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Anticipated and Actual Reactions to Receiving HIV Positive Results Through Self-Testing Among Gay and Bisexual Men

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Abstract

We explored anticipated and actual reactions to receiving HIV positive results through self-testing with a diverse group of 84 gay and bisexual men in New York City. Grounded Theory was used to investigate these reactions in a two-phase study, one hypothetical, followed by a practical phase in which self-tests were distributed and used. Three major themes emerged when participants were asked about their anticipated reactions to an HIV positive self-test result: managing emotional distress, obtaining HIV medical care, and postponing sexual activity. When participants were asked about their anticipated reactions to a partner's HIV positive self-test result, five themes emerged: provide emotional support; refrain from engaging in sex with casual partner; avoid high-risk sexual activity with both main and casual partners; seek medical services; and obtain a confirmatory test result. Although none of the participants tested positive, seven of their partners did. Participants provided emotional support and linked their partners to support services. The availability of HIV self-testing kits offers potential opportunities to tackle HIV infection among individuals with high-risk practices.

Keywords

HIV self-test; HIV testing; HIV positive results; Gay and bisexual men

Introduction

The U.S. Food and Drug Administration (FDA) approved in 2012 an over-the-counter rapid HIV test for self-use outside of the clinical setting. The decision was aimed at increasing accessibility of testing and facilitating early entry into care of those testing HIV-positive [1]. It is estimated that half of all new infections in the U.S. result from those who are unaware they are HIV-infected, and self-testing could increase the number of people who know their status [2]. The U.S. Centers for Disease Control and Prevention (CDC) estimates that about 20 % of the 1.2 million infected Americans do not know their HIV sero-status and that

another 50,000 are infected each year [3]. Getting an infected person onto successful antiretroviral therapy lowers the chance that he or she will transmit the virus to someone else by 96 % [4, 5].

However, questions remain about self-testing for HIV and its potential impact on population health and sexual behaviors [6-8]. Some researchers believe that use of the HIV self-testing kit could empower individuals to manage their HIV risks, help couples make informed decisions before engaging in sexual activities, and address three important barriers to testing: stigma, convenience and privacy [9-11]. However, others have expressed concerns about the potential drawbacks of self-testing including: lack of counseling and referral to care [12], misinterpretation of the test results [13], failure to detect cases of acute HIV infection due to the test's window period [14], ethical issues involved in testing partners prior to sex [15], and the psychological impact of receiving a positive result in a non-clinical setting [16]. In particular, opponents point out that of the nearly one million people known to have tested HIV positive in the U.S. by the year 2012, only 75 % have been linked to medical services at all, and only 51 % currently remain in care. These percentages may be even lower if no counselor or medical provider is on hand to make an initial referral [17].

Another concern that merits attention is the ethical implications of the self-testing practice when both partners test prior to engaging in sexual activity. Persons preparing to engage in a sexual encounter might not have adequate autonomy and decision-making capacity, hindering the fulfillment of recognized principles of American bioethics such as respect for persons and justice. In addition, persons agreeing to a home HIV test might put their privacy at risk by allowing the sexual partner access to the results of the test.

Self-testing, when implemented effectively, is highly acceptable among high-risk MSM [18-20]. Several studies have found that barriers to HIV testing may be reduced by the availability of HIV self-testing. In a recent study among gay men in Australia, two-thirds of participants indicated they would test more often if self-tests were available regardless of previous testing history [19]. In addition, Carballo-Diequez and colleagues [21] found that among at-risk HIV uninfected MSM, self-testing had high acceptability among ethnic minority participants, which is significant considering the high HIV incidence among this group in urban centers of the U.S. Based on the findings, the authors suggested that making self-tests available within networks where high-risk sexual practices are common may be a cost-efficient and effective prevention method.

