

Understanding the impact of HIV among recently diagnosed gay men in Vancouver

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CIHR Team in the Study of Acute HIV Infection in Gay Men

Early Recognition and Rapid Response to HIV Status

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The CIHR Team in the Study of Acute HIV Infection in Gay Men thanks the men who participated in our study, the staff at the British Columbia Centre for Disease Control and Positive Living BC who supported our work, and our community partners.

For more information about the study, please visit www.acutehivstudy.com

This study was conducted with funding from CIHR, and its offices were located at the British Columbia Centre for Disease Control (BCCDC). The CIHR Team in the Study of Acute HIV Infection in Gay Men includes researchers from sociology, public health, and clinical research, and was an opportunity for collaboration within public health disciplines. We used data collected from interviews, questionnaires and HIV testing specimens. Gay men were meaningfully involved in this study team, in leadership roles, as study staff and community partners. These men played key roles in data analysis.

The CIHR Team in the Study of Acute HIV Infection in Gay Men also developed partnerships with a variety of community-based organizations, including Positive Living BC, a member-based organization that provides community, information, and support for people living with HIV. As part of our collaboration with Positive Living BC, we set up a team of peer counsellors to provide support to study participants on a variety of issues related to their diagnosis and experience as a newly diagnosed HIV-positive person, and regularly met with these peers to share emerging findings from the study. Men were told about the peer counselling services upon their entry into the study, and were given the option to access the program on a voluntary basis throughout their participation. Beginning in January 2011, the peer counselling program was restructured into the Peer Navigation program developed by Positive Living BC and housed at the John Ruedy Immunodeficiency Clinic (IDC) at St. Paul's Hospital and at the Positive Living BC offices. Many of the peer counsellors we helped to train became involved in this Peer Navigator program. This client-centred, peer-based program provides support and education to people newly diagnosed with HIV, with a focus on navigating healthcare systems and the myriad issues presented by an HIV-positive diagnosis.

Along with the introduction of the pooled NAAT, we offered men diagnosed with in the acute HIV infection phase access to counselling services, through the study's professional counsellor and referrals to the peer counselling, and later, Peer Navigator programs at Positive Living BC. Newly diagnosed men were able to access these services whether or not they participated in the study.

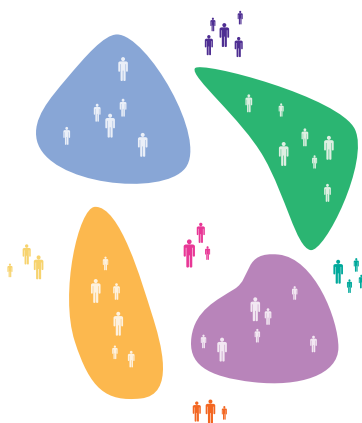


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What is this report about?

This is a report from the Canadian Institutes of Health Research Team in the Study of Acute HIV Infection in Gay Men. Here, we present data from interviews and questionnaires completed by HIV-positive study participants between July 2009 and June 2013.

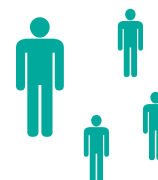
The main focus of our research was understanding men's experiences of being diagnosed with HIV early on in the infection period. As a result of new testing technology, the pooled nucleic acid amplification test (or NAAT), we were able to diagnose men as soon as 10-12 days after the event that led to seroconversion. In addition to hearing about men's experiences of this test, we also heard from men about the ways an HIV diagnosis impacted their physical, social, sexual and mental health.

This report is a summary of some of our key findings that pertain to people who provide health and wellness services to gay men, as well as providers outside Vancouver who may want to implement the pooled NAAT. This report also includes information that may be of interest to the men who participated in this study and gay men in our communities. The reference list at the end of this report includes information about where you can find more in-depth analysis of men's experiences.

Key messages:

- Access to pooled NAAT during the study period led to 25 men* being given an HIV diagnosis earlier than they would have through standard testing technology
- Implementation of pooled NAAT must include comprehensive educational materials aimed towards both priority populations (e.g. gay men) and health care professionals who provide testing
- Men reported diverse experiences with mental health and social support in the years and months before they seroconverted
- Following HIV diagnosis, men were cautious about having sex, particularly during the acute HIV infection phase, and took steps to reduce the possibility of transmitting HIV to their partners
- Men were aware of the concept of undetectable viral load and the impact this has on HIV transmission prior to, or in some cases, shortly after, their diagnosis
- HIV stigma posed ongoing challenges for some men when disclosing HIV status in social and/or sexual situations

Acute HIV refers to the initial weeks and months of HIV infection during which the body is producing an immune response to fight the virus. Until recently, many people who tested during this phase could not be diagnosed due to limitations in testing technology. Our team introduced new testing technology, the pooled NAAT, that can identify HIV during acute HIV infection. In our study, we heard from men diagnosed with this testing technology.



*Not all of the 25 men who were given an HIV diagnosis earlier than they would have through standard testing chose to participate in our study.

Introduction

New HIV infections continue to occur among gay, bisexual, and other men who have sex with men (MSM) in British Columbia, as in the rest of Canada (PHAC, 2010). Social determinants of health and structural inequities strongly impact HIV-related risks and health outcomes for people living with HIV (PHAC, 2013). These determinants factor into the health inequities among gay, bisexual and other men who have sex with men that continue to impact HIV transmission and HIV-related health (Ferlatte & Trussler, 2010; PHO, 2014).

Emerging research indicates a large proportion of new HIV infections can be traced to the acute HIV infection phase, the first phase of HIV infection during which the amount of HIV in a person's body (known as the *viral load*) is elevated. During acute HIV infection, the amount of HIV in a person's body is very high, making it easier to transmit to a partner. However, as a result of limitations in HIV testing technology, people with new HIV infections are often not aware of their HIV status. This pattern can be explained because individuals may not test immediately after becoming infected, and for those who do test immediately after infection, standard laboratory testing methods may not detect HIV during the acute phase. As a result, people may not become aware of the fact they have HIV until after the acute infection phase ends.

Beginning in April 2009, a more accurate HIV testing technology was introduced at several clinical sites in British Columbia commonly used by gay, bisexual, and other MSM (see Gilbert et al., 2013). Known as the pooled nucleic acid amplification test (NAAT), this technology is able to detect HIV earlier than standard methods, as early as 10-12 days after infection. While standard testing technologies may detect acute HIV infection, pooled NAAT is able to identify acute HIV infection more consistently. Pooled NAAT provides an earlier diagnosis for people living with HIV, which can improve individual health outcomes by facilitating earlier access to HIV treatment. In addition, pooled NAAT may also reduce the possibility of onward transmission to partners through behaviour change after diagnosis. Between April 2009 and March 2012, 25 men were diagnosed with acute HIV infection. Without this pooled NAAT technology, these men would have been given an HIV-negative test result.

In addition, research shows most men who are diagnosed with HIV take steps to prevent HIV transmission to their partners. Estimates suggest that one acute HIV infection diagnosis may prevent between 1 and 3 new infections in a one year period. As such, we believe that early diagnosis through pooled NAAT testing and men's subsequent behavioural changes potentially prevented at minimum, 25 new cases of HIV.

As a result of the pooled NAAT test, 25 men were diagnosed with acute HIV, all of whom would have been given an HIV-negative diagnosis without this testing technology. Overall, 11.5% of new HIV diagnoses given during the study period resulted from the availability of the pooled NAAT.

