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Gender, Sexual Orientation, and Adolescent HIV Testing: A Qualitative Analysis

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Abstract

Using qualitative data, this article explored the circumstances leading to HIV testing among 59 HIV-infected adolescents recruited from New York City HIV clinics. Results showed differences between the heterosexual women and the gay and bisexual men. Most of the young women were tested during routine health care or self-initiated tests, and most were asymptomatic when they tested positive. Their testing decisions were sometimes based on assessments of their boyfriends' risk behaviors, rather than their own. Many males were experiencing symptoms of illness when they tested positive, and about half of these recognized their symptoms as related to HIV and sought tests. Some young men expressed fear of learning about positive test results, which delayed their testing, and some providers did not initially recommend HIV testing for males who presented with symptoms. The article concludes that consideration of these gender and sexual orientation-related concerns can facilitate HIV testing among adolescents.

Keywords

adolescents; gender; HIV infection; HIV testing

High rates of sexual risk behaviors put young people at risk for HIV (Centers for Disease Control and Prevention [CDC], 2008a). The 2007 Youth Risk Behavior Survey indicated that

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35% of high school students were currently sexually active and 38.5% of those had not used a condom during their most recent act of sexual intercourse (CDC, 2008a). In 2006, 15% of new HIV diagnoses occurred among adolescents and young adults ages 13–24 years old (CDC, 2008b). It is estimated that more than half of all HIV-infected adolescents have not been tested and, therefore, are unaware of being infected with HIV (CDC, 2006).

A better understanding of adolescent HIV testing behavior can contribute to efforts to increase testing rates among high-risk adolescents. A number of survey-based studies have examined rates of and reasons for testing among adolescents, but to our knowledge there are no recent qualitative studies that explore the circumstances under which HIV-infected adolescents were tested for HIV. This study addresses this research gap by drawing on qualitative data on HIV testing, gathered from in-depth interviews with a cohort of Black and Hispanic HIV-infected adolescents and young adults.

Background

In the 2007 Youth Risk Behavior Survey (YRBS), 12.9% of high school students reported having been tested for HIV, not including those tested when donating blood (CDC, 2008a). Female students (14.8%) were more likely to be tested than males (11.1%), Black students (22.4%) were more likely to be tested than White (10.7%) or Hispanic (12.7%) students, and Black females (27.2%) had the highest rate of testing overall, followed by Black males (17.3%; CDC, 2008a). In 2006, the CDC found that among young adults ages 18–24, an estimated 15.7% had been tested for HIV in the previous 12 months (CDC, 2008c). Studies have found that high-risk adolescents and young adults had testing rates ranging from 53–63% (Kellerman et al., 2002; Moyer, Silvestre, Lombardi, & Taylor, 2007). One study found that among 14- to 24-year-olds in Pittsburgh who reported unprotected sex with more than one partner in the previous 6 months or who shared a needle, 53% had been tested in the previous year. The same study found that 62% of gay men had been tested in the previous year, and older youth (ages 21–24) were more likely to have been tested than younger youth (ages 14–20; Moyer et al., 2007). High-risk adolescents and young adults indicated lower testing rates than high-risk adult populations (Kellerman et al., 2002; Grant et al., 2006). A study found that among 18- to 24-year-olds surveyed in six states, including men who have sex with men (MSM), intravenous drug users, and heterosexuals recruited from sexually transmitted disease (STD) clinics, 63% had been tested for HIV, compared to 85% of those who were 25 years of age and older (Kellerman et al., 2002). Among high-risk adult populations, including adult homosexual and bisexual men and adult homeless and low-income women, testing rates ranged from 68–82% (Grant et al., 2006).

Studies of high-risk adolescents and young adults indicated that common reasons for HIV testing were health care providers recommending tests, proactively seeking tests because they suspected they were at risk of HIV infection or were experiencing symptoms of illness, and undergoing testing as part of screening for Job Corps, insurance purposes, military participation, blood donation, and/or detention (Grant et al., 2006; Murphy, Mitchell, Vermund, & Futterman, for the Adolescent Medicine HIV/AIDS Research Network, 2002). Murphy et al. (2002) found that adolescents who reported more risk factors, including more male partners, same gender partners (males only), and recent marijuana use, also reported having more HIV tests. However, Smith, Buzi, & Weinman (2005) found that among a sample of adolescents attending free inner-city family planning clinics who were offered HIV tests, those reporting more risk behaviors and symptoms were not more likely to agree to HIV tests than those with fewer risk behaviors. Studies have shown that female adolescents are often tested as part of routine gynecological, perinatal, or STD care (Arrington-Sanders & Ellen, 2008; Grant et al., 2006). In addition, Decker, Silverman, and Raj (2005) found that female high-school students who experienced both physical and sexual dating violence were three

times more likely to have been tested for STDs and HIV than those who did not experience such violence. Murphy et al. (2002) found that among both HIV-infected and uninfected adolescents who had been tested for HIV, significantly more males than females had sought HIV tests because they felt sick.

