

Why the Wait? Delayed HIV Diagnosis among Men Who Have Sex with Men

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ABSTRACT *We sought to identify factors associated with delayed diagnosis of human immunodeficiency virus (HIV; testing HIV-seropositive 6 months or more after HIV seroconversion), by comparing delayed testers to non-delayed testers (persons who were diagnosed within 6 months of HIV seroconversion), in King County, Washington among men who have sex with men (MSM). Participants were recruited from HIV testing sites in the Seattle area. Delayed testing status was determined by the Serologic Testing Algorithm for Recent HIV Seroconversion or a self-reported previous HIV-negative test. Quantitative data on sociodemographic characteristics, health history, and drug-use and sexual behaviors were collected via computer-assisted self-interviews. Qualitative semi-structured interviews regarding testing and risk behaviors were also conducted. Multivariate analysis was used to identify factors associated with delayed diagnosis. Content analysis was used to establish themes in the qualitative data. Out of the 77 HIV-seropositive MSM in this sample, 39 (51%) had evidence of delayed diagnosis. Factors associated with delayed testing included being African-American, homeless, "out" to 50% or less people about male-male sex, and having only one sex partner in the past 6 months. Delayed testers often cited HIV-related sickness as their reason for testing and fear and wanting to be in denial of their HIV status as reasons for not testing. Delayed testers frequently did not identify as part of the MSM community, did not recognize that they were at risk for HIV acquisition, and did not feel a responsibility to themselves or others to disclose their HIV status. This study illustrates the need to further explore circumstances around delayed diagnosis in MSM and develop outreach methods and prevention messages targeted specifically to this potentially highly marginalized population in order to detect HIV infections earlier, provide HIV care, and prevent new infections.*

KEYWORDS MSM, HIV/AIDS, HIV testing, Delayed diagnosis, Delayed testing

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INTRODUCTION

Human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) continues to be a major public health issue in the USA. By the end of 2006, there were an estimated 1.1 million people in the USA living with HIV/AIDS, about 21% of whom did not know they were HIV-seropositive.¹ Of newly diagnosed HIV infections in the USA in 2006, the Centers for Disease Control and Prevention (CDC) estimated that approximately 53% are among men who have sex with men (MSM),² the majority of whom tested at their private doctors office, a public health clinic, or a community health center.³ Studies have shown that people who test HIV-seropositive are more likely to decrease their risky behaviors and increase their use of condoms shortly after testing compared to people who test HIV-seronegative, thus helping to prevent HIV transmission.⁴⁻⁶ Despite the benefits of HIV testing and the availability of MSM-targeted HIV prevention programs and educational campaigns, a recent study of MSM in five major US cities, found that 58% of newly diagnosed HIV-seropositive MSM had not been tested within the previous year.⁷

While there is a growing literature on the factors associated with “late HIV testing” (being diagnosed with AIDS within 1 year of HIV diagnosis) in the USA,⁸⁻¹³ there is limited information specifically addressing “delayed HIV testing”. In 2005, MacKellar et al. defined “delayed HIV testing” as being diagnosed with HIV 1 year or more after HIV infection.¹⁴ Similar to late-testing MSM, MSM who delay testing are in turn delaying access to care necessary to slow their disease progression and are likely to be spreading the virus unknowingly.¹⁵ Given the high prevalence of HIV among MSM² and evidence of increasing numbers of new cases in recent years,¹⁶ it is important to understand the factors associated with delayed testing among MSM to improve early diagnosis, get more HIV-positive MSM into care, and help reduce the spread of HIV among MSM. Using qualitative and quantitative data from the Seattle Area MSM Study (SAMS),¹⁷ we sought to identify sociodemographic, behavioral, and testing history factors that distinguish MSM with delayed HIV diagnosis (delayed testers), defined as being diagnosed with HIV 6 months or more after HIV infection, from MSM with non-delayed HIV diagnosis (non-delayed testers), being diagnosed with HIV within 6 months of HIV infection. Due to the limited number of persons with new HIV diagnoses included in SAMS, we consider this report to be a preliminary look at delayed diagnosis among urban MSM.

METHODS

Study Design, Eligibility, Recruitment, and Data Collection

The SAMS study was a cross-sectional survey of HIV risk factors among newly diagnosed HIV-seropositive and HIV-seronegative MSM. The study collected data from July 2002 to May 2005. SAMS was conducted by the Public Health-Seattle and King County (PHSKC) HIV/AIDS Epidemiology Program under a cooperative agreement with the CDC. Recruitment and study procedures have been detailed elsewhere.¹⁷ Briefly, potential participants were passively referred to the study after testing for HIV at the PHSKC sexually transmitted diseases (STD) and HIV/AIDS Program (HAP) clinics, HAP community outreach testing sites, and two university HIV clinics. MSM were eligible if they were age 18 or older, reported sex with men during the preceding 6 months, and were able to complete the interview in English.