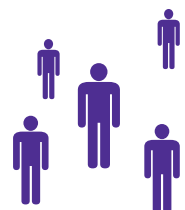


The social media campaigns, *What Are You Waiting For?* and *Hottest At The Start*, conducted in partnership with the Health Initiative for Men (HIM), were important tools in promoting uptake of this new testing technology. We believe these campaigns helped to increase awareness of pooled NAAT testing and the possibility of getting tested for HIV within days of possible exposure to HIV.

We introduced pooled NAAT into an existing landscape of gay men's specific health services and health promotion initiatives, including many led by our community partner, HIM. We believe that pooled NAAT is only one component of a comprehensive approach to addressing HIV among gay men. At the time this test was introduced, HIV treatment, prevention initiatives such as condom distribution and risk reduction campaigns, as well as support for gay men's wellbeing across all health domains, including social, physical, sexual and mental health, were available within Vancouver. At the time of the study, the Seek and Treat for Optimal Prevention (STOP) HIV/AIDS pilot project and roll out of 'treatment as prevention' (TasP) were ongoing in Vancouver. Our study data do not specifically account for the existence of these programs, yet we believe this landscape impacts the lives and experiences of the participants in our study, as well as the findings we present here. Part of our success in introducing pooled NAAT and communicating with men about this concept is based on the engagement of gay men in existing services, such as the HIM clinics and other health promotion activities.

In addition to primary prevention initiatives, HIV testing, and treatment, it is also necessary to respond to the social and structural factors that impact men's health, often referred to as the social determinants of health. These factors include interrelated determinants such as income, gender, sexuality, ethnicity, and migration, as well as structural determinants such as racism and heterosexism. All of these factors shape men's knowledge and experiences of HIV-related risk and access to HIV-related care. Therefore, it is crucial to consider the ways these social determinants of health may facilitate or reduce access to HIV testing, treatment, and prevention services. Our data clearly illustrates the ways these aspects of men's lives impact experiences of HIV-related risk and health outcomes.

For more details about acute HIV infection and pooled NAAT, see the CIHR Team in the Study of Acute HIV Infection in Gay Men Study Backgrounder, 2013 and our paper Targeting screening and social marketing to increase detection of acute HIV infection in men who have sex with men in Vancouver, British Columbia.



What we did:

Data Collection & Analysis



The CIHR Team in the Study of Acute HIV Infection in Gay Men introduced pooled NAAT testing in April 2009. In order to understand the impact of pooled NAAT testing among men who have sex with men in Vancouver, our study team talked to men who received HIV-negative and HIV-positive results from the pooled NAAT test. This report presents findings from the research we did with men who were diagnosed with HIV.

Over a one-year period, participants were asked to complete six questionnaires and four in-person interviews. We only spoke with the men who enrolled in our study, and did not have the opportunity to speak with their sexual partners, health care providers, or any other groups of people involved in their experiences. As such, all of the information presented here is based on participants' accounts after their HIV diagnosis.

The questionnaires and interview guides we used were developed with input from Positive Living BC. Data from the first study visits informed the development of subsequent questionnaires and interview guides.

Recruitment for the HIV-positive cohort of this study occurred between April 2009 and June 2012. All men who self-identified as gay, bisexual or a man who has sex with men and were diagnosed with an acute HIV infection after April 14, 2009 were eligible to participate in the study. After January 1, 2010 we expanded eligibility to men who were recently infected with HIV. In these cases, men tested positive for HIV after the period of acute HIV infection and had previously tested negative for HIV in the past 12 months.

Health care providers at the six clinics where pooled NAAT testing was available were asked to refer anyone who tested positive for acute HIV to the study, either by connecting them to the study counsellor or the study coordinator. In addition, the lab that processed HIV test samples included a message about the study counsellor when providing HIV-positive test results to health providers across British Columbia. The message informed health care providers that they could refer their patients to the study counsellor, and was included on lab reports for males aged 18+ if their test results were suggestive of acute HIV infection using standard testing technology at any HIV testing site in British Columbia (began June 2009), or if their HIV infections were not suggestive of acute HIV infection but they were diagnosed at one of our study sites (added April 2010).

During the study, we asked HIV-positive gay men about several experiences:

- receiving their diagnosis
- social and professional supports they accessed following diagnosis
- the encounter during which they believe they became HIV-positive
- their attitudes towards HIV prevention before and after diagnosis
- the ways they approach disclosing their HIV status in sexual and social scenarios
- the ways people respond to disclosure, sexual activity and HIV prevention strategies used since diagnosis, and any general impacts that HIV has had on their lives.

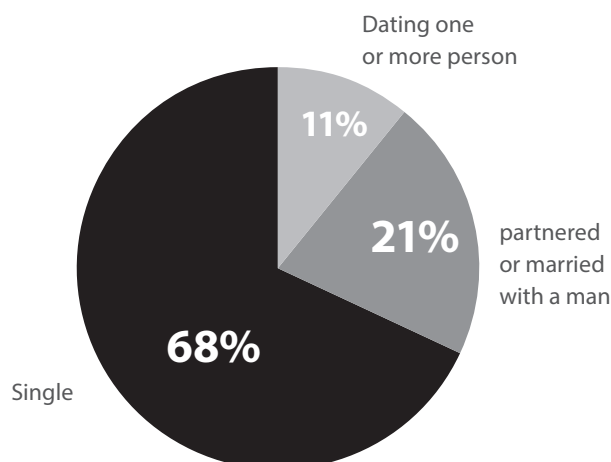
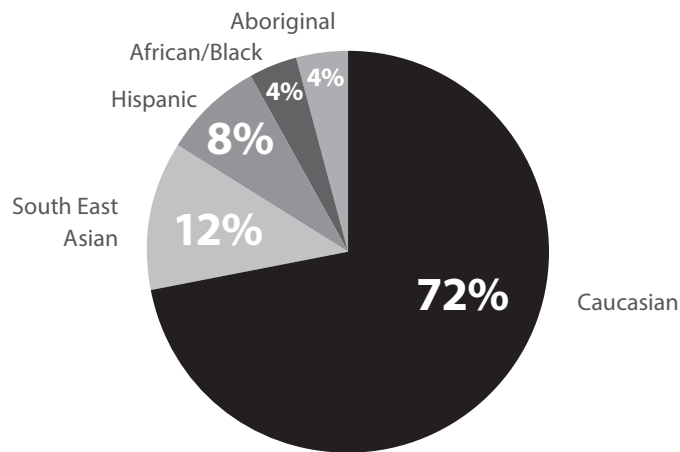
Participants who had been given an acute HIV diagnosis were also asked additional questions to help us understand the impact of pooled NAAT for these men.

Who was involved:

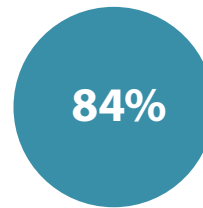
Study Participants

Throughout the recruitment period, 134 men were eligible to participate. To participate, men were required to speak and read English and be able to sign and fully comprehend the study consent form. Of the eligible men, 25 (19%) joined the study. Almost all men who joined were referred by the health care provider who gave them their HIV-positive test result.