Research investigating barriers to HIV testing among high-risk youth found that young people reported a number of deterrents, including low perception of risk for HIV infection, fear of positive test results, not being offered a test, not knowing anyone living with HIV, fear of needles, not wanting to think about HIV, and not wanting anyone to know if they had HIV (Kellerman et al., 2002; Moyer et al., 2007; Peralta, Deeds, Hipszer, & Ghalib, 2007). A study of high-risk youth ages 14–24 in Pittsburgh found that fear of positive test results was most often reported as a barrier to HIV testing by gay men and adolescents reporting risk behaviors, yet one third of high-risk youth and gay men reported not being at risk for HIV (Moyer et al., 2007). Findings from a study examining barriers to testing among minority adolescents (ages 12–24) from high seroprevalence areas in Baltimore emphasized the importance of health care providers in HIV test promotion among high-risk youth. Most of the participants had never been tested for HIV (70.5%) and, among them, the most common reason cited was never having been offered a test (62.8%; Peralta et al., 2007).

Methods

Study Design and Participants

This manuscript is based on an analysis of qualitative in-depth interview data on the circumstances leading to HIV testing among HIV-infected adolescents and young adults. These data were elicited as part of a larger, primarily qualitative, exploratory study designed to examine the experiences of living with HIV in a cohort of mostly African American and Latino youth who had contracted the disease as a result of high-risk sexual behavior.

Given the dearth of data on the testing experiences of behaviorally-infected youth, the decision was made to conduct a qualitative exploratory study as an appropriate and necessary first step toward describing and understanding the adaptive challenges facing adolescents and young adults contending with this disease, including the circumstances that led them to attain HIV tests. In-depth qualitative interviews can “expose” how young infected individuals mentally organize and cognitively structure their experiences (Taylor & Fiske, 1981). In addition, a qualitative approach is particularly well suited to discovering the personal meaning individuals assign to their lives and specifically their illness experiences and how those meanings guide behavior, including the decision to get tested for HIV. Qualitative interviews elicit contextualized data that also allow for consideration of the cultural and situational factors that may affect HIV testing behavior.

Recruitment and Procedures

We used a purposive sampling method; cases were chosen because they were representative of the population of interest—in this case HIV-infected adolescents and young adults who acquired infection through high-risk behavior. Eligibility criteria included (a) being 13–24 years of age, (b) having a diagnosis of HIV, (c) being cognitively competent to participate, and (d) having acquired HIV infection behaviorally, that is through unprotected sex or IV drug use. However, all participants included in the study had been infected through unprotected sex. Potential participants were excluded if they were infected with HIV perinatally or if they did not meet all of the other aforementioned eligibility criteria. Patients who were severely medically ill or believed not to be developmentally or cognitively capable of providing informed consent or completing the interview questions were not recruited. The study was

approved by the Columbia University Institutional Review Board (IRB), and the boards of collaborating institutions. It also received a federal Certificate of Confidentiality.

Study participants were recruited from five well-established adolescent HIV clinics in the New York City area. Each recruitment site provided comprehensive specialty medical and supportive ancillary social services to adolescents and young adults with HIV. Potential participants were all recruited at the time of their regularly scheduled clinic visits. At four of the clinics, the clinic staff described the study to their patients, conducted a preliminary screening of potential participants for eligibility, and scheduled the interview or contacted the study staff to inform them about specific days on which the potential study participant could be interviewed. At one clinic, the study staff directly approached potential participants in the waiting room or prior to group therapy sessions to describe the study and screen potential participants for eligibility. This was done at the request of the clinic to reduce demands on staff time. Study staff followed the same recruiting process the clinic staff followed in the other four sites. Thirty participants were recruited at the clinic where study staff recruited directly; the remaining 29 participants were recruited from the four other clinics by clinic staff. Eligible individuals were scheduled for an interview session where study eligibility was confirmed and informed consent explaining potential risks, benefits, and compensation was administered. The majority of potential study participants approached by clinic and study staff did participate in the study. Participants were recruited and interviewed between June 2004 and February 2007 and resided in the New York metropolitan area at the time of the interview. A total of 59 participants completed the qualitative component of the study. As Rubinstein (1994) has suggested, "In sum we have no hard and fast rules about numbers because, in fact, an adequate sample size in qualitative research is linked to the conceptual consistency of the data and thematic pattern saturation" (p.80). Our interactions with the qualitative data indicate that with this sample size we did achieve thematic saturation while exploring participants' HIV testing experiences. Specifically, after coding and analyzing approximately 50% of the interviews, the same types of barriers and facilitating factors by gender continued to emerge as interpretations of the participants' testing experiences. No new themes related to testing were elicited in interviews after identification of the themes presented in this report, which confirmed analytic saturation.

