

Syphilis Experiences and Risk Perceptions Among Repeatedly Infected Men Who Have Sex with Men

CONTEXT: In urban areas of the United States, syphilis is a major public health issue for men who have sex with men, despite widespread efforts to curtail a growing epidemic; repeated infections are not uncommon in this population. The ways that men who have sex with men experience and conceptualize syphilis, and how their attitudes and beliefs impact their risk for infection, are poorly understood.

METHODS: In-depth interviews were conducted in 2010–2011 with 19 Los Angeles County men aged 21–54 who reported having male sex partners and had had two or more early syphilis infections within the previous five years. Interview transcripts were analyzed inductively to uncover themes.

RESULTS: Participants had considerable knowledge about syphilis symptoms, transmission and consequences, and most felt that syphilis was a highly stigmatized disease. They had had 2–5 infections in the past five years, and the majority believed they were at risk for another infection because of their sexual risk behaviors. Many had a sense of fatalism about being infected again, and some expressed that this possibility was an acceptable part of being sexually active. Concern about syphilis often decreased as men experienced more infections. Most participants reported short-term sexual behavior changes after a syphilis diagnosis to prevent transmission; however, few were willing to make long-term behavior changes.

CONCLUSIONS: Additional qualitative studies of men who have sex with men should be conducted to better understand the continuing syphilis epidemic and to help identify the most promising intervention strategies.
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U.S. syphilis rates have more than doubled since 2000, largely because of increases in infections among men who have sex with men.¹ While approximately 7% of adult men in the United States have ever engaged in sex with men,² 75% of all primary and secondary syphilis cases in 2012 were among men who have sex with men.³ Untreated syphilis can cause permanent damage to multiple organ systems and even death.³ Of concern, the risk of HIV transmission and acquisition is 2–5 times as high among individuals infected with syphilis as among others.^{3,4}

Among men who have sex with men, syphilis is particularly common in those coinfecting with HIV and those engaging in sexual behaviors that are associated with a high risk for STDs.^{5–7} And among men who have sex with men, approximately 6–12% of those who have an initial syphilis infection are reinfected within two years.^{8–10} Importantly, those who have repeated syphilis infections are potential core transmitters, because repeated infection suggests continued practice of risky sexual behaviors.^{9,11}

Currently, the ways that men who have sex with men experience and conceptualize syphilis, and how their attitudes and beliefs impact their risk for infection, are poorly understood. Qualitative studies can offer insights into why such men become infected with syphilis at such alarming rates and are key to developing culturally competent intervention strategies.^{12,13} However, we could find only one

published qualitative study investigating syphilis experiences, attitudes or risk perceptions from the perspective of men who have sex with men. That study, conducted in Brighton, England, by Lambert and colleagues, found that men who have sex with men distanced themselves from responsibility for their syphilis infection through the belief that syphilis is a “rare” and “dirty” disease that would normally only infect others, and by attributing their infection to a onetime risky event.¹⁴ Study participants described a strong stigma surrounding syphilis, which was often felt to be worse than HIV stigma. The authors suggest that “the apparent failure of syphilis control measures so far may be due to our limited understanding of [men who have sex with men’s] views and experience of [sexually transmitted infections] other than HIV.”¹⁴ (p. 155)

In 2010, Los Angeles County reported the highest number of primary and secondary syphilis cases of any U.S. county,¹⁵ and 78% of cases were among men who have sex with men.¹⁶ An investigation of syphilis cases from 2002 through 2008 found that among men who have sex with men in the county, 6% of those with syphilis had a repeated infection within two years.⁹ Since 2000, rates of syphilis have risen sharply despite multiple efforts undertaken by the county department of public health to address the growing epidemic among men who have sex with men. These efforts have included increased community-based

screening, enhanced case management and partner notification,¹⁷ and several wide-scale social marketing campaigns^{18,19} designed to encourage men who have sex with men to undergo testing at least every 3–6 months if they have multiple or anonymous partners.

We conducted a qualitative study of repeatedly infected men who have sex with men to gain a better understanding of their knowledge, attitudes and motivations with regard to syphilis, and how these impact their risk behaviors. We chose to study repeatedly infected men because they likely remain at high risk for subsequent infections. Furthermore, research suggests that efforts to reduce syphilis rates at the community level among men who have sex with men should focus on those at highest risk.²⁰

METHODS

Study Setting and Participants

Potential participants for the present study were identified between 2010 and 2011 either retrospectively from the Los Angeles County Department of Public Health's syphilis morbidity data or during regular case management for new syphilis cases among men who have sex with men. Participants were eligible if they were male, were aged 18 or older, reported having male sex partners, and had received a diagnosis of early syphilis (primary, secondary or early latent syphilis) at least two times within the previous five years. In addition, a participant's most recent early syphilis infection had to have been within one year of recruitment into the study. Public health investigators, who are the primary promoters of syphilis intervention strategies in Los Angeles County, contacted individuals either by telephone or in person and asked if they would participate in the study.