Not only are gay and bisexual men disproportionally impacted by the virus, but they also are less likely to be linked to care and treatment than other groups [22-24]. As a result, strategies to increase both HIV testing and linkage to care for gay and bisexual men have been explored. Rapid HIV self-testing is one initiative that has had success in reaching gay and bisexual men [25-27]. Yet, given the recent availability of HIV tests for home, self-administered use, little is known about how people will react to a positive result for themselves or a partner and whether linkage to care will ensue. Furthermore, health care providers and policymakers should be aware of the concerns and issues arising from receiving positive results in a non-clinical setting to prepare an appropriate response. To our knowledge, this is the first study to examine the anticipated reactions of gay and bisexual

men towards receiving an HIV-positive result with a self-test, as well as actual reactions to HIV-positive test results. Our manuscript aims to address the existing concerns related to the lack of counseling involved in self-testing practices, and the possible psychological impact of receiving a positive result in non-clinical situations. We present data from a study designed to assess the feasibility of using HIV self-tests to screen sexual partners for sexual risk reduction among high-risk MSM.

Methods

Our study was conducted in New York City with approval from the New York State Psychiatric Institute Institutional Review Board (NYSPI IRB). Recruitment took place in person and online at sites frequented by gay men with advertisements indicating that researchers were studying possible uses of a rapid HIV self-test. Study candidates called the research office and responded to pre-screening questions. The study involved two phases: a hypothetical phase and an experiential phase. During the first phase, participants were asked hypothetical questions about using a self-administered HIV test and then offered the opportunity to self-test at the conclusion of the interview. In the second phase, participants were given a supply of self-testing kits to use over a 3-month period and were later interviewed about their use of the kits to test themselves and their sexual partners.

Phase I

Eligibility criteria for Phase I included: male (not transgender); 18 years of age or older; engages in receptive anal intercourse (RAI) with other men at least three times per month on average; HIV-negative by self-report; not involved in a monogamous relationship at the time of enrollment; uses condoms on 20 % or fewer of RAI occasions; aware that unprotected RAI may lead to HIV transmission; and fluent in English or Spanish. Phase I had 57 participants, after eliminating data from 3 participants.

Participants in Phase I responded to a computer-assisted self-interview (CASI) that included questions on sociodemographic characteristics, sexual practices, substance use, sexual sensation-seeking, importance of avoiding HIV, and sexually transmitted infection (STI) history. After completion of the CASI, a psychologist on the research staff engaged participants in an in-depth semi-structured interview to understand if and how participants might use rapid home HIV tests to screen sexual partners in different scenarios. Some of the topics discussed included: knowledge of rapid HIV tests and attitudes and anticipated reactions to an HIV-positive result. Participants were asked the following questions:

“Assume that in some of the scenarios you described, your partner ends up testing positive. What would happen then? How would you handle the situation? Would you use a condom? What if the person feels really distressed?” and “What if your test showed that, unexpectedly, you became HIV-positive? How would you handle this with your partner? Would there be any physical danger for you?” Finally, they were offered the chance to use an OraQuick™ oral fluid HIV test following written instructions while monitored by a researcher. Participants were asked then the following questions: “Now that you’ve had the chance to do the test yourself, how are you feeling? How do you feel about the actual procedures you just underwent?”

Data from the Phase I interviews were critical for the development of the questions that were used for Phase II, including recommendations for eventual general users. Phase I participants received \$50 for their time.

Phase II

Eligibility criteria for Phase II included: male, 18 years of age or older, fluent in English or Spanish, HIV-negative, not in a monogamous relationship, engages in anal intercourse at least three times per month, never or seldom uses condoms (no condom use in last 10 occasions for those with 4 or less partners or in <80 % of occasions for those with more than 4 partners in the past year), aware that unprotected RAI may lead to HIV transmission, understands the window period of OraQuick®, reports likelihood of using HIV self-testing to screen potential sexual partners, and feels he can avoid or handle potential violence resulting from proposing to use the test. Phase II had 27 participants, after eliminating data from 5 participants.

Participants in Phase II who pre-qualified by telephone were invited to an in-person screening interview (Visit 1). After consent procedures, men were given a comprehensive description of the rapid HIV home test, how it worked, and its window-period related limitations. Subsequently, they took the first half of a 2-part CASI that collected, inter alia, demographic information, HIV knowledge [28], sexual risk behavior in the prior 3 months, alcohol and substance use history, and prior history of STIs. Next, participants tested themselves with OraQuick™ following written instructions while monitored by a researcher. While waiting 20 min for the result of the test, participants completed the second part of the CASI with questions on whether the participant perceived he was capable of discussing the use of an HIV self-test with a partner and handling a positive result. Study candidates who fulfilled eligibility criteria returned to the research offices on a subsequent day (Visit 2). After a new consent process, they enrolled in the 3-month study. They received a bag containing condoms, 16 OraQuick™ HIV test kits, written instructions on test kit use, a card with HIV- and violence-related resources available in the community, the study website address, and a 24-h hotline number they could use for assistance from two senior clinical psychologists supervising the study.

