was past-year sexual activity: participants who did not discuss any sexual problems with their provider were more likely to have been sexually active in the past year (Table 1). Male and female participants were equally likely to discuss sexual problems with their providers.

Responses to the sexual health care inventory checklist indicated that participants discussed some topics with their providers more frequently than others. In the past year, 41.7 %

reported discussing problems with sex, 37.3 % discussed how medications affect (your) sex life, 31.7 % discussed lack of sexual desire, 28.3 % discussed problems with sexual arousal, 25 % discussed sexual pleasure, 20.7 % discussed problems reaching an orgasm, and 10 % discussed pain during sex.

Provision of Counseling/Care Related to Medication Side Effects

The vast majority (93.3 %) of participants reported being on medication, and 20 % ($N=12$) said they had experienced sexual side effects from their medications. Of the participants who reported being on medication, 46.4 % ($N=26$) said that their providers had *ever* discussed the impact of medication on sexual functioning. More than half the time (53.8 %), these were patient-initiated conversations, but a sizeable portion (42.3 %) was provider-initiated conversations; one participant indicated that the conversation was mutually initiated.

Participants were asked whether the discussion (or most recent discussion) with their provider about sexual side effects was general, personal, or both; 38.5 % indicated it was personal, with the remaining responses split evenly between general and both general and personal (30.8 % for each category). Participants also rated the pleasantness and ease of these conversations with a six-point scale and the helpfulness of these conversations with a five-point scale. The mean ratings were: pleasantness, $M=4.77$, $SD=1.42$; ease, $M=4.81$, $SD=1.36$; helpfulness, $M=4.62$, $SD=0.64$.

Provision of Counseling/Care Related to Other Sexual Problems

Aside from treatment-related problems already discussed, 40 % of participants ($N=24$) said they had experienced another problem with sexual functioning in the past year. However, only 10 (41.7 %) participants had discussed that problem with their provider. In all but one case, these were patient-initiated conversations. Assessments of these discussions were as follows: pleasantness, $M=4.80$, $SD=1.81$; ease, $M=5.5$, $SD=0.53$; helpfulness, $M=4.40$, $SD=1.26$.

Participants who had not discussed a sexual problem with their primary care provider were asked if they would consider doing so should a problem arise; 89.8 % said that they would. Most participants (61.2 %) said they would prefer to bring the issue up themselves (28.6 % would prefer that the provider ask about sexual problems and 10.2 % were unsure). Participants used six-point scales to rate the anticipated comfort and ease of such a discussion with their provider. The mean score on the comfort scale was 4.63 ($SD=1.47$) and the mean score on the ease scale was 4.67 ($SD=1.56$).

Specific Sexual Problems Experienced and Discussed

Three-quarters of the participants ($N=45$) reported having been sexually active in the past year. Responses to the self-administered sexual problems inventory indicated that sexual problems may have been more common in the sample than interviewers would have been led to believe. While only 40 % of participants ($N=24$) reported experiencing sexual problems when asked a general question by the interviewer, 80 % of participants ($N=48$) indicated that they had experienced at least one of the seven problems listed on the self-administered questionnaire.

A summary of responses to the sexual problems inventory is shown in Table 2. Among both male and female participants, the most common sexual problem experienced in the prior year was a lack of interest in having sex. The only significant difference by gender was on reports of pain during intercourse; women were significantly more likely than men to report this problem ($p=.04$, Fisher's exact test).

Nearly 42 % of participants reported avoiding sex in the past year due to the sexual problem(s) indicated. Men and women were equally likely to report avoiding sex due to the problem(s) they experienced. For a better understanding of which problems were related to the avoidance of sex, we tested for significant associations between each problem and reported avoidance of sex due to that problem in the past year. There were four problems that were significantly associated with avoidance of sex: (1) lack of interest in sex, $\chi^2(1, N=60) = 7.36, p = .007, \phi = .38$; (2) inability to reach orgasm, $\chi^2(1, N=60) = 5.36, p = .02, \phi = .34$; (3) anxiety before having sex about one's ability to perform, $\chi^2(1, N=60) = 8.24, p = .004, \phi = .41$; and (4) difficulty lubricating (for women) or achieving/maintaining an erection (for men), $\chi^2(1, N=60) = 5.22, p = .02, \phi = .33$. Participants who reported avoiding sex due to problems they experienced also reported significantly more problems on average ($M = 3.20, SD = 1.68$) than did those who did not report avoiding sex ($M = 1.57, SD = 1.58$), $t(58) = 3.84, p < .001$.