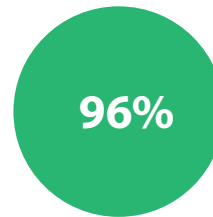
As demonstrated in Figure 1, most study participants lived in the Greater Vancouver Regional District, identify as gay and were single or dating. No participants reported a history of injection drug use. Using information from the provincial HIV surveillance system, we conducted a comparison of those men who did not participate and those men who participated in this study, based on information shared with public health nurses who follow up on each new diagnosis of HIV. Participants were more likely to have reported a partner they knew to be HIV-positive than those men who did not participate. Participants were also slightly older, less likely to have a prior diagnosis of an STI, and more likely to be recruited from a Vancouver family practice clinic which has many gay men as both patients and physicians.



mean age



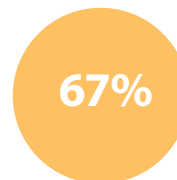
live in the
Greater Vancouver
Regional District



identify as gay



are employed full-time



have completed
university degree



were diagnosed with
an STI prior to being
diagnosed with HIV

Figure 1.
Demographics of questionnaire participants
at the time of study enrollment (n=25)

What we found:

Understanding the Context of Seroconversion



The men in our study were asked if they could identify a time when they were likely to have been infected with HIV, including how they met the sexual partner involved in that scenario, how well they knew this person, and what their perception of HIV-related risk at the time of the encounter (see Grace et al., 2014b).

Ongoing in-depth analyses of participants' responses were in progress at the time of the publication. This report highlights key preliminary results that provide a portrayal of men's experiences following HIV seroconversion.

Likely Infection Event

Most participants were able to identify a specific sexual encounter when they think they were likely infected. Men formed their perceptions of the likely infection event using many kinds of information, such as knowledge of their sexual activities and safer sex strategies, knowledge of how HIV is transmitted, and an understanding of acute HIV infection symptoms. For example, one participant was able to use his knowledge of the timing of seroconversion symptoms to determine the likely sexual partner:

“Because there was only one other person in the six-month period, and it was two or three months prior to the illness. And from my information, it takes [...] a shorter time period for the seroconversion to happen.”—28 years old, acute infection

Another participant described that he could not identify a specific partner because he had sex with multiple men at a bathhouse. However, based on his knowledge of HIV transmission, he developed a hypothesis as to how he became infected:

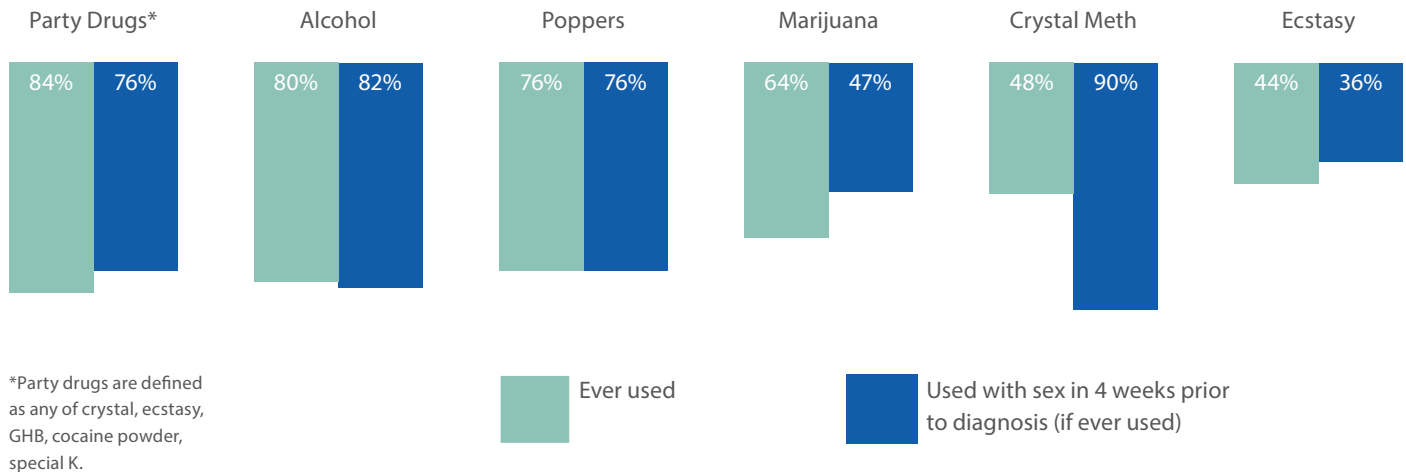
“So, there were two partners that I had, would have sex with while high on drugs, but we had sex a number of times, and I’ve asked both of them since, and they are both...they both say they’re undetectable. They could be lying. I trust them, though. So, I kind of ruled them out. [...] I’m thinking it’s someone just because of my genotyping, someone that had developed resistancy [sic], gone off and on meds, whatever, and I got it from them.”—25 years old, acute infection

This participant put together a number of pieces of information to identify a time when he thought he was likely infected. For example, he described that information he learned about his HIV genotype after he was diagnosed led him to believe he got HIV from someone who did not know his HIV status or was using his HIV medications inconsistently.

Some participants described the sexual encounters that they attribute to their HIV infection were with first-time sexual partners they had recently met in bathhouses or gay clubs. At the same time, many other participants believed they became HIV-positive through an ongoing casual sexual relationship (e.g. friends with benefits or fuck buddies). In some cases, these participants knew that their partners were living with HIV. Additionally, a number of participants attributed their likely HIV infection event to anal sex they had while away for vacation or work.

Most participants believed that they were exposed to HIV during receptive condomless anal sex, and many could identify a specific instance. About a third of participants said that they used a condom during the first part of sex, but it was removed part way through, either to maximize pleasure or because it broke. Some participants recounted scenarios including condomless receptive and insertive anal sex in partnered or group sex encounters. A few participants said that they were infected during “rough” oral sex with ejaculation or after dental work.

Figure 2.
Substance use with sex in the four weeks before diagnosis, results from the first questionnaire (n=25)



Substance use

Data from the surveys men completed, presented in Figure 2, show that many participants used substances (including alcohol). Among those men who use substances, many were using them during sex within the 4 weeks leading up to their diagnosis.

During the interviews, just under half of the participants described using substances before or during the sexual encounter that led to them becoming HIV-positive. Of the men who said they were using party drugs at the time of the specific sexual encounter that likely led to HIV transmission, the majority said that substance use increased risk taking. Some of our participants talked about crystal meth as a substance that increased sexual risk taking:

“When you’re on crystal meth, you...Sex becomes, you just... It’s, I don’t know how to explain it. It’s just so important to get that cock inside of you, that you don’t give a fuck about anything but that guy that’s fucking you, or whatever. How, like, you’ve just... You’re just so horny and such a sex pig that you don’t take the precautions to protect yourself, which you normally would if you were sober.”—25 years old, acute infection

While this participant took responsibility for making choices that led him to seroconvert, he also said, “I know I would most likely be negative now if I would have never done crystal meth”. However, other men said that they continued to use safer sex strategies (such as asking about HIV status, insisting on condom use) while using substances.

Personal responsibility for seroconversion

Overwhelmingly, participants indicated they believed they played a role in the events that led to their seroconversion, and that they described their own responsibility for the scenario that led to their seroconversion. This sentiment was shared by most participants whether or not substance use was involved.

Many participants acknowledged their responsibility while also emphasizing that all partners involved in sex have some responsibility to prevent HIV/STI transmission. For example, one participant said, “there’s responsibility in both parties. I mean, I have to be responsible to, ensure that it’s safe sex” (55 years old, acute infection).

Another participant who had been in an ongoing relationship with someone who was HIV-positive stated, “It was an accident. It happened. It wasn’t anybody’s fault” (44 years old, acute infection). This participant, along with some others, did not place blame on anyone for HIV transmission.