Visit 3 took place 3 months after Visit 2. Participants underwent an in-depth interview conducted by a clinical psychologist following an interview guide. The guide explored the factors that led participants to use (or not use) the test with different partners and the skills they employed to propose and use HIV self-testing, interpret results, and handle partners' reactions. Interview questions included:

You said you had a positive test result while using the home test during the past 3 months, and we contacted you about this experience. How did you feel about this test result? What did you do upon reading the positive result? Whom did you go to for support? How has having had a positive result affected your assessment of risk in your relationships? How has it affected your social life? Your sex life? Did any of your partners have a positive test result using the home test during the past 3 months? How did you feel about this test result? How did your partner react to his

test result? What did you do upon reading the positive result? How did the positive result affect your relationship with your partner?

Phase II participants received between \$30 and \$70 as compensation for their time at the different visits, plus a modest monetary incentive for using an automated telephone response system to report on their sexual behavior and self-test use; they also received a bonus if calls were received at least once a week, for a possible total of \$190.

Analysis

In-depth interviews were recorded, transcribed, and checked for accuracy. Grounded theory was used to describe participants' attitudes towards and anticipated reactions to an HIV-positive result from the use of an HIV self-test as well as the actual reactions of those who experienced HIV-positive results [29-31]. Repeated reading of transcripts by a team of four researchers led to the identification of the main themes that constituted the basis for codebook development. Peer review/debriefing and clarification of researcher bias were employed to establish rigor during data analysis [32]. To address researcher bias, other co-authors from a wide range of disciplines verified the categories and themes initially identified by comparing them to the data. A research assistant at the institution confirmed the findings by review of the study transcripts and results. Comments made by the research assistant were incorporated into the analysis.

Codes were defined with inclusion and exclusion criteria including examples. All transcripts were double-coded, and discrepancies were discussed until reaching consensus. Codes were reviewed to identify modal responses, cases that contradicted the main trends, and quotes to be included in the text by the first author. The codes selected for this article explicitly focused on aspects of reactions and ways to handle a positive test result. They also explored whether or not a condom would be or was used after a positive result as well as the actions taken after self-testing or partner testing.

Results

Table 1 presents demographic and background data for Phase I and II participants for a combined total of 84 participants. The mean age of the sample was 34, and the annual mean income was \$24,430. We recruited a diverse racial and ethnic sample. Among study participants, 27 (32 %) were Black/African American, 26 (31 %) were Latino, 23 (27 %) were White, 4 were Asian/Pacific Islander, 3 mixed race, and 1 refused to answer. Nearly half of the participants (42 %) reported partial college, and close to two-thirds (32 %) reported having completed college education or more. Although 70 % of the participants identified as gay, 31 % identified as bisexual. Most of the participants were either employed full time (27.4 %) or part time (33.3 %) or reported being in school (16.7 %).

Anticipated Reactions to an HIV Positive Self-Test Result

Participants reported numerous ways in which they anticipated they would react to an HIV self-test positive result in the context of a sexual encounter. Three major themes emerged: extreme emotional distress, need for HIV medical care and support services, and interruption of sexual contact.

Extreme Emotional Distress After HIV Diagnosis—Many participants ($n = 32$) anticipated feeling frustrated, devastated and emotionally distressed after an HIV-positive result. Participants also expected to feel vulnerable and feared rejection as well as a desire to escape the diagnosis, concern that others not infected with HIV would never understand them, and doubts about their future prospects and survival. There was also a pervasive theme that life would be permanently altered. One participant described how his emotions would be affected and how other factors would trigger remorse and personal regret. The participant expressed frustration with his uncontrolled sexual behaviors, his conscious lack of condom use, and his disregard of “safeguards” even when knowing the risk associated with his sexual behaviors:

I’m going to be extremely upset if I find out that I’m positive because my last test I was negative. And I haven’t done anything—no, I take that back. I’m always doing stuff that is risky. I need to stop it. I recognize that I’ve been lucky, and my luck will run out. And I’m saying that out loud to you as a way to manage me these days because I’m feeling the need to put in place many more safeguards around my not becoming HIV positive (Phase I, RHT002, Black, 57 years old).

