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HIV TESTING IN THE CONTEXT OF HIV STIGMA AND MINORITY STRESS

by

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Abstract

The HIV test is highly valued for its role in promoting personal health, aiding in HIV prevention, and enabling the epidemiological tracking of the virus. However, relatively few scholars have critically examined the social and cultural implications of testing practices (Scott, 2003). These implications are of particular concern because the groups targeted for testing (referred to as service priority groups) are marginalized communities, and have historically been further marginalized by many public health HIV prevention efforts (Waldby, 1996). This thesis examines the experience of receiving an HIV test from the perspective of individuals in service priority groups, which include gay, bisexual, and other men who have sex with men, trans people, African, Caribbean, and Black individuals, Indigenous communities, and people who use injection drugs. The study design and analysis is informed by HIV stigma theory (Parker & Aggleton, 2003) and minority stress theory (Meyer, 2003). Eighteen participants were interviewed following HIV testing and asked about their experiences receiving the test, and engaged in discussion about minority stress and HIV stigma. Analysis revealed that many participants found HIV testing to be stressful, and that this stress was related to being part of a "high risk" group. Individuals who had faced significant discrimination in their lives found the test more stressful than those who had experienced minimal discrimination. Additionally, those who held very negative opinions about HIV were more worried about the test compared to those for whom HIV was less stigmatized. Implications and recommendation for service providers and policymakers are discussed.

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Testing for HIV is a heavily relied upon intervention for HIV prevention, and is the central technology through which epidemiologists understand the spread of the virus. However, relatively little research has been done to critically examine the social implications of testing procedures. Individuals in groups disproportionately affected by HIV - referred to as “service priority groups” – are encouraged to seek HIV testing much more than those deemed lower risk. Groups consistently identified as being at heightened risk in Canada include gay, bisexual and other men who have sex with men (GBMSM), people who use injection drugs, youth, Indigenous people, and African, Caribbean, and Black (ACB) individuals, primarily those from HIV-endemic countries (Public Health Agency of Canada, 2014). Women are also considered to be at heightened risk compared to men, if they fall into one of the other heightened risk categories. Service priority groups are marginalized communities, therefore the impact of HIV testing is of particular concern as it may add to stress that these communities already face. This thesis examines HIV testing from the perspective of individuals in service priority groups, from the theoretical lenses of HIV stigma and minority stress theory.

Minority Stress Theory

Given that HIV vulnerability is so closely tied to certain marginalized groups, it is important to make use of a theoretical framework which deals directly with experiences of marginalization and the role that they play in producing health inequities. The current project also requires a theory that is broad enough to address multiple forms of oppression, as testing clinics by nature cater to a broad range of people. That is, most testing clinics are not specifically targeted to just one priority population, but rather are open to anyone seeking testing.

Therefore an exploration of experiences receiving testing requires a multifaceted theory to account for diversity within individuals who access clinics.

Minority stress theory (MST) is useful for understanding the connections between minority identities and disparities in health outcomes. The theory is based on the idea that health disparities exist in a large part because people in marginalized groups experience discrimination that others do not, including racism, sexism, homophobia, transphobia, or some combination of these (Meyer, 2003). These experiences of discrimination cause significant stress for people in marginalized groups. At its core, discrimination includes any action or value that places those in certain social groups as lesser than others. What might constitute discrimination is broadly defined; it can be an individual action or an institutionalized system. An individual action could be a comment which stigmatizes a particular social group, whereas institutional discrimination includes practices that disadvantage a particular group, for example government policy that prioritizes some groups over others (Meyer, 2003). Importantly, within the context of MST, an act is considered discrimination if it is *perceived* as such by the individual experiencing it (Meyer, 2003). Whether or not the perceived discrimination was intended is irrelevant.

Acts of discrimination that one experiences are referred to as distal stressors. Proximal stressors are the ways in which distal stressors are subjectively appraised and processed (Meyer, 2003). When individuals are chronically exposed to distal stressors, they often come to experience a significant amount of internal stress, which can include internalizing oppression. For example, if a gay man is chronically exposed to heterosexist messaging, he may come to hold negative views about his sexual identity. The combination of distal and proximal stressors may affect an individual’s health and wellbeing through complex processes. Meyer’s original work (2003) focused on mental health outcomes, positing that minority stress can help to explain why mental health problems are disproportionately high amongst LGB individuals. Other scholars have applied minority stress theory to the study of health disparities in other areas (e.g. Lick, Durso, & Johnson, 2013), showing that discriminatory experiences are also related to physical health issues including HIV vulnerability.

While it could be argued from a MST perspective that all people in a given marginalized group experience some degree of stress (e.g. all LGB people are necessarily impacted by heteronormativity in some way), the theory accounts for wide variation within these groups. Meyer (2003) acknowledges that individuals deal with stressors in their lives that are unrelated to minority identity, which are referred to as general stressors, and some individuals in a minority group may experience more general stress than others, which has an impact on well-being. In addition, Meyer (2003) highlights that individuals have many elements to their identities, and some people may experience multiple minority stresses if they belong to more than one minority group. For example the experiences of a white gay man are likely to be different from those of a racialized gay man.

Meyer (2003) emphasizes that stress does not necessarily lead to lower well-being and undesirable health outcomes for all individuals in minority groups. He examines coping and ameliorative strategies that people employ to deal with the stresses that they experience. Coping strategies can be individualized, such as individuals' personality traits that help them to deal with difficult or stressful situations. However, MST is more concerned with group-level resources, such as strong membership within a minority community (Meyer, 2003). Social support and group membership can help to affirm a person's identity, and while the individual may experience significant discrimination (distal stress), social support can help an individual to cope with this stress, rather than internalize harmful messaging (proximal stress).

To date, MST has largely been applied to examining the experiences of people who identify as LGB (Meyer, 2003) and people of colour (Clark, Anderson, Clark, & Williams, 1999; Harrell, 2000). The strong base of prior research in these areas makes MST an appropriate fit for HIV research given that GBMSM, ACB individuals, and Indigenous people are all at significantly heightened risk of contracting HIV.

HIV Stigma

To understand health disparities related to HIV, it is also useful to examine stigma associated with the virus. Stigma is often defined as an attribute that is perceived in society to be an undesirable difference, and results in discrediting of the person possessing that attribute (Goffman, 1963). Importantly, HIV and AIDS are more stigmatized than other comparable illnesses (Crawford, 1996). Herek and Capitanio (1999) propose that this comparatively heightened stigma is largely due to the fact that AIDS was originally thought of as a “gay disease” and continues to disproportionately affect GBMSM, and therefore HIV stigma is partially due to homophobia. Racism also plays a part in HIV producing HIV stigma, with Black individuals often being characterized as the face of HIV (Canadian HIV/AIDS Black, African and Caribbean Network, n.d.). The heightened amount of stigma related to HIV may also be in part due to a prevailing perception that people who engage in behaviours such as condomless sex and intravenous drug use deserve to contract the virus (Herek, Capitanio, & Widaman, 2002).

Stigma is quite commonly referred to in HIV research, however a clear and consistent definition of stigma has not been used. Parker and Aggleton (2003) argue that stigma should be understood as a social construct. Rather than conceptualizing stigma as a static attribute that a person can possess (as much of the past research has done), they argue that stigma is constructed by individuals in society as well as by social structures such as health policy. These social constructs allow for discrimination against groups that have been deemed by society to have an undesirable difference (Parker & Aggleton, 2003). The existence of this stigma then allows for others to assert their domination over a stigmatized group, resulting in unequal distributions of power and control. Based on this conceptualization of stigma, Parker and Aggleton argue that stigma should be addressed not only at the individual level, but also through the analysis of public policies which may contribute to discrimination based on HIV status. They also assert that understanding stigma surrounding HIV requires an understanding of the historical context that lead to the current societal perceptions.

Chesney and Smith (1999) theorize that many people delay seeking HIV testing due to stigma. That is, people fear that if they test positive that they will be subject to harsh stigma from others. This, in addition to the adverse health effects of the virus, contributes to fear which prevents some people from seeking testing. In the context of MST, stigma related to HIV can be understood as a stressor that prevents some individuals from seeking health services. Stigma and widespread negative perceptions about HIV can justify discriminatory behaviours (distal stressors), and can also be internalized by people who feel that there is a chance they may have the virus (resulting in proximal experiences of stress).

Purposes of HIV Testing

Before delving into the details of HIV testing practices, it is first useful to consider the fundamental purposes of HIV testing. It is often taken for granted that testing is beneficial for individuals and society, however the precise reasons for this benefit are not as often explicitly considered (Scott, 2003). There are a variety of reasons why individuals may wish to know whether or not they had contacted the virus, as well as reasons why public health authorities wish to encourage individuals to get tested (Scott, 2003). The purposes of HIV testing, I will argue, range from personal wellbeing to constructing cultural understanding of HIV.

Individual purposes: Wellness, empowerment, and entry into care. Campaigns to encourage HIV testing often focus on the test's potential to improve individual well-being, either by giving peace of mind for those who test negative or by providing the first step to receiving care for those who test positive (Scott, 2003). A language of empowerment is often used to describe the testing process, under the assumption that having knowledge of their serostatus allows individuals to take control of their health (Scott, 2003). Indeed, for people who test positive, the test is the crucial first step in order to begin receiving appropriate care, including access to antiretroviral therapy drugs (Hull & Montaner, 2012). Timely entry into care brings the personal benefit of lower mortality (Girardi, Sabin & Antonella d'Arminio Monforte, 2007). Treatment is also less costly if HIV is detected earlier because people who enter care later are more likely to have built up resistance to antiretroviral drugs and visit hospitals more frequently than those diagnosed earlier (Girardi et al., 2007). It is important to note though, that these benefits are only realized if the person is able to access adequate care after the test, which is not always the case (Kilmarx & Mutasa-Apollo, 2013).

Interpersonal purposes: Prevention, case management, and criminalization. Another purpose of HIV testing is to prevent transmission of HIV to others. It is perhaps the central reason why public health authorities rely so highly on testing. The case for HIV testing for prevention is very strong. The virus can lie dormant without symptoms for several years, and getting an HIV test is often the only way to learn of its presence in the body. An estimated 21% of people in Canada who are HIV positive are unaware that they have the virus (Public Health Agency of Canada, 2015). Once individuals become aware that they have HIV, their behaviours are significantly impacted. A meta-analysis of American research (Marks, Crepaz, Senterfitt & Janssen, 2005) found that people who were unaware of their HIV-positive status were more than twice as likely to engage in unprotected sex compared to people who were aware of their HIV-positive status (though it should be noted that the definition of unprotected sex was inconsistent in the studies used). Other more recent studies have found similar results (Fox et al., 2009; Steward et al., 2009). Additionally, after a positive diagnosis, an individual can begin taking antiretroviral drugs. These drugs greatly reduce the viral load present in semen and other genital fluids, which reduces the probability that the virus will be transmitted to sexual partners – a concept referred to as “treatment as prevention” (Cohen et al., 2011). In fact, a recent longitudinal study including almost nine hundred serodifferent couples found that even without the use of condoms, if a person is taking antiretroviral drugs and has a supressed viral load is, the risk of transmission is virtually zero (Rodger et al., 2014). These findings indicate that HIV testing is an effective strategy to prevent new HIV infections.

Besides relying on individuals to modify their behaviour, public health authorities take action to contact past sexual partners of anyone who tests positive, and encourage those individuals to get tested as well (Ontario Ministry of Health and Long-Term Care, 2008). Public health can also be involved in criminal cases against people living with HIV. Once individuals are identified by public health authorities as having HIV, they may become subject to criminalization for engaging in behaviours that put others at “significant risk” of contracting the virus (Canadian HIV/AIDS Legal Network, 2014). In the event that sexual or drug use partners wish to press charges, they can request that the court subpoena medical health records to prove that their partners knew that they had HIV. This can result in legal consequences for people with

HIV, usually on a charge of aggravated sexual assault, which requires that the person serves jail time (Canadian HIV/AIDS Legal Network, 2014).

This legal process has been criticized for being highly biased against people with HIV, as it places all responsibility of protection on the person with HIV, with no accountability for the other person involved (Adam, Elliott, Husbands, Murray & Maxwell, 2008). It can also be extremely difficult for individuals with HIV to prove that they disclosed their status to their sexual or drug use partners. Legal advisors recommend that people with HIV may wish to obtain a sworn statement from all sexual partners before engaging in risk behaviour, as this is often the only way to prove disclosure (Canadian HIV/AIDS Legal Network, 2014). Many of the laws relating to nondisclosure are also very unclear, and verdicts can vary for seemingly arbitrarily reasons from case to case (Canadian HIV/AIDS Legal Network, 2014). Court hearings have been criticized for relying on moral discourse, placing much more responsibility on some individuals than others (Wilson, 2013). As a result, verdicts are heavily biased based on race and gender, with heterosexual Black men being found guilty more than any other group (African and Caribbean Council on HIV/AIDS in Ontario, 2010a). Furthermore, research suggesting that disclosure laws are effective for prevention is very limited, therefore criminalization is not an evidence-based practice (Adam et al., 2008).

Cultural purposes: Surveillance and biomedical understanding of HIV. Besides its role in treatment and prevention, HIV testing is the primary technology through which the HIV epidemic is understood and monitored (Scott, 2003). Testing, along with the collection of socio-demographic information, allows for an understanding of prevalence of the virus, as well as knowledge of the characteristics of those most affected. Biomedical analyses of HIV infection largely affects how the public understands and conceptualizes HIV (Waldby, 1996). The mechanisms through which this process happens will be explained in detail in the following section.

The Evolution of HIV Testing Practices

To understand the contemporary response to HIV, it is necessary to understand the social and historical context through which these practices emerged. Broadly, three factors that have significantly impacted the development of testing practices are early moral panic related to HIV, the emergence of biomedical risk analysis, and political activism.

