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Grace, D; Steinberg, M; Kwag, M; Chown, SA; Doupe, G; Trussler, T; Rekart, M; Gilbert, M (2014) Diagnostic Technologies in Practice: Gay Men's Narratives of Acute or Recent HIV Infection Diagnosis. Qualitative health research. ISSN 1049-7323 DOI: 10.1177/1049732314549813

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# Diagnostic Technologies in Practice: Gay Men's Narratives of Acute or Recent HIV Infection Diagnosis

Qualitative Health Research  
2015, Vol. 25(2) 205–217  
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DOI: 10.1177/1049732314549813  
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## Abstract

Diagnosing HIV-positive gay men through enhanced testing technologies that detect acute HIV infection (AHI) or recent HIV infection provides opportunities for individual and population health benefits. We recruited 25 men in British Columbia who received an acute ( $n = 13$ ) or recent ( $n = 12$ ) HIV diagnosis to engage in a longitudinal multiple-methods study over one year or longer. Our thematic analysis of baseline qualitative interviews revealed insights within men's accounts of technologically mediated processes of HIV discovery and diagnosis. Our analysis illuminated the dialectic of new HIV technologies in practice by considering the relationship between advances in diagnostics (e.g., nucleic acid amplification tests) and the users of these medical technologies in clinical settings (e.g., clients and practitioners). Technological innovations and testing protocols have shifted experiences of learning of one's HIV-positive status; these innovations have created new diagnostic categories that require successful interpretation and translation to be rendered meaningful, to alleviate uncertainty, and to support public health objectives.

## Keywords

health care, users' experiences; HIV/AIDS; illness and disease, experiences; knowledge construction; technology, medical

Persons with newly acquired HIV infections experience very high viral loads in the first 2 months following exposure, and are relatively much more infectious during this acute HIV infection (AHI) period (Cohen, Shaw, McMichael, & Haynes, 2011; Gilbert et al., 2013; Pilcher et al., 2007). Although estimates of the proportion of new infections attributed to AHI vary widely, this might approach 50% (Brenner et al., 2007; Cohen et al., 2011; Powers et al., 2011). Unfortunately, current standard HIV testing approaches rely on the presence of sufficient antibodies to the virus, an immunological process that takes between 3 and 4 weeks, before showing a positive result (Cohen, Gay, Busch, & Hecht, 2010). As such, although individuals might test negative during this HIV antibody window period, they could in fact have AHI. Based on these test results, individuals might engage in sexual practices (e.g., condomless anal intercourse) with sexual partners assumed to be HIV negative under the assumption that they are themselves HIV negative.

The inability to diagnose very recently acquired HIV infections, and concern about onward transmission during this period (Brenner et al., 2007; Cohen et al., 2011; Powers et al., 2011), has prompted the expanded development and use of novel HIV testing technologies (Yerly &

Hirschel, 2012). In the Canadian context, pooled nucleic acid amplification testing (NAAT) technologies, capable of identifying persons with AHI in clinical settings prior to the appearance of detectable HIV antibodies, are currently available only in Vancouver (Gilbert et al., 2013).<sup>1</sup>

New HIV testing technologies reshape what are understood as specific stages of HIV infection, such as AHI, and how one knows about periods of heightened transmission risk during the initial phase of infection. Diagnosing HIV during this early stage of infection is a technologically enabled process of assessment and categorization. As Rosengarten (2005) put it, "The objects of medical science are materialized and delimited by the

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means by which they are made known” (p. 71). In our study we sought to examine new HIV testing technologies in practice (e.g., the means by which a client is given an AHI diagnosis), in clinical settings where HIV tests are situated within the spectrum of technologies and networks of providers and client users in which they are embedded (Epstein, 1996; Timmermans & Berg, 2003).

Although a number of studies outside of Canada have demonstrated the successful implementation of new testing protocols to detect AHI, little attention has been given to the range of challenges these new testing services have posed to clinical practice. These include challenges to clinical providers to understand and explain the full meaning of these technologies to their clients, and those posed to health promoters to successfully mobilize target populations to optimally engage these new testing opportunities soon after the occurrence of risk events.

An important study that attempted to assess the former challenge was the National Institute of Mental Health (NIMH) Multisite Acute HIV Infection Study, which explored the understanding of AHI among 34 individuals with a recent diagnosis in six U.S. cities (Remien et al., 2009). Their in-depth interviews with these individuals found a marked lack of awareness of AHI-related retroviral symptoms and misconceptions regarding AHI testing technologies. Our research extends the work of this NIMH study to appreciate the lived experiences of gay men newly diagnosed with a recent infection in Vancouver, British Columbia. We lengthened the follow-up period and number of in-depth interviews with participants (as compared with the NIMH study) from 12 weeks postdiagnosis to one year and from two interviews to four.

The findings presented in this article are situated in the context of our larger study. In this research we set out to explore the feasibility of using new testing technologies to detect very recently acquired infections as a first response to event-specific risk, and how this might result in enhanced detection and follow up of gay men. We chose to focus our study on this population given that the majority of new HIV diagnoses in Canada are among gay men and other homosexually active men—a group that has been disproportionately affected by the epidemic since its onset (British Columbia Centre for Disease Control [BCCDC], 2012; Grace et al., 2014; Hogg et al., 2012; Public Health Agency of Canada [PHAC], 2010). Overall, gay men have demonstrated high levels of HIV testing in British Columbia. The high rates of HIV incidence in Vancouver among this population offered opportunities for targeted testing approaches.