As exemplified in the previous quote, a cue for emotional distress was the participant’s awareness of risky behaviors and continued engagement in unprotected anal sex.

Another participant explained how devastated he would feel if he received a positive HIV result and how it would prevent him from engaging in sex with the partner with whom he self-tests:

Well, I would have the devastated look on my face because I wouldn’t be expecting that. And I’d be apologizing profusely. Or I’d be saying—actually I would probably be saying—that’s not necessarily true. I wouldn’t have sex with someone, that’s for sure. That would be a limit that I would, if I was in someone else’s place, I’d be putting my clothes on and getting out the door. If they were at my place, I would be encouraging them to do the same thing because I would be in no mood for having sex any-more (Phase I, RHT008, White, 40).

One of the participants anticipated emotional distress given the stigma, rejection, and vulnerability that would result from being positive:

I’d be terrified. I mean for me, that would signal the end of, you know, of that relationship. Because I don’t know how I would, you know. I’d have to deal with my family. You know, there’s—I mean there’s a lot of people. And then coming out as HIV positive...I think its 10 more—10 times more frightening than coming out as gay. (Phase I, RHT036, Black, 33).

While most of the participants freely expressed their anxieties, none of the participants mentioned or referred to suicide as a solution or coping mechanism to the stress. This was particularly encouraging given that this is a major concern among opponents of the self-test. However, emotional distress did emerge as a core theme among participants.

Seek HIV Medical Care and Support Services—A significant number of participants ($n = 25$) explicitly mentioned their willingness to seek medical care and support from local

HIV service agencies in the event of a positive HIV self-test result. Respondents described that they would use several sources of information to decide what to do, including physicians, the study's hotline number, hospitals and clinics in the community.

One of the participants anticipated that he would seek immediate support from a doctor in case of an HIV positive result from self-testing:

If my results come out positive, then I would go to the doctor and I would take that to the doctor and I would show that to the doctor and have the doctor do my regular blood work. And that's another step I would take if I come out positive (Phase I, RHT010, Latino, 32).

Another participant discussed the possibility of false positives and the need to confirm the status in a clinical setting:

Then I'd say, 'Hey, I'm positive for HIV. I have to go to the hospital and find out what's going on,' see if it's a false positive, or if I really have HIV, and then I see where I take it from there. I'm very accepting, I don't fear death, so it's like, oh, look at that, I've got HIV. Time to go to the doctor and see what I've got to do (Phase I, RHT016, Latino, 26).

Several participants mentioned they would go to a hospital to seek a confirmatory test. Others mentioned the need to seek help and support from local clinics and counseling services. One participant expressed confidence in his HIV-negative status but mentioned the local men's clinic as a venue to confirm his result. In addition, the participant felt that being HIV-positive would not be the end of the world, a diagnosis that he will be able to cope with and overcome:

I know my status [presumably negative] 'cause I know who I'm messing with, I know my status—and not to say that I feel invincible or nothing at all, but I know my status, and I have no problem, you know, taking a test to prove it to you. Now, if it comes out positive, you know, I guess I'll have to get that certified at the men's clinic and what not, but it's not the end of the world (Phase I, RHT021, Latino, 18).

Another participant referred to the importance of seeking help from local HIV testing venues and highlighted the availability of counseling in case of an HIV positive result:

Like, I'll accept it for what it is, and being that I have some information about that situation, I know where to go to get the help that I need, the counseling and so on and so forth. But at the same time, that could be a reality that—I probably would be devastated, I mean, emotionally, and I wouldn't know what's going to happen (Phase I, RHT027, Latino, 44).

As noted, many participants described the importance of having resources available in case of a positive HIV test result. In particular, they pointed to the emotional and social support obtained in the counseling process as an important component after an HIV-positive diagnosis. For participants in our study, being able to reach out to counselors, information and services for HIV-positive individuals was vital to getting emotional support and linkage to needed medical and social support services.

Refraining from Having Sex with Partner After HIV Positive Result—Many participants ($n = 16$) explicitly mentioned that they would refrain from sexual activities if they ended up testing positive as a result of feeling emotionally devastated and not wanting to expose their partners to HIV.