HIV-seropositive MSM were eligible if recruited within 3 months of their first HIV-seropositive test result and HIV-seronegative MSM were eligible if recruited within 1 month of testing. A structured quantitative survey questionnaire was administered to all participants via audio computer-assisted self interviewing (ACASI). All HIV-seropositive and half of the HIV-seronegative participants were asked to participate in the qualitative semi-structured interviews. For this paper, we conducted quantitative and qualitative analyses of data from the HIV-seropositive participants.

All persons testing HIV-seropositive at the PHSKC sites were routinely offered the less sensitive (LS) HIV-1 test, employing the serologic testing algorithm to assess recent HIV seroconversion (STARHS), to estimate recent infection in the testing population. All tests were performed by the PHSKC Laboratory (Vironostika-LS EIA; Bio Merieux, Raleigh, NC, USA). The estimated mean time from seroconversion (defined using a standardized optical density cutoff of 1.0) with the Vironostika-LS is 170 days (95% CI, 145–200 days).¹⁸ Delayed testers were defined as MSM who seroconverted 6 months or more before testing HIV-seropositive, based on a positive HIV-1 test combined with a reactive LS HIV-1 test (according to STARHS) or, in the case of a missing LS HIV-1 test, lack of a self-reported HIV-negative test during the past 6 months. Non-delayed testers were defined as those with infections acquired within the preceding 6 months, based on a positive HIV-1 test combined with a non-reactive LS HIV-1 test (according to STARHS) or self-reported HIV-seronegative test during the past 6 months. Two participants had reactive LS HIV-1 results while having a self-reported HIV-seronegative test in the past 6 months. In these cases, the classification of recency of infection was decided by the study investigators based on information the client provided in the quantitative and qualitative interviews about their testing history and usual frequency of testing. Given these participants' reported frequency of testing and the amount of details, including dates and locations, provided about their last HIV-seronegative test result, these two participants were deemed to be non-delayed testers. Among participants in whom we relied on self-reported last HIV-seronegative test, attempts were made to verify the date of last test by contacting the participant's medical provider or through PHSKC HIV testing records. Through this method, we were able to verify the date of last HIV-seronegative result for three of the non-delayed testers. In addition, six of the non-delayed testers were verified to be recent infections due to their diagnosis with a syndrome of primary infection at an HIV clinic that specialized in diagnosis and treatment of new infections in addition to their self-reported prior HIV-seronegative tests. Overall, 39 participants were defined as delayed testers and 38 were defined as non-delayed testers. This study was approved by the Institutional Review Boards of the University of Washington and the Centers for Disease Control and Prevention.

Quantitative Analysis

We used chi-square and Fisher's exact tests to compare delayed and non-delayed testers with respect to sociodemographic, behavioral, and testing history variables. Sociodemographic variables included: recruitment site (HAP clinic, HAP outreach, STD clinic, and other sites), age (18-29, 30-39, 40+), race/ethnicity (white, African-American, Hispanic, other), education (high school or less, more than high school), sexual identity (gay, bisexual), extent they had revealed their sexual practices ("out" to >50% of the people they knew about having male-male sex, "out" to ≤50% of the people they knew about having male-male sex), homeless (yes/no), and health insurance (yes/no). Homelessness was defined as self-reporting homeless or having a

non-permanent residence. Sexual and drug use behaviors included: recent (past 6 months) number of sex partners (1, 2+), anal sex partners (0-1, 2+), and unprotected anal intercourse (UAI) with sex partners (0-1, 2+), and recent (past 6 months) substance use (marijuana, poppers, methamphetamine, cocaine/crack, Viagra, ecstasy [methylenedioxy-methamphetamine or MDMA], ketamine, gamma hydroxyl butyrate, heroin, alcohol binging greater than or equal to four times/month, injection drug use), and recent (past 6 months) use of the same substances in conjunction with UAI. We evaluated HIV testing history in terms of number of previous HIV-seronegative tests during the past 2 years (never tested, no tests in the past 2 years, 1-2, 3+) and reasons for testing.

Sociodemographic and behavioral variables that were statistically significant in these bivariate analyses ($p < 0.05$) were entered into a multivariate logistic regression model to determine which were independently associated with delayed testing. To conserve statistical power for the purposes of this model, race/ethnicity and age were dichotomized: race/ethnicity (African-American, other), age (<40 years old, ≥ 40 years old). As over 50% of the participants with delayed diagnosis were over the age of 40, we felt that this was a natural cutoff. The final model was established using backward elimination to include only those variables that were independently associated ($p < 0.05$) with delayed testing. All analyses were conducted using SAS 9.1 (SAS Institute Inc., Cary, NC, USA).