Although much HIV research remains dominated by quantitative methods such as cross-sectional population surveys, Dowsett (2007) rightly pointed out that in the field of gay men’s health research, “the advent of the

human immunodeficiency virus (HIV) epidemics in many parts of the world proved a significant stimulus in calling forth qualitative methodology to assist in comprehending one of the most complicated public health problems of the modern period” (p. 420). The qualitative data we drew on in this analysis elucidated the dialectic of a new HIV technology in practice (Timmermans & Berg, 2003) by considering how participants’ accounts reveal aspects of the relationship between advances in HIV diagnostic technologies and the users of these medical technologies (e.g., clients and providers). Gay men’s accounts of their everyday lived experiences provided us with “entry” into processes of social coordination (Grace, 2013b; McCoy, 2005).

Although the focus of our analysis is patient narratives of HIV testing technologies “in action” (Latour, 1987), in this article we demonstrate the ways in which men’s diagnosis experiences speak to how HIV tests must be examined alongside the “entire gamut of mundane to sophisticated technologies, drugs, and even managerial instruments such as patient records” (Timmermans & Berg, 2003, p. 104). As Timmermans and Berg noted, “technologies are embedded in relations of other tools, practices, groups, professionals, and patients and it is through their location in these heterogeneous networks that treatment, or any other action, is possible in health care” (p. 104). In our analysis we take into consideration that the insights one has regarding one’s diagnosis experience can illuminate complex matters of social structure and institutional coordination (Pierret, 2003). As such, we endeavored to move beyond social scientific criticism to offer opportunities for the improved implementation of diagnostic technologies in everyday clinical practice.

## Method

The qualitative narratives drawn on in this analysis were collected concurrently with quantitative data as part of our longitudinal multiple-methods study design (Creswell, 2003). Where relevant, limited demographic and behavioral data collected during the baseline quantitative interview are used to describe the sample. In this article, we focus on the qualitative data collected at the first interview that related to men’s discovery and diagnosis of an acute or recent HIV infection.

## Procedure

Gay, bisexual, and other homosexually active men diagnosed with acute or recent HIV infection during the period April 2009 to June 2012 were offered entry into a Canadian Institutes of Health Research (CIHR) Study of Acute HIV Infection in Gay Men.<sup>2</sup> AHI cases were defined as those in which HIV RNA was detected using

NAAT in the absence of confirmed detection of HIV antibody (Gilbert et al., 2013). Recent cases were defined as those with a confirmed detection of HIV antibody and a negative HIV test during the previous 12 months. All study participants had to meet the following additional criteria: (a) self-disclose having sex with men (includes gay, bisexual men, and other men who have sex with men) at the time of their HIV test; (b) aged 19 years or older; (c) speak English; and (d) able to fully comprehend the study consent form. Participants were provided an honorarium of \$25CDN for each study component they completed (i.e., both the quantitative surveys and qualitative interviews). Ethics approval for this study was obtained from the University of British Columbia Research Ethics Board.

### Participants

In total, 25 HIV-positive men took part in this study. At the time of enrollment, the majority of participants were older than 30 years (80%), with the mean age being 39 years. Most men lived in Vancouver (79%) and self-identified as gay (96%), leading us to use this category to describe the sample of men interviewed.<sup>3</sup> The majority of participants were employed full time (64%); however, there was considerable diversity among those who were not (e.g., disability, student, unemployed). Most men reported completing college or university (64%), and the mean income was between \$30,001CDN and \$50,000CDN. Participants identified as White (72%); Asian (12%); Hispanic (8%); Aboriginal, First Nations, Metis, or Inuit (4%); and African/Black (4%).

### Data Collection

Interviews were conducted by the first and third authors in a community sexual health clinic located within a central gay area of Vancouver. During the course of interviews, interviewers probed further to explore emerging information regarding the lived experiences of participants. Interview guides were developed by the study investigators in consultation with community partners. Baseline quantitative surveys were administered after a median of 35 days postdiagnosis (range 8 to 128 days). The first qualitative interview was conducted approximately 14 days after study enrollment.

In-depth interviews focused on the following key domains: diagnosis experiences of newly diagnosed gay men; likely site(s) of HIV infection and risk assessment; perceived responsibility for HIV prevention and evolution of HIV views; experiences with the disclosure of HIV status, stigma, and social support; sex as an HIV-positive gay man; life as an HIV-positive gay man, including current and perceived future impacts on social

and sexual life; reasons for seeking or not seeking peer counseling; and the self-perceived impacts of research participation on study participants. The first two domains were the focus of baseline interviews, with the remaining domains being explored during three follow-up interviews (completed approximately 45 days, 180 days, and 360 days after enrollment in the study).

### Analysis

Qualitative interviews were digitally audiotaped, transcribed verbatim, and reviewed by a research assistant for accuracy. The coding approach to this baseline data was consistent with thematic analysis (Braun & Clarke, 2006). NVivo 8 was used to help manage the interview data and explore emergent themes (Bergin, 2011). In the first phase of the data analysis we reviewed 10 transcripts as a qualitative coding team to familiarize ourselves with the dataset, note initial trends and ideas, and create a provisional codebook. These codes were developed from a combination of overarching domains in the interview guide as well as key themes that emerged during the review of transcripts.

