“Just Because It’s Out There, People Aren’t Going to Use It.” HIV Self-Testing Among Young, Black MSM, and Transgender Women

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Abstract

HIV disproportionately affects young black MSM and transgender women in the US. Increasing HIV testing rates among these populations is a critical public health goal. Although HIV self-tests are commercially available, there is a need to better understand access to and uptake of HIV self-testing among this population. Here, we report results of a qualitative study of 30 young black MSM and transgender women residing in the New York City area to understand facilitators of and barriers to a range of HIV testing approaches, including self-testing. Mean age was 23.7 years (SD = 3.4). Over half (54%) had some college or an associate’s degree, yet 37% had an annual personal income of less than \$10,000 per year. Most (64%) participants had tested in the past 6 months; venues included community health/free clinics, medical offices, mobile testing units, hospitals, emergency departments, and research sites. Just one participant reported ever using a commercially available HIV self-test. Facilitators of self-testing included convenience, control, and privacy, particularly as compared to venue-based testing. Barriers to self-testing included the cost of the test, anxiety regarding accessing the test, concerns around correct test operation, and lack of support if a test result is positive. Participants indicated that instruction in correct test operation and social support in the event of a positive test result may increase the likelihood that they would use the self-test. Alongside developing new approaches to HIV prevention, developing ways to increase HIV self-testing is a public health priority for young, black MSM, and transgender women.

Introduction

NEW HIV INFECTIONS AMONG GAY, BISEXUAL, and other men who have sex with men (MSM), ages 13–24 years, increased by 133% between 2001 and 2011 in the United States (US).¹ HIV prevalence and incidence are disproportionately high among young black MSM (YBMSM).^{2–6} YBMSM were the only group in the US to have a statistically significant increase (48%) in new HIV infections between 2006 and 2009, with new infections among YBMSM representing 55% of all cases among MSM ages 13–24 in 2010 and 45% of all new HIV infections among black MSM.²

Current NHBS epidemiologic data indicate that a high percentage (71%, ages 18–19; 69%, ages 20–24; 72%, ages 25–29) of YBMSM were unaware of their HIV infection.⁷ New York City (NYC) remains an epicenter with the largest number of newly diagnosed HIV infections among MSM in the US.⁸ Further, new HIV diagnoses in NYC increased among young MSM between 2001 and 2010, with about half of all new cases among black MSM.⁹

Self-reported, and thus self-assessed, risk may underestimate the need for routine HIV screening.¹⁰ The Centers for Disease Control and Prevention (CDC) now recommends that MSM test annually and, if they have additional risk

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factors (e.g., multiple or anonymous sex partners, sex while using drugs, methamphetamine use, or have sex partners who engage in these behaviors), more frequently (every 3–6 months).^{7,11,12}

According to the CDC, in 2010, 38% of black MSM had not tested in the prior 12 months¹³ and 71% of new HIV diagnoses were among young black men (ages 18–29).¹⁴ HIV testing is less frequent among undiagnosed HIV-positive black MSM compared to HIV uninfected black men.¹⁵ The latest NHBS results suggest that HIV testing is increasing slightly among black MSM;¹⁶ the HPTN 061 study recently reported that almost a quarter of the 1379 black MSM with no prior HIV diagnosis had not tested in the past year. However, the men who had not tested were 4 times more likely to have an undiagnosed HIV infection compared to men who tested recently.¹⁷

Increasing HIV testing rates and HIV status knowledge among young black MSM (YBMSM) is a critical public health goal.¹⁵ Individuals aware of their HIV infection can benefit from antiretroviral treatment and become less likely to transmit HIV to others.^{4,18,19} The recently FDA-approved at-home oral fluid-based HIV test, here termed self-test, is a novel method that addresses several barriers to HIV testing common among YBMSM,²⁰ such as HIV testing stigma, mistrust of medical care providers/system, limited access to HIV testing, and confidentiality and privacy concerns.^{21–24}