Data Collection

All participants completed a brief survey that elicited demographic and behavioral data and a small battery of psychosocial measures collected for descriptive purposes. These data were collected using audio computer-assisted self-interviews (ACASI). Following the 30-minute ACASI, study staff conducted an in-depth qualitative focused interview with each participant aimed at eliciting his/her experiences of living with HIV, life conditions prior to diagnosis, and circumstances leading to HIV testing.

Public health and social sciences graduate students with prior interviewing experience conducted all interviews. In addition, each interviewer participated in an intensive 3-day interview-training program conducted by one of the authors. One of the authors conducted quality control reviews of a random sample of the transcripts of each interviewer and met with the interviewers on an approximately quarterly basis to ensure the high quality of interview data.

Interviews were typically conducted in a private office at the clinic. However, in a few cases they took place at the investigators' research offices when the participant preferred that venue. Written informed consent was obtained from all participants at the time of the interview. Permission for a waiver of parental consent was granted by the Columbia University IRB for all participants under age 18 ($n = 2$) due to the sensitive nature of the data collected and because many of the young people were estranged from their parents. An interview guide organized

around topic areas related to the study topics was used to structure the interview. However, the interviewers were also trained to explore issues raised in the interview that were not anticipated in the guide. It took, on average, 3–4 hours to complete the qualitative interviews, which were audiotaped. No personal identifiers were used on audiotapes or transcriptions. To combat participant fatigue, interview breaks were taken as needed and the option of completing study activities in one or two sessions was provided; all participants chose the single session option. They received compensation of \$50 for their participation and \$8 in transportation vouchers.

Data Analysis

The two PIs, along with a medical sociologist, and two Dr. PH candidates, developed, tested, and refined a coding scheme that allowed us to systematically identify and conceptually define the themes and sub-themes present in the transcripts, as well as the relationships among the themes while keeping them in context. We followed the process of developing a coding scheme for content analysis according to Strauss' (1987) method. Each member of the team independently developed selective codes and subcodes that addressed the study topics based on the same set of transcripts. In two subsequent meetings, the team agreed on a preliminary coding scheme that was then applied to a new set of transcripts for reliability testing and refinement. A third researcher, a Dr. PH hired to oversee the coding process, then tested the coding scheme on several transcripts for independent verification of the codes. Once the coding scheme was developed, parallel coding of 12 transcripts was carried out by the two Dr. PH candidates and then verified for inter-rater reliability, which was found to be high. The code *HIV Testing*, the primary code used for the analysis presented here, had a 100% inter-rater reliability score. Subsequent transcripts were equally divided and independently coded by the two coders. Application of the coding scheme to the qualitative data set served to systematically organize the data and facilitate analysis of the text. ATLAS.ti, qualitative data software, was used to assist in the coding and data analysis. In addition to the coding scheme that was applied to all interview transcripts, the research team constructed summary profiles for each participant, which were also reviewed for any material that might be related to HIV testing behavior.

Results

As demonstrated by Table 1, which describes the demographic characteristics of the study participants, the sample was heterogeneous in terms of age at time of diagnosis, sexual orientation, gender, racial/ethnic minority background, and level of education. Further, the majority of participants were raised in socioeconomically disadvantaged households, often characterized by poverty, housing instability, and parental mental health and substance abuse problems. In addition, given the lack of parental supervision and guidance, many of the participants across race, gender, and sexual orientation categories reported early sexual initiation, almost half of them at 13 years old or younger.

In the process of examining the study participants' accounts of their testing experiences, it became apparent that gender, sexual orientation, and the meaning they assigned to their sexual relationships played a significant role in the decision to undergo testing. Therefore, these concepts are an integral part of this analysis.