In the second phase of analysis, codes were applied to the whole dataset and refined as needed. At this stage, interviews were independently coded by two persons from an interdisciplinary team of researchers, including a PhD-level sociologist, MPH-level researcher, MD-level epidemiologist, and the study coordinator, who has experience in public health and community-based research with gay men. Codes were compared across interviews and the qualitative analysis team reviewed coding discrepancies until consensus was reached (Creswell, 2003; Mason, 2005). Memos were recorded throughout the iterative process of coding to capture analytic insights about emerging themes and relationships across the narratives.

It is important to note that the earliest study participants were among the first people to receive NAAT tests in Vancouver because this technology was implemented concurrently with the first phase of participant enrollment. Client experiences, including those of study participants, were used iteratively to improve provider education and clinical practices over the course of the study.

### Findings

#### *Experiences of HIV Testing and Learning of One's Diagnosis*

In this first section of the results we discuss three related themes that emerged across the narratives of men with an acute or recent infection ( $N = 25$ ): (a) testing rationale and

expectation of results; (b) delivery of results over the telephone (officially and unofficially); and (c) diagnosis in clinical settings. Among other important insights, men's narratives reveal the ways in which their experiences of learning of their HIV test results were embedded in social relations of other technologies such as past HIV testing experiences and the practices and processes used to manage patient records and regulate the disclosure of positive test results.

**Testing rationale and expectation of results.** The most common reasons for testing noted by men in this sample included one or more of the following: 48% reported a recent sexual encounter perceived to be risky (e.g., having unprotected, condomless anal intercourse with an unknown status or HIV-positive partner; the condom broke or came off); 40% reported experiencing symptoms of seroconversion illness (a flu-like illness commonly associated with very recently acquired HIV infection); 32% said they engaged in testing as part of their routine testing activity. Other common reasons reported for HIV testing included being recommended for testing by their doctor because it had been a long time since their last test (16%) and starting a new relationship (12%). This sample was composed of men with diverse expectations and rationales regarding what their test results would indicate (44% expecting a negative test result, 36% a positive test result, and 20% noting that they were not sure).

A combination of knowing a partner was HIV-positive and the experience of flu-like symptoms led a number of men to say they expected a positive test result. One man expressed that these "two ideas together equaled a pretty safe assumption." For participants who were diagnosed in the acute period and experienced seroconversion illness, these symptoms frequently were reported as their reasons for getting tested for HIV and informed what they expected their results to be. For example, one participant described that his experience of seroconversion symptoms meant that he was quite sure of his HIV-positive status prior to receiving his 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. And I had read about it because obviously I was very concerned about it, so I read a lot of information on the Internet on how it happened. And when I got that flu, and then I was so sick, I barely moved; and actually I went to [hospital] because I was burning fever. And I just knew that that was it.

Those participants who said that they tested for HIV as part of their routine testing most frequently talked about the expectation of negative test results. Some men who

described this testing rationale articulated that past experiences with receiving HIV-negative test results informed the expectations they had at the time of diagnosis:

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?

These narratives reveal that about half of the men interviewed received a positive diagnosis they were not expecting. Unlike men anticipating they would be given a positive diagnosis, many of these men reported that they did not perceive themselves to be "at risk" of HIV infection and/or they "got used to the idea" that test results would always be negative.

**Delivery of results over the telephone.** Most participants said that they were officially told of their test result in a clinical setting; however, a number of men reported being told of their HIV-positive status over the phone while they were at work, at home alone, with a partner, or with family. Many of these men indicated that receiving a phone call from a clinic or their physician's office, or simply seeing the clinic name come up on their caller ID (identification), either confirmed their expectation of an HIV-positive test result or was enough to reveal their status, even if they did not have prior concerns.

One participant discussed receiving a voicemail message from the clinic while on vacation, asking him to call back. The participant reported that he returned this call and was asked to visit the clinic to provide another blood sample. Although he was not given his test result over the phone, he explained that the phone call signaled something was definitely wrong: "But at that moment I knew something was wrong... I said, like, you know what? I think I'm positive. Most likely." Despite this initial suspicion, the participant described that he remained uncertain regarding the meaning of the phone call. He said he later came to reason through talking with his partner, with whom he continued to have condomless anal sex, that he would have been told he was HIV positive when talking to clinic staff if this had in fact been the case.

For another participant, his HIV-positive test result was given to him over the phone while he was at work:

They said it wasn't common practice to give numbers out to get results. But she had given me hers, and she told me to call on the particular day... So I did call to get my results, so I didn't have to go back there again.

The participant said that he had expected the test results to be negative—"I hadn't done anything different prior to any other test, like, I was always using condoms"—and

went on to describe the process of getting his HIV-positive diagnosis over the phone from another nurse, who read off the results from a form:

He read off the list of, “Okay, negative, negative, negative, negative.” And then the last one was, “HIV positive.” He said, “You’re positive for HIV.” And at that point it was, like, everything just went [makes noise like an explosion], like, just kind of blank. I was there for...I was in the supply room, and I had to go back to the front desk and do my job.

For this participant, receiving his results in this way created a difficult situation for him at work. He had to deal with the emotional reaction of learning of his HIV status while not wanting to disclose this information to colleagues. He also was not able to take advantage of the immediate support offered by the health care professional who provided his diagnosis.