Moral panic and the war on AIDS. In the early 1980s when the first AIDS cases were recorded, very little was known about this illness, which was debilitating for those who had it and costly on the healthcare system. Initially, the illness was thought to only affect GBMSM populations and people who used injection drugs. In fact, AIDS was originally termed Gay Related Immune Deficiency (Scott, 2003). Over the next few years, the profile of AIDS was expanded to include people from Haiti and some other countries where HIV was endemic (Silversides, 2003). When the virus was only thought to affect people in these groups, government response to the illness was very minimal (Waldby, 1996). Prominent political leaders did not publicly address the epidemic, and adequate funding was not provided for research (Cran, 2006). The first people to garner government concern were hemophiliacs who had contracted AIDS through blood transfusion (Silversides, 2003; Cran, 2006). Compared to other groups affected, hemophiliacs were characterized as having acquired AIDS through "no fault of their own". Their preferential treatment is clearly evidenced in considering that hemophiliacs were offered government compensation for having contracted HIV through blood transfusion, but this offer was not made to any other group (CATIE, 2014). By contrast, GBMSM, ACB individuals, and people who use injection drugs were characterized as being at fault for contracting the virus, as if they might have anticipated the AIDS epidemic and adjusted their behaviours accordingly.

Years after the emergence of the epidemic, government officials acknowledged that some people who did not fall into any high risk group were contracting the virus. This period marked an era of moral panic, and government focus turned to efforts to keep the virus constrained, so as not to affect the so called “general public” (Cran, 2006; Waldby, 1996). In particular, GBMSM communities were demonized as being a threat to the general public. At a time when very little was known about HIV and the ways in which it HIV could be contracted, there were widespread perceptions that AIDS was a consequence of the “gay lifestyle”, characterized by promiscuity and recreational drug use (Treichler, 1999). Some conservative groups when as far as to say that AIDS was a sort of punishment for engaging in homosexuality (Scott, 2003). It can be argued that homophobia has had a profound influence on early and contemporary responses to HIV (Herek, 1999).

Understanding the public panic related to AIDS is crucial for understanding the response of public health officials which followed. Waldby (1996) uses a military metaphor to explain how widespread determination to limit HIV transmission (the “war on AIDS”) justified a response with very little consideration for the implications for people living with HIV and those deemed to be part of high risk groups, “Declarations of war allow for the deployment of legitimate violence, and the suppression of normal human rights. (p.4)” When she describes “legitimate violence”, Waldby refers to state-sanctioned responses to HIV which cause undue pain to those with HIV or deemed risky. This metaphor highlights how panic and determination to win the war on AIDS has overshadowed considerations of human rights and sociological implications of public health messaging. For example, some government officials suggested internment of people with HIV, or allowing the virus to run its course in the GBMSM community, rather than intervening to save lives (Cran, 2006). While government discourse no longer includes such extreme suggestions, contemporary response still includes policies and procedures that put prevention efforts before human rights, as will be detailed further in the sections that follow.

Surveillance and the construction of "high-risk" groups. The emergence of the HIV epidemic coincided with a cultural proliferation of risk analysis as a means of addressing health problems, which saw a dramatic increase in the 1980s (Lupton, 2013). This period was marked by a notable shift in the way the term "risk" was used. Previously, risk generally referred to direct cause-and-effect relationships (Lupton, 2013). Contemporary use of the term includes much more abstract relationships (for example, a score on a psychological scale might be considered a "risk indicator" for some seemingly unrelated adverse outcome). At the heart of risk analysis are surveillance measures; it is necessary to gather large amounts of data on a given outcome in order to statistically calculate the ways in which various factors relate to it (Lupton, 2013).

Using a traditional definition of risk in the context of HIV prevention, there are a very limited number of factors that put a person at risk of contracting it (such as engaging in sex without a barrier or sharing needles). However, risk analysis allows for the construction of "high risk" groups, essentially creating a list of demographic characteristics that are considered to indicate risk for contracting HIV (Waldby, 1996). These calculations have lead epidemiologists to understand HIV as a concentrated epidemic, meaning that it affects some sub-populations at much higher rates than the general population. In the very early days of the epidemic, gay men were identified as the main demographic group at risk of contracting HIV (CATIE, 2014), and in more recent years this has been expanded to include other groups (Public Health Agency of Canada, 2014).

These groupings based on risk analysis have largely informed North America's response to HIV (Waldby, 1996; Scott, 2003). In the early days of HIV, because GBMSM communities were considered at high risk of contracting HIV, they were the targets of much intervention, including testing. It should be noted that at that time, testing was used only to prevent the spread of the illness and for surveillance purposes (Scott, 2003). Testing was of limited benefit for the person being tested, because early HIV tests returned a high rate of false positive results and were thus inconclusive (Weiss & Thier, 1988), and because no drugs or treatments were available for individuals should they test positive (CATIE, 2014). Critics have argued that the primary purpose of HIV prevention efforts in the early 1980s was to limit the spread of HIV from GBMSM communities into the "general public". Relatively little effort was put into reducing transmission within GBMSM communities, which some argue were written off as already being infected (e.g. Waldby 1996). Also, little effort was put into treatment for those infected, with the development of early HIV drugs taking an unprecedented amount of time (Scott, 2003).

Today, HIV testing continues to be marketed primarily towards those in service priority groups, and these individuals go for testing much more than those outside of these groups. In a systematic review of Canadian studies concerning HIV testing, Ha et al. (2014) examined the percentage of people in various groups who had received testing at least once within their lifetime. They found that the groups with the highest likelihood were intravenous drug users and prisoners (both over 90%), GBMSM (over 80%) and Indigenous people (over half). This compares with roughly one third of Canada's adult population overall.

Though the targeted approach has proven to be effective in prevention, it has been criticized for its role in stigmatizing people living with HIV and those deemed risky. Central to this is the conflation of HIV with the identities of those belonging to service priority groups. That is, the lines between correlation and causation are blurred, as if simply belonging to a high risk group - in the absence of any actual risk behaviour - makes a person likely to contract HIV. Waldby explain in the case of gay men, "gay masculinity has been so intensely medicalized and so closely associated with the AIDS epidemic that gay men are effectively treated by much public health discourse as if they themselves were the virus, the origin of infection" (p.13). ACB individuals are also often characterized as being personally responsible for the spread of the virus (African and Caribbean Council on HIV/AIDS in Ontario, 2010b). This conflation in effect makes HIV a burden carried only by those in high risk groups, while those not considered risky do not carry this burden. This dichotomy of risky and healthy is dangerous for HIV stigma and for stereotypes associated with already marginalized groups. It is also problematic for practice because risk of those in service priority groups is over-exaggerated, and risk of those considered healthy is under-exaggerated (Scott, 2003).

Activism. As I have detailed, public health response to the HIV epidemic has largely been informed by biomedicine and service priority groupings. Another social force that has impacted the response to HIV is activism within the gay community and other communities affected by HIV, including many people living with HIV (CATIE, 2014). Before government officials made any meaningful effort to address AIDS, activist groups mobilized quickly to support those living with AIDS, and demand government investment in research and care (McCaskell, 2012; Cran, 2006). In the very early days of the epidemic, many of the most vocal activists were part of the gay community, who were most impacted at the time (Silversides, 2003). At that time activist efforts were intensely focused on demanding government investment in HIV research, in order to develop drugs and a vaccine. Many of the gay activist involved in these protests were themselves living with HIV, and felt that research offered their only hope of survival. In this way, many early AIDS activists were literally fighting for their lives (Cran, 2006). In the years that followed, as ACB populations became recognized as a disproportionately affected group, activists within the Black community mobilized as well, engaging with issues that affect all people living with HIV, as well as those specific to the Black community, including racism and immigration issues (African and Caribbean Council on HIV/AIDS in Ontario, 2010b).

In 1987, the first drugs antiretroviral drugs for people with HIV, called AZT, were finally made available (CATIE, 2014). This represented a great achievement for AIDS activists, who had played a major role in creating pressure for government response. However, the first drugs made available were inordinately expensive. In fact, they were the most expensive drugs that had ever been released to date (Cran, 2006). Therefore, the drugs were only accessible to those with comprehensive health coverage, and the very wealthy. After AZT was released, the focus of activist efforts shifted towards making the drug financially accessible to everyone with the virus (McCaskell, 2012). In Ontario, activist lobbying eventually lead to the establishment of the Ontario Trillium Drug Plan, which has made drugs much more accessible (McCaskell, 2016). While antiretroviral drugs are still far from universally accessible, these efforts made by AIDS activists played a major role in advancing the cause.

Specific to testing, activists were the driving force behind the establishment of anonymous testing sites (Scott, 2003). When HIV testing was first introduced, test-takers’ names were generally recorded with their test. If individuals received positive test results, their names would be shared with public health officials for surveillance purposes. However, concerns were raised amongst activists, who argued that mandatory name reporting might deter some people from seeking testing, and that the practice violated the privacy rights of people with HIV (Scott, 2003). By 1992 Ontario established a number of anonymous testing sites as a result of these efforts (CATIE, 2014).

Contemporary Response: HIV Testing Procedures in Ontario

The factors outlined above have contributed to the HIV testing system that Ontario has today. A set of regulations and standard practices are in place which stipulate the requirements for administrating an HIV test (Ontario Ministry of Health and Long-Term Care, 2008). Standard practices include counselling before and after receiving a test, the collection of demographic and risk behaviour information and two types of tests that may be offered. Policies also include the legal mandate to report any positive test result to Public Health officials for epidemiological purposes as well as to allow for the notification of the individual’s past sexual partners.

Counselling. Before an HIV test is administered, practitioners are required to administer counselling so that the test-taker is informed about HIV risks as well as all aspects of the testing procedure (Public Health Agency of Canada, 2013). Counselling includes advising test-takers of practices that can reduce likelihood of contracting HIV, such as safer sex and safer drug use practices. Practitioners also explain the benefits of getting tested and explain how the test works. They discuss the confidentiality options offered, including any mandatory reporting and requirements to contact previous sexual partners in the event of a positive result. Once the test-seekers confirm that they understand the information, the test can be taken.

If an individual receives a positive test result, practitioners are required to provide post-test counselling. This includes providing psychological support to help individuals coming to terms with their diagnosis, educating individuals about risk-reduction practices, and reviewing services that are available for care. It also entails beginning the process of notifying past sexual and drug use partners, if applicable.

It is difficult to differentiate the positive effects of test counselling from the benefits of testing itself, given that the two components are delivered in close succession (Holtgrave & McGuire, 2007). However, the positive effects of testing and counselling in combination are well documented. As stated earlier, people who test positive for HIV are far less likely to engage in behaviours that put others at risk than those who have not been tested (Marks et al., 2005). This favourable outcome is no doubt in part because the test itself allows people to become aware of their HIV status. It may also be because the counselling helps people to cope with their diagnoses and understand risks of transmission (Holtgrave & McGuire, 2007). In addition to providing education, post-test counselling has the potential to encourage people to seek medical care. For various reasons, some people who receive a positive diagnosis do not enter into care, despite the fact that early entry into consistent care is crucial for optimal health outcomes including suppressed viral load (Mugavero et al., 2012). Post-test counselling may affect people's decisions to seek the care that is needed.

Much research has been done to assess the positive benefits of counselling for individuals who test positive for the virus. However, comparatively little attention has been paid to the potential benefits of counselling for individuals who receive negative test results, despite the fact that the Public Health Agency of Canada recognizes testing as "an opportunity [for clients testing negative] to receive information about protective measures and behaviours necessary to prevent

HIV infection” (2013). The research that does exist suggests that counselling may be beneficial in reducing risk behaviour, but that the quality and type of counselling are important considerations. A randomized control study compared people who receive patient-centred counselling along with testing to people who simply received brief didactic information about HIV risk when they received testing (Kamb et al., 1998). This study was possible at the time because it preceded the government regulation that counselling must accompany testing. Patient-centred counselling included a dialogue between the patient and the counsellor to address all of the service user’s concerns. The authors found that those who received counselling were more likely to report using condoms and less likely to be diagnosed with an STD at follow-up compared to the didactic information group. This supports the notion that counseling that is patient-centred and interactive can have a more positive impact compared counseling which simply includes information about HIV. Given that not all counselling models yield the same outcomes, attention should be paid to the quality and type of counselling offered. Holtgrave and McGuire (2007) suggest that testing organizations might employ creativity in order to improve the quality of counselling. Namely, they suggest that non-clinician staff might play an active role in counselling if clinicians do not have the time to offer such services. Some countries have also moved towards a model of peer led counseling and testing, where people with HIV or in service priority groups administer the test and/or provide counseling. Canada may eventually move towards this model, which has been piloted by a study in British Columbia (CATIE, 2013).

Education about ways to reduce risk behaviour is an important part of HIV prevention. Education initiatives which provide people with accurate knowledge about HIV have been shown to reduce transmission. Perhaps the most well documented example of this is the role of school-based sex education programs in dramatically reducing young people’s likelihood of engaging in risky sexual behaviours (Kirby, Laris & Rolleri, 2007). Beyond youth programming, education programming for adults about sexual health and safer injection practices can improve people's knowledge of HIV risk and subsequently their behaviours (e.g., Tobin, Kuramoto, Davey-Rothwell & Latkin, 2011; Choi et al., 2008). Ideally, testing clinics should help to increase test-takers' knowledge of risk reduction.

Types of testing offered: standard vs. point of care. After a test-seeker has received counselling and given consent, the test can begin. HIV tests are done using a blood sample. The test detects antibodies that the body builds up to fight HIV, as opposed to detecting the virus itself. It can take up to three months after exposure for the body to build up these antibodies. Therefore, when individuals receive negative test results, it can be concluded that they were HIV-negative up until three months before the test. They may still have HIV if they contracted it within three months prior to receiving the test (Public Health Agency of Canada, 2013). Based on a set of guidelines created by Ontario's AIDS Bureau (Ontario Ministry of Health and Long Term Care, 2012), healthcare practitioners can recommend if and when and individual should return for testing depending on the individual's risk profile.

Canadian clinics offer two types of HIV testing: standard and rapid point-of-care (POC) (Public Health Agency of Canada, 2010). Standard testing entails having blood drawn and sent to a testing lab. Results from standard tests are generally available within one to two weeks. Results from this test are considered conclusive up to three months prior to testing. Rapid POC testing is done with a finger prick and the results become available in a matter of minutes. If this test returns a negative response, it can be concluded that the individual is not infected as of three months prior. However, if the test returns a positive or inconclusive result public health requires that confirmatory tests are run using the standard method.