Some participants also noted that their perception of responsibility for their seroconversion changed over time. One participant described that at diagnosis, he wanted to blame another person, and subsequently questioned if he needed to blame another person at all:

“But as time goes by and started looking at myself on what I have done, then I was able to see myself as the cause, not the other person. Cause I can blame the other person as much as I want, nothing is going to change in who may have, who that was. I could have been, used condom and made them put a condom on and still enjoyed the sex, right? But I didn’t do it, so.”—37 years old, acute infection

Figure 3. HIV test results expected at time of diagnosis

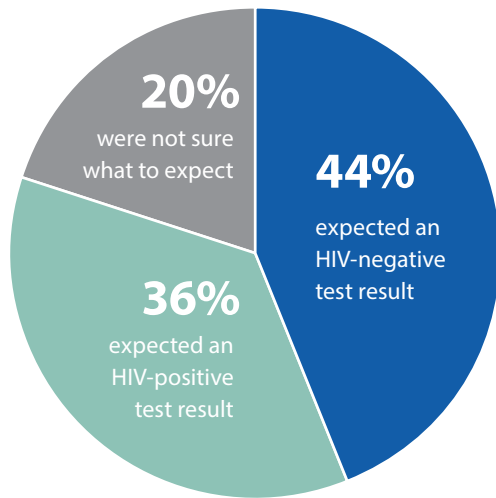
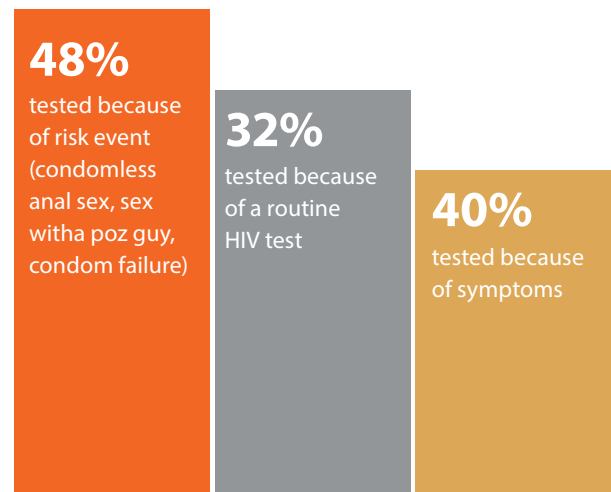


Figure 4. Reason(s) for most recent HIV test



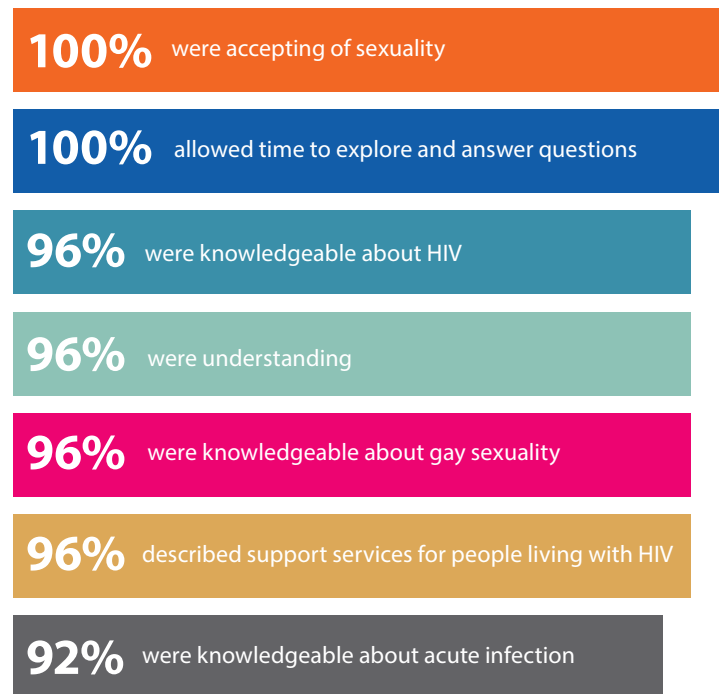
One participant initially felt as though his doctor had some responsibility for his seroconversion. This participant had sought post-exposure prophylaxis (PEP) following a sexual encounter he thought could lead to HIV transmission. However, after consulting his doctor he chose not to take PEP. The participant indicated his decision was influenced by his doctor’s medical advice, but ultimately was his own. He did not blame his doctor, but did emphasize he thought his doctor should act differently in the future.

Participants often acknowledged that drugs played a role in their seroconversion. One participant conceptualized his drug use as a choice that likely contributed to his HIV-positive diagnosis:

“So, like, I don’t blame crystal meth for me being positive – it’s choices that I made. But I know I would most likely be negative now if I would have never done crystal meth.”—25 years old, acute infection

Participants consistently acknowledged that their actions contributed to their HIV risk, and ultimately led to their seroconversion. In addition, many men remarked on the need for all parties involved in sexual encounters to engage in the negotiation of sexual safety.

Figure 5. Perception of person who gave HIV test results



What we found:

HIV Testing

Men's accounts of the testing experience that led to diagnosis

Figure 4 (see page 9) lists the most common reasons why men sought an HIV test at the time they were diagnosed. 48% of the men in our study sought an HIV test because they had identified a recent risk event. Other reasons for getting an HIV test included experiencing symptoms (40%), seeking a routine HIV test (32%), recommendation from a doctor (16%), long time since previous test (16%) and starting a new relationship (12%). Some of our participants indicated getting an HIV test on a regular basis was part of their sexual health, whether or not they had a recent risk event or another reason to get tested.

As shown in Figure 3 (see page 9), approximately 1/3 of the participants expected they would receive an HIV-positive test result. In the interview portion of the study, men cited knowing a partner to be HIV-positive and/or identifying seroconversion symptoms were reasons to expect an HIV-positive diagnosis:

“However, at the same time, that I was going back to get tested, I felt super-sick, and I never felt like that sick in my life. I had a high fever and I could barely move. And so I got tested at the same moment that I was probably seroconverting. . . . I think that’s why I knew before I got the results, that, you know, this was not just a flu.”—32 years old, acute infection

In contrast, participants who reported they were getting a routine HIV test frequently said they expected an HIV-negative test result:

“Well, I’ve been doing the HIV testing for the last eighteen years. Yeah, eighteen years. And I do it twice a year. And I always do it as a precautionary thing. And after eighteen times two, thirty-six results I got used to the idea that it’s going to be negative every time, right?”—37 years old, recent infection

Most men were told they were HIV-positive in a clinical setting during an appointment scheduled to provide results. In some atypical situations, men were given their diagnosis by phone. For example, one participant went into the clinic to get test results, but due to a delay his results were not available, and he had to phone in the next day to get his results. Some other participants said that receiving a phone call from the clinic was an indicator they had tested HIV-positive. One participant explained his perception of this policy:

“So it’s kind of ridiculous that you say, ‘Oh, I cannot tell you on the phone,’ yet I told you before that ‘I will only be calling you if there was something wrong’, right? . . .but I think it’s a lot better that you tell people either way we’ll call you, right? I mean, if things are good, we’ll call you. If things are bad, we’ll call you.”—32 years old, acute infection

Many men described a process of piecing together that they were HIV-positive that took place over time, and included, but extended

beyond, interactions with a health care provider. For example, a phone call from the clinic was enough to confirm some men’s expectations they tested HIV-positive.

Men consistently had positive impressions of the diagnosing health care provider and this was reflected in participants’ survey (see Figure 5) and interview responses. Further, men overwhelmingly reported that they had felt well supported at the time of diagnosis, and that the diagnosing health care provider acted appropriately. Some men described there were comprehension challenges at diagnosis, including some cases in which providers were uncertain about how to interpret and/or explain the acute infection results to patients.