In another instance, one man explained that although he had an extreme aversion to receiving his test results over the phone, a delay in processing his test meant that he was unable to talk with someone in person:

I was told that the [HIV] results would be back in seven days, or something like that. In reality, they weren’t back in seven days. They actually were back in eight days. So when I went back in seven days and the results weren’t in, that was the worst thing that could have ever happened to me, because I had to wait another twenty-four hours. So I, for me, that was a huge thing. It was, like, you know, I worked my way up to going in. I didn’t definitely want to hear it over the phone; I wanted to go in first face to face, and turns out it wasn’t there. So what I’d have to do the next day is they called me on the phone.

Finally, one participant’s experience with discovering his positive HIV status over the phone led him to develop a strong opinion that the current system for delivering results should be reviewed to standardize the delivery of results:

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 [that] 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.

*Delivery of results in clinical settings.* Men also highlighted the experience of officially learning of their HIV test results and interacting with health care providers in a clinical setting at the time of diagnosis. Learning of their results produced varying feelings for participants, including the alleviation of uncertainty. For one participant who had been very ill prior to diagnosis, relief was the main factor in his initial reaction:

In a way, I felt relieved, because at least I knew and at least the uncertainty was over. So now there was like, a game plan we could follow to get on with my life. For the record, two weeks before that, when I was waiting for results, it was like, you’re kind of in a state of limbo, not knowing what’s happening with your life. And, I mean, it may sound kind of flippant, but I don’t worry about getting HIV any more. It’s one less stressor in my life.

Overall, participants noted feeling extremely well supported by the professionals who gave them their test results, and believed they were offered adequate support services at the time of diagnosis in a health care setting: “I was treated with a lot of respect, with a lot of love and a lot of compassion. I think compassion is a main word. So, no, I would say I wouldn’t change anything.” When considering the professional who gave him his test result, another man said,

I identified with him; we were kind of cut from the same cloth. There was a lot of understanding. I already knew a lot of information....He was very helpful, yeah. He was awesome for that kind of an experience.

That being said, a few participants reflected on possible areas for improvement in their clinical experience. For example, two participants reported learning of their results indirectly, rather than through communication from a clinician (e.g., seeing their positive test result displayed on a computer screen in the clinic room).

### *Making Sense of an Acute Diagnosis*

Participants who received an acute diagnosis ( $n = 13$ ) reflected on how they felt when they were told they were in the acute phase of HIV infection, and the extent to which this additional information informed their diagnosis experience, including their reaction to being HIV positive. Analysis of men’s narratives of the “acute” impact on their experience of initially learning of their diagnosis revealed five interconnected themes: (a) initial provider and patient uncertainty about HIV test results; (b) uncertainty about the meaning of acute infection; (c) relationship to starting treatment; (d) relationship to having sex; and (e) relationship to identity formation as an HIV-positive man.

*Initial provider and patient uncertainty about HIV test results.* Participants who were in the acute phase of infection at the time of diagnosis shared their perception that the new “early” testing technology created varying degrees of uncertainty for providers regarding the initial interpretation of their HIV test results. When first discussing their HIV test results, some men recounted that their health care providers seemed “uncertain” or

“unclear” about how to interpret results they had been given, both at the time of diagnosis and during other testing procedures. Many participants noted that this uncertainty as to their HIV status increased their anxiety around the diagnosis experience and their own understanding of their HIV test result.

For example, one participant recounted that his doctor initially found the HIV test results confusing, and then assured him it was likely to be a false positive. The participant said his doctor later requested additional testing:

Everything was good until he got to the HIV test and he looked very puzzled because the results were confusing or conflicting, and the results came back negative. However, there was uh, one other, blood screen test which is very new, was the early detection. [It] showed the presence of antibodies, so, he didn't seem too concerned about it, um, and I wasn't either 'cause he was saying that there, you know, could be false [positive] and, and um, possibly people that have, um, arthritis or inflammatory problems like I do, um, that there could, pose false [positives], or, or whatever. So, um, left the office that day. And uh, I didn't really not, really too concerned about it. But then I got a phone call from him...and he said that there was the possibility of an early infection. That he wanted me to do more blood work, uh, the next day. Uh, so I was very concerned and very upset at that point. Uh, confused and uh, didn't know what to make of it.

The same participant went on to report his impression that his health providers did not have enough information to interpret his test results, and that he received conflicting information about his HIV status:

I don't think they know enough about the, that the ability to test it, [if] there's been a recent infection. Um, when I went in that same time, I had to have some inoculations done and the nurse there went over my blood work results and he, uh, asked me how long have I been on meds [medications]. And I said, “Well, I haven't been on meds.” And he said, “Well, that's unusual, because your blood work shows that you're undetectable and your CD4 is normal.” And I said, “Well, you know....” He was puzzled and then he said it “was bull, maybe it's not really an infection.” And, and, so again you have this whole confusion as to “What am I?” you know, “Am I positive or not positive? Am I, have I been exposed to the virus and um, it's just sitting there, or was I exposed a long time ago and my body somehow fought it off and there's just antibodies left there?” You know, I didn't know anything. Um, and they didn't know....So I'm just sitting like a time bomb here, waiting just to find out, when's this thing going to erupt?