In the mid 2000's when rapid POC testing first became available, research was done to assess its benefits and drawbacks compared to traditional standard testing. A study conducted at Hassle Free Clinic in Toronto (Guenter et al., 2008) found support for the benefits of offering rapid POC testing. This particular clinic offers exclusively anonymous testing. One of the most important benefits of POC testing found by the authors is that all test-takers receive their results and post-test counselling, since results are available immediately after testing. By contrast, the authors note that if receiving standard testing, some test-takers do not return for their results after the testing period is over. This is particularly problematic if the person received anonymous testing as clinicians are not able to take measures to contact an individual in the event that the test returns a positive result. The authors found that rapid POC testing was the preferred method for most test-seekers, with 91% of people seeking testing choosing POC over standard. It was also found that the POC method was easier for clinicians to administer compared to the standard method. Similarly, a large scale study of test-takers in California clinics (Smith et al., 2006) found that the vast majority of participants were satisfied with the rapid POC method.

Overall Guenter at al. (2008) supported making POC testing available. However, the authors did note some disadvantages of this method compared to standard testing. The immediacy of results requires clinicians to be prepared to administer post-test counselling in the event of a positive result. With standard testing, clinicians have time to prepare to give someone news of their positive result and to arrange for appropriate counselling. Additionally, the waiting period required to confirm a positive or inconclusive result can be extremely stressful for test-takers. Smith et al. (2006) found that some participants felt that they received results too quickly with POC testing. Some individuals prefer standard testing because results are conclusive. The preferred testing method depends on individual preference, therefore it appears to be beneficial for clinics to have both options available.

It is worth noting that a third method of testing does exist, though it has not been made available in Canada. In the United States and other parts of the world it is possible to purchase a home-based HIV test (Broeckaert, 2014). Home-based tests are convenient and anonymous, and have the potential to improve access for people who do not want to go to a clinic. However, home-based tests do not offer face to face counselling (if they offer any at all), and it is possible that some people might be coerced by others to take the test. Home-based tests are not approved in Canada, though some Canadians may access them by purchasing them in other countries.

Anonymity and partner notification. Besides the type of test that is offered, the amount of identifying information that is collected has important implications for a test-taker's experience. There are three options available in Ontario in terms of collecting personal information: nominal, non-nominal and anonymous testing (Public Health Agency of Canada, 2010). In the case of nominal and non-nominal testing, the health care practitioner records the name of the person being tested, the risk behaviours that the person has engaged in, and demographic information such as gender and age. In the event of a positive test, the health care practitioner is legally required to inform public health officials of the positive diagnosis, and the test result is recorded on the individual's medical record. The difference between nominal and non-nominal testing relates to the labelling of blood sampling. When a test-taker receives nominal testing, the individual's name accompanies the sample. With non-nominal testing, a numerical code is used instead. For the purpose of this thesis, nominal and non-nominal testing will be referred to as confidential testing.

As an alternative to confidential testing, some clinics offer anonymous testing. Anonymous testing is generally only available at specialized clinics, whereas confidential testing is more widely available. When a test-taker chooses anonymous testing, the health care practitioner does not record the identity of the test-taker and a code is used to identify the blood sample. Practitioners are still required to record risk behaviour and demographic information when a test-taker chooses anonymous testing. In the event of a positive result, the practitioner provides the risk behaviour and demographic information to Public Health officials. However, the name of the individual is not made available to public health, and the person's medical record is unaffected. A person who tests positive may also be able to receive viral load testing anonymously, though this is a very recent policy change and the procedures for this are not yet well established (HIV & AIDS Legal Clinic Ontario, 2016).

The debate about anonymous testing calls into question the principle purpose of the HIV test. Anonymous testing benefits individuals by allowing them to know their status, and since it is reportable, contributes to the surveillance of HIV at the epidemiological level. However, offering a test anonymously does not allow public health authorities the opportunity for case management, or to take disciplinary measures against those with the virus. If individuals take anonymous tests and receive positive results, this does not result in a record on their files. Then in the future, if sexual or drug use partners wish to prosecute individuals for putting them at risk, they would not be able to prove that the individuals knew they were HIV positive.

It has been questioned whether the benefits of mandatory name reporting outweigh the limitations. An important limitation to consider is the possibility that surveillance and criminalization may deter some people from seeking testing. O'Byrne and Bryan (2013) propose that government HIV surveillance is a self-limiting process. That is, the surveillance system is designed for public health officials to have knowledge of which individuals are living with HIV. However, the system may deter some people from seeking testing because they fear the consequences of government surveillance if they receive a positive diagnosis. Thus, those people remain unaware of their HIV status and are at an increased risk of transmitting it to others.

Mykhalovskiy (2011) examined the impact of laws which criminalize people with HIV from the perspective of service users and health care providers. Specifically, laws relating to nondisclosure of one’s HIV status to a current or past sexual partner were examined. Service users and providers discussed how criminalization contributes to stigma associated with HIV. This stigma is heightened by highly negative media representation of people prosecuted for putting others at risk of contracting HIV. It is argued that this stigma and fear of criminalization may deter some people from seeking testing and discourage some people with HIV from disclosing their risk behaviours to counselors. Mykhalovskiy argues that the public health benefits of prosecuting these individuals may not outweigh the risks of deterring people from seeking testing. More research is needed to understand the effect that surveillance and criminalization has on individuals’ decisions to seek HIV testing. It is especially important to understand this relationship for individuals at a high risk of contracting the virus.

Integration into other services. Though not a government requirement for testing, some clinics make efforts to connect test-takers to other services that might be useful to them. In addition to providing people with services that directly reduce HIV risk (e.g., education about safer sex practices), many organizations aiming to address HIV provide services which address social determinants of health and factors which increase a person’s likelihood of engaging in risk behaviours (UNAIDS, 2011). Broadly, some social determinants of health associated with HIV risk include socioeconomic status (income level, access to housing and food), stigma, access to education, community acceptance, and access to healthcare services.

When individuals come to a clinic for testing, it is potentially an opportunity to link them to appropriate health and community services. Testing is one of the only HIV related services that requires service users to physically come to a community organization's building. For example, one can acquire condoms and new needles from friends who have picked them up, and sexual health related information can be found online. Testing by contrast, requires that individuals present themselves in person. Therefore, a testing environment may provide an excellent opportunity to initiate discussion and engage people in other potentially useful services.

Conclusions from Literature Review

Past research and scholarly work suggests that social implications of HIV testing policy warrant further exploration. Research on policy indicated that testing offers an opportunity to positively impact HIV prevention in a variety of ways. Testing appears to be most effective when a high quality of counselling is available, when people are able to choose the type of test that they would like to receive, and when test-takers are given the option to remain anonymous. This thesis builds on this prior knowledge, and attempts to further understand how testing is experienced by test-takers in service priority groups.

Research Objectives and Questions

This thesis has two major objectives. The first objective is theoretical in nature, and is the focus of the results presented in this thesis.

Objective 1: To understand how minority stress and stigma relate to experiences of HIV testing.

Questions

a) To what degree have test-takers experienced discrimination in healthcare settings and/or generally in their lives, and what effect does this discrimination have on these individuals? What personal protective factors help individuals to cope with discrimination?

b) Is HIV highly stigmatized amongst test-takers? Do they view acquiring HIV purely as a result of individual choice, or do they connect HIV vulnerability to broader social factors? How do these conceptualizations relate to attitudes about members of service priority groups, and to notions of risk and responsibility?

c) What are participants’ experiences accessing the testing clinic? How do their attitudes about HIV and experiences with minority stress affect the way that they think about HIV testing?

The second major objective of this project is geared towards uncovering the direct applications that this research can have in informing the way that testing clinics are run. Reciprocity between researchers and the communities being studied is a key concept within Community Psychology (Nelson & Prilleltensky, 2010). As such I feel that it is important to recognize that the organization where I will be carrying out this research has made this project possible for me by contributing time and resources. This project was carried out at the AIDS Committee of Cambridge Kitchener Waterloo and Area (ACCKWA).

Objective 2: To explore policy and procedural improvements that a testing clinic could reasonably implement to improve the test-taking experience for people in service priority groups.

Questions

a) What factors facilitate or discourage HIV testing?

b) What education needs to test-takers have? How might ACCKWA better facilitate learning about best practices for HIV prevention?

c) What other health and community services needs to test-takers in the region have? Are these needs being met?

Method

The method section that follows is informed by theories and principles of community psychology. I believe that this project is a good fit for community psychology because it is intended to work towards making the experiences of people in marginalized groups more visible in arenas where they are likely to inform social change. In my choice of paradigm and methodology, I strive to design a research process that enables critical thought, as I believe this is key to meaningful and sustainable change within a community.

Critical Transformative Paradigm

I have chosen to situate this project within a critical transformative paradigm (Mertens, 2009). Broadly, research within a transformative paradigm operates under the ontological assumption that people experience reality differently from one another because of their social position. One’s social position is determined largely by social and institutional structures, which favour some groups in society over others. Within this framework, the HIV testing experience is shaped by institutional structures that necessarily have an impact on people’s perceptions of reality. As I detail in my review of literature, for example, testing procedures exist because of the Canadian government’s epidemiological assessment of how best to respond to HIV in the country (Public Health Agency of Canada, 2013). This assessment can be understood as a biomedical construction of reality. In this research project, I have investigated the ways in which the HIV testing experience in one testing clinic is situated within broader contexts of being part of a service priority group. These subjective experiences are not captured as part of biomedical research, though they are important for understanding the testing experience.

Beyond the assumption that personal experiences are shaped by social position, the critical transformative paradigm posits that social change requires that people in marginalized groups are engaged to think critically about the realities that they experience. Creating a space for critical reflection is viewed as necessary for a transformation in ways of understanding reality. For this project I have chosen to engage with people who are part of at least one group considered at heightened risk of contracting HIV, as these are the people who access testing most, and are most impacted by targeted testing campaigns.

Within the critical transformative paradigm, self-reflexivity is viewed as particularly important and a research project cannot be fully understood without thoroughly exploring the researcher’s position upon entering the project. In terms of methodology, research within this paradigm should be participatory, with a focus towards action and social justice. As opposed to research within other paradigms that operates within a largely predetermined research plan, research within the critical transformative paradigm remains open to critique and changes throughout the entire research project (Mertens, 2009). In a dialectic process, various groups are consulted, and additional background research is done, often resulting in reconsideration of elements of the project.

Reflexivity

McCabe and Holmes (2009) offer a useful perspective on the role of reflexivity in critical transformative research. Challenging the traditional notion that all researchers hold a “bias” that should be acknowledged and controlled for, they argue that the researcher’s position should be embraced and analysed as a part of the research itself. This offers a degree of validity by giving the reader contextual information about the background of the researcher. In order to create critical transformations in ways of thinking, it is important to begin with an understanding of how the researcher's experiences have influenced their current perceptions. Furthermore, critical transformative research rejects the notion of objective research, and view research instead necessarily political. Therefore, the researcher's worldviews add strength to the research, as the researcher brings a passion towards the social issue that the research examines. I recognize that my preconceptions have been shaped both by my past and present. Throughout my life I have been a member of social, academic, and spiritual communities that are very progressive, and largely from these experiences I am strongly inclined towards empowerment-based approaches to health promotion. In particular, I have become passionate about the potential that such approaches have to encourage positive sexual health outcomes. I strongly believe that interventions that encourage informed choice are far more likely to lead to improved health compared to those which are based on tactics of control and intimidation.

On a practical note, my past work has equipped me with knowledge relevant to the subject matter of this thesis. My academic background is in the areas of sexuality and social justice, so I am familiar with research and theory in these fields. Additionally, I have recently been involved in the strategic planning process at ACCKWA, which has entailed an extensive document review to understand the policies concerning AIDS service organizations in Ontario. This experience has been beneficial for me in two ways. Firstly, it has provided me with in-depth knowledge of research and policy that informs the way that AIDS service organizations in Ontario are run. Secondly, it has given me the opportunity to see first-hand how ACCKWA operates and to get to know ACCKWA's staff. Though I am quite familiar with the subject matter, this is my first experience conducting qualitative research, so this project has been a learning experience for me in that respect.

Beyond its role in the validity of a study, McCabe and Holmes (2009) argue that reflexivity is an acknowledgement of the power differences that exist between the researches and those being studied. As I have detailed in the introduction of this paper, academic and epidemiological research have been taken as the primary source of knowledge to inform Canada's response to HIV. Therefore such knowledge is more likely to inform change. It is a privilege for me to be a part of academia, where my work is likely to be seen as more legitimate than information coming from non-academic sources. My position as a researcher also puts me in a position of greater power than study participants because I have control over the interpretation of data. On a personal level, I do not identify as part of any HIV service priority groups. As an outsider, it is particularly important for me to work to ensure that the voices of those most affected by HIV testing policy come through in the results. Being mindful of these power differentials, I took steps to design this study and the data analysis plan so that the end product will accurately reflect the views expressed by participants.

Development of Interview Guide and Demographic Questionnaire

My interview questions include a brief demographic questionnaire and an interview guide. The purpose of the questionnaire is to capture information about risk behaviours and demographic characteristics. Many of the questions in this short survey are taken from a situational assessment survey that was recently conducted in Waterloo Region, in a partnership between ACCKWA and the region's Public Health division (Region of Waterloo Public Health, 2013). I used questions from that survey because the questions were developed so as to be relevant to, and easily understood by, people in the region.

The format of my interview guide is informed by the work of Bowen (2012) on Critical Social Work approaches to HIV research. Bowen cautions that much past HIV research has focused too narrowly on behavioural interventions. She argues that, while it is certainly important to address people's immediate needs, a researcher must also engage the participant in dialogue about the broader systems which perpetuate the epidemic. To ignore this latter element is to oversimplify and depoliticize HIV. Based on Bowen's suggestions, the interview guide has been created so as to address both practical concerns about the clinic, and more theoretical concepts relating to the connection between HIV and marginalization. Specifically, the theoretical questions relate to theories of minority stress and HIV stigma.