I don't even think the sex part would be—we don't even need to talk about it no more, because at that time I'm just trying to deal with what just happened (Phase I, RHT003, Latino, 28).

I would definitely have a dramatic breakdown. But like I said, sex would just go out the window. I wouldn't want to put that person at risk, whether he was positive or negative. It just, it isn't, to me, it doesn't balance out, doesn't make sense. Like, I would probably leave crying or something before anything else with the person. No, the sex stuff would go out the window (Phase I, RHT012, Latino, 25).

Some participants discussed the possibility of engaging in low-risk sexual activities if their partners consented.

So I'd probably say I think we'll have to stay with low risk behaviors right now if you want to continue. And if they didn't want to continue, if they were negative and I was positive, I'd certainly have to respect that (Phase I, RHT005, White, 62).

Anticipated Reactions to Partner's HIV Positive Self-Test Result

Participants were also asked how they would react if their main or casual partner tested positive for HIV. A wide range of behaviors, attitudes, and perceptions were identified. Five major themes emerged: provide emotional support; link partner to medical care; refrain from sexual activity with casual partner; engage in non-risky sexual behaviors with casual and main partner; and seek a con-firmatory HIV test.

Provision of Emotional Support—Most of the participants ($n = 32$) talked about the importance of providing emotional support to their main or casual partners in case they received a positive test result.

I'd probably put my arm around them and say, "you know, what can I do to help you? Is this a shock?" First I'd ask them. If he said yeah, I'd say, "well let's see if we can do something. Because I'm sure that's got to be a terrible thing to hit you, to find out about" (Phase I, RHT005, White, 62).

Provision of emotional support was often coupled with concrete steps to help the partner cope with the positive result. Several participants said they would help the partner find HIV resources in the community.

I just won't leave them cold turkey. I just won't be in a relationship with them, but I'll be their friend and their mentor just trying to help them feel better about themselves, telling them what to do, like they've got groups for HIV positive people, all types of stuff for HIV people. You know, I would just speak to them, and tell them like, you know, I don't know, like I try to comfort them the best way I can, and still be on their side. I won't just leave—you know, abandon them, I just won't be in a sexual relationship with them no more (Phase I, RHT041, Black, 24).

Linkage to Care—Several participants ($n = 18$) explicitly mentioned that they would connect their partners to health services after a preliminary HIV positive result. This action was often coupled with emotional support as these two participants explained:

I'd just sit them down, like, say it's okay. I'd say, "it's not over, we'll just—you know, I can take you to the clinic" or, "It's really early so you can always get treatment for this. It's, it's not the end result" (Phase I, RHT032, Latino, 23).

I think you'd have to have the compassion to sit with them and help them, you know, find the resources or an ambulance if they were like hyperventilating. I don't know. I don't know.... I think that's kind of cold to say, "Let's call an 800 number and find out what to do next. I'm sorry, you have a terminal disease." Where, you know, I mean, I know there are drugs to keep people on the doorstep of death, but it really is a terminal disease, and an 800 number, it just seems so cold (Phase I, RHT045, Unspecified race, 36).

Refrain from Engaging in Sex with Casual Partner—Several participants ($n = 22$) talked about refraining from engaging in sexual activities with a casual partner after a preliminary HIV positive result, both for the risk of getting HIV and the impact on the sexual experience.

Yeah, yeah, I think that would ruin any mood whether it be sex or anything like that. I think that would pretty much throw a wrench in anyone's day (Phase I, RHT009, Latino, 20).

I think, you know, their life just changed dramatically. So I think, you know, having sex at that moment would just would, uh don't think it would be, you know, something that would be on the top of the priority list (Phase I, RHT025, Black, 23).

Others said they would refrain from sexual activities despite knowing that using a condom could reduce the risk of HIV transmission.

I mean, realistically speaking, I probably wouldn't involve myself sexually with them. As, however that may sound, it's probably the truth. Like I wouldn't want to intentionally take any more risks, that you know—because like I'm educated with HIV and how it spreads, but I think I'm just too paranoid. Like knowing obviously that certain things can't transmit it and, et cetera, It's just like an irrational fear (Phase I, RHT019, Latino, 25).