Data Collection and Analysis

Fifty-eight percent of individuals who were approached agreed to participate, and 19 interviews were conducted from October 2010 through June 2011. The two trained, gay male interviewers disclosed their own sexual orientation to participants prior to conducting the in-depth interviews. Participants were asked to give informed consent before the interview began. Interviews took an average of 56 minutes to complete and were conducted at locations of participants' choice (a private office at the Los Angeles Gay and Lesbian Center or health department, a public STD clinic, a drug rehabilitation center or the participant's home). Investigators collaborated to develop a semistructured, open-ended interview guide, which was designed to explore syphilis-related knowledge, experiences, attitudes and behaviors. All interviews were audio-recorded, and participants received \$100 for their time. Participants' race and ethnicity, age, sex, number of syphilis infections and HIV status were extracted electronically from the county health department's STD case management system. The institutional review board at the Los Angeles County Department of Public Health approved this study.

For this analysis, we examined participants' general attitudes toward syphilis, personal concern about syphilis, syphilis risk perceptions and self-reported sexual behaviors; life circumstances surrounding participants' most recent syphilis infection; and any steps participants reported having taken to avoid another infection for themselves or their sex partners. We also explored data on their understanding of symptoms, transmission and consequences of untreated infection; the frequency with which they underwent testing; and their general health behaviors.

We applied a grounded theory approach to our analysis and used both open and axial coding to identify themes.²¹ As interviews were conducted, they were transcribed and compared with the audio recordings for accuracy. A codebook was developed on the basis of the interview guide and themes found in reviewing transcripts. The codebook was refined as additional interviews were completed and reviewed. As transcripts were completed, two investigators (the first and second authors) coded them to identify major themes and subthemes, discussed any coding ambiguities and refined codes until any discrepancies were resolved. Once 19 interviews had been completed, we determined that data saturation had been reached, as no new themes or subthemes continued to emerge.

RESULTS

Sample Characteristics

Ten participants were white, six were Latino and three were black; their ages ranged from 21 to 54 years. Most (13) were HIV-positive. The number of early syphilis infections within the five-year period prior to the interview ranged from two to five. There were no meaningful differences between those who agreed to participate in the study and those who refused with respect to mean age (38 and 40, respectively), proportion who were HIV-positive (68% and 79%) or mean number of early syphilis episodes (3.5 and 3.6). The most pronounced difference was in race and ethnicity; among men who refused to participate, 36% were white, 43% Latino, 14% black and 7% Asian.

Most participants discussed a commitment to staying healthy, reporting that they engaged in frequent exercise, maintained a healthy diet and made routine doctor visits; HIV-positive participants particularly noted going for regular HIV care. All but one participant got tested for syphilis at least every 3–6 months.

In general, participants had a high level of knowledge about syphilis. Nearly all said that syphilis is transmitted through both anal sex and oral sex, and many mentioned skin-to-skin contact, a term that public health practitioners often use to describe its mode of transmission. Most participants were able to describe common syphilis symptoms, such as a sore or rash, and most knew that it is possible to have syphilis and be unaware of the infection. Just a few men believed that a lack of knowledge about syphilis transmission impeded their ability to protect themselves from getting infected again. Furthermore, nearly all felt that syphilis is a dangerous disease and mentioned

possible negative health consequences of untreated infection, including brain or other organ damage, vision loss and death. Several participants believed that syphilis was not particularly dangerous as long as it was treated within a few months.

Syphilis Attitudes and Stigma

Participants described a strong stigma associated with syphilis in the local gay community. When asked what comes to mind when they think about syphilis, several said that it was “dirty,” and others said it was an “ugly,” “nasty” or “gross” disease. A 33-year-old Latino man, who had been infected four times, said, “Um, it’s nasty. It’s disease. It’s no good. Unhealthy, can kill you, brain damage...horrible things.” Some men described how this stigma prevented them from talking about syphilis. A 28-year-old white man explained, “I’ve had syphilis three times, and I have not discussed it with anyone. I—I can’t....I’d be ashamed.” Several other men said that syphilis was rarely talked about by their peers or sex partners. While most HIV-positive participants reported being comfortable disclosing their HIV status to partners, two said that because of syphilis stigma, it would be more difficult to tell partners they had syphilis than that they had HIV. A few participants thought that syphilis was more heavily stigmatized than HIV among gay men. A white man, aged 44, who had had three infections, put it this way: “It’s, uh, a pretty heavy stigma....I think it probably has more of a stigma these days than...being [HIV-positive] does, quite honestly.”