Females: Relationship as Context for Testing

Many of the young women were tested for HIV when a health care provider suggested it during routine gynecological, perinatal, or STD care, or they proactively sought tests because they suspected they were at risk of HIV (See Table 2). What stood out in the females' testing narratives was an emphasis on relationships as the context for testing experiences. Several of the young women reported that they got tested at the suggestion of a health care provider. In

many cases, these descriptions of their reasons for getting tested were followed by accounts of suspicions that their boyfriends had infected them.

For example, an African American woman tested positive for HIV when she was 17 years old. She went to Planned Parenthood for a pregnancy test and agreed to take an HIV test as well when the provider suggested it, “I went there originally for a pregnancy test and um...they asked to take, you know, they offered me to take an HIV test, and I was like ‘OK’ just real like nonchalant, like not really caring.” Her pregnancy test was negative, but her HIV test was positive. She was surprised by the results but attributed her infection to her first and only boyfriend who she had dated in high school for 8 months. She reported in her interview that at one time, he had held her against her will for several days and had made her engage in sexual activities that she had not wanted to do (she did not elaborate about what happened). After she learned her seropositive status, she said that she believed her former boyfriend knew he was infected when he had sex with her.

In a few cases, suspicion was aroused when a young woman's partner refused to get tested with her. These young women implied that HIV testing could also be a “test” of the relationship. Their narratives indicated that in the context of a relationship, getting tested together is a sign of commitment and honesty, but when a partner refused to get tested, it raised concerns about infidelity and lies. A 22-year-old Latina heterosexual woman who tested positive for HIV at age 16 believed her former boyfriend, the father of her child, had infected her. She began to suspect him of lying to her about his HIV status when he would not get tested with her. This suspicion led her to get an HIV test. When she got home from the clinic, he was not there, but she noticed a paper indicating his positive test results in his pocket:

Because I was like—I felt kind of weird because like I was like let’s both go and get tested but he was backing up like he didn’t want to get tested. So I left it alone...so I got tested, then when I come back home I had seen the paper in his pocket and that’s from there that’s how I know what was going on, why he didn’t want to get tested, because he had already got tested and he was positive.

Similarly, a 20-year-old West Indian heterosexual woman and her boyfriend initially got tested regularly together, but when he stopped agreeing to the tests she began to suspect that he might be lying to her about his HIV status:

Before...when we first got together. Both of us used to show each other results. Both of us went to the same clinic, got tested, and gave each other the results. I had his results from then. When he left the program that we both was in...I used to, like every 6 months, I used to like go, “Come on get tested with me.” And he used to refuse. So I was like, “Hmmm...since when you refuse to go and get tested?” I’m like, “That’s something that any female asks you to do; in a heartbeat you’re supposed to jump on it.”

This young woman continued to get tested based on her suspicions about her boyfriend and apparently mistakenly believed that the tests themselves were protective against HIV infection. “That’s one thing about me. I get tested every 6 months due to the fact that I don’t know what you do and I’m protecting myself. To cover myself I get tested...” However, she continued to have unprotected sex and stayed in the relationship until she tested positive.

Some of the young women suspected their boyfriends were infected with HIV because they heard rumors. An African American woman who was diagnosed with HIV at age 19 described how she mistakenly assumed that her partner would not be infected because he had recently gotten out of jail:

Like I guess like...soon as he came out of jail we started talking like a week later... a week or 2 later we started having unprotected sex. I don’t know why I did it but I’m

thinking that, he come from jail like he clean and stuff but then I was young and I didn't know like what to expect and stuff like that.

Motivated by these rumors that her boyfriend had HIV, she got tested, and her negative test results led her to the conclusion that the rumors were false:

Somebody had came up to me and told me that he might have AIDS. So I asked him and he was like, "No," like it was a whole big argument. We were about to fight and all that with the other girl that told me and all that stuff. So I'm thinking that, naw it's not serious, but then I kept getting... I went to get myself checked around August and November and um yeah in November and it came up negative...

Although she continued to have her doubts about her boyfriend's honesty, she did not get tested again until she applied for the Job Corps program that mandates an HIV test. After she tested positive, the young woman reflected back on her boyfriend's response to the accusation from the other girl. She realized that his refusal to get tested with her then should have been a cause for suspicion:

'Cause I'm thinking back at it now like he was really serious like... 'cause if it wasn't true he wouldn't... he wanted to kill the girl and all that stuff and he wanted to really get in my head that he didn't have it and that's something I didn't look at. He really didn't want that out. Like after that situation there was no more talk about... after that. No tests. No getting tested just to make sure, nothing. And I brung it up to him a couple of times like, "You're sure?" "Oh I don't want to talk about it. I don't want to talk about it." And I didn't talk about it after that.