Engage in Non-risky Sexual Behaviors with Main and Casual Partner—While some participants said they would refrain from sexual activities with the casual partner testing positive, others ($n = 17$) mentioned the possibility of protected sexual activities with their main and casual partner.

"But if I really do, like, really love that person, you know, I would just have to take safe sex precautions every time we do have sex" (RHT029, Latino, 27).

One participant stated that he would continue engaging in non-risky sexual behaviors with a casual partner despite a positive HIV test. Given that he had previously assumed the risk of

contracting HIV from casual partners he believed to be HIV-positive, finding out the HIV status of a new partner would not make a difference:

But I had to say to myself now, what if the test comes up positive and stuff like that, would I continue to have sex with him, with um, yeah. I would think that that's been my experience in the past, like if, you know, if you're not sure about somebody's status or whatever, or you just have an inkling that somebody's status is not right, or just by the way they respond to, like, HIV or something like that, sometimes you pretty much tell that something's just not right with him. I'm more likely use a condom then, you know, because I have met some people and the um, it's like you begin to talk about HIV and stuff like that they begin to get really uncomfortable and jittery and stuff like that, or they'll change the subject really quick (Phase I, RHT003, Latino, 28).

Another participant was aware of the risk associated with having unprotected sex with a positive individual and emphasized the importance of condom use as a risk reduction strategy.

Yeah, I would. I would have sex but on a strict level though to use protection. Because let's say if we're both positive, OK, if we use unprotected sex he may have one strain of it and I may have one strain of the virus. Let's put it that way. And if we have sex I may get his strain of the virus and he may get mine. And once when you get another strain of virus it's nothing they can do (Phase I, RHT010, Latino, 32).

A participant further explained that he would have sexual activity with the casual partner and was aware that several factors, including alcohol use, might affect his ability to use a condom:

If I'm out, and I'm partying, and I'm high, and I'm drinking, sometimes that does affect your judgment, let's be honest, but I wouldn't, unless I thought he was really gorgeous, then I'd say, OK, let's put this condom on (Phase I, RHT048, White, 49).

Desire to Seek an HIV Test—A few participants ($n = 4$) mentioned that they would seek additional testing for themselves if their partners tested HIV-positive.

If I got tested negative, I would still go test, secondary testing. But I would go directly or, you know, as soon as possible to get blood tests, and, you know, take it from there (Phase I, RHT029, Latino, 27).

Reactions to Positive HIV Results

None of the participants enrolled in either phase of the study tested positive using our self-testing initiative. However, five individuals in Phase II did have partners who tested HIV-positive on seven occasions. In their discussions of these experiences, two major themes emerged: provision of emotional support and connecting those with a positive test result to health services. No sexual contact ensued after HIV-positive results were obtained.

Provision of Emotional Support and Connection to Health Services—

Participants who actually did have a partner test positive in their presence described scenarios that generally were consistent with the hypothetical responses provided in the Phase I interviews. In addition, the theme of linkage to care and services was also reaffirmed when actual positive results were encountered. One of the participants described his experience and elaborated on how he reacted by providing support:

He had no idea, I guess. Yeah. You know, the 20 min, he gets the result, he's like, What do you mean? I'm pretty sure it didn't give you a false positive, this is a, you know, this is pretty straightforward. Listen, I still like you, we can still fool around if you want to. You know, I don't know what you're going through at the moment, I know for me, when I found out about the Hep [hepatitis], I thought my world had come to an end, you know, and I basically wanted to crawl up and die anyway, you know, bring the 40–50 years forward and just kill me now. So if you want to hug, I'll give you a hug, like, I'm here for you. I'm a very compassionate person. So I understand that that's a very scary thing to find out. And he got pretty upset, you know, it was hard to see that. I said listen, I'll go with you, if you want to go to another clinic and get retested, if you want me to bring you down to, you know, one of the counseling centers, if you want to contact the people in my study, I can do that. He just said, you know, I'd really like to just kind of take some time alone. And I said, Are you going to be all right? You know, like, I worry he might do something crazy, you know, and I really didn't want to see that happen. So, I gave, you know, I left him with my number, I said, If you need to call me, please do. You know, please leave all the sexual stuff aside, like, you're another person, and I care, you know? We can always fool around later if you want to, but that doesn't change how I feel about you and what I think of you. So, you know, nothing really happened after the testing, but as far as I know, he said he was going to go get services (Phase II, RHT1015, White, 33).