The oral fluid-based self-test represents a promising new method of increasing testing among subpopulations unlikely to test at all and/or test consistently. Further, providing additional options to promote more frequent testing is critical for identifying undiagnosed HIV infections, which may facilitate increased linkage to HIV care among a population that is severely impacted by the HIV epidemic.^{15,17} The feasibility and acceptability of self-testing using oral fluids has been demonstrated in three US studies,^{25–27} with more recent reports from Singapore²⁸ and Malawi.²⁹ Spielberg et al.³⁰ found that participants who had never tested or had not tested in the past year were significantly more likely to prefer home self-testing, echoing results of an earlier post-market research on self-testing using dried blood spots, which revealed that half of the new positives identified had not tested previously.³¹

Some research exists on self-reported likelihood of using the self-test.^{32–34} An on-line study of MSM in six US cities who had never been tested for HIV found that 86% of those who were ‘very likely’ to be tested in the next year reported strong intentions to conduct a self-test, if available.³⁵ Another recent on-line study found that willingness to take a home test was higher for black compared to white MSM, for those reporting unprotected anal intercourse and those unaware of their HIV status.³⁶

There is limited information, however, on barriers to and facilitators of self-testing among YBMSM and transgender women, now that the test is commercially available. While self-testing inherently minimizes select barriers to testing³⁷—such as lack of access to traditional testing venues, potential stigma, and confidentiality concerns—perspectives of YBMSM and transgender women on self-testing remain relatively unexplored. Here, we present results of a qualitative study to understand facilitators of and barriers to a range of HIV testing approaches, including HIV self-testing.

Methods

Eligibility and recruitment

To be eligible for the study, participants had to: (1) report being male at birth; (2) self-identify as black, African American, Caribbean black, African black, or multiethnic black; (3) be able to read and respond in English; (4) be between 16–29 years of age; (5) not be known to be HIV-infected; (6) report insertive or receptive anal intercourse with a man or transwoman in the last 12 months; (7) reside in the NYC metropolitan area; and (8) provide informed consent or assent for the study. Participants who were enrolled in any other HIV research study involving HIV testing or who had been a participant in an HIV vaccine trial were not eligible. Sexual identity was not a criterion, as self-reported behavior was used to establish eligibility.

A recruitment plan was developed to identify online and mobile sites that YBMSM and transgender women frequented in the NYC metro area. This plan included online websites; mobile apps and 45 Facebook LGBT related pages and group pages. Specific recruitment language was developed to include transgender women in the study. On-line recruitment occurred over a 4-month period (February–May 2014) on sites such as: Craigslist, BGC, HeMeetsHim, Backpage, Facebook, Grindr, and the homepage of a local black organization (GMAD).

Using this method, 321 potential participants either started or completed the online screener, and 20% (77) were eligible during the study period. Twenty-nine potential participants were ineligible due to age; 46 because they did not report anal sex in the past 12 months; 44 because they were HIV-positive; 41 because they did not self-identify as African American or black; 21 because they did not reside in the NYC metro area, and 8 because they were born female. The remaining potential participants were eligible but either not interested (57) or did not leave contact information (18). In order to reach participants ages 16–19, we conducted focused, face-to-face recruitment at two events (a kiki ball, which is a mini-House Ball, a subset of the larger House and Ball community, and at “The Piers” an outdoor venue in lower Manhattan) where YBMSM and transgender women congregate. A total of 18 contacts were collected and 14 were eligible (78%).

Study procedures

Participants who screened as preliminarily eligible via web-based recruitment were contacted by telephone to confirm eligibility and to set up a study visit appointment. If a potential participant reported their age as less than 16 years on the web-based screener, they were immediately redirected to a page informing them that they were ineligible and offering information on HIV testing. Potential participants who reported being aged 16 and 17 and either wards of the state or foster children, were immediately directed to the ineligible page, as the IRBs had not approved waiving parental consent for children not living with their parents or guardians.

