HUMAN IMMUNODEFICIENCY VIRUS (HIV) AND THE LIVED EXPERIENCE OF MALE INMATES IN CANADIAN FEDERAL PENITENTIARIES: A SNAPSHOT OF THE ONTARIO REGION

by

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A thesis submitted to the Department of Kinesiology and Health Studies
In conformity with the requirements for
the degree of Master of Science

Queen’s University
Kingston, Ontario, Canada
(September, 2017)

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Abstract

The HIV prevalence rate inside Canadian Federal Penitentiaries is estimated to be 7 times higher than the rate in the general Canadian population. Additionally, a survey of Correctional Service of Canada (CSC) HIV-positive inmates showed that over half were worried about HIV-related stigma while incarcerated. This study of HIV-positive current and former inmates, the first Canadian study of its kind, investigated participants’ lived experiences in and out of prison. Topics investigated include experiences of stigma and disclosure of HIV status during incarceration. This study consisted of semi-structured, in-person interviews. A total of 20 interviews were conducted with 10 currently incarcerated, 5 recently released HIV-positive males, 4 Peer Education Course (PEC) workers and 1 recently released HIV-negative male. Currently incarcerated participants were recruited through the health care departments of penitentiaries in the Ontario Region of CSC. Formerly incarcerated participants were recruited from social service organizations in Kingston, Ontario, that focus on working with PLWH and formerly incarcerated individuals. Participants reported experiencing or witnessing enacted, perceived and internalized stigma in and out of the prison environment. Experiences of enacted stigma ranged from verbal insults to being ostracized, threats of violence, and actual violent attacks. Variations in experiences of enacted stigma were explained by non- or limited disclosure based on fears of discrimination, as well as perceived standing in the prison hierarchy. Additionally, the majority of participants reported having experienced a variety of childhood traumas and feelings of poor self-worth and suicidal ideation. HIV-related stigma is a common experience of HIV-positive current and former inmates. Although there are HIV prevention programs including testing, bleach kits, condom distribution, and HIV treatment within CSC prisons, there are no reported programs that specifically target the reduction of HIV-related
stigma. As a result, future research is needed to develop and evaluate possible avenues for intervention to prevent experiences of stigma for people living with HIV, both within and outside of the prison environment.
Acknowledgements

This project would not have been possible without the constant support and encouragement of my supervisor, Dr. Stevenson Fergus. I thank you for giving me the autonomy to build this project from the ground up and for providing with encouragement when the project stalled. I am so grateful for the opportunity to learn from you.

I would also like to thank the Correctional Service of Canada for allowing me the opportunity to conduct research inside their agencies. Specifically, I would like to thank Jonathan Smith, Emily Kom, and Janice Thompson for providing immense amounts of feedback and guidance throughout the entire project.

Importantly, I would like to thank the Infectious Disease Nurses at the Penitentiaries and Diane Smith at HIV/AIDS Regional Services Kingston for recruiting participants for my study. Without your work, this project would not have been possible. A huge thank you is for all my participants for sharing their incredible stories with me. It is an honour and a privilege to have been able to hear and write about your experiences. Your stories have been inspiring and I sincerely hope that they will lead to positive change in our Canadian Federal Penitentiary System.

Finally, an immense thank you to my loving and supportive family is needed. You have allowed me to chase my dreams all over North America, which has led me to my graduate studies. For allowing me to chase my dreams, and so much more, I thank you from the bottom of my heart. Thanks to Mama Lisa, Papa KG, Cale, and Elizabeth.
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List of Abbreviations

CCRA- Corrections and Conditional Release Act
CSC- Correctional Service of Canada
HARS- HIV/AIDS Regional Services Kingston
HCV- Hepatitis C Virus
HIV- Human Immunodeficiency Virus
MSM- Men who have Sex with Men
PEC- Peer Education Course
PLWH- People living with HIV
STI- Sexually Transmitted Infection
Prologue