We looked more closely at the 48 participants who indicated, using the inventory checklist, that they experienced at least one sexual problem in the past year. We compared the responses of the 10 individuals who had discussed a sexual problem with their provider to the responses of the 38 who had not discussed a sexual problem with their provider. There was only one problem (coming to a climax too quickly) that was significantly more prevalent in the group that had discussed a sexual problem with their provider, as shown in Table 2. For all other sexual problems, prevalence was not significantly different between the groups of participants who had and had not discussed a sexual problem with their provider.

Patient Experiences of Sexual Problems and Related Care

Responses to the open-ended questions in the interview provided us with a better understanding of (1) why some participants who experienced sexual problems did not discuss them with their providers and (2) what led to a positive experience in seeking out care for sexual problems.

Among the participants who had problems they had not brought to their provider's attention, some thought what they were experiencing was to be expected or part of a natural process. For example, a 47-year-old woman who had lost interest in sex explained why she had never brought this issue to her provider's attention:

In the past year, have you ever had a problem with sexual functioning?

"Yeah, but I know it's a result of the medication, so I don't question it really."

Can you tell me what kind of problems you experienced?

"I have no—I don't want to say no—very little sexual desire, where I haven't been with anybody in like, five years, and it doesn't bother me."

Have you discussed this problem with your primary provider in the past year?

"No."

Is there a specific reason why not?

"Yeah, because I know that the majority of the medication I'm on affects your sex drive, to one extent or the other, so, I know it's the medication, it's not anything I'm doing."

A 29-year-old man, who was also experiencing a loss of interest in sex, explained the reason why he had not brought the issue to his provider's attention as follows: "I thought maybe, I

mean I'm not old, but I'm 29...I did have a lot of sex, when I was younger...So I thought maybe I'm old. All done."

Some participants indicated a hesitancy to discuss potentially sensitive issues with their providers. A 29-year-old man who was experiencing problems with arousal, when asked if there was specific reason why he had not discussed this problem with his provider, said, "I felt kind of like embarrassed, a little bit. I felt embarrassed." For one woman, age 45, it was the specific nature of her problem that was difficult for her to talk about:

Can you tell me what kind of problems you experienced?

"I've never orgasmed. So I always felt like, why can't I, the partners that I had, why can't at least one of them make me reach that peak?"

Have you discussed this problem with your primary care provider?

"No. Not that."

Is there a specific reason why not?

"I mean, I talk about everything with my doctor, but that is like, I don't even tell nobody that I never reached an orgasm with a partner. It has nothing to do with [my provider], it's just me." [Later in the interview she adds:]

"...I feel like embarrassed towards...I don't feel embarrassed about being HIV positive, being bisexual, bicurious—I'm not embarrassed of none of that. But I cannot see myself talking about something that—I claim so much to enjoy it, and how come I haven't reached an orgasm? So it's like, mmm, I don't want to talk about that."

Other participants indicated they did not feel the need to discuss sexual problems with their primary care providers. For instance, one 46-year-old woman who had lost interest in sex was accustomed to coping with what she had experienced and did not find it problematic:

Can you tell me what kind of problems you experienced?

"Not interested [in sex]."

Have you ever discussed this problem with your primary provider?

"No."

Was there a reason why you didn't talk to him about it?

"Because first of all I wasn't active, and second of all my partner accepted – accepts it and there's not a problem."

A 45-year-old woman who had difficulty achieving an orgasm did not feel an urgent need to seek help from with her primary care provider:

Would you know where to go to get help for this issue?

"I'd probably talk to my doctor. But right now, since May, I have not indulged in sex, because my partner is [away] and I'm here. So it really doesn't pertain to me right now, but when the time comes, if I *still* can't come it's going to be a problem and I'll take it to my doctor then."

A 50-year-old man explained that the problems he experienced tended to resolve on their own or were not serious enough to discuss with his provider:

In the past year, have you ever had a problem with sexual functioning?

“Yeah, but it just—time, time solves it, you know. It takes a little time and it solves it. Like, it—you know, like, it’s not your fault, it’s like, all you gotta do is take time, and everything will be fine.”

So you have had some problems?

“It’s just like, maybe it’s not the right time to be making love, and to be sexually aroused. All you gotta do is wait until tonight, or wait until later in the afternoon.”

So it was arousal kind of problems?

“Well, yeah, but then later on it just turned out fabulous.”

Have you ever discussed this problem with your primary care provider?

“It never really got that bad.”