Eligible participants completed a 60-min, in-depth, qualitative interview and a brief web-based survey on demographics and sexual behavior. Participants who completed the study visit received \$30 compensation for their time,

along with a two-way Metrocard for travel. The interviews were conducted by trained and experienced interviewers in a private room; interviews were audio-recorded and professionally transcribed. All interviews were checked for accuracy by the primary qualitative study co-investigators (LW & VF). The interview was semi-structured, employing a guide who covered a variety of concepts including: personal background; experience of and connection to communities; thoughts and feelings about HIV testing and most recent testing experience; experiences with and perceived facilitators of and barriers to various testing approaches (e.g., couples testing), venues (e.g., mobile units), and operators (e.g., self-testing); and use of and thoughts about web- and smart phone application-based technologies for health and testing purposes.

During the interview, the interviewers described the two commercial self-tests currently available, the OraQuick In-Home HIV Test[®] (OraSure Technologies; Bethlehem, PA), approved in July 2012, and the Home Access[®] HIV-1 Test System (Home Access Health Corporation; Hoffman Estates, IL), noting the cost of, process used, and specimen collected in each method. All participants provided written informed consent and the study was reviewed and approved by the Institutional Review Boards of the New York Blood Center, Binghamton University and Public Health Solutions. All participant names have been changed to protect privacy.

Analytic methods

Using a grounded theoretical approach to the analysis of the in-depth interviews, we applied both contextualizing and categorizing strategies to code and analyze the data.^{38,39} To help contextualize the data, immediately after each interview, the interviewers developed a summary document that described the participant's life history, experiences with HIV testing, and select personal and social characteristics. All summaries and transcripts were read by the analytic team and the lead analysts (VF and LW). A list of analytic areas represented in the data were composed and given a code. Then, the primary analyst (VF) reread the transcripts and identified blocks of text to be given the descriptive label or code of "self-test." This typically was text that included the phrases "self-test" or "home test" or "at-home test" or where the participant talked about using a rapid HIV test themselves or at home.

Once these data were coded and identified, they were compiled, re-read, discussed, and organized into themes by the lead analysts (VF and LW). In addition, using QSR International's NVivo 9 qualitative software (QSR International Pty Ltd. Version 9, 2010), we conducted coding of all the data using multiple codes not analyzed and discussed here. Finally, all transcripts were re-read in full to confirm that no reported quote was overly de-contextualized from the larger narrative. We paid attention to data that did not confirm emerging or dominant themes, noting these in the results. In addition, we assessed whether the dominant themes were evenly represented among the four participants who self-identified as transgender and/or described being gender fluid. Here, we present accounts of the major, representative themes related to self-testing identified in three broad categories: facilitators of and barriers to use (potential and actual) of the HIV self-test, the "types" of people who might use

HIV self-tests, and strategies to increase uptake among YBMSM and transgender women.

Results

Sample

The recruitment methods resulted in a sample of 30 participants with a mean age of 23.7 (SD=3.4), with 40% residing in the Bronx, 30% in Brooklyn, 27% in Manhattan, and 3% in Queens. The majority (87%) self-identified as African American; 23% as Caribbean or West Indian; and 20% as Afro-Latino. Ninety-three percent of participants self-identified as male, with two participants identifying on the computer-based survey as transgender women. During the interviews, however, another two participants revealed that they were gender fluid, sometimes identifying as transgender male-to-female, sometimes as female and sometimes as male.

All but two participants were born in the United States and all reported spending most of their lives in the US. Fifty percent had some college or an associate's degree; 30% had a high school degree, GED, or trade/vocational degree and the remainder had a bachelor's degree or more. Seventy percent reported providing their own rent, food, utilities, and other living expenses; 43% reported that parents/other relatives supported them. The sample was characterized by low incomes and income insecurity. About a third (30%) reported that they "fairly" or "very often" did not have enough money for rent, food, or utilities; 54% reported an annual, personal income of less than \$19,999 per year. Despite this, over half reported working either full (33%) or part-time (20%).

The majority (83%) of participants reported that they had health insurance or other medical coverage; 57% reported that they usually sought medical care from a private medical doctor's office; nearly a quarter, however, went to the emergency department for care, and 13% went to a community clinic.