Men reported different experiences of being told about their acute HIV infection. Many men were told they were in the acute HIV infection phase when they were given their test results; however, not all men received this information at diagnosis. Men who were told about the acute infection at diagnosis reported it was hard to understand the implications of this information at the time. Some men told us that they looked for further information about acute HIV after being told about it to improve their understanding.

At diagnosis, many participants recalled a health care provider giving specific information about acute HIV. For example, men remembered being told that they had a high viral load, that they were very contagious, or that they were more likely to transmit HIV during the acute phase. Some men told us health care providers told them to exercise caution in terms of sexual activity. For example, one participant recounted a nurse saying, “You’re really infective [sic], so to abstain, so for now, it’d be best to abstain until your viral load comes down.” For many participants who were sexually active, this information about being in a highly infectious period impacted their sexual decision-making. Many of these men talked about wanting to avoid transmitting HIV to their partners.



approximately 1/3 of the participants expected they would receive an HIV-positive test result

What we found:

Sex after HIV diagnosis

Men were asked to describe their recent sexual experiences during each of the four interviews in our study (see Grace et al., 2014a). Many men shared their thought processes about being sexually active as a man living with HIV. Figure 6 presents data about men's attitudes and perspectives on their sex lives since diagnosis from the first survey.

Most participants described a period of time after their diagnosis when they stopped having sex altogether for a variety of reasons. These reasons included a focus on adjusting to life with HIV, avoidance of possible HIV transmission to a sexual partner and concerns about disclosing their HIV status to a partner. However, men's HIV diagnosis was not the only factor that led to changes in their sex life. For example, one participant mentioned age and length of time in Vancouver as possible factors for changes in his sex life.

The length of time men abstained from sex following diagnosis varied, with some men returning to sex within weeks of diagnosis while others waited for a much longer period. Some participants found it difficult to abstain from sex and related that sex was an important part of their identity.

Over time, most men returned to being sexually active. Men described making decisions about returning to sexual activity based on a combination of biological (e.g. decreased viral load), psycho-social (e.g. addictions issues, mental health), and contextual factors (e.g. serosorting, relationship status prior to diagnosis). Many men who were diagnosed during the acute HIV stage waited until the acute infection phase ended and their viral load had dropped to have sex again.

Becoming Undetectable

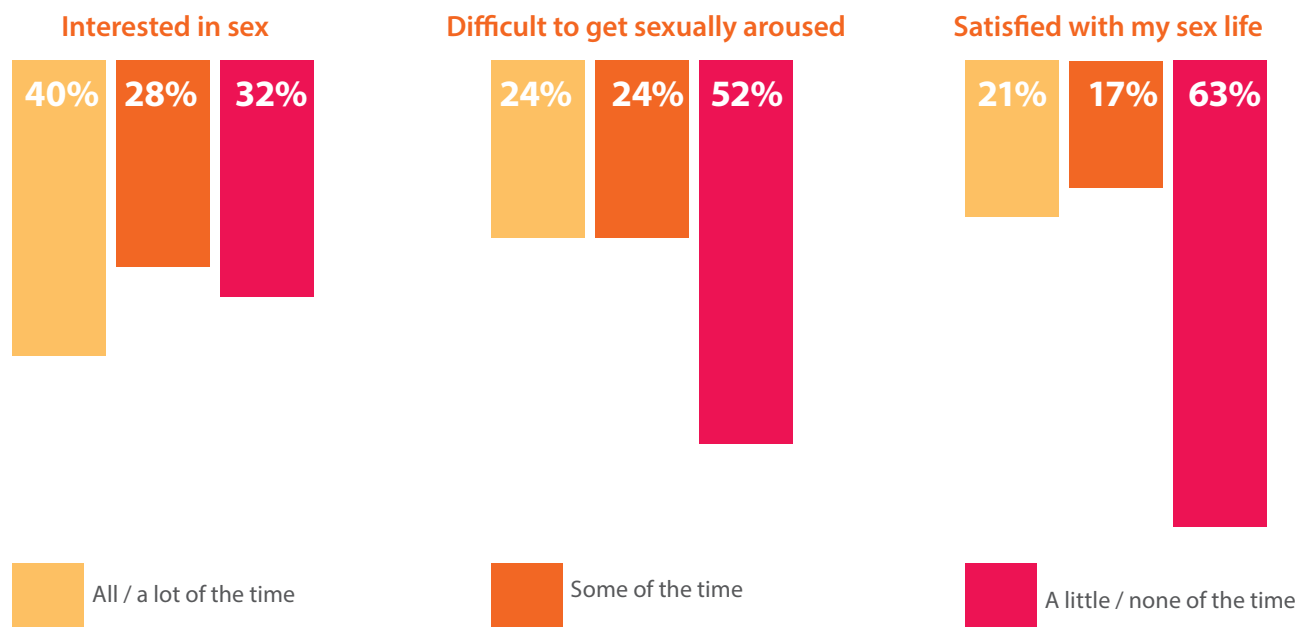
For many participants, a decreased viral load was an important factor in making decisions to return to sexual activity. Many men's narratives highlighted reasons why they wanted to become "undetectable". For example, some men knew they wanted their viral load to be undetectable as quickly as possible early on. In some cases, this motivated decisions to start HIV treatment:

"Everything seemed really good. My CD4 is over a thousand, and [my doctor] said... My doctor actually said that she wouldn't personally, would not put me on medication, just because [...] everything seemed to be really good. [...] So, but my attitude is, I just want to be undetectable. [...] I don't want to be, like, a public health risk. Which I am, I feel, unless I'm celibate, and I'm not going to be celibate. So I told her if she would approve putting me on meds, that I would like, I would rather that. And she had no problem with it. She understood where I was coming from. [...] So, being undetectable is important." —25 years old, acute infection

This participant described the importance of "being undetectable" in order to reduce the possibility that he would transmit HIV to a partner. In this scenario, he described initiating treatment although his doctor said starting treatment was not medically necessary at the time.

Becoming undetectable was also described to be important to some participants because it meant it would be easier for them to talk about their HIV status with potential sexual partners. One participant

Figure 6. Sex since diagnosis, results from the first questionnaire (n=25)



63% of men reported they were unsatisfied with their sex lives following diagnosis.

told us he was avoiding a conversation with an ongoing partner until his viral load was decreased:

“So I wouldn’t even, I have this one ongoing f-buddy [sexual partner] and he keeps phoning and e-mailing me, but there’s no way I would even consider having sex with him. You know, knowing my HIV count was so high. But knowing now that it’s getting basically down to that, you know, it makes it that much more okay. [...] Because there’s no way I would have entertained doing anything with anybody with two million [copies of HIV in their bodies]. You know, so. [...] That’s respect for myself and respect for others too, you know.”

—51 years old, acute infection

In addition to having conversations with ongoing sexual partners, participants also described that they saw references to “undetectable” or “undetectable viral load” used in profiles on online apps, such as Grindr, to describe HIV status. For example, one participant told us some men record their HIV status on these app as “undetectable”, actually, instead of that they’re ‘positive’ (35 years old, recent infection). This participant, as well as other men in our study, observed that there are new categories being used to describe HIV status beyond HIV-positive and HIV-negative.