Participants who had experience talking about sexual problems with their providers pointed to factors that facilitated helpful conversations. Some had initially experienced some awkwardness in discussing sexual problems with their providers, as a result of the discordance between their provider’s personal characteristics and their own (i.e., provider was female and patient was male, provider was older than patient). The quotations below illustrate how the provider’s gender or age affected the communication dynamic from the patient’s perspective. One male, age 45, who experienced loss of libido and problems with arousal and orgasm explained why he felt that the conversation was pleasant, somewhat easy, and very helpful:

“Well, it’s hard to tell a woman [provider] that you’re not feeling, you know, excited all the time. I’m trying to find the right words. (*laughs*) Excited all the time and that your urges are going away. So it’s hard to express it to a woman. But, due to the fact that we have a good repertoire [*sic*] between each other it was somewhat easy. But then again, being a male, it kind of like—hard for me to speak out about it. But after awhile it just became easier.”

A woman, age 45, experiencing a lack of interest in sex and problems with orgasm answered to the question why the conversation was somewhat unpleasant, somewhat easy, and somewhat helpful:

“Well, somewhat unpleasant was—I wasn’t getting my shit off.” (*laughs*)

But how about talking to your doctor about it?

“Talking with him was complicating because he’s *older*. He’s real older. And I didn’t want him to think I was a horny toad. (*laughs*)...But it was somewhat easy to do it once he started talking back to me because he was giving me pointers. And I’m looking back at him like...*you still do that stuff*(*laughs*). And, it was helpful. It was real helpful. I took his advice...Even though it sounds weird and I be looking at him like, *oh, he don’t do things like that*...But yeah, he does (*laughs*).”

In these cases, any awkwardness resolved itself and the participants had positive experiences. Participants also referred to their providers’ attitude (e.g., “easygoing,” “calm”), conversation style (e.g., “straightforward,” “only talking medical”), and professionalism/expertise as factors affecting their assessment of the ease, comfort, and helpfulness of each conversation. Participants also appreciated the informational or instrumental support offered by their providers, in the form of advice, treatment, or referrals for care from other providers, as described in the quotations below:

It sounds like you felt pretty positive about this conversation. What made you feel that way?

“Well, basically I was positive with it because I came and I was for real and she gave me back positive answers, the best that she was able to give to me. Not to say that I went home and I--and [the advice] worked, but, it was the best that she was able to do for me, to give you that peace of mind.” (Female, age 53, experiencing loss of libido)

What made you feel that the conversation was good?

“He told me what I needed and not what I wanted to hear. Well, I have to see—I don’t have to, but he suggested I see a psychiatrist, and maybe get some medication. He checked my testosterone level, and it was pretty normal, so he said, ‘I can’t give you the’ –whatever you call them pills?—‘Cialis.’ He said, ‘Got to see a psychiatrist, this happens often with the medication, but in your instance I think it’s more psychological.’” (Male, age 45, experiencing problems with arousal)

Finally, participants who had discussed sexual problems with their providers also referred to and valued the closeness they had with their providers and indicated that their providers knew them and their medical and sexual histories well. Participants were comfortable with their providers in part because issues in the participants’ histories such as alcohol abuse, mental illness, and sex work had already been disclosed and addressed. One female participant, age 44, who was experiencing loss of libido and problems with orgasm, summarized her comfort in discussing sexuality with her provider: “Me and [my provider] we have a very close relationship. I mean she knows more about me than my mother does.”

DISCUSSION

Our findings offer insight into how often problems of sexual functioning are addressed in HIV primary care and how such counseling or care is experienced by the patient. Sexual problems were common among the participants in our sample, and, in some cases, led to the avoidance of sex. Participants who experienced certain problems—a lack of interest in sex, the inability to reach orgasm, anxiety before having sex about one’s ability to perform, and difficulty lubricating or achieving or maintaining an erection—were most likely to report avoiding sex as a result of the problems they experienced.

Participants’ reports of sexual health topics discussed with providers in the past year follow expected patterns. The most general topics, *problems with sex* and *how medications affect your sex life*, were those most frequently discussed. The fact that treatment side effects were one of the more commonly discussed topics is not surprising. Nearly all of the participants in our study reported being on some type of medication, and many who had not actually experienced a side effect reported that they were advised of the possibility at the time that the medication was prescribed. In general, participants indicated that conversations with their providers about the sexual side effects of medication were pleasant, easy to have, and helpful.

In comparison to conversations about the sexual side effects of medications, which were almost evenly split in terms of being provider- or patient-initiated, conversations about other sexual problems were more likely to be patient-initiated. Participants who had discussed sexual problems with their providers were, in general, pleased with the experience. They could identify several factors that facilitated a good experience, such as an easygoing attitude or conversation style, the way the provider conveyed his or her medical expertise (neutrally communicating factual information about the situation), and an existing long-term relationship with the provider. These factors could compensate for what some patients initially saw as barriers to comfortable conversations, such as discordance between the gender or age of the patient and provider.