In terms of perceived vulnerability to acquiring HIV, the plurality of respondents (46%) reported that they were "extremely unlikely" or "very unlikely" to get HIV; 39% said that they were "unlikely" to acquire HIV. Just 14% reported that they were "likely" to get HIV. Yet, nearly two-thirds of participants (66%) were at least moderately worried about getting HIV. Forty-six percent of participants reported between one and two anal sex partners in the past 6 months, 36% reported between three and five, and 25% reported 6 or more. All but one participant reported a lifetime history of HIV testing and most (64%) had been tested in the past 6 months; 7.1% had not been tested in the past 12 months. Just under half (47%) were last tested at a community health/free clinic or CBO; nearly a quarter (23%) were tested at a private medical doctor's office. Two participants tested on a mobile unit most recently, the remainder tested at hospitals, emergency departments or at research sites. One participant reported the use of a HIV self-test. In terms of specimens collected, 37% of participants had whole blood drawn via venipuncture, 33% had an oral swab, and 20% had their fingers pricked.

Facilitators of self-testing

Several themes emerged in terms of the facilitators of use of the self-test, including the roles of convenience, privacy,

and control, and (related to privacy and testing) anxiety and stigma. Convenience was noted by some participants who stated that it would “save [me] a lot of time” while others indicated that having a test available and in the medicine cabinet when needed would be helpful and address lack of access as an excuse not to test. One participant said, when asked about what was appealing about the self-test, “Just that I’m busy and I don’t have to go anywhere. Don’t have to travel to anywhere to get the test, you know” (USAAM014).

Several participants reported that the self-test was attractive to them because it guaranteed privacy and confidentiality. Accounts around these interrelated issues stemmed from two experiences: privacy of test results and the emotional experience of being tested at a testing venue. Regarding the latter concern, one participant noted that the benefit of the self-test is that “You don’t have to go to clinics or have that overwhelming feeling of nervousness or anxiety. You can do that behind closed doors” (USAAM002).

Several participants noted that the anxiety associated with testing was exacerbated by being tested at venues where they perceived that they were identified as HIV testing clients or that the venue was not private or felt “public.” To be actively experiencing anxiety related to HIV testing in such an environment was a strong disincentive to testing more often; the self-test was identified as an opportunity, for some, to alleviate some of the anxiety and, for others, to experience it in private. In terms of privacy, several participants noted this as a major benefit: “Yes, that sounds awesome, it’s all private” (USAAM014). Another participant noted, “It’s good for privacy. Everybody wants privacy” (USAAM034).

Another participant noted that receiving results in private might better enable someone to accept the results, offering time and space to digest the results. Finally, being in control of the test and situation appealed to several participants; one said, “you feel a little bit more independent about it, like you’re making an initiative, as opposed to your putting yourself out there ...” (USAAM003). Asserting control over the testing experience was identified as something that the self-test facilitated by these participants.

Barriers to self-testing

Major barriers to self-testing that emerged included cost, feelings of self-efficacy around test operation, anxiety related to purchasing the self-test, general testing anxiety, and being alone or unsupported during or after testing. In terms of cost, several participants assessed the \$40 price associated with the OraSure At-home test to be too high. One participant noted that a more manageable price would be between \$15 and \$25. Another participant indicated that they would pay the \$40 price, if “funds were available.” Another participant thought that the Home Access test cost in particular was too high, given that it does not produce results immediately or at home.

Regarding confidence in operating the test, some participants described apprehension about doing it correctly and/or the test functioning properly. One participant commented, “What if I’m doing it wrong?” Later in the interview, this participant said, “But me, myself, for the first time, I’d be sitting there ‘Did I do it right? It says negative, but I could have slipped up, and could it be positive?’” (USAAM006). Another noted that a “con” was “people might do it wrong” (USAAM011). Another participant said “Yes, the person

administering the test, whether they—that would be me—whether I’m qualified to do it” (USAAM024). Another participant said, “I feel like I would mess it up because I just don’t like looking at directions. I wouldn’t feel medically qualified to take it” (BXAAM011).