The interview guide begins with questions aimed at gathering information about participants' experiences with ACCKWA's testing clinic, such as how comfortable they felt during the process and whether or not they were satisfied with the testing options available. The guide then moves into a set of questions aimed at encouraging theoretical discussion. I began this section with open-ended questions relating to minority stress and stigma (e.g. "Why do you think that certain groups are at heightened risk of contracting HIV?"), in order to gather participants' initial thoughts and opinions on these matters. Next, I included brief explanations of the concepts of minority stress and stigma, and probing questions to gather reactions to these concepts. This was done to allow participants an opportunity to critically engage with these issues, potentially eliciting agreement or counter-arguments from participants to further understand their perspectives. I also included questions asking participants to reflect on whether they could connect these theories to their own personal experiences.

The critical transformative paradigm emphasizes community input in all parts of the research process, including development of the study (Mertens, 2009). The need for a study should be agreed upon within the participating community, as opposed to being decided by an outside researcher. Community input is also valuable in insuring that study questions are appropriate for the participating population and that the questions can be easily understood by participants. In developing my interview guide, I worked closely with the Executive Director at ACCKWA (Ruth Cameron) as well as the prevention staff, who were all able to provide input in both of these areas. The staff at ACCKWA have in-depth knowledge of local testing policies and procedures, and could thus provide feedback on the ways in which the research could translate into action. They work with service priority groups on a daily basis, and most staff have lived experience of being part of a service priority group and/or living with HIV. Therefore, they are very well positioned to provide feedback on the study development.

Ruth was consulted at various stages in the process of planning and carrying out the study, and she paid particular attention to ensuring that results would have concrete implications for ACCKWA’s testing clinic. After I developed a first draft of my questions, I met with the prevention team at ACCKWA to refine the interview guide. The prevention team includes all staff who work to prevent new HIV infections (as opposed to support staff who work with people living with HIV). Each staff member on the prevention team is responsible for providing preventative services for a priority group in the region, including GBMSM, ACB individuals, women at risk, youth, and people who use injection drugs. The team was able to provide insight about whether questions would be easily understood by service users, and also advice on using anti-oppressive language.

Local Context of Waterloo Region and ACCKWA

This project took place at the AIDS Committee of Cambridge, Kitchener, Waterloo and Area (ACCKWA), the AIDS service organization serving Waterloo Region. Waterloo Region encompasses three cities and four townships, with a total population of approximately 575,000 (Region of Waterloo, 2016). At the last census, which was done in 2011 (Region of Waterloo, n.d.), immigrants made up 22.3% of residents, and an estimated 15% of residents were visible minorities. The median age in the region was 37.7, well below the provincial median. Unemployment in the region was lower than the provincial average, and median income was higher than the provincial median. The region of Waterloo has lower rates of HIV compared to those in Ontario overall. Between 2010 and 2014, rates of new infections per year have ranged from 0.6 per 100,000 to 3.6 per 100,000 (Region of Waterloo Public Health, 2015). Some individuals had developed AIDS by the time they were tested for HIV. The region has three dedicated testing clinics, two at public health locations and one at ACCKWA. In the region, both rapid and standard testing are available. However, anonymous testing is only officially available if an individual receives standard testing. It is not necessary to present photo identification in order to receive a test in the region (Region of Waterloo Public Health & Emergency Services, 2015).

ACCKWA is an AIDS services organization offering a range of services directly or indirectly related to HIV prevention and care. Their testing clinic runs one evening per week. When individuals come in for testing a staff member at ACCKWA checks them in, then a public health practitioner administers the test. During the process of receiving testing, participants may also be referred to various services.

Target Sample and Sampling Technique

I chose to use a purposive sampling technique for this study because I aimed to understand testing experiences of people within certain groups, rather than opening the study to anyone who might access the clinic. I have done so because these are the individuals most likely to be affected by HIV stigma and minority stress. The target sample for this study included people at heightened risk of HIV, including GBMSM, ACB individuals, people who use intravenous drugs, trans people and Indigenous people. People under the age of 16 were excluded because this group is served by youth-specific testing clinics in the region (Region of Waterloo Public Health & Emergency Services, 2015), and thus youth are not of primary concern in informing the protocol at ACCKWA's clinic. Women are not specifically included, because they are only considered to be at heightened risk if they belong to another service priority group, and thus those considered high-risk would be eligible based on the other criteria. When individuals signed in for their test, a staff member at ACCKWA let them know of the study, and they were invited to participate if they met the eligibility criteria.

Procedure

When individuals come to ACCKWA for a test, they must first speak with a staff member who provides them with the necessary forms to fill out before the test. While the study was running, potential participants were given a flyer describing the study and its eligibility criteria, along with the standard forms. After they completed the test, individuals who wanted to participate in the study were directed to a private room for the interview. There, I briefly described the aims of the study and the procedure and asked them if they were interested in proceeding. If they indicated interest, I presented them with the participant consent form (see Appendix A), and I informed them that I was available for them to ask questions about the form if they required clarification. Once the form was signed, participant filled out the demographic questionnaire (see Appendix B). Next, I proceeded with the interview (See Appendices C and D for the interview guide and a chart relating interview questions to my objectives). In total, I conducted eighteen interviews, ranging in length from 12 to 40 minutes, with most lasting close to half an hour.

Addressing Ethical Concerns

HIV testing is a sensitive subject for many people, so it is crucial to take steps to create an atmosphere where people feel comfortable sharing their thoughts and experiences. Before asking the interview questions I assured participants of their right to skip questions or terminate the interview. The interview questions were designed so as not to require excessive self-disclosure, and the process of getting feedback from the staff at ACCKWA was helpful in ensuring that questions were worded using language that was not likely to be emotionally triggering for participants.

Confidentiality is a concern in research involving sensitive topics, and may be of particular concern to participants in qualitative studies, because qualitative interviews do not allow for the same level of anonymity that quantitative methods can offer (Padgett, 2012). To ensure participant confidentiality, I stored transcriptions on a password protected computer, with names and identifying information removed, and deleted audio files after each interview was transcribed. Participants were also given the option to refuse to have their direct quotations included in the final report, as an added confidentiality measure.

Data Analysis

My approach to analysis fits most closely within a phenomenological framework (Saldaña, 2011), though it is not a perfect fit as I have also integrated previous research and theory which is not typical of phenomenology. A phenomenological analysis is used to understand the meaning that individuals derive from experiencing a particular phenomenon. The phenomenon under examination in this project is that of receiving an HIV test as a member of a service priority group. As I have detailed in my introduction, HIV testing is a practice ingrained in cultural meaning, largely because of HIV stigma and its connection to marginalized groups. I believe that phenomenology provides an appropriate fit for research within the critical transformative paradigm because it allows for the exploration of new ways of understanding a phenomenon, as opposed to a more restrictive analysis used to test a researcher's specific hypothesis.

Data were collected quite gradually (averaging approximately one interview per week), which allowed for a cyclical process of coding and recoding, and for adjustments in coding methodology. For the first several interviews that I conducted, my process of analysis began with simple descriptive coding to categorise content. This helped me to be able to map the various topics that were often emerging. Many of these descriptive codes were in vivo quotes, which I did in an effort to ensure that descriptive codes were closely grounded in the data, as opposed to my interpretation. As more data were collected and response patterns emerged, I began a stage of values coding, a process used to gauge the meaning that participants attach to a given topic (Saldaña, 2009). Values coding involves paying attention to the importance that individuals attribute to a topic (value), individuals' feelings about a topic (attitudes), and their evaluation of realities related to the topic based on information available to them (beliefs). In working to identify values that were common across interviews, I made memos to document hunches that emerged and topics that might benefit from further probing in future interviews. This allowed me to tweak my interview guide throughout the process in order to more deeply explore topics that were emerging as potentially important. Throughout the process of analysis I actively referred to past research and theoretical writing to help to contextualize the codes that emerged, which I found very helpful in making sense of sentiments that participants expressed.

Once all data had been coded in for content and values, I grouped smaller codes into themes and sub-themes to summarize the major commonalities in participants' experiences.

A number of common experiences emerged from the data, however some very pronounced differences in meaning and beliefs emerged among participants. In order to capture interrelations in data, I first examined the reasons that participants gave for having particular experiences, which in some cases painted very clear connections to explain why one person's experience was different from others. To find additional connections which were not as readily apparent to participants, I made frequency comparison tables. This method helped me to gain a general sense of the ways in which one theme connected to another, as well as the ways in which themes connected with demographic characteristics.

Knowledge Transfer Plan

I anticipate that the information from this thesis will be most useful to testing clinic staff, policy makers and HIV/AIDS scholars. In order to communicate results from this thesis to the academic community, I hope to publish a journal article which will largely focus on my first objective concerning the connection between HIV testing and MST and stigma. I plan to provide ACCKWA's testing staff with practical knowledge of the applications of this research through an oral presentation of the results, and a facilitated discussion to develop recommendations. ACCKWA's staff will benefit most from information with a direct application to practice, therefore the information provided to them will mainly come out of my second objective outlined above.

Results

Demographic Characteristics

Eighteen participants were interviewed for this study. The sample includes sixteen cisgender men, one cisgender woman, and one trans woman. Participants' ages ranged from 19 to 69. Twelve participants identified as gay, three identified as bisexual, and the remaining three identified as pansexual, questioning and heterosexual. All participants had at least one male sexual partner in the past year, four had a female partner, and one had a partner who was trans. Thirteen participants identified their ethnicity as Caucasian, and others identified as East Asian (N=2), Black (N=1), Spanish (N=1), and Native American (N=1). Four participants were born outside of Canada, and education level ranged from not having completed high school to having completed a graduate degree. One participant had used injection drugs in the past, and no participants had used injection drugs in the past year. Twelve participants had condomless sex with a partner whose HIV status was unknown to them in the past year, and one participant had condomless sex with someone who he knew to be living with HIV. All participants had received a POC test, and therefore knew their test results before the interview. All had tested negative for HIV. Each direct quotation included below notes the gender, sexual orientation, ethnicity, and age of the participant, for context.

Choice to include all participants

Given that the majority of participants are GBMSM (N=16), it might be suggested that I only include those participants in this thesis, as this would create a more homogeneous sample. I have chosen to include all participants, firstly because I feel that it would be unfair to the other participants not to use their data, as they took time to complete the interview and share their personal stories. Secondly, I have chosen to include these participants out of an awareness that certain marginalized groups are often excluded from research and other services because of low numbers. For example, trans people are frequently excluded from research findings because studies often have a very small sample of people who identify themselves as trans. This has a cumulative effect of erasing trans stories and experiences from academic literature, which limits the volume of information that is available to inform trans-specific services (Bauer, et al., 2009). For these two reasons I feel that it is important to include responses from all participants. Some of the findings that follow relate specifically to GBMSM identities, however many of the themes are applicable to people outside of this group, and contributions from all participants provide insight into these areas. Comments that relate specifically to female and trans identities should be viewed as case examples, which can add context to previous research findings, or serve to inform future research with larger samples of people from these groups.

Minority Stress and Intersections in Identity

Experiences of discrimination varied greatly between participants, with some describing profound experiences, which markedly affected their lives, while others shared more minor experiences. Some had experienced almost no discrimination. As part of the eligibility criteria, all participants fit into at least one service priority group, however the diversity in experiences within these groups was significant. A number of themes emerged which helped to explain why some participants appeared to be affected by discrimination to much higher degrees that others. These factors related to individuals’ identities and personal circumstances help to account for differing levels of privilege *within* these service priority groups.

Situations of discrimination & minority stress. Most participants recounted at least one experience that they identified as discrimination either in a healthcare setting or more generally in life. Participants spoke of the emotional impacts of these experiences, and the ways in which their behaviours were influenced.

Significance of HIV test. The HIV test itself emerged as a source of stress for many participants. They described a significant amount of worry about a positive result, even when they judged their risk to be very minimal:

> Regardless if you know one thousand percent whether you're HIV negative or whatever, you know, if you've had no sexual relations, you still do the test, you still feel anxiety. [GBMSM, white, 34]
>
> Yes. There's just always that that thought of ok, what if my result it positive? I mean I know I've never, I haven't experienced anything that would make me feel maybe so or whatever. But still there's always that, in the back of your mind, how do I handle it if the result is positive today? [GBMSM, white, 49]

Narratives throughout the interviews suggest that stress was largely tied to being part of a service priority group. All eighteen participants were aware that certain groups were at heightened risk of contracting HIV. The conflation of risk grouping and HIV was expressed throughout interviews; one participant stated “The big assumption is if you have HIV you're gay, or if you're gay you have HIV” [GBMSM, Black, 27].

Some participants explicitly expressed how their worry was connected to being a part of a high risk group. For example, one man talked about feeling anxiety about the test when he was in the waiting room looking at a poster targeted at men who have sex with men:

> So then when you see that on the wall, and I'm getting tested, and I've had bisexual acts with men, it's like, plus my fear of the results, and I'm like, you know. So it does have an impact. [GBMSM, white, 45]

Another participant expressed why he was somewhat uncomfortable with the fact that testing is heavily marked towards certain groups and not others:

> Statistically yeah I know that gay people get more chance to get infected with HIV, but I still feel not that comfortable yeah cause... just cause you're gay doesn't mean you have HIV right? [GBMSM, East Asian, 26]

For those who described the test as a stressful experience, receiving a negative test result significantly helped to relieve this worry.

> I was a little bit nervous but I know I would [come for a test] eventually because I sometimes... sometimes if you're not sure, are you positive or not you get scared. I don't want to stay scared. [GBMSM, East Asian, 26]
>
> It helps my anxiety to know my status, um ‘cause I got really anxious when I didn't know my status. [Trans woman, white, young adult]
>
> I know like there's a very very low risk, but still just like to be sure and kind of to keep my own like head about me, so I'm not worrying all the time about it, yeah. [GBMSM, white, 21]

While many participants found the test stressful, some participants felt little or no worry leading up to the test. For them, the test was described as merely a health routine. Those with little worry about their results also came for testing even when they felt their risk was very low:

> Participant: Well like in the past I have come and it's like oh I had a situation where ah maybe a condom had broken, but this time around I was very confident that like for the last six months I've used condoms consistently.
> Interviewer: Ok so you just wanted to make sure even though you felt like there was very little chance?
> Participant: Yeah it's just the whole twice a year assurance. [GBMSM, white, 26]

Discrimination in healthcare settings. Roughly half of participants reported at least one experience in a healthcare setting that they viewed as discrimination. Discrimination was often related to GBMSM or trans identities, or because of disclosing sexual or drug use behaviours. Notably, most discriminatory experiences occurred during HIV testing and other visits related to sexual and reproductive health.