In addition to uncertainty among providers, participants' understanding of the meaning of receiving a “partial” or “provisional” positive test result varied. One participant understood that he had a “partial-positive”

result from the NAAT test and that there was still the possibility that it might have been a “false positive”:

That it was only a partial-positive mode, that it may have been a false positive was, you know, it made me hope for the best but fear for the worst. You expect the worst, but you keep praying that it's a fluke, and that it's a false positive.... So in a way, you did, you delayed dealing with reality, I think.

*Uncertainty about the meaning of acute infection.* Different participants reported being told about their acute status at different points in their care, with some men being notified immediately at the time of diagnosis and others discussing this additional information at a later point with their primary care provider or not at all. For many participants, the meaning of acute infection was unclear, with some undertaking additional research either prior to diagnosis or after receiving their acute diagnosis. That being said, following their diagnosis, overall men described knowing they were in a period of extremely high viral load regardless of their knowledge of acute infection.

Participants who were told about their acute infection at diagnosis often noted that they were not able to fully “absorb” the information at the time. For example, one man explained that although his doctor was thorough and patient, at the time of diagnosis, “emotionally, I wasn't able to probably hear.” Another participant said that although he did not remember any discussion about acute infection at the time of diagnosis, his doctor “may have [discussed it] and I just...my mind was elsewhere. But I don't remember him saying it.”

For men who engaged with this information about their stage of infection, many reported being unclear about the significance of the acute component of their HIV diagnosis:

At that point I still wasn't exactly sure what acutely infected meant. I know it's a high viral load, which means the virus was extremely, you know, high. My immune system was extremely low, obviously. So I was just worried about getting sick with a flu or something....I was just confused, you know. I didn't really know, understand what exactly my stage was, and you know, I was just kind of worried about it. But they said that they caught it early enough that they can, you know, give me lots of help with it, so, so, yeah....They just mentioned some numbers to me, which didn't really make sense.

Some participants reported seeking information about acute HIV infection online, both prior to testing and after receiving their acute results. For example, one participant noted his partner took on additional research: “He knew a lot about, like, since the phone call [when I received my diagnosis]. He started researching online.” Another man

recounted seeking more information about seroconversion symptoms and the acute phase of infection when he was feeling ill:

To be honest, I didn't even know a lot about the acute phase until I was actually feeling sick, and like, "Crap, what the fuck is this?" I'm like, "Is this HIV? Is this the acute sickness?" And I looked it up, and did all my research.

One participant explained that he first became aware of acute HIV infection through a locally organized HIV-testing advertising campaign—called "Hottest at the Start"—led by our community partner, Health Initiative for Men (HIM).<sup>4</sup> He noted that the campaign informed his overall diagnosis experience and might have influenced his decision to get tested months after looking up information on the campaign online (Gilbert et al., 2013). Because of this prior information, he described assuring the nurse at the time of diagnosis that he was knowledgeable about HIV and did not need her to provide additional explanation regarding viral load.

A number of men reported that the terminology of "acute" infection was not used when their diagnosis was initially relayed to them. In some instances, participants discussed that their provider focused on the concept of viral load rather than talking about their stage of infection in terms of acute status:

No, he didn't use those terms, "acute," no. But he basically diagnosed it from the moment it started so I am sure we are all on the same page here.... Oh, he drew some charts on a paper. He had charts and just told me how that, how my level is going to be in probably, you know, some people go up to ten million in their count, and my rate is going to be up here, and that my body is fighting it and eventually, I was there for almost like an hour and drawing all the charts, where I am right now and where I'm going to be in a month from now. And he's been very accurate. Because what I read the first time it was like a two-and-a-half-million count, and today is twenty-two thousand, so it's a huge drop in three weeks or four weeks. So the next time he's predicting it's going to be a thousand. So he said by August it will be zero. So, and I realize he also does a lot in his field, but he's been very accurate on his predictions.

Finally, for some men, receiving information about their acute or early HIV infection stage at the time of diagnosis was described as a welcome "relief" and helped to explain symptoms they were currently experiencing or had recently experienced:

Being told I was in the acute phase helps explain some things, like why my energy levels were lower, why I was still, you know, still getting night sweats, why I was feeling just kind of run down in general. [It was] because my body was working so hard to try and fight off this infection. So yeah, having an understanding that, okay, this is normal

during the early phase has definitely helped putting my mind at ease that this isn't going to be forever, that I sort of have to get through this initial stage.

*Relationship to starting treatment.* Among participants who engaged treatment shortly after diagnosis, being in the acute phase of HIV infection was articulated as a major motivating factor for this decision. Men described that their health care providers often initiated treatment in the context of needing to "bring down" high viral loads. As such, participants understood that the positive significance of receiving their diagnosis during the acute phase was related to how fast they could start treatment and, in some cases, become "undetectable."

Many participants who had already started treatment at the time of their first interview noted that it was "rewarding" to see their viral loads—which initially were very high—fall after beginning medication. Men's narratives reveal the ways in which HIV testing was one part of an overall and ongoing diagnosis experience, which included discussions of viral load measurements, including having an undetectable viral load following optimal antiretroviral treatment and the functioning of their immune system, as measured by the number of CD4 white blood cells:

Oh, well, see, remember that I didn't hear how incredible high my viral load was when I was sick until I was starting to feel way better and my viral load had been reduced many, many, many times, to the thousands. You know, knowing that I had that big improvement, the fact that at that point I had now found out how horribly high it was when I was sick, it was a shock, but I mean, it didn't change my attitude with being HIV positive. It made me think, "Okay, these drugs really work," so that was a good thing. But it wasn't about the HIV; it was about the drug: "Oh, my God, these drugs are amazing. Look what they've done in two and a half weeks!"