For many participants, being told they were undetectable was an important “milestone” in their HIV diagnosis extending beyond just their sexual health. Men told us that knowing they were undetectable also had positive impacts on their physical, mental and emotional health:

“Once the doctor says to you that you are undetectable and you are, like, well on your way, and when you find out that you are this healthy, I mean, how do you go wrong? Where do you go wrong with that? Do you know what I mean? You feel like, ‘Okay, I can live again. I can go date guys.’...So mentally and emotionally, in so many different ways it relieves that block knowing, okay, I can tell you I am HIV positive, but I am undetectable which means it’s a lot harder to get it from me.”

—41 years old, recent infection

This participant’s narrative clearly indicates he knows that being undetectable decreases the possibility of HIV transmission to others. However, men reported varying degrees of confidence as to the impact of an undetectable viral load on reducing the possibility of transmission. Whereas some participants who were undetectable were comfortable having condomless sex with HIV-negative men, others remained concerned about the possibility of transmission.

Participants in our study discussed many different ideas about the significance of an undetectable viral load. To some degree, this differential knowledge reflects the challenges that men encounter in accessing and identifying consistent and reputable information in the context of newly emerging research about new biomedical approaches to HIV prevention. For example, men described differ-

ential knowledge of the possible health risks associated with having condomless sex with other HIV-positive men.

Interpretation of information about HIV viral load also varies between media, health care providers, and other professionals within the field. This information is then shared in a myriad of ways, including via word-of-mouth and various web-based sources. One participant observed there is limited availability of sexual health information for men living with HIV:

“...there is very [little] information for positive people about how damaging it can be to have unprotected sex with other HIV people. . . . I will say there is a huge, huge task or like work to do in terms of preparing positive people to not get their condition worse, you know what I mean? There is very little information. It’s more like, you know, ‘You’re negative? We can still save you.’ You know? But once you’re positive, it’s almost like, you know, ‘You’re off the track,’ right? And that’s a big lie, because positive people are now regular citizens, you know, like real people can live an entire life. But if you become, like, sexually promiscuous with other positive people, you’re making the strains worse.”—32 years old, acute infection

This participant articulated frustration about the limited availability of information for HIV-positive men about sexual health, especially in comparison to the information available for HIV-negative men. In particular, he described his concern about superinfection, wherein HIV-positive people may acquire another strain of the HIV virus from condomless sex, and the inconsistencies in information about the possible health and treatment impacts. Participants described differential knowledge of possible health risks associated with having condomless sex with other HIV-positive men.

Attitudes Towards Safer Sex

Participants reported positive attitudes towards safer sex, and overwhelmingly described a role for themselves in preventing HIV transmission. In fact, preventing HIV transmission featured prominently in men’s narratives about sexual decision making before returning to sex after diagnosis as well as after they were sexually active. Many participants emphasized their personal commitment to preventing the spread of HIV, and described a range of strategies to ensure they did not pass the virus, including using condoms and taking HIV medications consistently. 96% of participants agreed or strongly agreed with the statement, “It is my responsibility for not transmitting HIV.”

HIV Disclosure & Social Support

Support at diagnosis

Friends and family members, sexual and/or romantic partners, as well as counsellors and therapists obtained privately or through HIV service organizations were all listed by participants as important

88% of participants agreed or strongly agreed with the statement, “I have a responsibility to the men I care about to have safer sex.”

sources of social support following HIV diagnosis. Many men said that they had a strong social support network they could access when they found out they were HIV-positive. Many of these men described feeling well supported at diagnosis. Some participants said that close friends, sexual, and/or romantic partners who were HIV-positive were helpful to speak with as they had been through an HIV diagnosis themselves. For example, one participant described the value of having strong role models of people living with HIV in his support network:

“And my friend was with me, and he hugged me and held me, and I cried, and then I went and I slept. I went to bed for... And that was it. And then, and it was hard for a couple of days after. But, I have a really great support network of friends, most of whom are all positive. And they’re shining examples of the fact that this disease doesn’t need to slow you down or beat you down. So, I had that great support network.”

—25 years old, acute infection

Several study participants also said that having a relationship with someone known to be knowledgeable and compassionate about HIV was an important resource in coping with their diagnosis.

Some participants told us that the people in their lives were unsure about how to give support. In contrast, a few participants reported they had a very limited support network at the time of diagnosis.

Negotiating HIV Disclosure

Participants did not report forming an identity relating to an acute HIV diagnosis. Instead, participants said that they understood their identities as HIV-positive men, and reflected on this identity throughout their narratives. Men shared that they did not distinguish between men in various periods of HIV infection when they were HIV-negative, that not all men know about acute HIV infection; and that, “HIV is HIV” or “positive is positive”. In most cases, participants did not disclose they were in the acute HIV phase when disclosing their HIV status, although some men did discuss the issue of being acutely infected in the context of sexual encounters.

Most participants were highly selective of the people they shared their HIV status with, and reported that the notion of disclosing their HIV status was a significant source of stress and anxiety. Many men commented that pervasive HIV stigma makes it difficult to be open about their status; some participants noted that HIV stigma is seemingly based on misperceptions of living with HIV. For example, one participant described that his experience of HIV differs significantly from the words many people associate with HIV:

“I mean, I have an infection. I don’t feel diseased. I don’t think I am a diseased person. I think that is very emblematic of the stigma out there, and it doesn’t have to come directly from one person to another, I think, for me or for anyone else to feel stigmatized. So sometimes it is just people’s choices of language. Words are powerful things... The picture has changed... [...] I think a lot of attitudes don’t line up with where reality is now, and so again, in that sort of context, I mean, you definitely feel stigmatized. When people make remarks like that.”

—29 years old, acute infection

For many of our participants, disclosing HIV status in this context of HIV stigma and misinformation was a challenge. However, many participants reflected that they needed to disclose their HIV status to get the support they needed. For example, participants told us they sought support to cope with the initial shock of their HIV diagnosis, plan to tell others about their status, start HIV treatment, negotiate sex as an HIV-positive person, and deal with HIV stigma. Many men disclosed their HIV status to people in their lives on a ‘need-to-know’ basis.

While many participants reported they felt supported when they disclosed their HIV status, that was not everyone’s experience. A few men described judgemental and/or unsupportive reactions from those they approached for support following diagnosis. Negative responses from family members, friends, and partners included shock, disappointment, and judgment. In many cases, these negative reactions were from people who had outdated information about HIV relating to the health impacts of HIV and/or how HIV transmission occurs. Our participants also described both HIV stigma and stigma towards gay men as reasons for negative reactions.

A significant number of participants reported they did not feel comfortable disclosing their HIV status to certain individuals due to concerns that they would be treated or perceived poorly after disclosure:

“Well, fear is the main thing. I don’t want myself to be labeled as, I’m already labeled as, you know, ‘This is my gay friend, blah blahblah’. I don’t want to certainly have that ‘gay HIV positive’ friend. You know, like, I mean, I still want to be me. I still want people to see me for me, and there is a lot of misconceptions and a lot of fear and a lot of pity, perhaps, and sympathy. Like, things that I feel I don’t really want to deal with.” —34 years old, acute infection

Several participants compared their experience of disclosing their HIV status and their experience of coming out as a gay man. One participant recalls the same fear and uncertainty that accompanied his coming out experiences when thinking about having to disclose his HIV status:

Men reported side effects including nausea, vomiting, dizziness, and changes to their sleep patterns and/or appetites.