Yet we also saw that many participants who may be experiencing sexual problems never discussed these issues with their providers. Those who did and did not discuss their sexual problems were, for the most part, experiencing the same types of problems. Coming to a climax too quickly was the one problem that appeared to be more common among those who did seek provider support. Participants who did not have the experience of discussing a sexual problem with their provider were open to doing so in the future, with most indicating that they would expect such a conversation to be comfortable and easy to have. This finding suggests that, with the exception of participants who reported embarrassment about or submissive acceptance of what they were experiencing, some may simply not consider their symptoms disruptive enough to warrant mention to their providers.

To the best of our knowledge, this is the first study to report about experiences receiving care related to sexual functioning among people with HIV. Overall, the emerging picture looks positive, especially compared to limited findings from studies conducted among health care providers (Bell et al., 2006; Morin et al., 2004; Myers et al., 2007) that have identified barriers to the provision of sexual health care in the context of HIV primary care. Our findings might be specific, though, to the site where the study was conducted. It also was not our aim to conduct a study with results generalizable to all persons living with HIV that are in care.

Our findings must be interpreted with acknowledgment of the study's limitations. This was a descriptive study and our sample was small. Our data are based on participant self-report, which is subject to recall bias. Underreporting of sensitive information, such as sexual problems, would also be a concern. We tried to minimize underreporting by emphasizing confidentiality and giving study participants the opportunity to report sexual problems both in their interview and by means of a self-administered checklist, which the interviewer did not review in the presence of the participant. Furthermore, while we asked about sexual problems participants may have experienced in general and as treatment side effects, it is not clear whether participants were able to accurately make such distinctions and correctly attribute symptoms (cf. Siegel, Scrimshaw & Dean, 1999).

Given the topic of the interview, it is also possible that there was some participant "yea-saying." That is, participants may have reported the desire for certain services only because they were asked. It is unlikely that people reported experiencing sexual problems that they had not actually experienced, but it does seem that, in some cases, people reported issues that they never would have bothered reporting to a health care provider.

There was also some selection bias inherent in our recruitment method: the clinic patients who participated were self-selecting or were referred to the available interviewer by their provider. The interview was offered in English only. Those patients who were not fluent in English, or those most disconnected from the clinic—perhaps for health reasons or because they were unhappy with their care—could not be reached. These limitations would be more concerning if our goal had been to obtain a sample that was representative of the clinic population, but it was not. Still, the generalizability of our findings to other populations of people living with HIV is limited by the characteristics of the sample we recruited and the specifics of the setting in which we conducted this study. Our sample consisted mainly of people in their 40s and 50s, and who had been living with HIV for many years. The large patient volume (with roughly 100 patients per day being seen) and comprehensive service delivery model of the clinic (allowing for in-house referrals from primary care providers to mental health specialists, adherence counselors, etc.) is also noteworthy.

Despite the study's limitations, our findings have practice implications for providers working with people living with HIV. Providers should be aware of the types of sexual

problems their patients with HIV may experience and how common they are, and they should be prepared to address these problems. It is telling that patient had to bring up non-medication-related sexual problems, while providers could legitimize discussing these issues by taking initiative. Screening patients for sexual problems might also help some individuals overcome any embarrassment they feel about bringing such problems to their provider's attention. Addressing problems such as pain during sex—which can be a symptom of a larger health problem or problems—with arousal and orgasm—which could potentially lead to sexual risk taking—is especially important. It is unlikely that screening for sexual problems would create substantial new demand for treatment of sexual problems, however, since some individuals do not consider what they are experiencing to be urgent or serious. Additionally, addressing sexual health among people living with HIV from a perspective that assumes they can and should enjoy sexual relationships may be a new angle from which to approach topics that are probably more familiar, such as safer sex and HIV status disclosure.

Providers should also feel confident that they can successfully address sexual problems in HIV primary care. The participants in our study were generally quite pleased with the way their providers had handled discussions about sexual functioning, were open to receiving this kind of care and counseling from their primary care providers, and valued this component of their overall health care. For providers with less experience addressing such issues among their patients, additional training relating to screening for, discussing, and treating sexual problems among people with HIV may be indicated.

Our findings suggest several directions for future research. First of all, HIV-positive persons' experiences with the way their sexual problems are addressed in health care should be studied in larger, more representative populations, also including a younger age group. Combined with providers' perspectives on this issue, it would become clear to what extent there is a need for training of health care professionals and changes on an institutional or policy level. Furthermore, understanding of how HIV-positive persons experience sexual problems and how they interpret the causes of these problems might indicate what needs there are for psychoeducation. Although it was not our aim to assess the validity of our participants' assumptions and attributions, we expect that providing patients with accurate information might in some cases improve their sexual well-being. We must also learn more about the relationships among treatment for sexual problems, sexual behavior, and treatment adherence. In particular, understanding how perceptions of sexual problems as treatment-related affects treatment adherence needs further study and could inform adherence-related interventions.