Qualitative Analysis

We included four questions from the semi-structured interview in our primary qualitative analysis: (1) "What made you decide to get tested this time?", (2) "Were there any changes in your risks for HIV since the last time you tested?", (3) "Did you discuss your results with anyone?", and (4) "Has there ever been a time you thought you needed to get tested but waited?" We additionally analyzed the question "Do you have any ideas of how to prevent HIV transmission among men in King County?" specifically in the delayed testers to inform prevention messages and outreach methods that could be directed toward this population. All participants were asked these questions with additional specific probes to further engage the participant as necessary. For example, for the question "Has there even been a time you thought you needed to get tested but waited?" the probes included: (1) "What kept you from getting tested earlier?", (2) "In general, what has helped you come in for testing?", (3) "In general, what has made it difficult for you to come in and test?", and (4) "What helped you get to the point of testing this time?"

All interviews were audio recorded with concurrent supplementary written notes taken by the interviewer. Within a week of each interview, the interviewer would create a write-up of the interview including their notes. These write-ups would include a combination of descriptions of the substantive content of the discussion along with verbatim transcribed quotes and notes on the context of the quotes. Verbatim quotes were chosen based on their direct relation to the study goals, whereas lengthy, less relevant, or off-topic sections of the interviews were summarized by the interviewer in the write-up. This method has a long history of successful and reliable use within traditional ethnography and is an efficient way to contain write-up costs.¹⁹ To validate their accuracy, write-ups were reviewed by two additional research team members. To establish and contrast factors associated with delayed and non-delayed testing, we conducted a content analysis using CDC EZ-Text software.²⁰ Two coders developed a codebook designed to identify themes in the interview write-ups.²¹ Overall, final intercoder reliability was that 85.4% of the

codes had kappa values ≥ 0.8 . The codes were used to identify common patterns of beliefs, opinions, and behaviors, and to search the database for the illustrative verbatim quotes presented below from the delayed and non-delayed tester samples. Coded interview data were available for analysis from 75 of the 77 participants who tested HIV-seropositive, including 38 delayed and 37 non-delayed testers.

RESULTS

Sample

Among the 77 HIV-positive MSM enrolled in SAMS, 39 (51%) were defined as delayed testers and 38 (49%) were defined as non-delayed testers. Delayed testers included 28 MSM with reactive LS HIV-1 results and 11 with lack of self-reported HIV-seronegative results during the past 6 months. Non-delayed testers included 23 MSM with non-reactive LS HIV-1 results, nine with self-reported HIV-seronegative results during the past 6 months, and six diagnosed with a syndrome of primary HIV infection in addition to self-reported prior HIV-negative results in the last 6 months.

Quantitative Analysis

In univariate analysis, delayed testers were more likely to be older (18-29 years old: 21% vs. 32%, 30-39 years old: 28% vs. 53%, and 40+ years old: 51% vs. 16%, $p < .01$), African-American (29% vs. 3%, $p < .01$), homeless (31% vs. 5%, $p < .01$), and "out" to 50% or less of the people they knew about having male-male sex (44% vs. 13%, $p < .01$) compared to non-delayed testers (Table 1). Delayed testers also were more likely to have never previously tested for HIV or have not tested within the past 2 years (18% vs. 0% and 55% vs. 17%, $p < .01$). In terms of drug use, delayed testers were almost three times as likely to have used crack/cocaine in the previous 6 months, but this result was not statistically significant (34% vs. 13%, $p = .06$). Additionally, delayed testers were less likely to have used poppers with UAI during the previous 6 months (21% vs. 47%, $p = .02$). Finally, delayed testers were more likely to report having only one male sex partner (23% vs. 5%, $p = .04$), less than two anal sex partners (46% vs. 13%, $p < .01$), or less than two UAI partners in the previous 6 months (59% vs. 21%, $p < .01$). They were also less likely to report any UAI during the previous 6 months (72% vs. 95%, $p = .01$).

In the multivariate analysis (Table 2), delayed diagnosis was independently related to African-American race (OR=17.2, 95% Confidence Interval (CI): 1.8, 166), homelessness (OR=15.4, 95% CI: 1.6, 146), being "out" to 50% or less people about male-male sex (OR=4.7, 95% CI: 1.2, 17.9), and having had only one sex partner during the past 6 months (OR=6.9, 95% CI: 1.1, 42.9). No other variables were shown to be independently associated with the delayed testing status. Additionally, to assess the impact of using self-report compared to STARHS, we repeated our analysis excluding those whose case definition relied on self-report and found no appreciable differences in the results (data not shown).