I never knew what my test results were until I actually was told. Right? And that I was going to go on medication. So, you know, some people, I don't know. I don't know what the decision was, or why, what the decision was to put me on medication immediately. I think it was because my counts went so high, and my CD4s dropped so low, whether they thought they were going to come back up or not, but they just decided to, say, "Go on it right away." And, I mean, you know, the way that I am right now, I'm undetectable, and my CD4s are up, at this point. I expect to find them somewhere between three hundred and fifty and four hundred and fifty at this point. You know, from a low of two hundred and fifty, when they took the first one. But they were already up at three hundred and fifty by the time I got my second test results, after a month on the medication, three weeks on the medication, so.

In these examples, new technologies of "early" testing interacted with existing technologies and knowledge of viral load and treatment to impact participants'



experience of their diagnosis and decisions about ongoing care.

In a related narrative, one man explained that his health care provider described the benefits of detecting HIV early in terms of both dropping his viral load and having optimal flexibility about accessing future treatment options:

What the doctor tried to do is, he tried to explain it in a very positive way, in the sense that, "Because we caught this so early, there is a much greater chance of shutting the virus down quickly, or quicker." And potentially down the road, because I was diagnosed so early or so quickly, there might be potential treatments that others may not have the option of taking. So, from that perspective, I thought, "Okay, well, you know, there might be a little more hope now than if I'd found out six months later."

For many participants, an acute HIV diagnosis impacted their decisions around treatment. They identified medical benefits, as explained by their health care providers, of early diagnosis and treatment debut. Some also described that treatment decisions were motivated by concerns regarding onward transmission during this initial phase of infection; for these men, wanting to have sex and minimize risk to their partner motivated the decision to start treatment promptly.

*Relationship to having sex.* Nearly all participants described an initial period of refraining from sexual activity following their HIV diagnosis, although the length of time varied. In many cases, participants explained that providers initiated conversations about reducing sexual activity; however, a majority of participants explained that they undertook to reduce sexual activity themselves as a result of high viral loads and concerns with onward transmission.

Many participants described that at the time of diagnosis, their nurse or doctor explained the significance of the acute diagnosis in relation to the need to be cautious when engaging in any sexual activity:

She [nurse] said, "You are acute, like, so you're highly contagious. Highly, highly contagious." So, she was like, "For everyone's health, it would be good if you just, like, take it easy for a little bit."...At first I felt like, "Okay, I'm not having sex till I have this phase of being acute." That's my first thought. It was like, "Okay, I'm not having sex at all." But I don't know. Like, right now, it's just, like, I mean, after a few weeks, well, it's not that I'm bad, it's not that I'm not going to have sex ever again, so, like, well, I'm just going to live my life. I just need to be careful. And that's how I feel right now.

The nurse said, "So you're super, super infectious right now. Your viral load is up eight hundred thousand. You are in an extreme [situation]." Oh, yeah. So, in fact, that was part of my confirming. The nurse told me, you know, "You're really

infective, so to abstain, so for now, it'd be best to abstain until your viral load comes down."

For some participants, this concern about being hyper-infectious resonated very strongly: One participant said, "Well, it definitely made me terrified of having sex at all, because I know how infectious one is in that early stage. So it just definitely, just made me completely step back from sex for a while." Another man talked about this in relation to becoming "undetectable":

I want to be undetectable. Like I said, I don't want to put anyone else in danger. So, being undetectable is important. But I am nervous...A little nervous about the side effects...I also want to be undetectable. Because I truly feel that if I am undetectable, I have a very slim chance of passing on the virus.

One man noted that being diagnosed in the acute phase did not have much of an impact on his sexual behaviors because his sex life was not a major focus for him at the time, and he was not planning on having much, if any sex in the upcoming months:

Not really, because my sex life was, or still is, kind of on the down-low part of my life. I have other things I need to focus on. So, being in the acute phase was not a very prominent, important thing in my life, at the time. However, the positive result, or knowing that I had seroconversion, did have an impact on whether I wanted to have sex or not. So, the acute phase may be part of that as well.

Another participant reported that he felt he would be more comfortable telling his former sexual partners he had seroconverted once his viral load was "undetectable," given the sexual nature of their relationship:

Participant (P): Well, knowing that my viral load came from two and one-half million down to twenty-two thousand in three weeks, I find that very consoling, you know.

Interviewer (I): Yes.

P: So I wouldn't even, I have this one ongoing f-buddy [sexual partner], and he keeps phoning and emailing 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. You know?

I: Okay.

P: Because there's no way I would have entertained doing anything with anybody with two million. You know, so.

I: Right.

P: That's respect for myself and respect for others, too, you know?

I: Right. Okay. So it might be easier to talk to at least some of these guys that you have sexual relationships with about being [HIV] positive after you find out that you have an undetectable viral load?

P: Exactly. If they'll believe that to be true.

Finally, many participants noted that knowledge of being in the acute phase of infection provided them with insights about their likely HIV infection event. Participant's retrospective accounts of the event or events that they believed might have led to their seroconversion reveal diverse experiences and understandings of HIV transmission risk. These infection-event attributions are the subject of a forthcoming analysis.