There was a prevalent perception among participants that healthcare providers were passing judgement during healthcare visits:

> What I find about [other locations in the region] and having something like this done, is that there's this sense of being looked down on. And I don't like that feeling, you know.

> My choice shouldn't cause you to look down on me for my decisions, right? [GBMSM, white, 49]

In some cases healthcare providers quite explicitly passed judgement because of sexual behaviour:

> …the medical doctor sort of slut shamed me [laughs] for lack of a better term. Yeah, he was like, what are you getting tested for? What have you been doing? Why are you not in a long term relationship? Why are you here? I was like I'm here for the testing, he was like, well how many partners have you had? And I don't want to tell him at that point [laughs] because he'd already sorta shamed me for coming to his office, I'm seeing him to get tested and now I'm being you know, anyway. [GBMSM, Black, 27]

One participant descried facing discrimination simply for seeking out an HIV test:

> So I went to the test. And, uh, first I went to the wrong department, that is for dermatology. Yeah, and uh that doctor freaked out when I said oh I want to have, "Oh, what kind of test do you want?" I say HIV, and he just freaked out and he just didn't want to... wanted to get rid of me as soon as possible. And that's the first time I faced the discrimination. And actually I know I'm not positive, and I feel a little bit bad about that yeah… I still went to uh, went to the doctor who would do the test the next day. But, uh, that's something, something not good. Because, at that moment I'm very fragile, I feel very nervous and finally I summon up my courage to do the test, and eventually the doctor pushed me away. And if I'm not strong enough I think I'd never go back to do the test. [GBMSM, East Asian, 26]

Healthcare providers lacked knowledge and competencies in caring for GBMSM and trans people. This is exemplified well by a trans woman's experience at an HIV testing clinic, where the healthcare provider lacked understanding of gender pronouns for trans people:

> The very first question she asks me is 'are you a man who has sex with men?' And like, what they're asking is like a valid question, but like just the language completely excludes me, and is really harmful especially when I clearly indicated on the piece of paper that I don't identify as a man. Um so that [laughs] so immediately like at the very start of the clinic, of like our talk, I immediately wanted to leave. [Trans woman, white, young adult]

A gay man provides another example of service provider ignorance, as he explains his experience of having his sexual orientation doubted:

> Um, well I had a doctor prior to this doctor that I have now, who, ah he was a little older and he didn't believe in homosexuality. Ah he thought everybody, every man would be attracted to a woman. And when I told him, he just didn't believe it. He didn't, I didn't feel that he ah, was um disrespect to me in any way, ah he just didn't believe it. [GBMSM, white, 69]

Throughout these stories, many participants expressed that these situations made them hesitant to be open with the healthcare provider about their identity and behaviours. In most cases after an experience that they labeled as discrimination, participants chose not to return to that particular service provider and went elsewhere for service. Participants generally did not feel that these experiences greatly influenced their behaviours.

The majority of discriminatory experiences in healthcare settings shared by participants happened while receiving testing for HIV and/or other STIs. This may be in part because participants had just received testing before completing the interview, so the comparison was easy for them to make. It is likely also the case because many other medical services do not require participants to disclose their sexual orientation or sexual behaviours. Some noted that they choose not to disclose their sexual orientation to their primary healthcare providers: “my first family doctor, like I never told him I was [gay]” [GBMSM, white, 40], “I mean I've never gone to my doctor about any, like I don't think he would know that I'm gay so…” [GBMSM, white, 36]. Another man explained that when he is seeking care unrelated to sexual health, providers do not necessarily know his sexual orientation:

> I'm not, I don't think I'm very obvious. So it's, I think it's just automatically assumed that I'm straight. And it's not like I go and advertise it, so I don't personally see a lot of discrimination [in healthcare settings] … like my family doctor would know obviously. And I don't see any discrimination there…. But it's not like I go to a hospital and I don't get cared for or anything. [GBMSM, white, 34]

Testing and other services related to sexual health are somewhat unique in that they require a certain level of self-disclosure, and thus participants become vulnerable to judgement and other forms of discrimination.

Discrimination in other areas. Outside of healthcare settings, many participants reported very few experiences with discrimination. For example some spoke of a time when someone said something to them that they viewed as homophobic, but emphasized that this was a very uncommon experience for them. Some participants who did not give concrete examples of discrimination still expressed generally feeling a lack of acceptance throughout their lives:

> When you're growing up, you have this um, you're taught that homosexuality is bad, it's wrong, and well the further back in time you go, they didn't realize it was genetic and all that, the churches called it a choice, ah an illness, a disease and all this so if you grow up in that environment, saying oh am I diseased? Am I wrong?... And so there was always this stigma, ah against homosexuality but when you are homosexual there's not really a lot you can do about it. So you either learn to accept it or abstain. [GBMSM, white, 69]

The most common experience of discrimination reported was being bullied or teased in as a child or teenager:

> Even in high school, there was these, I can tell you their names now… those three, just taunted the hell out of me in high school. And uh, by name calling and uh, just doing like come up and take their arm, push all my stuff onto the floor, laugh and walk away, "clean it up, faggot or fruit cake", whatever. So, that ah, that had an effect on my all my life, yeah. [GBMSM, white, 49]

The majority of participants who experienced bullying or teasing said it affected them at the time, but that they were able to move on in the years since, and they did not feel that these experiences had a lingering impact on them.

Dimensions of identity and life circumstances related to discrimination. As the previous section highlights, experiences of discrimination varied greatly from participant to participant. A number of characteristics and life circumstances were identified which help to explain this diversity in experience.

Mental health and addiction. Mental health and addiction were prevalent themes both in participants' personal experiences and in their understanding of how HIV affects some communities more than others. One man explained his concerns about the lack of affordable mental health services for the gay community:

> If there was one thing that I would say that the services that could be provided, it's probably mental heath, I know that is something that tends to get overlooked. I know that probably would have been at some point something I would have liked. And I'm, I'm fortunate that my work covered, or where I did work at covered mental health, uh, for visits. But I mean, not everyone's work has that kind of benefits. So I think that would be something extremely - it is something that could save lives I think. [GBMSM, white, 34]

A number of participants shared that they had at some time in their lives experienced mental health issues, and many of them were currently dealing with these issues. The most common mental health issues discussed were depression and anxiety. Many participants also felt that their service providers did not genuinely care about their wellbeing. One woman expressed that she felt her psychiatrist was disinterested in having dialogue, instead being focused on prescribing medication. Similarly, another participant who was dealing with mental health and addiction issues reflected on his past experiences accessing health care services:

> Interviewer: Have you ever had times you've felt discriminated against if you disclosed using drugs?
> Participant: Oh definitely, and mental illness, I suffer from bipolar, so it's the same.
> Interviewer: Okay, and you find doctors don't deal with that appropriately sometimes?
> Participant: I have one, he's an awesome doctor, man. He really cares about his passion to help people who suffer from an illness, so. Yeah I've had that belief in myself, that they don't care, they're pill pushers, they got no time for me, they just want me in and out as quick as they can. 'Cause ah they only give you five or ten minutes, and they're constantly from 9 to 5, clients coming in, hundreds a day or whatever it is… So I, I do see discrimination. [GBMSM, white, 45]

Another participant discussed the lack of preventative services related to mental health issues:

> Participant: I had to admit myself to the hospital because I didn't know what I was gonna do to myself at the time. But when I was released, there was no follow up as to what was going, what I was doing or how I was doing or whatever.
> Interviewer: Okay so you think it's reactive rather than proactive?
> Participant: Yeah! [GBMSM, white, 49]

People with mental health and addiction issues reported experiencing more discrimination than those without these issues, and were more negatively affected by these experiences.

Socio-economic status and education. Socioeconomic status and education level were closely related to discrimination. Some participants discussed financial constraints that limited their access to mental health services that would benefit them. Additionally, many participants drew connections between socioeconomic status and HIV risk, such as understanding that people with fewer financial resources may be more vulnerable to manipulation from sexual partners. Those who indicated having completed some post-secondary education had fewer experiences of discrimination, and were less impacted by those experiences compared to those who had not completed education beyond high school.

Social Support. Having supportive friends and family was often cited as a reason for experiencing minimal discrimination, or for not being overly affected by discrimination. Participants often explained that they did not face discrimination that others might because they were part of supportive communities, in particular LGBT communities.

> No, I'm I think for me it's a little bit different because I'm, I'm active in the gay community… [GBMSM, white, 38]

Beyond personal social groups, many participants also found support in making use of organizations that they felt provided a positive non-judgemental space. For example one described why she comes to ACCKWA:

> I like [that the staff at ACCKWA] can understand people when they're unique and different. [Native American woman, bisexual, 35]

By comparison, those who described having unsupportive friends and family members tended to have faced more discrimination, and worried about social abandonment and other adverse social consequences in the event that they were to contract HIV.

Religious influences. Discrimination based on religion was a prevalent theme. For some, religion had relatively minor influences, for example some participants noted not having received sex education in religious-based public and high schools. Individuals with very religious families spoke most strongly of negative effects of discrimination based on religious beliefs. Having a very religious family was associated with not being out, or facing negative reactions for coming out: “One half of my family are Baptist, they love me anyways, ah they just think I shouldn't be a practicing homosexual” [GBMSM, white, 69].

Some participants were able to make direct connection between religious influences and their behaviours. For example, a gay man explained that he travels out of the region for sexual encounters, in order to avoid being seen by someone who knows him. He described his experience of not being out to his family, which he directly associated with having more sexual partners than he would otherwise:

> Um, it's tough for me because I, I never plan to come out. Just cause of what that would, what would happen, uh to our family probably. So um, I think that's why, why I tend to travel and do things like that, cause I don't really ever, I'll probably never have a partner and live a normal life with a partner. Or a normal gay life I guess. [GBMSM, white, 36]

Participants also had concerns about reactions of religious communities if they were to test positive, as highlighted by a man with a very religious extended family.

> Like outside of my family like let's say cousins or my aunts and uncles, I definitely wouldn't want to know. ‘Cause they go to church a lot more and, they would understand and pray and worry but you know they would be more disappointed. [GBMSM, white, 40]

Relationships between factors associated with discrimination. Some of the factors outlined above are very closely connected with one another. In particular, those with mental health and addiction issues were of lower socioeconomic status compared to those not dealing with these issues. Social support was also associated with socioeconomic status. Those with higher levels of education tended to be more integrated into supportive friend groups, compared to those with lower education levels. Participants’ level of family acceptance did not appear to be closely connected to the other factors.

HIV Stigma and Other forms of Oppression

This second major theme describes the ways in which individuals think about HIV, and how they perceive the marginalized groups most affected by the virus. It includes general opinions, as well as ways in which stigma and discrimination impact personal behaviours and well-being. Many participants appear to have internalized messages that stigmatize HIV, while others resist such dominant narratives.

Opinions about HIV, GBMSM communities and other service priority groups. As with minority stress, attitudes relating to HIV stigma were very diverse among participants. Some participants held quite negative attitudes towards individuals in service priority groups, while others resisted homophobia and other oppressions.

Individualized and structural understandings of HIV risk. Many participants attributed disproportionately high rates of HIV amongst gay communities in part to promiscuity, as one GBMSM explains:

> I think for gay people, gay people usually don't have a stable partner, sexual partner, usually gay people, they have more, multiple sexual partners. That's why you have more chance to get infected. But for straight people usually they have one girlfriend or one partner, or one wife or one husband. That's why they have less chance. [GBMSM, East Asian, 26]

This was often stated matter-of-factly, but some participants expressed this with a tone of judgement. For example, one gay man expressed that "…a lot of gay men just sleep around a lot unfortunately" [GBMSM, white, 40]. Another characterized engaging in unprotected sex as being careless and immature:

> There's still a large number of young gay people getting AIDS ah, because they're careless and quite possibly this ah. And I think there may be some ah, sexual attraction to this concept of bareback, and which I think is immature. [GBMSM, white, 69]

Participants also cited practical reason such as easier transmission through anal sex, and not having need to worry about pregnancy (and therefore not using condoms).

Compared to individual-centred reasons, fewer participants identified structural or systematic reasons for these disparities. A common structural factors cited is the lack of LGBT-specific sexual health information:

> Um, yeah and I feel like a lot of uh health education in school is really heteronormative, uh I don't feel that way I know it is, I've been through the school system [laughs]. It's really heteronormative, it's very cissexist, um so a lot of what we learn about safe sex is like, has to do with a very specific type of sex. Um, and like there, there was mention of, of like using condoms and things but, absolutely no mention of like insertive condoms, no mention of um, of the fact that like it's safer to use condoms for sex acts like other than just intercourse. Um, so I think a lot of that is just lack of proper information and lack of proper education. [Trans woman, white, young adult]

Other participants cited reasons why some individuals' choices are limited, because of discrimination that they experience:

> I think it is a socioeconomic thing really. I think that if an individual has problems in their wider life, and that is more likely to happen if you're Black or Latino, in a white society, um that other important things like sexual health sorta go out the window. And I often use this example to explain what I'm trying to say. If a gay dude is kicked out of his parents' home, and has to go stay with his boyfriend, and his boyfriend demands like raw sex, what is he to do? You know, live on the street or comply with this. And no, he doesn't know the status he might be concerned but like what does he do? He probably will go ahead and have unprotected sex, and that affects, and that like, his situation dictates what he has. [GBMSM, Black, 27]
>
> Aboriginals I can understand because everybody sort of heard through the media that their isolation and poverty in they're using drugs and alcohol and they don't have a lot of employment opportunities or education opportunities and that kind of thing so I can see that. [GBMSM, white, 40]

Reactions to Minority Stress Theory. Though most participants initially cited individualized reasons for health disparities, most indicated that MST made sense to them once the concept was briefly described. Many said they could see how particular life circumstances could translate into greater risk for some individuals:

> Yeah, yeah it makes sense. And I could just see somebody if they're really bummed out and, and depressed about it probably would have an escape, drugs and whatever, heaven forbid, needle use and stuff. [GBMSM, white, 40]

The concept of systemic reasons for disparities in HIV was new to some participants, but most made sense of it after a brief discussion.