The participant added:

I mean, what I did is I guided him down to the LGBT center because I frequent there for social and 12-step groups. So I said I know that they have counseling there, I know that they also have a mental health facility on the premises. If you need to talk to someone, and I'm pretty sure, especially for this situation, I'm pretty sure it would be free of charge. So you can go there any time, you know, not like after hours, but any time that the regular, you know, maybe nine to five that they're open, maybe even after for the psych stuff over there—that's not the way I said it, you know, but for the mental health facilities, that they'd be more than happy to help you. And they have a lot of services that are connected to other services to get you, you know, medication if you want to take it. You know, there's a lot here, so I don't want to overwhelm you at all. You know, there's a lot going on, but this is something that I can suggest. A lot of my very good friends are HIV positive. I love them dearly, you know, and I hope that you make forward steps so that you can take care of your health because you're worth a lot, and you have a great personality, you're a good person, and you deserve good things (Phase II, RHT1015, White, 33).

Two participants each had two potential sexual partners test positive in their presence. One of these participants reported that in both instances he provided emotional support and guidance. In particular, he was able to establish a strong relationship with one of the partners that ended up being positive:

You know, it's a joyous occasion, the rest of the night could continue. You come up positive, it's like damn, I was having such a good time here, and I was like—it's like boom, it's like you know, it's a damper on the situation now. And it's just really awkward because I'm sitting there, and I know I'm negative, and I just administered the test to you, and I'm just like sitting there twiddling my thumbs. Or like you know, I can't do anything, and I'm just thinking of the best way for me to leave. Honestly, like or you know what I'm saying, because I'm just thinking about the best way for me to leave. You know, with the young kid he just found out that he was just he just happened to be cool. Like he cried, like when we spoke about it. And then the next day we spoke, and we just continued our conversation. You know, we've been friends for like 2 months now. Like we still go out, we still hang out. You know, we get up, we chill, we drink, talk, laugh. I try not to bring it up to him about it all the time. You know, but he's in good spirits though. We speak about it every once in a blue. I ask him how he's doing, and you know, his doctor (inaudible), if his count is going up, down, and stuff like that. And he said he's fine, he's good, so (Phase II, RHT1030, Latino, 26).

Discussion

Our study sheds light on how gay and bisexual men with habitual high risk behavior might use rapid HIV self-testing and how they would react in case of a positive test result. All participants saw self-testing as an empowerment mechanism. In particular, for participants in Phase II who had the chance to use the HIV self-testing kit, the tests not only served to screen their partners to determine whether or not they should engage in unprotected sexual behaviors but to gain self-knowledge and awareness of their own status.

The theme of emotional distress coupled with fear sends a message to the public health field regarding the stigma and prejudice surrounding HIV. Based on our findings, preliminary positive rapid HIV test results can trigger strong feelings of emotional distress and fear. Participants felt that not only would they have to deal with a positive HIV result, but also the societal stigma and discrimination on many levels. While those partners of our participants who tested positive during the study were able to receive emotional support, self-testing might not always occur in the presence of partners. Therefore future initiatives, programs, and interventions should explore how to better include emotional, social, and health support mechanisms for those who test HIV positive outside the clinical setting in the presence of a partner.

As noted, most of our participants mentioned the importance of resources, information and counseling after receiving a positive HIV test result. Therefore, there is a need to create and maintain comprehensive referral systems for individuals to link HIV positive individuals to care. Comprehensive counseling services to cope with the emotional distress and post-

traumatic stress disorder after HIV positive results should also be provided. Our participants noted the importance of counseling, human and social support after a preliminary positive rapid HIV test result. Hence, comprehensive hotlines and guidelines are needed for those individuals testing outside a clinical setting. As we strengthen the test and treat approach, the inclusion and maintenance of counseling services is needed to cope with the continuing epidemic. In particular, counseling might be more important for recently-arrived immigrants coming from nations that lack HIV prevention infrastructure and whose citizens are not aware of the modes of transmission and treatment of HIV and other STIs. The counseling component will help address the problematic mental health issues that might occur as a result of being HIV positive, including depression, anxiety and post-traumatic stress disorders.