Several of the transgender women participants were similar to the other women in the study in that their testing narratives focused on their boyfriends as the source of their risk for HIV infection and their relationships as the context for making HIV testing decisions. A 22-year-old Latina transgender woman participant, who was diagnosed with HIV at age 16, also heard rumors that her much older male partner was "sick." However, she did not believe the rumors because he denied them, even when she assured him she would stay with him if they were true:

He like, "Nah they just talking shit," I'm like, "All right. You're sure if you're sick you know you can tell me. I'll still be with you. I'll just protect myself more. You know, let me know..." And I was young then, so ...

She continued to believe her boyfriend, even when his friends told her he was sick, because she had previously tested negative for HIV. She reported getting tested every 3 to 6 months during their 2-year relationship while she was in high school:

And like the last year one of his ex came to me and told me that he was sick and I was gonna get sick. But I didn't believe it because I was taking HIV tests and they was all coming back negative.

However, as she continued to hear the rumors and overheard her boyfriend secretly taking medicine in another room, her worry that her boyfriend might actually have HIV and might have infected her began to grow. Nevertheless, until she tested positive at a school-based clinic, she clung to the notion that her boyfriend was telling her the truth about his HIV status. "Because once I started getting suspicious, that's when I went for the test, which I thought was gonna come back negative because he kept on telling me he wasn't sick..." Like other female and transgender women participants, this respondent viewed her negative test results within the context of a relationship as evidence of her partner's loyalty and her protection from HIV infection.

Males: Fear Delays Testing

The young men, most of whom were gay or bisexual, provided different reasons for HIV testing than the young women. Many of the males were experiencing physical symptoms, such as nausea, fever, vomiting and body aches, when they found out they were infected (See Table 2). Some of them had been sick for several months and some intermittently for several years before learning their HIV status. About half of them sooner or later recognized their symptoms as related to HIV and sought HIV tests, while the others sought health care for symptoms and a provider recommended testing.

Fear of a positive result accounted, in part, for why so many of the young gay and bisexual men delayed getting tested for HIV until they became symptomatic. Further, while the young women often grappled with partner loyalty issues and blamed their partners for putting them at risk, some of the young men engaged in self-blame and agonized over their feelings of guilt regarding the risky sexual behavior that led to their becoming infected. One 22-year-old gay Latino man described waiting months before seeking an HIV test. He articulated his fear of testing:

And I was kind of nervous but I already knew all the things that I have done, that I had did, so...I already knew. That was the fucked up part. That I already knew... before the results were given to me. I knew for months and that's why I didn't get tested because I was so scared to hear about it on the paper or to read it, you know what I mean? ... I knew what I did with people. I knew the people I was doing it with...It kind of feels like you killed yourself, if that's what the feeling is like...And that's why sometimes like that's why I don't feel sorry for myself. Or that's why sometimes I don't cry. 'Cause it's like... "How could you sit there and cry? You did this."

An African American MSM got tested for HIV after going through a time with a number of partners and then experiencing various illnesses and symptoms for a couple of years. He reflected on his decision to get tested when he was 21 years old and how he was only partially prepared to learn his test results:

Respondent: I ended up going through a very promiscuous phase... It was kind of like being more out of the cage, just kind of just doing whatever... And I was noticing certain changes in my body. You know, getting colds and different ailments, and the doctor would be like, "well you just have to let it pass," and this, this, and that. And I kind of knew. But I wasn't ready to actually face that I could be HIV positive. I knew it was gonna be either STD or HIV or something. So I just decided one day just to go down there and just get it over with...

Interviewer: So what did you expect the results to be?

Respondent: Well I mean—you don't want to say that it's gonna be positive. You don't want to say that. You know pretty much it's gonna be but you still have that little inkling of hope that it could possibly be negative, so I went in there with that little pebble-sized thing of faith that it could possibly be negative, but I pretty much knew 85% that it could be a positive result. Um, I was prepared for it a little bit but once the person does finally read the results you're not prepared, as you thought you would be.

After hearing his test results, he did nothing about it for 2 years and refused to accept his HIV diagnosis. "For 2 years I didn't go anywhere. I didn't do anything. I just finished school, continued working, continued doing everything I was doing and that was it."

After 2 years, he was tested again at a Black Gay Pride event, but once again was not ready to face his diagnosis, so he gave the testers a fake name and address and did not pick up his results.

Soon afterwards, he was ready to deal with his status, and sought testing and HIV care at a program for young people. When asked why he delayed confirming and acting on his HIV status, he said: “Um, uncertainty. Uncertainty about the future—I mean I knew some things about HIV and AIDS and everything but most people don’t make it out to be such a positive thing, you know what I mean? So I guess the uncertainty.”