Qualitative Analysis

Reason for Testing Delayed and non-delayed testers were markedly different in their identification of reasons for testing. Many delayed testers identified getting sick as the reason they had been tested. Most reported an illness associated with HIV or an illness that had persisted much longer than it normally would have in an

TABLE 1 Sociodemographic characteristics, health history, and drug-use and sexual behaviors of HIV-infected SAMS participants by delayed testing status, Seattle, WA, 2002-2005

	Delayed testers	Non-delayed testers	
	<i>N</i> =39 <i>n</i> (%)	<i>N</i> =38 <i>n</i> (%)	<i>P</i>
Sociodemographic and disclosure characteristics			
Recruitment site			0.15
HAP clinic, outreach, and other sites ^a	29 (74.4)	22 (57.9)	
STD clinic	10 (25.6)	16 (42.1)	
Age in years			<0.01
18-29	8 (20.5)	12 (31.6)	
30-39	11 (28.2)	20 (52.6)	
40+	20 (51.3)	6 (15.8)	
Race/ethnicity			<0.01
White	19 (48.7)	26 (68.4)	
African-American	11 (28.2)	1 (2.6)	
Hispanic	6 (15.4)	4 (10.5)	
Other	2 (5.1)	7 (18.4)	
High school or less education	14 (35.9)	7 (18.4)	0.12
Gay sexual orientation	33 (84.6)	32 (94.1)	0.27
Out to ≤50% about male-male sex	17 (43.6)	5 (13.2)	<0.01
Homeless	12 (30.8)	2 (5.3)	<0.01
Health insurance	14 (37.8)	11 (29.0)	0.47
Health history			
Number of negative HIV-1 tests in past 2 years ^b			<0.01
Never tested before	7 (18.4)	0 (0.0)	
No tests in the past 2 years	21 (55.3)	5 (16.7)	
1-2 tests	10 (26.3)	14 (46.7)	
3+ tests	0 (0.0)	11 (36.7)	
Reason for testing			
Time to test	10 (25.6)	16 (42.1)	0.15
New sex partner	8 (20.5)	7 (18.4)	1.00
UAI ^c	11 (28.2)	13 (34.2)	0.63
UOI	7 (18.0)	7 (18.4)	1.00
Shared injection equipment	5 (12.8)	0 (0.0)	0.05
STD check	12 (30.8)	11 (29.0)	1.00
Sex partner referral	4 (10.3)	3 (7.9)	1.00
HIV-infected sex partner	11 (28.2)	4 (10.5)	0.08
Substance use behaviors (last 6 months)			
Any illicit drug use	31 (81.6)	30 (79.0)	1.00
Marijuana	22 (59.5)	21 (55.3)	0.82
Poppers	15 (38.5)	21 (55.3)	0.17
Methamphetamine	14 (35.9)	17 (44.7)	0.49
Cocaine/crack	13 (34.2)	5 (13.2)	0.06
Viagra	8 (20.5)	11 (29.0)	0.44
Ecstasy (MDMA)	4 (10.3)	8 (22.2)	0.21
Ketamine	3 (7.7)	6 (15.8)	0.31
Gamma hydroxy butyrate	3 (7.7)	8 (21.1)	0.11
Heroin	3 (7.7)	2 (5.3)	1.00
Alcohol binge greater than or equal to four times/month	11 (28.2)	10 (26.3)	1.00
Injection drug use	6 (15.4)	8 (21.1)	0.57

TABLE 1 (continued)

	Delayed testers	Non-delayed testers	P
	N=39 n (%)	N=38 n (%)	
Substance use during UAI ^b (last 6 months)			
Any illicit drug use	20 (51.3)	23 (60.5)	0.49
Marijuana	9 (23.1)	10 (26.3)	0.80
Poppers	8 (20.5)	18 (47.4)	0.02
Methamphetamine	9 (23.1)	16 (42.1)	0.09
Cocaine/crack	8 (20.5)	4 (10.5)	0.35
Viagra	6 (15.4)	8 (21.1)	0.57
Ecstasy (MDMA)	3 (7.7)	6 (15.8)	0.31
Ketamine	2 (5.1)	5 (13.2)	0.26
Gamma hydroxy butyrate	3 (7.7)	8 (21.1)	0.11
Heroin	1 (2.6)	1 (2.6)	1.00
Alcohol	9 (23.7)	16 (43.2)	0.09
Sexual behavior (last 6 months)			
Total male sex partners			0.04
1	8 (22.9)	2 (5.4)	
2+	27 (77.1)	35 (94.6)	
Anal sex partners			<0.01
0-1	18 (46.2)	5 (13.2)	
2+	21 (53.8)	33 (86.8)	
UAI sex partners			<0.01
0-1	23 (59.0)	8 (21.1)	
2+	16 (41.0)	30 (79.0)	
Any UAI	28 (71.8)	36 (94.8)	0.01