Some participants noted that anxiety associated with purchasing the self-test was a barrier, as well as the notion of waiting for the test result alone and at home. One participant noted that if agencies offered the test for free, they would not have to “deal with going to Walgreens to get it and getting a stare back from the lady” (USAAM016). As well, one participant who had used the self-test noted the anxiety associated with waiting for the result remained, although the test was done in private. This participant stated, “I was biting my nails, oh gosh, so I’m at home now and nobody to talk to if this comes out bad, and thank God it didn’t come out bad but still you were nervous. It’s like a pregnancy test for a woman” (BXAAM011).

Finally, several participants were concerned about what happens if a positive self-test result occurs. “If you’re at home and you find out you’re positive, what are you going to do? Who are you going to talk to about it? I think it’s a good idea but then it’s just like the after-effects is what I am always concerned about” (USAAM016). Because of this, one participant said “I think I’m more comfortable being in an environment where there is somebody there” (USAAM010).

What type of person uses the self-test?

We asked participants if the self-test was appropriate for a certain “type” of person. User characteristics that were perceived to make the self-test a good option included having the financial resources to purchase the test regularly and requiring the convenience the self-test offers, desire for privacy, age, and having the space and privacy at home for self-testing. Thus, “busy professionals” who could afford the price of the test, but could *not* squeeze clinics or doctors in their busy schedules, were identified by some participants as ideal users. Some participants noted that the type of person to use a self-test would be someone who would be “ashamed” of a potential positive result or who wanted to keep a positive result secret. Related to the privacy that self-test engenders, a few participants stated that they feared that the self-test would be used by the “type of people” who would screen partners for HIV in order to be “irresponsible” sexually.

Regarding privacy and age, one participant noted that young gay people may not have a private space at home to operate the self-test, as they often live with their parents, and thus may not be able to imagine themselves as self-test users. In contrast, another participant noted that had the test been available and affordable when he was emerging sexually, he would have used it. “When I was younger, I was really worried; when I first started having sex, I was really worried to actually go to a center... If I had a cheaper option to have like an at-home test, where I could do it myself, I would probably did it that way. But, it took me 2 years after I started having sex to go to ... [a] clinic because I just was really scared” (BXAAM011). Thus, some participants described how perceived characteristics of self-test users potentially limited participants’ likelihood of using the test. We did not find evidence that the experiences and perspectives of the transgender or gender fluid participants in the study varied

significantly from the participants who did not identify as transgender or gender fluid.

Addressing barriers to self-testing

In order to address the barriers to self-testing identified, we asked participants what would increase the likelihood that they would use the self-test. Several participants noted that offering self-tests free at the health department or community organizations would significantly increase the likelihood that they would test themselves. Others reported that they want to have someone show them how it is done and be given a chance to practice. One participant said, "I prefer it by myself, so like teach me how to do it and then, from there, I will take the other steps" (USAAM001). Participants noted that receiving a reactive test result alone was not ideal and being able to test with a friend or in a socially supportive environment was positive. In discussing the notion of testing with friends, many participants were supportive. However, one participant noted that a concern of doing a self-test with a friend is that if they learned they were positive, the friend may "change up" on them as a result of the information (USAAM020).

Discussion

This exploratory qualitative research suggests that several barriers to and facilitators of HIV self-testing exist among young black MSM and transgender women. Barriers included the cost of the test, anxiety regarding obtaining the test, concerns about test operation and lack of support if a test result is positive. Facilitators included the convenience, control, and privacy, resulting in reduced anxiety associated with testing at venues. We did not note discernible differences in accounts of experiences and perceptions between MSM participants and those participants who self-identified as transgender and/or described being gender fluid.