*Relationship to identity formation as an HIV-positive man.* For most participants, their acute diagnosis had very little impact on the ways in which they reported viewing themselves as HIV-positive men, and few made a distinction between receiving an acute diagnosis and a learning of their HIV-positive status more generally. For example, some participants described thinking about how they would have reacted to someone who was HIV positive and "undetectable" prior to their diagnosis:

I don't know. Before, when I was negative, being positive is positive. Either [they're] acute or they're not acute. Many people don't know about this phase, so it's just the fact that you are positive. Like, I don't know, before, if somebody said, like, "Okay, I'm positive, but my viral load is undetectable," or someone is, like, "Oh, I'm positive but my viral load is half a million," to me, you're positive. Period.

Another man explained: "I really don't know the difference. I, I'm HIV positive. But, am I any different from my friend who's HIV positive from thirteen years ago? And I can still transmit the disease. You know, where, what's the difference?" Many participants described thinking that "HIV is HIV" or "positive is positive," and noted the lack of significance of the acute diagnosis in their overall thinking of themselves as HIV-positive men.

## Discussion

Technological innovations in the scope of medical practice have led to ontological and epistemological transformations of HIV (Mol, 2002; Timmermans & Buchbinder, 2011). Our findings suggest that the integration of new HIV testing technologies to diagnose HIV soon after infection, and before it can be detected by standard testing protocols, demands additional reflection regarding the institutional processes for providing test results and the challenges of interpreting the meaning of new diagnostic technologies (e.g., NAAT) and illness categories (e.g., acute HIV infection) for providers and patients alike.

As Pilcher, Christopoulos, and Golden (2010) argued, "Acute HIV infection detection adds a new and potentially powerful tool to the prevention armamentarium" (p. S9). The prevention premise for the use of NAAT to complement antibody-based HIV testing is based on the

understanding that knowledge of HIV-positive status typically leads to reduced risk of transmission (Marks, Crepaz, Senterfitt, & Janssen, 2005); for example, emerging evidence from studies that have focused on persons with very recently acquired infections suggest that these individuals are likely to reduce high-risk behavior after being informed about their serostatus (Fox et al., 2009; Steward et al., 2009; Vallabhaneni et al., 2013).

In addition, early diagnosis provides clinical opportunities: for immediate identification of a patient's HIV status; for timely interventions such as acute-stage prevention counseling; for outreach to recent sexual partners; and for early enrollment into antiretroviral treatment programs that can lower viral loads and infectiousness (Hogg et al., 2012). These initiatives might assist those who engage in high-risk behaviors from further transmitting HIV and/or acquiring other sexually transmitted infections postdiagnosis (Crepaz et al., 2009; Gorbach, Drumright, Daar, & Little, 2006).

Acute HIV infection is an important public health concern. The rationale for the expedient delivery of test results and the use of new HIV testing technologies is clear from a public health perspective. Acute HIV infection calls on public health programs to respond in a timely fashion because of the increased probability of onward transmission as a result of very high viral loads. These opportunities for intervention are afforded by the availability of pooled NAAT and the subsequent diagnostic category, "acute HIV infection." However, the public health goal of reducing onward transmission needs to retain the complementary goals of providing psychosocial and medical support when delivering a positive test result, and is reliant on the successful use and interpretation of diagnostic technologies.

Learning of one's HIV status is a process of discovery that is experienced differentially, and often over a period of time. Participants made evident that coming to know of their HIV-positive status was often not a single clinical event but involved a process of ascribing meaning and connecting a range of factors such as biological symptoms, self-assessments of past risk behaviors, and "unusual" institutional practices (e.g., a phone call from a doctor; being asked to come to the office for test results). However, the significance attributed to such phone calls and requests to visit the clinic for results differed for participants. As such, this data has implications for clinical and public health practices, including how and when people are given their HIV diagnosis.

Delivering HIV test results is important work, and it is not without challenges. Although many of the participants described being well supported, their narratives also illuminate potential institutional failures that can arise in the process of giving an HIV-positive diagnosis. Men's experiences raise questions concerning the

circumstances under which disclosure of HIV status should happen over the phone. Although we have highlighted the possible dangers of giving results over the phone (both officially and unofficially in some cases), we have also considered the institutional consequences of not giving results over the phone, which are particularly significant in cases where there are heightened public health risks, such as with acute infection. It is important to note that client demand for the delivery of test results over the phone led, in part, to this relatively recent shift in institutional process.

It is clear from this sample that many men understood the significance of their acute infection in relation to initiating early antiretroviral therapy to hasten viral load decline during the acute-infection stage. This insight demonstrates the need to consider the relationship between diagnostic technologies for early testing and when biomedical technologies, such as antiretroviral therapy, are given for early treatment. From the perspectives shared by many participants, talking with health care providers led them to understand that the use of the diagnostic technology was significant because it enabled the timely delivery of the treatment technology. These narratives relate to sociological research literature that explicates the importance of positive doctor–patient relationships in facilitating clear explanations of medical processes (McCoy, 2005).