Individual categories may not add up to total because of missing data for those specific variables

UAI unprotected anal intercourse, UOI unprotected oral intercourse

^aIncludes 6 HIV-positive participants who were recruited at two university HIV clinics

^bExcludes the HIV-seropositive test that resulted in their inclusion in the study

immunocompetent person. One delayed tester came in to test because he “knew something was wrong with [his] body” because he had been having “night sweats for almost a year” (African-American, 40-44 years old). Another got diagnosed with Kaposi-Sarcoma (KS), an AIDS defining illness, before he got tested and said, “Once I found out it was KS, then, that prompted me to get an AIDS test. I knew it would be positive. I couldn’t imagine any other reason to have a KS lesion” (white, 45+ years old). In contrast, a relative handful of non-delayed testers sought testing because of seroconversion symptoms and/or identifying themselves as high risk for HIV acquisition. One non-delayed tester indicated that he had a “horrible fever, night sweats, day sweats, incredible fatigue, and a small rash on my upper torso” (white, <25 years old). Another said, “I knew the symptoms of seroconverting because of being part of the study (vaccine trial). I would be asked that every month, if I had any symptoms” and when he had symptoms he knew he needed to test (white, 35-39). Finally, one non-delayed tester stated, “I recognize that I am high risk, so I get tested a lot” (white, 25-29 years old).

Additionally, only a few delayed testers identified any sort of regular pattern to their testing (i.e., testing every 6 months or year), whereas most non-delayed testers identified themselves as regular testers, and often indicated that they tested every 3-

TABLE 2 Multivariate analysis of factors associated with delayed diagnosis for HIV in HIV-infected SAMS participants, Seattle, WA, 2002-2005

	Delayed testers	Non-delayed testers	Crude OR (95% CI)	AOR (95% CI)
	N=34 n (%)	N=37 n (%)		
African-American	9 (26.5)	1 (2.7)	13.0 (1.5, 108)	17.2 (1.8, 166)
Homeless	10 (29.4)	1 (2.7)	15.0 (1.8, 125)	15.4 (1.6, 146)
Out to ≤50% about male-male sex	16 (47.1)	5 (13.5)	5.7 (1.8, 18.1)	4.7 (1.2, 17.9)
Total number of male sex partners (last 6 months)				
1	7 (20.6)	2 (5.4)	4.5 (0.9, 23.6)	6.9 (1.1, 42.9)
2+	27 (79.4)	35 (94.6)	1.0	1.0

Numbers are different from those in Table 1 due to missing data in the variables included in the multivariate analysis

OR odds ratio, AOR adjusted odds ratio, CI confidence interval

6 months. Non-delayed testers also identified a sense of responsibility to themselves and their community to test. As one non-delayed tester put it, “as a gay man, it’s the socially responsible thing to do to know your HIV status” (white, 30-34 years old). Another non-delayed tester stated that he tested to avoid infecting anyone else; that he did not want “the burden on my conscience of having infected younger men who I adore” and spreading the virus (white, 30-34 years old).

Reasons for Not Testing When asked about their reasons for testing, delayed testers often spontaneously spoke about reasons they chose not to get tested. One common reason delayed testers cited for not getting tested was fear. As one delayed tester said, “It took me months to get tested because I was scared of the results. I was scared of finding out the results that they could come back positive. And they did” (Missing Race, <25 years old). Another delayed tester stated, “It was always in the back of my mind, always...I needed to get tested, I need to get tested. I just held it off. Because I was scared, I was confused” (Hispanic, 45+ years old). Accompanying the fear of testing, delayed testers expressed a desire to stay in denial about their HIV-seropositive status. One delayed tester said that he did “not want to know the results, not wanting to deal with what the results could be, knowing that I had been exposed to somebody who not only was HIV-positive but might have had a breakout of AIDS is really, really scary” (white, 40-44 years old). Another delayed tester noted, “it was the non-thinking of it—putting it away (the idea of being infected), so it doesn’t exist, so I could avoid dealing with it” (white, 45+ years old).

Another reason often cited by delayed testers for not testing was feeling that they were at low risk of HIV acquisition. One delayed tester said that he generally did not test for HIV “because I don’t do high risk things” and “there was no reason to get tested” (African-American, 45+ years old). Another said:

I wasn’t [concerned]. I searched my memory and the things I’d done. Sure, I realized it takes just one time. But with my lifestyle—I haven’t been in a bar since 1979. I don’t drink. It’s not my thing. I don’t smoke. With my lifestyle—I’m not out there. My [sexual] contacts are so minimal. I’ll go months without doing anything and then, I’ll go for a hand job or something. As a rule I don’t take it up the ass. Of course I did with M (the participant’s ex-partner of 8 years). And with EC (a one time casual sex partner)” (white, 45+ years old).