Beliefs About Acquisition

Participants were asked to describe what had been going on in their life during the time they were most recently infected with syphilis. While most said that nothing had been out of the ordinary, nearly half said that they had been experiencing or doing something different, such as partying too much, taking drugs or drinking excessively, dealing with mental health issues or experiencing temporary homelessness. For example, a 43-year-old white man, who had had three infections, attributed his most recent syphilis infection to a onetime “relapse” into using methamphetamines. Another participant—a Latino aged 21, who had had three infections—said he had been “partying hard, being careless, dumb [and] going out, drinking.” Nine participants had been unemployed at the time of their last infection, and most of these men said they had had more sex partners than usual when not working because of excessive free time and boredom. A 36-year-old Latino, who had been infected three times, reported having had one or two sex partners each day while he was unemployed. He explained, “Last year, I wasn’t working, so I had nothing to do....[Having sex was] all I was doing, my entertainment.”

Concerns and Risk Perceptions

More than half of the men said they were worried about getting syphilis again. Some attributed their concern to the potentially serious health effects of syphilis. As a 48-year-

old black man, who had had three infections, said, “No one wants [HIV], but you can live with it....But syphilis, you don’t even know you have it, and...it can eat your brain up.”

In general, concern was greatest among HIV-negative participants, all but one of whom reported being worried about getting another syphilis infection. One of these participants (a Latino, aged 28, who had had three infections) said, “It’s something major....It can cause your own death. It can blind you.” Even among HIV-negative participants, however, there was some ambivalence. A 28-year-old HIV-negative white man, who had had syphilis three times, stated, “Syphilis is awful, but you know, because I know that there is a cure for it, I’m not as scared or concerned. Well, I’m still concerned, but not as much.” Reflecting the notion that syphilis is treatable, a 21-year-old HIV-negative Latino, who had had three syphilis infections, said that when syphilis comes to mind, he thinks, “At least it’s not HIV.”

Similarly, among HIV-positive participants who were not concerned about getting syphilis again, most said this was because syphilis is treatable. A 33-year-old Latino, who had had three infections, put it simply: “I don’t think that [syphilis is]...that bad.” He went on to say, “They have a shot, so it’s okay.” Some participants were not worried about syphilis because they already had HIV. As one participant—a 36-year-old white man who had had three infections—stated, “Nothing is worse than HIV.”

All but four participants considered themselves to be at risk for another syphilis infection, primarily because of their sexual behaviors. Most participants discussed having had numerous recent sexual partners, anonymous partners and partners they had met online, and using condoms infrequently or inconsistently. A white man, aged 37, who had had four infections, echoed many others when he said, “I know my behaviors....I don’t like condoms.” While about half of the men reported some level of past substance use with sex, few associated their current syphilis risk with drug use, and just four said that their current behavior included combining drugs and sex. Finally, a 48-year-old white man, who had had four infections, believed his risk was due to his being bipolar. He stated, “When I’m manic, then I’m like very sexually, you know, ravenous. And, um, you know, that probably also leads to, you know—you know, my behaviors.”

A few men attributed their risk for a subsequent syphilis infection to their partners. For instance, a white man, aged 51, who had been infected five times, said, “I think everybody is [at risk] who’s gonna have sex, ‘cause you can’t trust your partners.” Another participant—a 21-year-old Latino, who had had three infections—said, “It still worries me that I’m attracting the wrong guys,” whom he defined as men who might take advantage of his youth and inexperience. A third participant (a black man, aged 48, who had had three infections) felt he was not currently at risk because he “wasn’t messing with those type of people.” But he added, “Then again, who are those type of people? [They’re] just

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like me. I mean—promiscuous, you know, just out there randomly [seeking] sex.”