Future research could also explore how patient-provider communication about sexual problems influences the sexual behavior of people living with HIV. This issue might best be studied through in-depth, qualitative interviews with people living with HIV about how (or if) communication or messaging from their providers influence sexual decision-making and behavior. The assumption is that positive attention to the sexuality of persons living with HIV will improve their well-being as well as the way they cope with their status. Whether this is the case needs to be tested.

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Table 1
Characteristics of All Study Participants and of Participants Who Have and Have Not Experienced Sexual Problems

	Total sample	Participants who did not experience sexual problems	Participants who experienced at least one sexual problem	t or χ^2	p
<i>n</i>	60	12	48		
Mean (SD) age (in yrs)	45.8 (7.9)	45.3 (7.8)	45.9 (7.9)	<1	ns
Gender and sexualorientation					
<i>Women</i>	38.3 (23)	41.7 (5)	37.5 (18)	--a	
<i>Heterosexual men</i>	35.0 (21)	25.0 (3)	37.5 (18)		
<i>Men who have sex with men</i>	26.7 (16)	33.3 (4)	25.0 (12)		
Race/ethnicity				--a	
<i>Black, non-Hispanic</i>	46.7 (28)	33.3 (4)	50.0 (24)		
<i>Hispanic</i>	45 (27)	50.0 (6)	43.8 (21)		
<i>Other</i>	8.3 (5)	16.7 (2)	6.3 (3)		
Speaks only English at home	66.7 (40)	66.7 (8)	66.7 (32)	--a	
Education				--a	
<i>Some high school</i>	37.3 (22)	50.0 (6)	33.3 (16)		
<i>High school degree</i>	28.8 (17)	16.7 (2)	31.3 (15)		
<i>Some college</i>	22.0 (13)	25.0 (3)	20.8 (10)		
<i>College degree</i>	11.9 (7)	8.3 (1)	12.5 (6)		
Reported STD diagnosis in past year	15.0 (9)	8.3 (1)	16.7 (8)		ns ^b
Sexually active in past year	75.0 (45)	100 (12)	68.8 (33)		.03 ^b
Mean (SD) years since HIV diagnosis	14.4 (7.0)	13.7 (5.6)	14.5 (7.3)	<1	ns
Mean number of sexual partners in past year	1.7 (2.8)	1.6 (.5)	1.7 (3.1)	<1	ns

Note. All numbers are percentages (n) unless otherwise indicated.

^aDifferences were not tested due to small cell sizes.

^bFisher's exact test

Table 2

Specific Sexual Problems Reported by Male and Female Study Participants and by Those Who Did and Did Not Discuss Such Problems with Primary Care Providers

<i>n</i>	Total sample	Males	Females	²	<i>p</i>	Participants who experienced sexual problems but did not discuss them with a primary care provider	Participants who experienced sexual problems and discussed them with a primary care provider	<i>p^a</i>
	60	37	23			38	10	
Lacked interest in having sex	53.3 (32)	48.6 (18)	60.9 (14)	<.1	ns	63.2 (24)	80 (8)	ns
Unable to orgasm	33.3 (20)	29.7 (11)	39.1 (9)	<.1	ns	36.8 (14)	60 (6)	ns
Climaxed too quickly	21.7 (13)	27 (10)	13 (3)	-- <i>a</i>	ns	18.4 (7)	60 (6)	.02
Experienced physical pain during intercourse	20 (12)	10.8 (4)	34.8 (8)	-- <i>a</i>	.04	23.7 (9)	30 (3)	ns
Did not find sex pleasurable	33.3 (20)	29.7 (11)	39.1 (9)	<.1	ns	36.8 (14)	60 (6)	ns
Felt anxious just before having sex about your ability to perform sexually	33.3 (20)	37.8 (14)	26.1 (6)	<.1	ns	42.1 (16)	40 (4)	ns
Had trouble lubricating (women) or achieving or maintaining an erection (men)	30 (18)	29.7 (11)	30.4 (7)	<.1	ns	31.6 (12)	60 (6)	ns
Avoided sex due to problem(s) indicated	41.7 (25)	40.5 (15)	43.5 (10)	<.1	ns	47.4 (18)	50 (5)	ns

Note. All numbers are percentages (n).

^aFisher's exact test.