Our findings point to considerations for public health programs that elect to use new HIV testing technologies such as NAAT. The first speaks to the need for additional provider education about the virological and immunological response to infection in the first few months following exposure, and the relation of testing technologies to these responses. Education needs to include clear guidelines for communicating the results of various testing approaches, including meanings associated with antibody, antigen, and viral genetic material identification, as well as the related concepts of infectiousness and onward transmission to patients. Opportunities for providers to practice explaining these concepts to patients might prove beneficial.

Some patients are not able to take in this detailed information at the time of diagnosis. Follow-up appointments, at which point the significance of their stage of infection can be explained in an accessible manner, should be considered. Future research might explore what types of information would be most useful for newly diagnosed men in the AHI phase, as well as the long-term impact of provider-led discussions cautioning patients to abstain from, or limit, certain types of sex during AHI.

The second consideration involves providing and supporting communication strategies and initiatives to assist those individuals seeking information from print- and Internet-based resources provided by AIDS service

organizations and community-based organizations regarding seroconversion illness symptoms, viral load, and the availability of “early” HIV tests; for example, the meaning of acute infection, and the differences between “early” and “rapid” tests must be clearly communicated to gay men to increase community knowledge regarding the window period of heightened transmission risk and to support the uptake of these tests. There were a number of participants who said that they had knowledge of these concepts, and engaged in processes of “self-diagnosis” before and/or after being tested for HIV. Their experiences highlight the possible impacts of providing accessible information regarding the diagnostic opportunities afforded by technological innovations such as NAAT.

Finally, the third consideration of our findings concerns the need to recognize new psychosocial challenges that potentially confront those diagnosed with very recently acquired infection. For example, these persons might encounter questions about the nature of hyperinfectiousness and should be supported in describing what might be viewed as a new category or stage of illness to significant others. Practitioners must also consider the possibility that patients diagnosed earlier will have an increased sense of certainty regarding their infection event (Grace, 2013a). Our findings support the idea that receiving an acute diagnosis does not appear to impact men’s overall narratives of incorporating HIV into their biography (e.g., noting that “HIV is HIV,” irrespective of the stage at which one is diagnosed). However, acute infection is made meaningful to patients through conversations with health care providers about sexual practices, knowledge of likely infection events, and the early accessing of treatment.

New technologies often inadvertently create new social problems while trying to solve existing ones. For example, complex challenges exist within clinical settings to achieve optimum institutional disclosure processes of HIV-positive test results to clients with newly acquired HIV infection. Budgetary constraints have created incentives for policymakers to devise more efficient mechanisms to deliver HIV test results while ensuring that a higher proportion of patients receive their results. Evaluation of test-result provision practices was not an *a priori* study objective for this research, but instead revealed itself inductively as a salient theme across baseline interviews, and speaks to an evolving landscape of these practices in British Columbia.

Although we noted the opportunities of interviewing men who received HIV test results very soon after acquiring their infections, it is possible that many of our insights might resonate for other gay men diagnosed with HIV, irrespective of the stage of infection. The generalizability of these study findings is limited by our focused data from mostly gay men from six clinical sites in British

Columbia, Canada. Research with non-gay-identified men, as well as men outside of these clinic sites (e.g., in rural or remote areas of British Columbia), would be of benefit. In addition, recall bias could have impacted on the validity of the narratives we captured, because men were interviewed at different periods of time following their diagnoses. That being said, it is important to note that the majority of these interviews were conducted in a relatively proximate time period to infection and diagnosis; this is an important strength of these baseline qualitative data.

We do not have access to men's experiences beyond their detailed narrative accounts of diagnosis. As such, this analysis might benefit from future research that accounts for provider narratives of implementing new testing technologies. Complementary institutional ethnographic research (Grace, 2013b; Smith, 2006) on the everyday actualities of conducting work in clinical environments would provide added insight into the technologically mediated process at play in these diagnostic settings. Nevertheless, we believe that the HIV diagnosis experiences shared by participants provide tremendous insight regarding the need to consider how diagnostic technologies are used and read in clinical practice amid a landscape of other communicative and biomedical technologies.

### Acknowledgments

We acknowledge our community partners, including Positive Living Society of BC and Health Initiative for Men. We thank the men who volunteered to take part in this research and the entire CIHR Team in the Study of Acute HIV Infection in Gay Men.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was supported by the Canadian Institutes of Health Research (CIHR), FRN: HET-85520.

### Notes

1. NAAT tests detect the presence of viral ribonucleic acid (RNA) and result in a shortened window period of between 10 and 15 days, compared to most standard testing approaches that use third-generation enzyme immunoassays (EIA) that have window periods of between 20 and 30 days (Branson & Stekler, 2012).
2. Additional information is available on the Web site of the CIHR Team in the Study of Acute HIV Infection in

Gay Men: [www.acutehivstudy.com](http://www.acutehivstudy.com). Also see Gilbert et al. (2013) and Grace et al. (2014) for related publications.

3. Although any man who met the additional inclusion criteria and identified as a man who had sex with men (e.g., could identify as gay, bisexual, queer, trans, straight, two-spirit) was eligible for participation, only gay ( $n = 24$ ) and bisexual ( $n = 1$ ) men enrolled in the study. We use the word *gay* to describe the sample overall, given the salience of this concept for most participants and the highly problematic nature of the term *men who have sex with men* (MSM) (Young & Meyer, 2005).
4. Information on this campaign is available at Health Initiative for Men's Web site: [www.checkhimout.ca/hottest/](http://www.checkhimout.ca/hottest/).

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