In another case, a 19-year-old African American man went in for an STD check because he had sores on his body. He had not planned to get an HIV test that day and was frightened to learn his status. After 90 minutes of contemplation and conversations with the health educator and the physician, he was finally persuaded to get tested. When asked why he was resistant to taking an HIV test, he answered:

Respondent: Because I was scared. I was like—I didn’t come here to do that. I came here to do the other stuff and—then I started thinking like oh God what if I have...freak me out, so you know it was like we don’t know and you’ll never know if you don’t get tested and you might as well do it now than later so like okay I’ll do it. So I did.

Interviewer: How long was this discussion going on with them talking to you about getting an HIV test?

Respondent: Probably took like a good hour and a half.

Interviewer: ...And who specifically were you speaking with?

Respondent: Both the health educator and the doctor himself...I was back and forth, actually, back and forth.

Interviewer: Meaning that you would speak to one—

Respondent: And then she sent me to the other, and he would notice that I didn’t want to do it, and he ask me why I didn’t want to do it, and...I went back to her and she said, “oh you changed your mind, what made you change your mind?” And then she talked to me about it and stuff like that...

The providers succeeded in persuading him to get tested, and when they later told him about his diagnosis, he said, “It was just like something just shut down, like my whole life shut down...I got cold and I just thought the world was ending.”

In some instances, health care providers failed to recommend HIV tests even when the young men presented with symptoms. For example, a 19-year-old gay African American man went to the same public hospital three times with high fever and thrush, yet his providers did not recommend he get an HIV test:

Interviewer: *And then you had this really high fever and red spots on your tongue.*

Respondent: Yeah

Interviewer: And did they test you then?

Respondent: They took blood, I don’t know what they tested for. Like I went to (a public hospital) and (its) like the quack hospital and they were supposed to call me back and they never called me back...Then I had like a throat infection, like white stuff in the back of my throat. I went to (a public hospital) again because that’s the closest hospital...and they took a sample and stuff...They were supposed to call me back again, never did. And I went in there, they told me they wasn’t sure what I had, it could’ve been mono, or tonsillitis, they said...And

I got it again like a month later, I went back there—I don't know why I keep going there—and they still didn't know what it was. They didn't tell me nothing, they gave me penicillin again and sent me on my way.

Eventually, his mother looked up his symptoms on the Internet and learned that they might be related to HIV infection, and he sought HIV testing at another location.

In another case, a 21-year-old gay Cuban man described how he had been to the emergency room several times over several months with severe flu-like symptoms. During this time no health care provider suggested he get an HIV test. Finally, he suspected he might be infected and sought a test:

Yeah I took the test because I was sick and nothing worked and, um, I'd been going to the emergency room like I went to the emergency room like four or five times and they kept like injecting me with crap and not really telling me what's going on with me, just kept telling me that I had the flu. But the flu lasted for almost like 4 fucking months. I'm like this must be like an STD or something or like HIV. So I just prepare myself mentally, just go there and take the test.

A bisexual African American man was diagnosed at age 16 after going to the hospital with nausea, vomiting, and flu-like symptoms. He reported that this visit was the first time a doctor had ever asked him about his sexual history and recommended an HIV test.

Respondent: ...when she asked that question I said to myself, I might be HIV positive. I said why would she ask me that question.

Interviewer: What did she ask you?

Respondent: She said am I having sex with anybody. I said no doctor has ever asked me that question before. So that got me started thinking. And that's when she referred me to the (adolescent HIV clinic). She referred me to the (adolescent HIV clinic), that just made me think—okay I have AIDS or HIV.

After the young man sought a test at the adolescent HIV clinic, he said that he had expected his test result to be positive, but he still expressed shock upon hearing that he had HIV. He also blamed himself for his HIV infection. He said, "I was in shock. At my age I didn't think that would ever happen to me. So I really can't say anything about that. What a stupid mistake... The honest truth, I don't know who gave it to me."

Discussion

The principal finding in this study was that HIV testing decisions among this sample of HIV-infected high-risk youth were influenced by gender and sexual orientation. A number of the young heterosexual women, as well as some of the transgender women, were tested within the context of a relationship with a male partner who they suspected of cheating on them or lying to them about their HIV status. These young women sometimes made decisions about HIV testing by attempting to evaluate their partners' risk behaviors, rather than viewing their own behaviors as risky. Some sought HIV tests after hearing rumors that their partners were infected or when they suspected that their partners were being unfaithful. Others became suspicious and sought tests when their partners refused to get tested with them. When the young women tested negative, they interpreted the test results as a sign of their partner's loyalty and of their seronegative status. In these ways, the HIV test symbolized a "test" of the relationship.