> Like what you said, you said people feel discriminated, just now I just have a, how to say, epiphany, maybe you're right because they face a lot of discrimination, and they get scared and, I don't know. [GBMSM, East Asian, 26]

None of the participants outright denied that systemic factors played a role in disparities in HIV prevalence, though some doubted that minority stress played a major role:

> Participant: I think it's, yeah it could be. But I would say like, should be a minor, it's not like... I think of it in minor and major so it's like fifty-fifty.

> Interviewer: Ok, so you don't think [minority stress is] a big part of it?
> Participant: Um I don't think so. [GBMSM, East Asian, 21]

Some participants maintained that individual behaviour is the main factor that accounts for this disparity:

> Yes, it's true. But I think the other more significant reason there's higher risk is a lot of the younger people feel that well there's a pill if you get HIV so really don't have to be that careful anymore. And so there's this, you know when you're young you're immortal, uh ‘til you hit thirty or something like that, I'm not, the age is different for other people and um, so when you have that thinking, ah you tend to be a little less careful. [GBMSM, white, 69]

Opinions about anonymous vs. nominal testing. A number of participants expressed support for nominal reporting practices, so that people could be prosecuted for putting others at risk of contracting the virus. Most acknowledge that it is likely a minority of people who might do so. In almost every case they characterized the behaviour as irresponsible.

> For me just because I'm a responsible citizen if I had something, I think the authorities should know and I think other people should know. Because I was thinking if this guy gave me something I'd be calling the cops on him. Just so that they could, look buddy you know. Like if you knew and, who have you been, for sure. So I'm all for that. [GBMSM, white, 40]

> It's a difficult question, um because um, I think I would prefer not to notify the government if I were positive. Um, but I suppose there are some people that may not um handle it maturely and responsibly. And I guess there has to be some way of regulating that to a degree. [GBMSM, white, 69]

Participants with these concerns often mentioned particular cases of intentional infection, either in the media or someone known to them:

> Uh, I was in jail and a fellow was in there because he actually was told he had HIV, and he was going around having unprotected sex with people. So it's a charge, criminal charge. So they charged him. So this I felt, by being real and giving my real name, if I do have [HIV], it's in a database, it can be used in a database. I have no qualms about that. So I'm here just to lay it all out on the line. [GBMSM, white, 45]

Others were more in support of offering anonymous testing, generally because they acknowledged that it might make people more likely to come in for a test. The argument for anonymous testing was generally practical (more people come in for testing if it is offered anonymously).

> Oh yeah definitely, because there is people that are closeted out there and there's people you know that might use drugs or what have you so they don't wanna tell, say their name right? So it is very important to have anonymous, it's important to have both for sure. [GBMSM, white, 39]

One participant challenged the assumption that intentional infection is common enough to warrant mandatory nominal testing:

> I personally think that most human beings, if they found out they were positive, in Canada, would probably do something about it. As opposed to like just leaving it. And I'm sure there are some people who will take that and run with it and ad infect other people - I'm sure that happens - but I don't think that's the majority and so I wouldn't, like I wouldn't bank on the latter happening I would bank on people being a little more responsible with something like HIV that you know can kill other people, I yeah, I wouldn't be worried about that. [GBMSM, Black, 27]

Arguments in favour of anonymous testing were not generally based in beliefs about human rights related to privacy of information, or out of concern for rights of people living with HIV.

Personal impacts of stigma. When considering the social consequences if they were to test positive, most participants felt that they would be impacted by HIV stigma in some way. This includes the reactions of family and friends, as well their own self-perceptions.

Self-blame, language of "I should", and personal responsibility. A language of personal responsibility was prevalent throughout the interviews. Some participants expressed large amounts of guilt about their behaviors:

> Well the fact that I know better, which I do. And um, it's not like I haven't been brought up a little better than to give into those kinds of behaviours, 'cause I was brought up very well. [GBMSM, white, 40]

In addition, getting an HIV test was described with as "responsible":

> Honestly for me I think it's like something to be proud of, because it's like I am being responsible. I'd be like, I'm being responsible, so it's like what can they say to that. [GBMSM, white, 26]

While worry about reactions to of friends and family in the event of a positive result was prevalent, some participants expressed that their own reactions would be worse.

> Um, I was kindof, I don't know like I'm not, I was more worried just like about myself. Like a lot of my worries were like, oh, like if I did test positive a lot of it would be self-negativity it would be a lot of like 'how could you let this happen?', 'how could you not have been tested before?' [Trans woman, white, young adult]

Concealment of identity and behaviours. Throughout the interviews, concealment of identity emerged as a prevalent theme. As discussed earlier, some participants chose to conceal their sexual orientation from people in their lives, out of fear of the consequences of coming out. This concealment theme is also applicable to HIV. Many participants indicated that they would prefer not to be seen coming in for testing. Some were concerned about judgement:

> Well it's not even just the concern of being HIV positive, it's the concern of, oh I'm going for testing, what do other people think about me, what kind of, you know, sexcapades do they think that I've been in kind of thing. [GBMSM, white, 34]

Many participants expressed that they appreciated that ACCKWA offers a discrete location for testing, and they liked that most people who came to the clinic are also part of service priority groups. In some cases concern about being seen was primarily because of the association between HIV and risk groups, for example one participant explained why he would not want others to see him coming in for a test: “Not because of the HIV thing I think as much as not really wanting to come out to them” [GBMSM, white, 36].

When asked about social consequences if they were to test positive, many participants took comfort in the knowledge that they would not need to disclose their status to others. Some said that they would tell very few people, including keeping it from family and close friends, “I'm very private so I probably wouldn't share that very much” [GBMSM, white, 38].

Social consequences if tested positive. Participant perceptions of social consequences if they were to test positive varied widely. Of those with high concern about social consequences, it was often tied to a concern of abandonment and isolation from friends and family:

> I worry about that actually. I worry about what if some people found out. What if I'm positive, what if my, my, cause now I'm in school what if after graduation, what if my boss found out? What if my friends found out? What if my best friend found out? Will they abandon me or stay with me? Yeah, will they hesitate to hug me or not? Yeah there's a lot of stress actually. [GBMSM, East Asian, 26]

Some participants had concern of social consequences more broadly, outside of their close social circles, including fears of social stigma. Some participants were unsure how others would react:

> I don't know [laughs]. I have no idea, this one is like, this one is a hard question I would say because like you don't know like how people will look at you right? [GBMSM, East Asian, 21]

Again, the language of irresponsibility was used to describe perceptions of how others would react if they learned that someone had HIV:

> Um, well yeah I mean, when people do know, they definitely would treat you differently. And like, they'd see you perhaps as like lesser or like irresponsible maybe or like, I dunno like that you're gonna like try to infect other people maybe. Yeah like there'd be a lot of problems with that. [GBMSM, white, 21]

Participants who were less concerned about social consequences often cited having strong social support as a reason. While they acknowledged that stigma and discrimination were prevalent in broader society, some felt that their family and friends provided a more supportive space. In particular, those who were very integrated into the gay community felt that they would receive support in the event of a positive diagnosis:

> When I think about like the social consequences for it like most of my friends, like the majority are gay men, ah the majority of like my um, friends are gay men so I don't think

> I would face any stigma from any them. They're all good people, I've been with my boyfriend for almost seven years, and if I told him I had HIV, um I wouldn't see him leaving me of anything like that. [GBMSM, white, 26]

In line with this, many participants who were connected to the local gay communities also had friends or acquaintances who were living with HIV. Communities that included people living with HIV were seen as being particularly supportive:

> I have a lot of positive friends. And I really think that the stigma is, in my circle, is almost gone. [GBMSM, Black, 27]

Social support was not always connected to membership within marginalized communities. Some participants expressed that their friends and family were generally supportive:

> I don't think my true honest to God friends and family [would treat me differently if I had HIV], unconditional love, right? [GBMSM, white, 45]

Resistance and reframing. Throughout the interviews, many participants challenged dominant perceptions about HIV and marginalized groups in various ways. This was done through a process of changing one's own mindset, and through engagement with social issues.

Resisting HIV stigma and other forms of marginalization. Some participants described consciously making an effort to change their mindset relating to HIV. One described working to challenge dominant narratives about HIV:

> Yeah, um not so much the social stigma, although it's there but it's um, for me personally it's not something that I think about, cause I try very hard to de-stigmatize it in my own brain, and it's something that's taught to us, it's not something that is innate. [Trans woman, white, young adult]

Many participants acknowledged that medications have improved in the decades since the first HIV infections, and challenged the mindset where HIV is thought of as a “death sentence”, characterising it instead as a manageable chronic health condition:

> And as, like we, like we have a, you know you don't have to let it, you know you're still you, you can kinda just, you have to take medication I guess for the rest of your life and that. But it is a serious thing and I definitely hope that I would never get it. But I think um people can still keep living their normal lifestyles. [GBMSM, White, 36]

Some participants described a process of rethinking HIV because of knowing someone with the virus. One participant challenged HIV stigma in describing his experience of having a friend die of AIDS:

> And being in the hospital with my good friend … I thought of you know what? And I said to him, it doesn't matter to me what you have. I'm here because of who you are, not because of what's happening to you. And I, I said to him, I'm a smoker. That doesn't mean I deserve to die of lung cancer. I said it's the same thing with you. This is not some punishment to you because of what you chose in life, this is a choice that you made, and this is the outcome of it. The same as my choice with smoking, and if I were to come down with lung cancer. But it doesn't define who we are as a person. [GBMSM, white, 49]

Interestingly, this participant used language of individual blame and personal choice discussed earlier, however he challenged the conceptualization of HIV as a punishment. Another participant explained how his mindset changed over time, largely because of becoming sexually involved with someone who is living with HIV:

> I have a long-term friend, fuck buddy, whatever you'd like to call … who is positive but has been undetectable for like 15 years. I'm negative. Uh and I, I had sex with him without a condom and was completely ok with it, like five months ago, and I'm still negative. And I didn't think for a second that he could or would infect me. So if you, if I had asked the same question a year ago, I would have said no, like loudly, resoundingly, no. But now I, if you had asked me the question 'would you sleep with someone who it is HIV positive?' I would have to have a bunch of follow-up questions for you. [GBMSM, Black, 27]

In addition to challenging narratives that stigmatized HIV, many participants described a process of coming to terms with elements of their identity. In particular many gay men expressed struggling with their sexuality earlier in their lives, but coming to terms with the identity as they got older. For some, this process took significant time and effort. One man explains this shift in mindset:

> But I reached a point now where, I don't care what they think. You know what I mean? Like the sad part is, um I um, I knew I was gay from a very early age, right? But because of my religious background and my parents and whatever, what do I do? I go and get married [to a woman]. Because that was what boys did. Boys did not go and, you know. So I lived my life, all my life, trying to please someone else, what they think I should do. And now I've reached a point, I'm at a point where you know what? Fuck you. It's time for me. [GBMSM, white, 49]

Empathy and desire to see change. Throughout the interviews, many participants expressed concern about the treatment of people in marginalized groups. Particularly those who discussed structural reasons for health disparities spoke passionately about their desires for positive social changes. These sentiments sometimes came through in discussions of particular events that participants viewed as discrimination. For example, a gay man reflected on a situation when he was in line at a fast food restaurant, and someone was making homophobic remarks towards another person in line. He intervened by confronting the harasser, however he was discouraged that nobody else in the busy restaurant was willing to intervene:

> I think because I'm fairly confident… I'm stable, I'm you know I'm financially stable even, like I, I'm not struggling with a whole lot that this point, us, the ones that are okay, need to kind of stand up for the rest. But, it's not just me that was okay in there, and it doesn't have to be just the gay person. So what happened to everyone else? [GBMSM, white, 34]

Frustration with social structures also came through in discussions of institutional systems. In particular, two topics emerged as being of particular concern to participants. Many expressed concerns about the lack of LGBTQ-specific health information in school-based sex education programs, felling that this has a major negative impact on these communities. Secondly, many participants felt that mental health services should be improved in general, and specifically for GBMSM and trans people.

Many participants spoke very passionately about social issues related to HIV stigma, homophobia and other forms of oppression. It was evident that some participants had spent a great deal of time considering these issues. Many were actively engaged in social justice initiatives, or indicated a desire to get involved with ACCKWA or other social service organizations as a volunteer. This indicated that there is a strong desire for social engagement within service priority groups.

Discussion

Minority Stress Theory

HIV testing as a stressor. Worry about HIV test results can be understood as a contributor to minority stress. Aware of their membership in a "high risk" group, many participants felt stress or anxiety leading up to the test. Participants expressed that these fears were intrinsically linked with the social identities associated with HIV, and the perception that those who acquire HIV are irresponsible. Some participants had this fear even in the absence of high-risk behaviour. This provides clear evidence of the conflation of HIV with service priority identities discussed by Waldby (1996), where membership within a "high risk" group is taken as a risk factor in and of itself. Therefore, though any person could experience worry leading up to an HIV test (i.e. it could be viewed as a general stressor), only those in service priority groups experience stress related to being targeted based on identity, which is a *unique* minority stressor, by Meyer's definition (2003).

The reasons for worry about test results were rooted in perceived social consequences in the event of a positive result, including fear of abandonment. In MST terms, the can be understood as a distal stressor, a prevailing social attitude which positions some groups as lesser than others (Meyer, 2003). Responses also indicated high amounts of self-blame amongst participants in regards to the risk behaviours that they had engaged in. This shows an internalization of negative attitudes, or proximal stress. Namely, participants internalized attitudes which blame individuals for contracting HIV. In this way, GBMSM and those in other service priority groups are burdened with guilt about their sexual practices to a degree that those outside of these groups are not.