There are some limitations to our study procedures. Our convenience sampling of high-risk gay and bisexual men in New York City is not representative of all gay and bisexual men in New York City. Our findings regarding the experiences of an actual HIV-positive result are limited to the small sample of five participants whose seven partners tested positive for HIV, which do not reflect all reactions to an HIV-positive self-test result. Yet, this small sample offers encouraging insights into the empathic response that may follow an HIV-positive result.

To provide the most effective combination of proven behavioral and biomedical approaches for those who are not infected but are at highest risk for HIV, self-testing appears to be a feasible approach to increase testing and reduce risky behaviors [11, 21]. The HIV self-testing tool empowered this specific group of gay and bisexual men who engage in risky sexual behavior to test themselves and their partners and know their status. As a result, participants refrained from engaging in risky sexual behaviors with potential sexual partners after those partners received an HIV positive result. HIV self-testing offers an opportunity to scale-up testing and when combined with other prevention strategies, including the use of condoms, can significantly reduce HIV acquisition and transmission.

Conclusion

This paper responds to the urgent need to better understand participants' reactions to the use of the HIV self-testing test. Dismantling some of the myths associated with self-testing, including participants' self-harm after a positive self-testing diagnosis, effectiveness for facilitating entry to care, and the possibility of engaging in risky sexual behaviors are crucial for the dissemination of the self-testing practice.

While participants in our project reported that they would experience emotional distress from receiving a positive result from self-testing, they also expressed a desire to seek HIV medical care and support services as well as refrain from engaging in risky sexual behaviors. Participants also anticipated that in the event of a positive result from their partners they would provide emotional support, refrain from sexual activity, link such partners to available resources, engage in non-risky sexual behaviors with main or casual partners, and seek a confirmatory HIV test with a medical provider. Although none of the participants tested positive in the second phase of the study, seven of their partners did. These

participants described how they reacted to these situations with specific reference to providing emotional support and facilitating linkage to healthcare services.

The availability of the HIV self-testing kits offers potential opportunities to tackle the HIV epidemic affecting MSM. Several strategies have been proposed to promote the use of the self-testing kits. For instance, given the willingness to receive HIV testing materials through the mail [33, 34], distributing HIV self-testing kits through social media channels including Facebook and other social networking applications might increase testing frequency among MSM [35]. In addition, given the success of the use of social networks in identifying persons with undiagnosed HIV [36], *navegantes* or lay health educators, could promote and distribute self-testing kits among high-risk individuals [35, 37]. Additionally, future HIV prevention studies and sexual health promotion programs could incorporate HIV self-testing practices into their strategy to increase testing and facilitate linkage to care.

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Table 1

Demographics ($n = 84$)

Characteristics	Phase I ($n = 57$)			Phase II ($n = 27$)			Total sample ($n = 84$)		
	Mean (SD)	Range		Mean (SD)	Range		Mean (SD)	Range	
Age	34.28 (11.93)	18–62		34.0 (11.4)	18–58		34.18 (11.70)	18–62	
Income (in thousands) ^a	26.30 (22.06)	0–100		20.59 (22.86)	0–90		24.43 (22.31)	0–100	
<hr/>									
<i>Race/ethnicity</i>									
Black/African American	18	32		9	33		27	32	
Latino	22	39		4	15		26	31	
White	12	21		11	41		23	27	
Asian/Pacific Islander	4	7		0	0		4	5	
Mixed ethnicity/other	0	0		3	11		3	4	
Refused to answer	1	2		0	0		1	1	
<i>Education</i>									
High school graduate or less	13	23		9	33		22	26	
Partial college	24	42		11	41		35	42	
College graduate or more	20	35		7	26		27	32	
<i>Sexual orientation^b</i>									
Gay/homosexual	39	68		20	74		59	70	
Bisexual	18	32		8	30		26	31	
Straight/heterosexual	2	4		0	0		2	2	
Other	1	2		0	0		1	1	
<i>Occupation status^b</i>									
Full time	16	28		7	26		23	27.4	
Part time	20	35		8	30		28	33.3	
Full/part time in school	10	18		4	15		14	16.7	
Neither work nor in school	8	14		6	22		14	16.7	
On disability	3	5		3	11		6	7.1	
Other	5	9		2	7		7	8.3	

^a Only 64 participants responded

^b Participants could select more than one category, hence % exceeds 100