Other studies have shown that adolescent females often were tested for HIV during gynecological or perinatal health care visits (Arrington-Sanders & Ellen, 2008; Grant et al.,

2006). Our study is unique in adding depth to the understanding of the circumstances under which high-risk heterosexual female adolescents made decisions about HIV testing. The study findings indicated that young heterosexual females may be operating under incorrect assumptions about their relationships and focusing on their boyfriends' risk behaviors rather than their own. Moreover, they seemed motivated to give their boyfriends the benefit of the doubt in an effort to convince themselves that they were in a caring and trusting relationship. This may have led them to underestimate their own risks for HIV infection and to delay testing.

In addition, some of the young women and transgender women who had previously tested negative for HIV assumed that their negative test results provided evidence that their boyfriends were not infected with HIV, that their unprotected sexual behavior was safe, and, therefore, that they were not at risk for infection. However, many of the young females in this study found out that their boyfriends were infected and did not tell them. This finding has implications for test counselors who may need to address relationship issues when counseling young women about HIV risk factors. Counselors need to directly debunk myths that young people may be operating under, such as the assumption that negative test results mean that their sexual practices are sufficiently safe and preclude risk of future HIV infection. Furthermore, when a young woman who claims to be in a monogamous relationship undergoes repeated HIV tests, counselors ought to address the issues of fidelity and disclosure/concealing an HIV diagnosis. Misconceptions that HIV-infected persons appear thin, weak, and sick are particularly common among adolescents and young adults and should also be dispelled.

Among the males, many reported experiencing symptoms before going for testing. Some did not recognize their symptoms as related to HIV and health care providers recommended testing. Others suspected their symptoms were related to HIV and eventually sought HIV tests. Some experienced symptoms for a long time before seeking health care or HIV tests. One explanation for the reluctance of some of the young gay and bisexual men to get tested sooner was the evidence of difficult internal struggles prior to deciding to undergo testing. In hindsight, some of the young men described how their fear of positive test results and self-blame for putting themselves at risk led to delays in testing or HIV care. Other researchers also have found that fear of positive test results can be a barrier to HIV testing among high-risk youth (Peralta et al., 2007) and young gay men in particular (Moyer et al., 2007). In addition, some young men who sought health care for symptoms of illness were not offered HIV tests by health care providers, even after multiple visits with HIV-related symptoms. The accounts of how psychologically challenging it was for many male participants to accept and, moreover, to reveal their same sex behaviors to family members and heterosexual friends suggest that some of them probably did not reveal their homosexuality to their medical providers. In addition, many of these men sought care for their HIV-related symptoms in emergency rooms and did not have the benefit of having continuity of medical care prior to the diagnosis. These factors also could have contributed to not being offered an HIV test sooner, despite symptoms.

In our study, only one adolescent male was tested during a routine medical check-up. Other studies have found that opportunities for testing among sexually active youth, particularly adolescent males, were often missed because they did not seek routine care as often as adolescent females, but also because topics such as STDs, HIV, and pregnancy prevention were seldom discussed with the males (Burstein, Lowry, Klein, & Santelli, 2003; Marcell, Klein, Fischer, Allan, & Kokotailo, 2002). Providers and testing counselors need to take advantage of all opportunities to talk to young men about sexual behavior, STDs, and HIV, as young men infrequently seek routine health care. Moreover, training providers on ways to elicit accurate information on young men's sexual behavior and orientation is important, given the psychosocial and cultural obstacles young people confront in disclosing same sex behavior and embracing a non-heterosexual identity. A more open communication between providers and young men about sexuality will certainly increase the offering and uptake of HIV tests among

this population. Indeed, some recent research has substantiated the significance of the provider-patient communication in HIV testing. A study of high-risk Baltimore youth ages 11–21 who were seeking STD care found that the degree of provider training affected HIV testing rates: Youth treated by adolescent fellows and subspecialty nurses were significantly more likely to have been tested for HIV than youth treated by resident physicians, who may have tended to view HIV testing as outside the scope of routine care (Arrington-Sanders, Ellen, & Trent, 2008).