To deal with the stress of not knowing their HIV status, individuals seek HIV testing. Therefore, HIV testing is a coping mechanism. Receiving a negative result provides peace of mind, and many participants expressed relief when receiving their results. Meyer describes coping as a way for individuals to resist dominant narratives that paint people in certain groups as deviant, allowing individuals in minority groups to evaluate their social identities more positively (2003). The test can be seen as a marker of identity, a way for GBMSM and people in other service priority groups to differentiate themselves from stereotypes of irresponsibility. A negative test result provides reassurance that one will not assume an HIV positive identity, and thus will not be subject to associated social consequences.

Importantly, not all participants felt this high level of stress when taking the test. For some individuals, the test was described as merely a health routine, much like someone might describe going to the dentist or getting an annual checkup. This indicates that stress in not inherent to the test, but that it is dependent on social and personal factors which influence the way a person thinks about HIV. This finding is particularly important to note because of its implications for public health messaging. Some could argue that heightened worry about HIV is useful because it motivates individuals to seek testing. However, findings suggest that this is not necessary, that it is possible to depict HIV vulnerability realistically while maintaining motivation to seek testing, and at the same time lowering stress that test-takers experience.

Diversity in experiences and limitations of biomedical risk analysis. Though all participants were part of at least one service priority group, findings reflect a great diversity of experiences and life views between participants. In addition to identities based on sexual orientation, race and gender expression, factors including socioeconomic status, mental health and addiction issues, social support and family acceptance were shown to play roles in an individual's experiences. In particular these factors were associated with the severity of discrimination that individuals experienced. This highlights a flaw with the biomedical risk model, and the overreliance on service priority groupings as an indicator of who should and should not be targeted to receive services. The identity-based targeting approach runs the risk of oversimplifying vulnerability, by not accounting for important individual factors which impact health and well-being (Scott, 2003).

This oversimplification of risk based on identity categories poses a problem for service delivery, as it ignores the complex service needs that individuals may have. In his recommendations for future development of HIV testing policies, Scott (2003) cautions that "prevention campaigns limit themselves... when they are dependent on people self-identifying as members of high-risk populations and when they zero in on particular identities and contexts without accounting for the complexity and movement of risk." (p.235) He suggests that client-centred counselling can help to account for this complexity by assessing a person's needs individually, rather than having assessment based solely on their group membership. This approach can allow for referrals to a network of services that are appropriate for an individual's particular situation.

HIV stigma

Individual-blaming and implications for service priority groups. Parker and Aggleton (2003) write that stigmatization “involves the marking of significant differences between categories of people, and through such markings, their insertion in systems and structures of power” (p.17). Individual-blaming language points to a distinct marking of difference between service priority groups and the “general population”, the difference being that those in service priority groups (gay men in particular) are characterized as being more promiscuous and sexually irresponsible than the more responsible general public. This individual-blaming mentality is perceived as the prevailing public opinion, and is also internalized by individuals in these groups. Internalization of individual blame is in line with Parker and Aggleton’s theorization that stigma is largely maintained in hegemony, legitimized and accepted even by those who it places at a disadvantage.

This prevailing assumption leaves little room for challenging unfair social systems, negating any responsibility on the part of policymakers, lawmakers, or the so called general population. Instead the burden is placed on the shoulders of those in service priority groups, who are subject to a level of stress that others are not. Waldby (1996) writes of hierarchies of pathology, where targeting “maps itself onto the hierarchies already implied in the binaries of sexual identities so that women are targeted as threats to men, and homosexuals as threats to heterosexuals” (p.9). She explains that individuals in targeted groups are marked as unhealthy compared to those outside of these groups, and thus they take on the onus of responsibility. In this way, individual blame works to maintain the social order described by Parker and Aggleton (2003).

Stigma and perceptions of people living with HIV. Attitudes about people living with HIV are closely tied to the narratives of personal irresponsibility discussed above. However, the impact of stigma on individuals living with HIV warrants separate analysis as this group is impacted the most. If Waldby's hierarchy of pathology can be extended to include those living with HIV, these individuals occupy the lowest position, being burdened with complete responsibility for protecting those who are not infected. This is evidenced in examining participants' expectations for people living with HIV. Participants were unsympathetic to the notion that individuals living with HIV might not disclose their status to their sexual partners (despite the fact that many were aware that the chance of transmission with a reduced viral load is extremely low). In contrast, participants did not describe condomless sex with someone whose sexual status was unknown to them with the same disapproval. Even when describing their own hypothetical behaviour, participants were adamant that they would inform their sexual partners of their status if they were to test positive, though most participants had engaged in condomless sex with someone whose status was unknown to them.

This points to a double standard in the level of responsibility expected for people who know they have contracted HIV compared to those who are either negative or unaware of their status. In Parker and Aggleton's terms (2003), this is another socially constructed significant difference between categories of people. People living with HIV are positioned as having been irresponsible, and therefore deserving a burden of responsibility higher than what is expected for anyone else. By contrast those who are HIV-negative or unaware of their status enjoy relative freedom, and are not held accountable for their behaviours in the same way (Adam et al., 2008).

Addressing HIV Stigma and Minority Stress

Critical engagement and activism. Some participants showed strong critical engagement with issues that affect marginalized groups. Particularly participants with high amounts of social support and membership within LGBT communities were able to largely reject messages of personal responsibility and HIV stigma. This is in line with Meyer's conception of stress ameliorative factors, or coping mechanisms (2003). He posits that social support allows members of marginalized groups to reappraise dominant messages that position them as lesser, and adapt values that enhance their social identities. This critical evaluation can greatly improve a person's well-being. This was shown in the current study, as those with high amounts of social support experienced less stress in seeking testing and less worry about social consequences if they were to test positive, compared to participants with lower social support.

To encourage critical reflection, organizations should work to better convey information that points to systemic issues related to HIV vulnerability. All participants were acutely aware that certain communities are disproportionately affected by the virus, a message that is widespread. However, many participants were not aware for example of the ways in which socioeconomic status and mental health impact health of LGBT individuals, or that nondisclosure laws are unfairly biased against people living with HIV. Conveying these messages can help to resist messages which blame individuals. Beyond providing this information, organizations should create social environments for individuals in marginalized groups to support one another, and to engage critically with social justice issues. Research suggest that such approaches, which focus on fostering strength and reliance within marginalized communities rather than focusing on deficits, carry untapped potential to improve well-being of those in marginalized groups, and are beneficial for HIV prevention (e.g. Herrick et. al., 2011).

Beyond its role in helping individuals to cope with minority stress, critical engagement can fuel activist efforts, which work to change the system which is causing stress. Activist efforts help to address stigma, by challenging power structures in place which privilege some groups at the expense of others. The history of HIV activism discussed earlier shows the potential that activist initiatives have to markedly improve the lives of people in marginalized groups. Scott (2003) suggests that those who are most affected by testing policies should be actively involved in the process of designing testing practices and other services related to HIV, to ensure that their interests and rights are fully considered.

Policies and laws. When considering stigma as a social power structure, perhaps the most concrete means of addressing it is to enact laws and create policies that protect those with relatively little power (Parker & Aggleton, 2003). As discussed earlier, biomedical science and public health discourse are taken as authoritative sources for understanding HIV (Waldby, 1996). Changes to policies which reflect the rights of marginalized groups are likely to impact public understanding and beliefs. The connection between policy and public opinion is evidenced when considering the communalities between participants' perceptions and current policies in Canada. The tendency to view HIV risk in simplified individualistic terms in many ways parallels Canada's response to the epidemic. As I have argued, the general Canadian response to HIV emphasizes individual behaviour change for those within service priority groups, and dedicates relatively little resources to systemic change efforts (Waldby, 1996). Similarly, the characterization of people living with HIV as "irresponsible" parallels Canada's non-disclosure laws, which place all responsibility on people living with HIV to ensure safety, and are heavily biased against them in sentencing (Adam et al., 2008). If policies were instead written with the aim of protecting the rights of marginalized groups, it would greatly help to balance the power structure currently in place, and reduce stigma related to HIV.

To address minority stress, laws and policies should be written in a manner that does not assume that HIV risk is synonymous with identity-based risk groupings. A relevant example is Canada's blood donation laws (Canadian Blood Services, n.d.-b). In Canada, it is illegal to donate blood as a man who has had sex with another man within a certain time period (currently five years, but will be reduced to one year in August 2016). The screening questions ask nothing about physiological risk, such as whether these individuals are in a long-term monogamous relationships or whether they consistently use condoms, rather it is simply assumed that all men who have sex with men are at heightened risk of contracting the virus. This institutional policy quite clearly validates the conflation of HIV and with GBMSM communities. Similarly, other "high risk" groups are excluded without consideration of actual risk. Individuals who have been to certain HIV-endemic countries within the past year and their sexual partners are not permitted to donate. The Canadian Blood Services website insists that this policy is "based on risk factors [and] has nothing to do with race and ethnicity" (Canadian Blood Services, n.d.-a). However, this policy affects ACB individuals much more than any other group, and does not in fact take into account actual risk. Additionally, effective August 15th, trans individuals who have received lower gender affirming surgery in the past year will be excluded from donating blood (Canadian Blood Services, n.d.-c). To account for the diversity within service priority groups, policies should avoid harmful assumptions based on identity characteristics.

Additionally, acknowledging that many systemic factors contribute to minority stress, policies should be written so as to proactively address various social determinants of health which contribute to vulnerability (e.g. those outlined by UNAIDS, 2011). Most preventative approaches have implications for change only for people within service priority groups, however these strategies may not be as effective in the long term as more systemic approaches would be. This lack of government support for addressing social determinates of health is not specific to HIV. Rather, it is part of a larger political trend towards individual responsibility that began in the 1970s (Mooney, 2012). At a time when government is focusing on lowering operational costs, problems that would have traditionally fallen under the domain of public health are now being addressed by privatized entities, or promoted as the responsibility of individuals (Dodds, 2002). It has been argued that this shift in funding structure and health messaging contributes to victim-blaming public opinions. Dodds (2002) observes the irony that government bodies have high amounts of power, influence, and resources, yet "the individuals who are most vulnerable and possess the least power have the greatest obligation to 'take responsibility' and change their 'lifestyles' in order to become healthier citizens" (p.141). Systemic approaches require an acknowledgement that other factors play a significant role in HIV vulnerability, and that it is not simply an individual's choice of whether or not to use a condom or seek testing that accounts for the spread of HIV. This type of change requires a call for accountability from those outside of service priority groups.

To address stigma, policies should be developed by considering the rights of people living with HIV and should not be built around the assumption that people are likely to intentionally spread the virus. A local example is helpful in making this point. As I mentioned earlier, currently in the Waterloo Region, individuals cannot legally receive anonymous point of care HIV tests (Region of Waterloo Public Health & Emergency Services, 2015). If individuals wish to take tests anonymously, they must take a standard test where the result is available two weeks later. This rule is impractical on an individual level, as those who get tested anonymously using the standard method could conceivably not return for their results, and thus if they tested positive they would remain unaware. The rule is likely in place to encourage test-takers to have their names recorded with the test. However, it could deter some individuals from coming in for testing, and it could be argued that this is a coercive strategy to encourage test-takers to forfeit their right to privacy. With this policy, Waterloo Region's public health authorities show a clear prioritization of government surveillance and discipline over individual well-being. Allowing individuals access to anonymous testing through whichever method they desire would greatly help to defend individual privacy rights. It would also help to destigmatize HIV and the people living with it by rejecting the assumption that intentional transmission is a common enough occurrence to warrant mandatory name reporting.

Future Research

This thesis has highlighted some ways in which cultural implications are not fully considered when HIV prevention strategies are developed. I recommend that research related to HIV testing, or HIV prevention more broadly, take into consideration potential impacts that strategies might have on those most affected by the virus. Even in studies that might appear on the surface to fall solely into the domains of medical or epidemiological research, there is always room for these considerations. As much as these types of research aim to be objective and impartial, the language used in them and the recommendations that are drawn from their findings are necessarily political. Communities most affected by HIV have historically been marginalized by biomedical-based prevention strategies that have often neglected meaningful considerations of their human rights. Particularly in light of this history, researchers have a duty to these individuals to consider the ways in which polices affect them.

As the present study was composed primarily of white GBMSM, future research focusing on other priority populations is needed in order to more fully understand HIV testing and its complex context. Such research would provide insight into the ways in which HIV testing is experienced in the context of racism, colonialism, cisnormativity and discrimination faced by people who use injection drugs. Furthermore the present study was completed only by people who accessed the clinic. Research involving people who do not access HIV testing would provide further understanding of barriers that exist which prevent some individuals from seeking testing.

In terms of research to build on the content of this thesis, I recommend that studies examine interventions that might flow from some of the recommendations found in this thesis and from other scholars who have critically examined testing practices (e.g. Soctt, 2003). For example, researchers might evaluate an intervention aimed at conveying risk realistically, or implementing a more complex and individualized counselling and referral process to account for varying needs of test-takers. I have found qualitative inquiry to be an effective method for examining the complexities of test-takers’ experiences and perceptions, and thus I would recommend this method to other researchers seeking an in-depth understanding of the meaning that participants draw from their experiences receiving testing.

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Appendix A

WILFRID LAURIER UNIVERSITY - DEPARTMENT OF PSYCHOLOGY

INFORMED CONSENT FORM

Study Title: An Exploration of Strategies to Optimize the HIV Testing Experience
Researcher: Mallory Harrigan (MA Candidate, Wilfrid Laurier University)
Research Supervisor: Dr. Robb Travers (Associate Professor, Wilfrid Laurier University)

Purpose of Study

You have been invited to participate in a research study designed to look at the HIV testing clinic at The AIDS Committee of Cambridge, Kitchener, Waterloo & Area (ACCKWA). The aim is to gain a better understanding of the ways that ACCKWA can optimize the testing process so that it encourages people to return for testing, facilitates learning about safer sex and safer injection, and helps to connect people with other health and community services that they might benefit from. It also aims to further understanding of the role that the testing clinic plays in shaping the attitudes that people have about HIV, particularly for people in marginalized groups.