A handful of delayed testers spoke about other priorities in their lives. One delayed tester stated, “I spend pretty much all day drinking and trying to get crack, you know, so I got other things going on” (American Indian/Alaskan Native, 40-44 years old). Another delayed tester said, “I should have been tested every year since ’94, but my state of mind, working and struggling to survive. I ignored it” (white, 45+ years old). Multiple delayed testers also identified not being sick as a reason for not testing. One delayed tester who had never tested before stated that he had not tested because he “hadn’t felt sick or anything. Also, [he] hadn’t had that many partners, not recently. And being busy a lot, working and stuff like that” (Hispanic, 45+ years old). As the majority of non-delayed testers tested regularly, no clear themes emerged around their reasons for not testing.

Disclosure of Results Delayed testers and non-delayed were also markedly different in both their willingness and reasons to disclose their HIV-seropositive status. Delayed testers often spoke about not wanting to disclose their HIV-seropositive status to anyone (including family, friends, or sex partners), or wanting to disclose to a limited number of people. Some indicated that they did not feel that it was their responsibility to inform people or that it was no one’s business unless they were very sick. One delayed tester said, “There’s no reason to tell people. I don’t see this big overwhelming reason to let everyone know, except for my very close friends who would feel bad if they didn’t know” (white, 45+ years old). Another delayed tester who did not tell anyone his status said, “Why bother? If I’m not going to die soon” (Hispanic, 30-34 years old). When talking about telling sex partners about his HIV-seropositive status, one delayed tester said, “I hope that they know their status but they claim that they’re not positive. I don’t feel any kind of responsibility, right now” (Hispanic, 45+ years old). Another delayed tester explained that it is too difficult to talk to his sex partners about HIV. In the moment when he is getting ready to have sex with someone, “you are trying to focus on sex and [if we] start talking about diseases it is a turn off.” He then went on to say that he cannot ask sex partners their status because he thinks “it is mean [to ask someone if they are positive]” (Hispanic, 35-39 years old). Finally, while discussing telling sex partners about his status, one delayed tester said, “If I decide to tell them I wouldn’t tell them without enough confidence that they’re going to be in my life for a long time” (African-American, <25 years old).

Non-delayed testers were more willing to tell family and friends about their HIV-seropositive status, and often cited a desire for social support as their reason for disclosure. One non-delayed tester spoke about telling his family his result:

My family was great. My dad was like, well, it’s not cancer—you’re not going to die tomorrow. So get out and mow the lawn. Which is great. That’s the way it should be. He’s right. My chances of getting sick—I have 8-12 years before something probably will happen. I’ve been really lucky” (white, 30-34 years old).

Another non-delayed tester spoke about having a “friend appreciation dinner” to tell his friends about his seroconversion. He said, “It was nice in the group—if I wasn’t in tears and I wasn’t having a big issue, then you shouldn’t be, especially if you’re friends—because you should be there for my support, not the other way around—and it ended up that nobody cried, and after 10 min we were all joking” (white, 30-34 years old).

Non-delayed testers also were more willing to tell sex partners (past, present, and future) about their HIV-seropositive status due to feeling a sense of

responsibility to themselves and their community. One non-delayed tester indicated that telling former sex partners was “a moral responsibility” and that he had “an obligation to do that” (white, 25-29 years old). Another non-delayed tester said, “I must tell my sex partners, so that’s not even a decision. I see it as my responsibility” (white, 25-29 years old). One non-delayed tester spoke about telling his past sex partners about his HIV status because he “wanted to be responsible and let them know to make sure that they are okay, [so] that they don’t pass [HIV] to others...I should be responsible and let them know that they are at risk...It’s just my conscience” (white, 25-29 years old). Several non-delayed testers further stated that they wanted to tell sex partners their HIV status in the hopes of influencing other people in their community to talk to their partners about HIV. As one non-delayed tester said, “Maybe I’ll help someone else be more responsible” (Asian, 30-34 years old). Another non-delayed tester spoke about trying to influence his sex partners:

Even though they might be the type of person to have sex and not tell them that they’re HIV positive, I don’t know—it doesn’t matter, but it might be one person—that one person could be forewarned—as long as that one person got the message before and maybe prevented sex with one person, it was all worth it...I was just hoping that someone’s life might be changed by something I did (white, 30-34 years old).