While the majority of participants were worried about another syphilis infection, many explicitly stated that their concern was not sufficient to result in a reduction of risk behaviors. A 44-year-old white man, who had had three infections, said he was afraid of getting syphilis again, but “not enough to keep my pants on....I’m not going to, um, you know, sit and, you know, hide underneath a rock... for something like that. At least it’s fixable.” He went on to say, “If you’re going to play in the pool, you’re bound to get wet.” Several other men seemed to consider the possibility of syphilis infection an acceptable risk of being a sexually active gay man. A 55-year-old white man, who had been infected five times, said, “While I am concerned about STDS, um, I guess just not enough...to use condoms consistently. So I guess, you know, that’s the issue for these guys as well. I mean there’s this, uh, unspoken acceptance that this is what we’re doing, we’re having unprotected sex, and there’s the possibility.” While all of the HIV-negative participants expressed a strong concern about avoiding HIV infection, only one—a 37-year-old Latino, who had had four syphilis infections—made the connection that getting syphilis likely meant he had put himself at risk for HIV as well. Despite this recognition, he discussed using condoms for anal sex with only about half of his average of 60 partners per month and stated that the decision to use a condom depended on “how intense the moment is.”

The few men who described themselves as not at risk for another infection reported this was because they were not currently having sex. However, even these men acknowledged the difficulty of maintaining abstinence or practicing safer sex for extended periods of time. For example, a 54-year-old white man, who had had two infections, said, “Instead of addressing...your real issues, you just fall back into your, you know, your old habits. And then...you tend not to think about it.” A Latino, aged 37, who had had four infections, said his behavior change “only lasts for a brief moment, and it’s usually after—right after I get diagnosed or treated. But then I revert back to my old behaviors. I just hate using condoms. That’s the thing.” Another participant, who was Latino and had been infected five times, said that he “relates sex with drugs” and thought he would not be at risk for syphilis as long as he avoided drugs.

Many participants expressed a sense of fatalism about subsequent syphilis infections. As a 45-year-old white man, who had had four infections, put it, “I seem to be a magnet for it.” Similarly, another man (who was white, was 51 years old and had had five infections) said, “If somebody’s walking across the street and has it, I’ll get it.”

Several men expressed diminished concern with each syphilis infection, often coupled with a sense of fatalism. A 30-year-old white man, who had had four infections, reported, “I’ve been reinfected so many times, I’m just—it’s like I’m waiting for when it’s the next time. So I mean, I am a little bit worried, but not that much.” Another participant (a 44-year-old white man, who had had three

infections) similarly expressed how he had become familiar with the infection: “I guess it’s almost like—like hearing an old friend’s coming to town....I’ve had it so many times, it seems like that. It...doesn’t weird me out like it used to.” As a 21-year-old HIV-negative Latino said, by his third infection, “I kind of grew numb to it already....I had just said, you know, ‘Here we go again.’” One participant (a white man, aged 51, who had had five infections) described a high level of concern when he ended up in the hospital with his second infection. He said, “The second time, when I had to spend 14 days in the hospital and they had to do spinal taps and...make sure that it was all cleared up, and I realized the danger of it if it isn’t taken care of, then it became much more serious.” However, this concern had decreased substantially by his next infection. He explained, “The third time, I was more upset about how I got it and from who I got it than I was actually having it.”

Preventing Transmission

Nearly all participants said they were concerned about not transmitting syphilis to their partners. Indeed, more than half reported not having sex or using condoms temporarily after a syphilis diagnosis to prevent transmission. A 37-year-old white man, who had had four infections, stated, “I never would want to knowingly give someone anything, whether it’s syphilis or a common cold or the flu or HIV or anything.” While some described a concern for their partners’ health, several also mentioned wanting to avoid the embarrassment of infecting someone. However, not all participants waited to have sex until they were non-infectious. One participant (a 30-year-old white man, who had been infected four times) started having sex again right after treatment, even though a nurse had instructed him to wait 7–10 days. Another (a white man aged 36, who had had three infections) said, “I would wait until I had the first shot, and then I would wait 24 hours after that, and then I would continue my escapades.”

DISCUSSION

These qualitative interviews offered important insights into the experiences with and beliefs about syphilis among repeatedly infected men who have sex with men, including how these men conceptualize their risk for subsequent infections. Consistent with Lambert and colleagues’ findings,¹⁴ participants in our study described a strong stigma associated with syphilis in the gay community, and some believed that this stigma was even greater than the stigma surrounding HIV. The men in our study, as in the earlier study, expressed that having HIV was in many respects normalized within the gay community, whereas syphilis was considered something that was especially “gross” or “dirty.” In addition, some participants attributed their syphilis risk to their partners or to a specific period of especially high risk behavior. However, our findings contrasted with those of Lambert et al. in important ways. Overall, the men in our study were concerned about becoming infected again, and most recognized that they remained at risk because of their

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own sexual risk behaviors, including having numerous sexual partners and being reluctant to use condoms. These differences likely reflect that our study population comprised men who had experienced syphilis multiple times and were therefore likely to recognize their risk.