“It feels like, like I’m kind of out of the closet again, right? Exactly the same. I can relate those feelings to these feelings and I remember when I was nineteen years, being worried about how people, what was going on.”—37 years old, recent infection

Another participant highlighted the shame and stigma that is often projected onto gay men living with HIV:

“It’s not any one thing. It’s a whole quantum shift. It’s all shifted. None of it is the same. You know? It’s, like I said, it’s that invisible, there is just a curtain that’s come down, and it’s like coming out all over again. [...] It’s like, it’s okay that I’m gay, but the fact that I’m now positive, it’s somehow that it’s pariah, or tainted, or all this sort of stuff. There is a stigma that’s involved there.”—44 years old, acute infection

One participant noted that not being out about his sexuality meant he was not able to talk about his HIV status or seek support following diagnosis within his social network:

“Well, no, not really. I didn’t really want anyone to know, so, I’m not really open with my sexuality or anything, so, it’s kind of difficult. I did go talk to the guy from Positive Living, so that was pretty good.”—44 years old, recent infection

Most participants could identify at least one or more people they did not want to tell about their HIV status. Some men discussed the possibility of serious social consequences as a result of disclosing their HIV status. For example, one participant explained his reluctance to disclose his status in relation to the social exclusion experienced by a friend whose HIV-positive status became common knowledge:

“Only because I’ve heard, I’ve had a friend that I used to talk to, he disappeared but he was HIV positive. [...] A group of those people were quite nasty to him. Right now I don’t even know where he is now, he was pretty much outcast, and I feel really bad for him because, like, I lost contact with him. I don’t know how to get a hold of him, but I was pretty good friends with him and people kept saying, oh he goes to have sex and he doesn’t tell people that he has HIV, but you don’t know that for a fact unless you’re having sex with him. [...] The cruelty, it was just very cruel the way they talked about it and, plus everybody knew about it.”—26 years old, recent infection

In addition to reaching out within one’s social network, several participants reported seeking support elsewhere, such as a counsellor or therapist based in a private practice or through a publicly funded program (i.e. addictions counselling).

Participants were given an option to see a counsellor as part of their involvement in the study. While the vast majority of participants accessed the study’s professional counsellor for at least one session, most participants declined the option to utilize the peer counsellor service. Some men in the study reported they only needed HIV-related medical care after diagnosis, and were not looking for professional emotional or mental health support. Participants who reported having a good support network often indicated their preference for reaching out to their friends and/or partners due to having an established level of trust, familiarity, and comfort. In many cases, these existing support networks included knowing others living with HIV who were equipped with knowledge and resources to help cope with the diagnosis. Many of these participants reported little or no change in their social network or activities, and saw little personal interest or need in accessing HIV-specific resources or organizations.

HIV-Related Care & Physical Health

All participants reported feeling more conscious of their physical health and well-being after finding out they were HIV-positive, particularly in light of new HIV-specific health care needs.

Many participants reported feeling like their HIV diagnosis was a “wake-up call to personal health issues” (55 years old, acute infection). These men told us they intended to make this an opportunity to improve physical health and well-being. For example, men discussed changes to their health-related behaviours:

“I’m taking care of my health a lot. I’m having better sleeps. I’ve stopped doing drugs. I’m not drinking as much. I’m trying to eat healthy. So I’m thinking about myself more.”—31 years old, acute infection

Along with this participant, many others described struggles with addictions, or who talked about the frequent use of substances prior to diagnosis, reported a desire to reduce or give up drugs altogether to improve their overall health and well-being. One participant emphasized the impact of both relapsing into drug use and his HIV diagnosis:

“relapsing on crystal meth as well as becoming HIV positive, it’s changed my entire thought pattern. [...] I want to live a really long, healthy life [...] something’s happening. It’s changed me profoundly.”—53 years old, recent infection

Participants shared concerns including finding an HIV specialist for primary care, making decisions about HIV treatment, monitoring their viral load and side effects, adherence to HIV medications, and the

impacts of HIV on quality of life and life expectancy. For many men, one of the most challenging aspects of adjusting to living with HIV was changes to their daily routines:

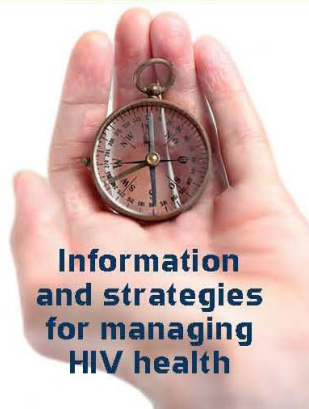
“Well, you have to adjust to having a chronic disease and I’ve always been extremely healthy so that’s been a big adjustment. I’m not a pill taker so every time I take those pills in the morning, I have to kind of steel myself to do it. So there’s that aspect.”—64 years old, acute infection

Short and long-term side effects from HIV treatment were a prominent area of concern, especially for men who had witnessed the effects of HIV medications first hand (i.e. friend or partner). However, despite these concerns, most men reported few difficulties incorporating their HIV medications into their daily routine, although some men reported experiencing side effects. A few participants reported changing their medications because of side effects, or problems with their liver or gastrointestinal systems.

Most men also expressed a high degree of confidence in currently available HIV treatment and their HIV caregivers to successfully manage their health impacts of their infection. However, some respondents reported concerns about the potential for other health conditions to develop in the future as a result of having HIV. One participant told us that most of the time, he did have a positive attitude, but also had some concerns:

“And you know, always the worry in the back of my mind that an opportunistic cancer or something is going to get me and make life really, really miserable, because I’ve lived through that with a couple of people and I know, you know, even the best treatments can’t be successful when you are immunocompromised and the last couple of years are pretty awful when you have some of these cancers. So that’s not something I really want to go through and so there’s always this worry.”
—64 years old, acute infection

Peer Navigator Services



Information and strategies for managing HIV health

Newly Diagnosed: Peer Navigators

Positive Living Society
of British Columbia
www.positivelivingbc.org

What we found:

Changes to life perspectives



Many men said they were surprised to find themselves feeling that being diagnosed with HIV led to positive changes in their lives. For example, some participants shared that learning they were HIV-positive provided new direction and motivation in life:

“Now, that’s basically, and basically, yeah, a blessing in disguise. [...] I was just fading and I just didn’t have, like it takes, it took an effort just to even want to eat or to do whatever, and then since I’ve been HIV positive I have been making, not all the time, but I’ve noticed little changes. I’ve been taking care of myself a way better. Things have changed for the better in a weird way.”—42 years old, recent infection

“The most important thing that’s changed for me? Probably the way that I see life, or live life, I guess. I’m definitely not going to take things for granted.”— 21 years old, acute infection

In contrast to the participants who talked about positive shifts in life perspectives, some men described feelings of shame and disappointment, as well as uncertainty as to the full impact of the diagnosis. Some participants discussed the challenge of being an HIV-positive gay man, given the societal expectation that gay men can and should avoid HIV infection. One participant described feeling a “burden of guilt” following diagnosis:

“There is a feeling of having disappointed my friends and my family. There is a sense of impending doom. I am personally torn between giving up on life and trying to find the best way to live the rest of my life, if I get the rest of my life. And it’s made settling in Canada much harder, but compulsory.”—46 years old, acute infection

This participant’s comments are also indicative of the ways an HIV diagnosis can affect future plans: in his experience, an HIV diagnosis has meant living in Canada is necessary to ensure access to HIV treatment and care. Other participants shared this perspective, highlighting that access to HIV services was a previously unnecessary health and logistical consideration. For example, some men reported turning down opportunities to study or work abroad because of limited access to HIV care outside Canada.