Prevention Messages and Outreach Methods When asked about potential methods to prevent HIV transmission in men in King County, delayed testers had a variety of ideas. Suggestions included more direct messages about the effects of HIV and the numbers of people getting diagnosed, more non-print educational promotions, such as radio and TV advertisements, information directed towards all men instead of specifically towards MSM, and messages placed in areas that were not MSM specific such as grocery stores and sports magazines. As one delayed tester put it, “get the information out there and don’t sugar coat it, you have got to scare people in order for it to stick in their minds” (white, 25-29 years old). Another stated, “It would be an in-your-face kind of thing. Letting people know that they are susceptible (to HIV and STDs) if they are doing unsafe sex” (white, 45+ years old). One felt that the messages should be “more graphic, and show that this (physical deterioration) is what can happen to you if you get this (HIV/AIDS). Just throw it in their face” (African-American, 30-34 years old). Finally, one stated that “[Current approaches] target a lot of people who already associate themselves with gay, or the fashion magazines or the typical [magazines that are thought to be read by] gay men, and they are missing normal guys who don’t go to bars or don’t go to bathhouses but still have sex with guys all the time” (white, 40-44 years old). Delayed testers also suggested that there was a need for testing in alternative locations such as public parks, homeless shelters, bars, and gyms. One delayed tester felt that testing in bars would be particularly helpful, stating, “let’s face it humans tend to be lazy and not inspired or have the incentive to do something until something happens in their life, until they get a scare, until somebody comes up to them and says, ‘hey, I just got tested for gonorrhea, you should get tested’, and when they are out at a bar and see the testing, they are more apt to do it” (white, 35-39 years old). Another suggested testing in parks, stating, “[Park] (a large park that is a well-known gay cruising spot). That’s a big one. At night. From dusk until they close the park. Hell, even after they close the park there’s a lot of activity there” (white, 45+ years old). Finally,

delayed testers endorsed using incentives and peer referral programs to increase the number of men who test. As one delayed tester put it, "I have such a fear of coming in for a test. If I wasn't referred, I would not have tested at all this last time...having a referral for testing come from someone I know is really effective." He then went on to suggest that "paid incentives, and referrals [peer driven] to come in for testing" would be the most effective way to get new men to come in to test (African-American, <25 years old).

DISCUSSION

Delayed diagnosis of HIV in MSM is a topic that has not been well explored. In this preliminary report, more than half (51%) of the MSM who tested positive for HIV primarily through health department counseling and testing programs had evidence of delayed diagnosis. Additionally of those who had evidence of delayed diagnosis, less than a third (26%) had tested within the past 2 years, indicating the need for more frequent testing in this high-risk group. Delayed testing for HIV was associated with being African-American, homeless, being "out" to fewer people about male-male sex, and having had only one male sex partner in the past 6 months. Delayed testers often ultimately tested because of an illness, cited fear as a reason for not testing, identified themselves as low risk, and were non-disclosing of their HIV-seropositive status. Overall, our findings suggest that delayed testers tend to be marginalized, less sexually active with male partners, and non-disclosive about their sexual practices, as well as less likely to recognize their HIV acquisition risks and less likely to express a responsibility to themselves or others to disclose their HIV status. There is also a need for outreach to this population that targets men in general instead of just MSM, uses incentives and peer referrals, and emphasizes alternative locations, such as homeless shelters, bars, and gyms. In contrast, non-delayed testers tended to be more likely to use poppers during UAI, more sexually active with male partners, less marginalized, more "out" about their male-male sex, more engaged in the MSM community, felt a responsibility to that community, had better social support systems, and recognized their HIV acquisition risks. Ironically, they tended to be well aware of their risk for HIV acquisition but continued to engage in risky behaviors despite, or perhaps because of, frequent HIV testing. This suggests a potential cognitive dissonance in the non-delayed testers between wanting to protect themselves and their community from HIV while still risking infection by engaging in high risk activities.

We are aware of only one previously published paper that specifically addressed delayed HIV testing. In that study, participants who reported having never previously tested for HIV or having previously tested 1 year or more prior to participation were defined as delayed testers. Delayed testing was evaluated among 15-29 year-old participants in the venue-based Young Men's Survey (YMS) and 55% of the young MSM who were unaware of their HIV infection were found to be delayed testers.¹⁴ Those delayed testers tended to perceive themselves as being at high risk of infection, had no regular source of healthcare, and had less than monthly attendance at MSM-identified venues. In contrast, our study found that delayed testers did not perceive themselves as being at high risk of infection. This difference may be due to the difference in delayed testing definition, age differences between these populations, or the difference in recruitment strategies. Similar to delayed testers in SAMS, the YMS participants with no previous HIV testing history most often stated their reason for not testing was a fear of learning their results.