Participation

If you choose to participate in this study, you will complete a one-on-one interview with the researcher, Mallory Harrigan, which should take 30-60 minutes of your time. The interview will be audiotaped. You may choose to complete the interview directly after your appointment, or at later date (i.e., you may arrange with the researcher to meet at ACCKWA or the Laurier Waterloo campus). We anticipate that approximately 20 people will take part in this study.

Eligibility

You must be 16+ years of age to participate in this study. You must also identify with at least one of the following groups: Trans, gay, bisexual, or a man who has sex with men; Indigenous/Aboriginal, African, Caribbean or Black; injected drugs within the past 12 months.

Risks

There is a potential for personal and possibly difficult topics to be discussed during the interviews, which might make you feel uncomfortable. These feelings are normal and should be temporary. However, if you experience any persistent negative emotions or feelings following the interviews please let me know immediately. Staff at ACCKWA can also provide referrals to counseling services if you experience distress from the subjects discussed in the interview. You are free to omit any answers you do not feel comfortable answering and you can withdraw from the study at any time without penalty.

Benefits

By participating in this study you will help to expand the body of knowledge regarding the experience of people who receive HIV testing.

Confidentiality

If you decide to participate in this study your responses will be completely anonymous and confidential. The only time confidentiality can/will be broken is if you disclose that you are currently thinking of hurting yourself or someone else, in which case the researcher is under obligation to inform the proper authorities. Your name and any other identifying information will not be associated with the data (unless you choose to review the use of your quotations – see below), and you will not be personally identified in any publications resulting from this research. The only people who will have access to the data are Mallory Harrigan, Dr. Robb Travers, and other members of the Equity, Sexual Health and HIV Research Group at Wilfrid Laurier University. Any members of the research group other than Mallory and Dr. Travers will only be involved in transcription and will only have access to de-identified forms of data. All electronic data, including audio recordings, will be stored on a password protected computer, while all hardcopy data, including consent forms and contact information (if you choose to provide this information for the purpose of reviewing your quotations – see below) will be stored in a locked filing cabinet in the Equity, Sexual Health, and HIV Lab at Wilfrid Laurier University. All identifiable information will be destroyed by the researchers at the end of the study (i.e., by April 30, 2016). The de-identified data will be kept for 7 years and will be destroyed by Dr. Robb Travers by April 30, 2023. At no time will any staff members at ACCKWA be provided with names of people who completed the study, and no personal information that you disclose will be shared with ACCKWA's staff. Participating or declining to participate in the study will in no way impact your access to services at ACCKWA.

Compensation

You will receive a $10 Tim Hortons gift card in compensation for your time. If you choose to withdraw from the study, you will still receive the $10 Tim Hortons gift card.

Contact

If at any time you have questions about the study or experience any adverse effects as a result of participating in this study, you can contact Mallory Harrigan via email at harr3640@mylaurier.ca or Dr. Robb Travers at rtraver@wlu.ca. This project has been reviewed and approved by the University Research Ethics Board (REB #4665), which is supported by the Research Support Fund. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Robert Basso, Chair, Wilfrid Laurier University Research Ethics Board, at (519) 884-0710 ext. 4994 or rbasso@wlu.ca.

Participation

Your participation in this study is voluntary; you may decline to answer a question or withdraw from the interview altogether at any time without penalty and without loss of remuneration (i.e. you will still receive the Tim Hortons gift card if you choose to end the interview early). At any time during or after the interview, you have the option to request that your data be destroyed immediately and your request will be granted. Please note that you can consent to being a part of the study while also not allowing any quotations to be used in the final reports.

Feedback

After the completion of the study, information about the study's findings will be available to participants who wish to access it (i.e., by August 31, 2016). To obtain these results, contact Mallory at harr3640@mylaurier.ca. The data collected in this study will be used for an assessment of ACCKWA's HIV testing clinic, as well as for a Masters Thesis completed by Mallory Harrigan. Findings may also be presented at provincial, national, or international Psychology conferences, published in academic journals, and/or made available through Open Access resources.

Consent

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature____ Date ______________

Investigator's signature____ Date ______________

Quotations

Remember, you may participate in the study regardless of whether you consent to the use of your de-identified quotations. After the interviews are transcribed, you have an opportunity to review your quotes before they are used in any form of publication. If you would like to review the use of your quotations, you can do so over email or in person with the Mallory Harrigan. (Note: If completed via email, confidentiality of data cannot be guaranteed during transmission over the Internet.)

If you choose to review your quotations, your contact information will be stored along with the transcript from your interview, on a password protected computer. Once you have given feedback on the use of your quotations, your contact information will be deleted from the file.

Please check one of the following regarding the use of your quotations:

☐ I AGREE to allow the researchers to use my de-identified quotations.

☐ I DO NOT allow the researchers to use my quotations.

If you agree to allow the researchers to use your quotations, please choose one of the following:

☐ I do not wish to review the use of my quotations. As long as they do not contain identifying information, the researcher can freely use my quotations in analysis.

☐ I would like to review my transcript via email. Please send the document to the following email address: ____

☐ I would like to review my transcript in person with the researcher. Please contact me to arrange a meeting for this purpose (provide phone number and/or email address):
____

Appendix B

DEMOGRAPHIC QUESTIONNAIRE

Age: __________

What sex were you assigned at birth?

☐ Male
☐ Female

Do you identify as:

☐ Trans male/Trans man
☐ Trans female/Trans woman
☐ Genderqueer/Gender non-conforming
☐ Gender identity not listed above, specify if desired: ______________________________
☐ Not applicable

What is your sexual orientation? Please select all that apply.

☐ Heterosexual (straight)
☐ Gay
☐ Bisexual
☐ Two spirited
☐ Queer
☐ Unsure or questioning
☐ Sexual orientation not listed above, specify if desired: ____________________________

In the past 12 months, your sexual partners have been (check all that apply):

☐ Male
☐ Female
☐ Trans male/Trans man
☐ Trans female/Trans woman
☐ Genderqueer/Gender non-conforming
☐ Gender identity not listed above, specify if desired: ______________________________
☐ Not applicable

Are you perceived as a person of colour?

☐ Yes
☐ No
☐ Unsure / Sometimes

What is your race/ethnicity?

____

____

Were you born in Canada? If not, how long have you lived in Canada?

- ☐ I was born in Canada.
- ☐ I was born outside of Canada and I have been here more than five years.
- ☐ I was born outside of Canada and I have been here less than five years.

What level of education have you completed? Check all that apply

- ☐ Elementary / primary school
- ☐ Secondary / high school
- ☐ College diploma / undergraduate level university degree
- ☐ Graduate education (e.g. MA, PhD, MD degrees, etc.)

Please choose the statement that best describes your injection drug use:

- ☐ I have never injected drugs.
- ☐ I have injected drugs in the past but no longer do.
- ☐ I currently use injection drugs.

In the past 12 months, have you injected drugs using a needle that had previously been used by someone else? If you have not injected drugs in the past 12 months, please skip this question.

- ☐ Yes
- ☐ No

In the past 12 months, have you had condomless vaginal or anal sex with someone whose HIV status was unknown to you?

- ☐ Yes
- ☐ No

In the past 12 months, have you had condomless vaginal or anal sex with someone who you knew to be HIV-positive?

- ☐ Yes
- ☐ No

Appendix C

INTERVIEW GUIDE

Thank you for agreeing to participate in this study. As you read in the consent form, you have the right to end this interview at any time or to skip any questions that you do not want to answer. Before we begin, I want to clarify that the aim of the study is to see what ACCKWA can do to improve their testing clinic, I am not evaluating the work of the Public Health nurse who administered the test.

I am going to record this session so that I can transcribe the interview later. [Begin recording]

The first set of questions that I am going to ask are about your experience with the testing clinic and your access to health and community services.

- Can you start by telling me why you decided to come for HIV testing today?
    - Why did you choose to come to ACCKWA rather than somewhere else?
    - Where did you hear about it ACCKWA's testing clinic?

- Did you have any hesitation about coming in for testing? If so can you tell me why you were hesitant?

- How comfortable did you feel throughout the process of receiving testing?

- As the nurse may have explained to you, there are two types of test that you can get. The point-of care test is done by a finger prick and you get your results within minutes, and the standard test is done by having blood drawn and you get results within a week or two.
    - Were you offered both types of test?
    - Which type of test did you get today? Why?
    - How important is it to you that your preferred option is available?
    - Would you have come in for testing if your preferred option was not available?

- As the nurse likely also explained to you, you can elect to have your test taken anonymously, or you can have your name recorded with your test.
    - Did you get an anonymous test today?
    - How important / unimportant is it to you to have anonymous testing available?
    - Why is anonymous testing important / unimportant to you?
    - Would you have come in for testing if anonymous testing was not available?

- How knowledgeable are you about safer sex practices (e.g. using condoms)?
- How knowledgeable are you about safer injection (e.g. best practices for injecting, where to get needles)?
    - Where did you learn about sexual health and safer injection
    - How satisfied are you with your knowledge of these topics? Would you like opportunities to learn more?

- Did you learn anything that you didn't already know from the nurse who administered your test today?

- Did you learn anything new from ACCKWA's staff today?

- How comfortable do you feel asking the staff and nurse questions about safer sex or safer injection?
    - What did they do that made you comfortable or uncomfortable?

- If you go for an HIV test in the future, where will you go?
    - Would you return to ACCKWA? Why or why not?

My next few questions are about your access to healthcare and community services more broadly, not just the testing clinic. I am asking these questions because ACCKWA's testing clinic has a secondary goal of connecting test-takers to various services that they might benefit from.

- Healthcare services include being able to see a doctor when you need to, and having access to any specialists that you might need.
    - In the past 12 months, have you gone to any doctors or specialists? If so, what kind?
    - How satisfied are you with your access to healthcare services?
    - What makes you satisfied or unsatisfied?
    - Are there any healthcare services that you are lacking?

- Community services can include services such as community support groups, help with access to housing and food, job search help etc.
    - In the past 12 months, have you accessed any community services? If so, what kind?
    - How satisfied are you with your access to community services?
    - What makes you satisfied or unsatisfied?
    - Are there any community services that you are lacking?

- From what you know of ACCKWA, do you think that you would benefit from any of the services they provide besides testing? Some of the services that they offer are condoms and needles, education, support groups and referrals to other health and community services.
    - If yes: Can you specify?
    - If no: Are there any services that you would like them to provide that they currently do not?

My next set of questions are meant to explore the reasons why HIV affects some sub groups of the population more than others.

- Are you aware that there are certain groups that are more likely to contract HIV compared to other groups? Which groups do you think are affected the most?

- Why do you think that certain groups are at heightened risk?

Some people argue that HIV affects certain groups more because those people experience discrimination more, and are less likely to seek health services because of that discrimination. For example, a gay man may have had bad experiences in the past with doctors discriminating against him because of his sexual identity, which might make him less likely to go to see a doctor when he needs to.

- What do you think of this idea?

- Can you speak about any experiences of discrimination that you have encountered in a healthcare or community service setting?
    - Did that experience affect your access to services?

- Can you speak to experience of discrimination more generally in your life?

Another line of thinking about why people do not access services such as testing is that HIV is highly stigmatized in our society. That is, people do not want others to know that they are getting tested, and also might fear others reactions if they were to test positive.

- When you came in for testing, did you have any worry about who might see you coming in for a test?
    - Why or why not?

- Do you worry about social consequences if you were to test positive?
    - More so than if you were diagnosed with another comparatively serious illness? Why or why not?
    - What do you think the social consequences would be if you were to test positive?

For my last question, I am looking at the combination on discrimination and stigma. Most of ACCKWAs services are geared towards people in service priority groups, you’ve likely noticed that posters and flyers at ACCKWA target specific groups (gay men, people from countries where HIV is endemic etc.) This is referred to as a targeted approach.

- How do you feel about ACCKWA’s targeted approach?
    - Do you like that ACCKWA works to make the materials relevant to these group?
    - Does the targeted approach bother you in any way?

Thank you very much for completing the interview!

Appendix D

Chart of Objectives, Research Questions and Interview Questions

Objectives	Research Questions	Interview Questions
To explore policy and procedural improvements that a testing clinic could reasonably implement to optimize outcomes for test-takers in high-risk groups.	What factors facilitate or discourage HIV testing?	Can you start by telling me why you decided to come for HIV testing today? Did you have any hesitation about coming in for testing? If so can you tell me why you were hesitant? How comfortable did you feel throughout the process of receiving testing? Questions about type of test and anonymity options.
	What education needs to test-takers have? How might ACCKWA better facilitate learning about best practices for HIV prevention?	How knowledgeable are you about safer sex/ safer injection practices? How satisfied are you with your knowledge of these topics? Would you like opportunities to learn more? Did you learn anything that you didn't already know from the nurse who administered your test today? Did you learn anything new from ACCKWA's staff today? How comfortable do you feel asking the staff and nurse questions about safer sex or safer injection? What did they do that made you comfortable or uncomfortable?
	What other health and community services needs to test-takers in the region have? Are these needs being met?	Questions about healthcare and community service access, including quality of services received. Do you think that you would benefit from any of the services that ACCKWA provides besides testing?

To understand how minority stress and stigma relate to experiences of HIV testing.	To what degree have test-takers experienced discrimination in healthcare settings and/or generally in their lives, and what effect does this discrimination have on these individuals? What personal protective factors help individuals to cope with discrimination?	Can you speak about any experiences of discrimination that you have encountered in a healthcare or community service setting? Did that experience affect your access to services? Can you speak to experience of discrimination more generally in your life?
	Is HIV highly stigmatized amongst test-takers? Do they view acquiring HIV purely as a result of individual choice, or do they connect HIV vulnerability to broader social factors? How do these conceptualizations relate to attitudes about members of service priority groups, and to notions of risk and responsibility?	Why do you think that certain groups are at heightened risk of contracting HIV? Do you think people should have the option to receive an anonymous test? Do you worry about social consequences if you were to test positive?
	What are participants' experiences accessing the testing clinic? How do their attitudes about HIV and experiences with minority stress affect the way that they think about testing?	Did you have any hesitation about coming in for testing? If so can you tell me why you were hesitant? How comfortable did you feel throughout the process of receiving testing? How do you feel about ACCKWA's targeted approach? When you came in for testing, did you have any worry about who might see you coming in?