Some men who had relocated to Canada for short-term educational or professional opportunities reported that living with HIV would make it difficult for them to return to the places they had lived in previously. One participant shared that concerns about his treatment regime meant he turned down an opportunity for graduate schooling outside Canada:

“Yeah, [HIV treatment] was producing like abnormal liver enzymes and so they had to switch my meds. So when that happened I realized that, yeah, I mean, maybe I shouldn’t go to Europe, maybe I shouldn’t, you know... I should stay here and do my graduate work here because my doctor is here and it would be just too complicated if I go somewhere else for my studies.”—35 years old, recent infection

This same participant shared that he was “happy” with his decision, but recognized the impact of his HIV infection as a new factor in decision making about where he wanted to live.

Participants’ perceptions of the HIV-related changes to their life perspectives also varied by generation. For example, older participants frequently talked about their recent HIV diagnosis, in relation to the friends they had lost earlier in the epidemic.

What's next:

Implications for gay men's HIV-related care



These findings, which are based on interviews with participants and the surveys they completed, identified numerous opportunities for healthcare providers and researchers to strengthen the provision of HIV-related prevention, testing, treatment, and care. While our data is limited to gay men, these implications may also improve services for other groups of people living with HIV.

Participants' narratives indicated diverse experiences prior to diagnosis and in the following months after diagnosis. However, participants' narratives consistently illustrate the ways HIV impacts multiple aspects of health, including physical, social, mental and sexual health. Our participants' experiences of HIV-related risk, accessing testing and care following diagnosis were shaped by social determinants of health and happened in the context of participants' multiple identities, such as race, sexual identity, and socioeconomic status.

Some of these findings were included in the July 2014 Provincial Health Officer report, *HIV Stigma and Society: Tackling a Complex Epidemic and Renewing HIV Prevention for Gay and Bisexual Men in British Columbia*. This report includes several areas for action that build upon the findings from our study, as well as other data sources. Here, we present opportunities for health care providers and health promotion workers to continue to strengthen gay men's health.

New testing technologies lead to earlier diagnoses

Targeted use of pooled NAAT testing has been demonstrated to identify acute HIV infections effectively. Our study reveals the utility of this new testing technology among gay men and other men who have sex with men whose sexual activity includes condomless anal sex. Access to pooled NAAT testing is an important public health intervention for gay men, particularly for men who are at higher risk and/or when seroconversion symptoms are present.

Timely delivery of results to patients, along with a clear explanation of their meaning, maximizes the benefit of a pooled NAAT test as a secondary prevention tool. As such, implementation of new testing technologies must also include reviewing policies regarding the provision of test results to ensure they maximize the benefits of testing technologies.

Some findings from this study have also impacted the roll out of Get Checked Online, another new testing initiative in British Columbia that provides increased access to testing for gay men. Get Checked Online will include pooled NAAT and the campaign will be promoted using the same diffusion of innovation theory that informed *Hottest At The Start*.

Promotion and education are key to the success of new HIV technologies

Both gay men and their health care providers need to receive promotional messages about new HIV technologies in order to maximize their uptake and ensure they can be accessed in a timely manner. Participants' experiences in our study demonstrate the need for clear information about technologies such as PEP, as well as the pooled NAAT.

Men have many sources of information relating to new developments in HIV-related technology. It is important men are able to access reliable, consistent, and up-to-date information about these developments. For many men, health care providers are one source of this information. As such, it is important that knowledge translation efforts include providers, and that these providers are confident in their knowledge about when to use these technologies, how they work, and how to interpret the results. Further, these professionals should also be given opportunities to practice explaining these technologies to their patients.

Retaining new, complex information can be challenging at the time when an HIV diagnosis is provided. As such, not all participants with acute HIV had a clear understanding of how the acute HIV infection phase impacted their own health and/or the possibility of transmitting HIV. Opportunities to provide education about the acute HIV infection period extend beyond diagnosis, and include follow up appointments with health care providers, as well as programs such as the Peer Navigator program.

Criminalization of HIV non-disclosure

In Canada's current criminal law landscape, people living with HIV who engage in sexual activity under certain circumstances without disclosing their HIV status may be subject to criminal charges.* We anticipated that the implementation of pooled NAAT technology may make it easier for men to identify a specific sexual partner that led to seroconversion, and that this may make it easier for men to pursue criminal charges (see Grace et al., 2013).

Men consistently identified a likely seroconversion event using biomedical reasoning. However, rather than blaming their sexual partners exclusively, men overwhelmingly accepted personal responsibility for the circumstances that led to their seroconversion.

To our knowledge, none of the men involved in our study were involved in criminal charges. This experience also reflects the fact that MSM represent few cases of criminalization of HIV non-disclosure in Canada (Mykhalovskiy et al., 2010). While our study did not specifically ask men to discuss the criminalization of HIV non-disclosure, men's narratives of personal responsibility may be one reason criminal charges were not pursued.

Quality primary care and social supports for newly diagnosed men

Concerns about primary health care, managing HIV-related health, and adjusting to life with HIV are common following diagnosis. As such, it is important to ensure providers who give an HIV-positive diagnosis are able to make referrals to primary care and social supports, and that newly diagnosed patients are supported in accessing these services. Following referrals, it is important that individuals who access services are seen in a timely manner.

*In 2012, the Supreme Court of Canada determined that people living with HIV have a duty to disclose their HIV status to sexual partners before vaginal sex, unless they are both using a condom and have a low viral load (Canadian HIV/AIDS Legal Network, 2012).

Limitations

Study participants were recruited from men who were given an acute HIV diagnosis or a recent HIV diagnosis at one of several clinics which serve a high proportion of gay men throughout Vancouver. These study findings do not represent all HIV-positive gay men. It is also important to note that men who are diagnosed within days or weeks of HIV acquisition may engage in care differently than those who are diagnosed at a later point. Further, data collection began after men were diagnosed with HIV, and we do not have access to men's accounts of their possible seroconversion event or their HIV testing experience prior to their diagnosis. However, the data we report on provide insight into these men's experiences that have implications for providing diagnoses to gay men and service delivery for gay men newly diagnosed with HIV. For specific limitations of each analysis, please refer to the journal articles available via acutehivstudy.com.

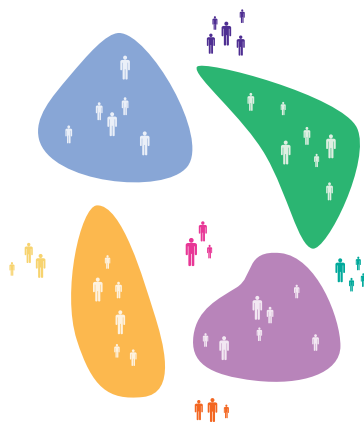
Conclusion

These findings highlight the strengths of current initiatives to provide timely HIV testing, diagnosis and HIV-related care to gay men in our communities, as well as provide opportunities for growth. HIV stigma continues to impact men's experiences of diagnosis and accessing care. It is crucial to increase men's awareness of initiatives that support gay men's mental and social health, particularly following an HIV diagnosis.

The men who participated in our study provided many insights for health care providers, people engaged in health promotion, and public policy makers to consider. We thank these men for their participation in our study.

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- More information and analysis about The CIHR Team for the Study of Acute HIV Infection in Gay Men, including a backgrounder on the study and an up-to-date publications list and summaries of the articles, is available online at www.acutehivstudy.com. The website also includes a listing of academic publications which include fuller descriptions of the methods and limitations of our analyses, as well as more in-depth results.*



Understanding the impact of HIV among
recently diagnosed gay men in Vancouver