Participants described two important concerns around proper test operation and receipt of a positive test result alone and unsupported. The potential for reduced test sensitivity due to test operator inexperience and/or error and the lack of a counseling component in self-testing have been identified as concerns.⁴⁰ Research has found some support for the concern around proper test operation, suggesting that sensitivity is higher for supervised self-testing than unsupervised tests.³² A related concern is that using antibody-only tests may also not be enough among high prevalence populations.⁴¹ However, one modeling study reported that unprotected sex after a negative rapid self-test among MSM who never used condoms would lead to a lower probability of infection.⁴²

The lack of in-person counseling constitutes a significant concern around HIV self-testing.⁴⁰ Despite the recent finding that counseling received by clients in STI clinics throughout the US had no positive effect on incident STIs,⁴³ the role of the HIV test counselor is argued to be critical in the event of a reactive rapid test result, as the counselor links newly identified positive people to medical HIV care and social services.⁴⁴⁻⁴⁶

Individuals who test positive and have social support are more likely to connect to medical HIV care. Further, the linkage component of the test and treat strategy is a critical link in the care continuum/treatment cascade.^{44,47} HIV infections identified via alternative methods, such as mobile

vans and the social network strategy, are less likely to be successfully linked to care than those identified in clinic or health care settings.^{48,49} Given that social support is associated with linkage to care⁵⁰ and HIV testing,⁴⁴ systematically building social support into rapid self-testing may also increase likelihood of care linkage.

Several participants in our study indicated that they were open to training on self-testing, as well as self-testing with social support from friends. One potential way to increase self-testing is to train peer educators to instruct potential users systematically on proper test administration. Peer-based approaches have been shown to be effective in reducing sexual HIV risk behavior and alcohol and drug use (AOD) related risk behavior⁵¹⁻⁵⁴ and represent a promising approach to increasing proper self-testing.⁴⁷

Another potential method of increasing correct test operation is through video instruction. The video provided by the self-test manufacturer provides clear instructions on use, but some recent research has noted that users often do not watch the video and make errors, such as not inserting the test paddle into the tube without spilling and reading results within the recommended time frame.⁵⁵ Videos are a prime example of using media to engage and instruct and have been used in HIV prevention since the 1980s,⁵⁶ and there is evidence that video has more potential to instruct learners than conventional text/graphics in web-based or print materials.⁵⁷

Finally, related to testing positive alone and unsupported, one potential solution would be to train friends to test together. By integrating friends into the self-testing process, for example, by adapting Couples Voluntary Testing and Counseling (CVTC) for friends self-testing together, the potential for connecting an individual who receives a reactive test result to care may be increased.

Although our study yields rich findings on HIV self-testing among YBMSM and transgender women, there are several limitations that need to be considered. First, our purposive sampling strategy recruited participants using web-based approaches primarily, followed by in-person recruitment methods to reach younger participants. It is important to note, however, that this sampling strategy was employed to reach MSM and transgender women who do not frequent community spaces or venues, where testing interventions frequently occur.

Second, we used a cross-sectional qualitative methodological approach in conducting in-depth interviews with participants, which posed a limitation in that data were captured at one point in time. A longitudinal qualitative research design would have allowed us to conduct multiple in-depth interviews to gain more nuanced insights into the multifaceted nature of the HIV self-testing process over time.

Third, the majority of our sample had tested for HIV within the last 6 months and most had recently tested at a community/public/free clinic or private doctor's office. Only one of the participants reported the use of a HIV self-test. To strengthen our reach, more emphasis needed to be placed on recruiting participants reflecting more variability in HIV testing experiences (e.g., participants who had not HIV tested within the last 6 months or last year, as well as those who had used the HIV self-test).

Fourth, while the sample reflected the diversity of New York City's African American population, the sample was

generally lower income; additional representation of participants from more diverse socioeconomic backgrounds and a larger sample of transgender women would have provided a broader understanding of this understudied area in HIV testing.

These results contribute to our emerging understanding of the barriers to and facilitators of HIV self-testing among YBMSM and transgender women in urban communities. As the HIV epidemic continues to disproportionately affect these subpopulations, the goal of increasing access to HIV self-testing increases in importance, alongside developing and testing new approaches to HIV prevention.⁵⁸ Self-testing represents a promising strategy for increasing regular HIV testing and addressing unrecognized HIV infections among YBMSM and transgender women. As HIV diagnosis facilitates entry into medical care and treatment and reduces transmission, increasing access to the full range of HIV testing options is a critical public health goal.

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