While we have identified only one previous study that had assessed delayed testing,¹⁴ there is a growing literature on late testing for HIV, i.e., persons who have been diagnosed with AIDS within a year or less of testing HIV-seropositive.^{8–13} Because late testers are a subset of delayed testers, it is likely that many of the characteristics associated with late testing also may be associated with delayed testing, which is partially substantiated by our findings. In the USA, late testing has been associated with a number of factors including male gender, being a person of color, lack of self-identified risk for HIV, being an immigrant, having an opportunistic infection as reason for AIDS diagnosis, and feeling sick as reason for HIV testing.^{8–10,12,13} Most of these factors also were evident in our study (being a person of color; illness, including AIDS-related disorders, as a reason for testing). However, there have been inconsistencies across studies in the association between age and late testing.^{8,9,11–13}

Our study found differences in disclosure patterns between the delayed and non-delayed testers which may be influenced by social connectedness. Prior research has found that greater perceived social support is associated with a greater likelihood of disclosure of HIV-seropositive status.²² The differences seen in our study may suggest that delayed testers are marginalized and non-delayed testers have better social support systems.

There are several limitations to note in this study. First, the small sample size limited our power to detect small differences in our quantitative data and resulted in wide confidence intervals. Second, the use of self-reported variables for past HIV testing and risk behaviors may be prone to social desirability and recall bias. Our use of ACASI may have diminished underreporting of sensitive and stigmatized information.^{23–26} To lessen recall bias, participants were asked to recall details about sex partners and risk behaviors during the past 6 months rather than a longer period of time. Third, due to the small sample size and the recruitment locations,¹⁷ the study population may not be representative of MSM in the broader community who are recently diagnosed with HIV. Finally, there are potential limitations in our use of a cross-sectional design and the associated classification of delayed and non-delayed testers. Given the window period for the Vironostika-LS HIV-1 test using STARHS (145–200 days)¹⁸ it is possible that while a person was reactive on the LS HIV-1 test they in fact seroconverted within the past 6 months. Additionally, as not all participants were evaluated using STARHS, there were some cases where we relied on self-reported HIV testing history to establish whether a person seroconverted within 6 months of testing or not. Thus, it is also possible that while a person did not test within the past 6 months, he, in fact, seroconverted within the past 6 months. While this may be the case, given that the majority of participants classified as delayed testers identified an illness associated with HIV or an illness that persisted much longer than what would normally be expected in an immunocompetent person as their reason for testing, in addition to the majority having not tested within the past 2 years, it seems likely that most delayed testers seroconverted longer than 6 months prior to their HIV-seropositive test. Additionally, we conducted an analysis excluding those whose case definition relied on self-report to assess for the impact of using self-report compared to STARHS and found no appreciable differences in the results.

It is also important to note the benefits of using both quantitative and qualitative analysis methods in assessing the differences between delayed and non-delayed testers. The quantitative results give us a broad sense of the sociodemographic, behavioral, and HIV testing characteristics associated with an increased likelihood of delayed testing. The addition of qualitative results allows for more insight into the potential rationale behind these characteristics and behaviors. Using

these techniques together gives us a better understanding of not just “who” delayed testers are, but also insight into “why” they are delaying testing.

In summary, despite continued emphasis on HIV testing, our preliminary report on this topic supports previous reports that many MSM are not being diagnosed with HIV in a timely manner. This study illustrates the need to further explore why some MSM are not accessing testing and to develop targeted outreach methods and prevention messages to reach them. Specifically, there is a continued need for outreach among African-American and homeless MSM that emphasizes the importance of testing even among those who may not consider themselves to be a part of a stereotypical HIV risk group, but continue to engage in high-risk activities. Our findings suggest that prevention campaigns directed towards this population may need to be more direct in their message, targeted towards men in general instead of just MSM, and be distributed more widely to locations that are non-MSM specific. There is also a need for testing in alternative locations that delayed testers frequent such as homeless shelters, public parks, bars, and gyms. Finally, the use of incentives and peer referral programs may help increase the likelihood of encouraging this population to be tested. When used together, incentives and peer referral have been shown to be an efficient and potentially cost-effective method of case-finding.²⁷ In addition, our findings also suggest a continued need for effective and innovative risk reduction efforts among those MSM who test often, but continue to engage in risky behaviors. Overall, we hope that this study and future studies assessing delayed diagnosis will help inform outreach and prevention messages, increase early diagnosis and entry to HIV care, and ultimately help slow the spread of HIV.

DISCLAIMER

The findings and conclusion in this report are those of the authors and do not necessarily reflect the views of the Centers for Disease Control and Prevention.

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