Despite a high level of personal concern and knowledge about syphilis and the potential health effects of untreated syphilis, nearly all participants were unwilling to make long-term behavior changes to avoid further infections. One of the strongest themes to emerge from the interviews among both HIV-positive and HIV-negative men was a sense of fatalism about syphilis reinfection, even as most also acknowledged that their sexual behaviors had led to their past infections. The sense of fatalism was often connected to decreased concern as men experienced more syphilis infections. Indeed, many men reported their first diagnosis with syphilis to be the most disturbing, and found that the later infections were merely annoying, frustrating or disappointing. Likely this sense of fatalism, coupled with a diminished concern, contributes to their unwillingness to change their risk behavior to prevent syphilis.

Most participants reported taking steps to maintain their health, including getting exercise and good nutrition, making routine doctor visits and having frequent syphilis tests. This concern for general health may seem incongruous with the unwillingness to take steps to avoid syphilis infection, which most participants believed to be dangerous. However, this is consistent with research showing that men who have sex with men are unlikely to change their sexual behavior to avoid syphilis infection.^{22,23} Some men who have sex with men may feel that infection with STDs other than HIV is an acceptable risk of being a sexually active gay man,²² a belief that several participants expressed quite explicitly, and others did more tacitly. These results suggest that for many of the men we interviewed, the benefits of their current sexual behavior outweigh the risks of another syphilis infection, especially since they are being tested frequently and effective treatment is available.

This study has potential implications for developing successful intervention strategies to prevent syphilis infection among men who have sex with men. Participants' general awareness of the risks of syphilis and unwillingness to change their behavior to avoid possible future infections suggest that interventions aimed at reducing risk behaviors are unlikely to succeed with these men. Alternative approaches may be more acceptable, however; findings from other analyses we have conducted with data from the men in this study²⁴ suggest that interventions aimed at encouraging more frequent testing or the use of pre-exposure prophylactic medication may hold promise. Encouragingly, the men in our study were concerned about preventing transmission to partners and reported taking steps to avoid transmission. Yet, some men acknowledged that they disregarded health providers' instructions about when they could resume sexual activity after being treated for syphilis. Therefore, intervention efforts may have to better emphasize the need to wait to have sex until the

infectious period is fully over or encourage condom use during this period. In addition, since HIV-negative participants expressed a strong desire to avoid HIV infection, programs for men like these could stress that syphilis facilitates HIV transmission.

Limitations

Several limitations to this study should be considered. First, the results may not be generalizable to other populations or settings because we interviewed a relatively small number of men who have sex with men within Los Angeles County. Although this can sometimes be considered a drawback to qualitative research, our goal was to obtain an in-depth understanding of how this very specific group of high-risk men who have sex with men experience and conceptualize syphilis, and how their syphilis-related attitudes and beliefs influence their sexual risk behavior, rather than to demonstrate the frequency or intensity of their attitudes or behaviors. Furthermore, because this is a complex subject and requires participants with a very specific risk profile, a large sample would not necessarily have been beneficial for our purposes. Indeed, we found a high degree of consistency in themes across the 19 interviews, indicating that this relatively small number of participants was sufficient. A further limitation of the study is that we did not collect data on participants' income or education level, which could have added to our understanding of these men. Finally, as the study relied on self-reporting from participants in a face-to-face interview, the responses may have suffered from recall or social desirability bias.

Despite these limitations, this study adds to the extremely limited qualitative research about men who have sex with men and syphilis. We believe that additional qualitative studies are needed to further investigate the syphilis experiences of men who have sex with men, especially high-risk men within this population, and ideally should be conducted in other cities or countries to see whether results are consistent in different locations.

Conclusion

Qualitative studies are key to understanding what motivates men who have sex with men to engage in sexual risk behaviors, as well as behaviors that are protective against STDs. Many of the men in our study viewed the possibility of a syphilis infection as an acceptable risk and were unwilling to change their sexual behavior in the long term. Their concern about getting syphilis generally decreased as they experienced more infections. Further qualitative studies among men in this population who are at high risk for syphilis should be conducted to better understand what continues to drive the epidemic and to help identify the most promising strategies for interventions.

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