Several of the adolescents and young adults in our sample indicated that providers' attitudes made a difference in the decision to get tested. As noted, one young man who was afraid of testing positive for HIV spent considerable time in the clinic and spoke to both a health educator and a doctor several times before he finally decided to get tested. Another stated that prior to his HIV diagnosis, a doctor had never asked him whether he was sexually active. Additionally, some young women seeking gynecological care were receptive to HIV tests when their providers recommended them, even when they had not planned to have one. These adolescents most likely harbored suspicions about the risk of infection that caused them to accept testing when a clinician offered it. Therefore, integrating discussions about sexuality, STDs, and HIV risk factors into routine adolescent health care or when adolescents seek care for other reasons, may result in more frequent testing and earlier detection of HIV among high-risk youth.

Implications

The findings of this study reinforce the importance of health care providers as key players influencing adolescent testing, and an awareness of gender and sexual orientation-related concerns may improve HIV testing rates among high-risk youth. For adolescent females, testing through routine health care is most common, and HIV screening should continue to be integrated into family planning, STD services, routine gynecological care, perinatal care, and general check-ups.

Providers should also take into account the relationship context for testing adolescents, especially among young women and transgender women, urge them to focus on their own risk behavior when making HIV testing decisions, and address potentially false assumptions about their partners' behaviors. Stronger attempts also should be made to encourage adolescent males to seek routine health care more frequently and to urge providers to discuss HIV risks and offer testing. The fear of testing positive among young gay and bisexual men should be considered by test counselors, and efforts to encourage early detection for an improved prognosis should be emphasized. Offering HIV testing in emergency rooms to all young patients who present with HIV-related symptoms instead of attempting to assess whether a patient belongs to an HIV high-risk group will also contribute to earlier HIV detection and treatment, especially for young gay and bisexual men. Research on the challenges faced by test counselors working with high-risk adolescents in various health care settings would be a departure point for future investigation.

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Table 1
 Selected Demographic Characteristics of a Cohort of New York City Adolescents with Sexually-Acquired HIV Infection

Transgender (Male-to-Female)	Females TOTAL (n = 26)			Males (n = 28)				
	M	SD	n	M	SD	n		
(n = 5)	(N = 59)							
Age in Years	21.0	1.91	20.8	2.34	19.8	2.86	20.8	2.19
Age at HIV Diagnosis	17.6	3.43	18.5	3.67	18.0	2.94	18.1	3.48
	n	%	n	%	n	%	n	%
Race/Ethnicity								
African American	17	65.4	17	60.7	3	60.0	37	62.7
Latino/a	6	23.1	10	35.7	2	40.0	18	30.5
Other	3	11.5	1	3.6	0	0.0	4	6.8
Sexual Orientation								
Gay/Lesbian	0	0.0	18	64.3	2	40.0	20	33.9
Heterosexual	19	73.1	2	7.1	1	20.0	22	37.3
Bisexual	5	19.2	5	17.9	1	20.0	11	18.6
Not sure/Undecided	0	0.0	1	3.6	0	0.0	1	1.7
Data Missing	2	7.7	2	7.1	1	20.0	5	8.5
Education								
< High School	1	3.8	1	3.6	0	0.0	2	3.4
Some High School	9	34.6	14	50.0	4	80.0	27	45.8
High School Grad	8	30.8	4	14.3	0	0.0	12	20.3
Acquired GED	2	7.7	2	7.1	0	0.0	4	6.8

Transgender (Male-to-Female)	Females TOTAL (n = 26)			Males (n = 28)				
	M	SD	M	SD	M	SD		
(n = 5)	(N = 59)							
Some college/ Associate's degree	5	19.2	7	25.0	1	20.0	13	22.0
College graduate	1	3.8	0	0.0	0	0.0	1	1.7
Employment								
Part-Time	2	7.7	6	21.4	1	20.0	9	15.3
Full-Time	3	11.5	4	14.3	1	20.0	8	13.6
ART Prescribed	16	61.5	13	46	3	60.0	32	54.2

Note. ART – antiretroviral therapy; GED = graduate equivalency exam

Table 2

Reasons for HIV Testing Among Adolescents at Positive Test (N = 59)

Gender	Routine Health Care ^d	Symptoms ^b	Suspicion of HIV ^c	Other person suggested test ^d	Other reasons ^e
Female (n = 26)	11	2	8	3	2
Male (n = 28)	1	17	4	4	2
Transgender Female (n = 5)	0	0	4	1	0
Total (N = 59)	12	19	16	8	4

^aGeneral, perinatal, STD, or gynecological check, but no symptoms

^bExperienced symptoms of illness

^cSuspected HIV infection, but no symptoms

^dPartner or family member

^eJob Corps, blood donation, or in response to testing incentives