This project was not an easy one to complete. It started years before, when I began volunteering at the Street Health Centre’s needle distribution program. I volunteered once a week in the needle distribution program for around 2 years. The relationships I developed in this volunteer position led me to working in collaboration with their youth program on my undergraduate thesis. The volunteer experience with the organization, along with my collaboration on a research project, led me to this current study completed in Federal Penitentiaries. I was fortunate to work as the needle distribution’s summer student the summer before entering my Master’s degree. It was here as I was talking through potential Master’s Theses projects that one of the hepatitis C nurses connected me with Dr. Wendy Wobeser, who is a communicable disease specialist with the Correctional Service of Canada. After meeting with Dr. Wobeser, the project began quickly with a meeting at National Headquarters for the Correctional Service of Canada approximately 10 days into my Master’s program. Although it may seem like the project came to be quickly, it took years of building relationships with various stakeholders that allowed me to be introduced to CSC officials to have a discussion about a project.

Although this project was completed within the timeframe of my degree, it was not without its challenges. One major challenge involved working with CSC themselves. At times, they and I held competing priorities about decisions as consequential as who to interview, or as seemingly inconsequential as what the title of the project and thesis should be. However, working in collaboration with CSC meant that I was able to have fruitful discussions with CSCS officials on these and other issues. In all instances, we were able to work towards a compromise. Working with CSC was a valuable learning experience that I will always treasure.
If I were to offer advice to anyone wanting to conduct research with CSC, I would say be patient, be understanding of the processes and protocols that are in place, and most importantly take care of yourself. The stories you will hear may be distressing, so you should have strong systems of mental and social support in place before entering prison, and you should regularly debrief and take time for yourself throughout the process. Although the stories may be hard to hear, it is important that they be heard, and that more student and non-student research be conducted within Canadian prisons.
Chapter 1

Introduction

This research project focused primarily on HIV positive inmates who were incarcerated in Federal Canadian Male Penitentiaries in the Ontario Region of the Correctional Service of Canada (CSC). The project also included prisoner peer support (Peer Education Course; PEC) workers, and HIV positive males who had been released from a Canadian Federal Male Penitentiary between the years of 2011 and 2016. The topic of the research was HIV stigma.

This project began with an introduction of me by the CSC HIV specialist doctor for the Ontario Region to other CSC officials. After a meeting with officials from CSC to discuss potential projects, one centered on the experiences of HIV positive inmates was selected, in part due to a national survey conducted by CSC that stated over 50% of surveyed HIV positive inmates were worried about being discriminated against (CSC, 2010). This led to two main research questions:

1. To what extent does HIV-related stigma exist in CSC federal medium- and minimum-security male institutions?

2. What form does HIV-related stigma take and how does that affect the lives of HIV-positive male inmates?

The research project also had several sub-questions, which included:

1. Does disclosure of one’s HIV status in prison affect inmates’ lives during incarceration and if so, how?

2. How are HIV and HIV-positive inmates perceived in the prison environment?
3. Are there any supports currently available to HIV-positive inmates and, if so, what are they and are they effective?

4. What do participants see as reasons for HIV-related stigma in the prison environment?

5. What do participants see as solutions to the increased prevalence rate of HIV in the Canadian Federal Penitentiary system?

6. What do participants need to improve their quality of life while incarcerated and how can CSC combat HIV-related stigma?

The following thesis discusses literature in the field of stigma theory, along with published research from the fields of prison studies and HIV studies. I use Chapter 2 to define different types of stigma and to discuss the current state of the Canadian Federal Penitentiary System in regards to HIV, harm reduction, and health care. Chapter 3 discusses the structure and design of the research project. This chapter describes the different participant groups, the research methodology used, and the process of data collection through the use of in-person interviews. This section also discusses ethical considerations for the project, but also issues I faced with the ethics approval process at Queen’s University because of my plan to interview men who were currently incarcerated. Chapter 4 highlights the results of the study, where Chapter 5 analyzes the results and draws conclusions. Lastly, the manuscript completes with a journal entry of how the entire research project as a whole has affected and changed me.
Chapter 2

Literature Review

2.1 HIV 101

Human Immunodeficiency Virus (HIV) is a virus that attacks and weakens one’s immune system, leaving one susceptible to opportunistic infections. Acquired Immunodeficiency Syndrome (AIDS) is the disease caused by HIV. The first cases of what would become known as HIV/AIDS were reported on June 5, 1981, as a strain of pneumonia known as pneumocystic jirovecii (Merson, O’Malley, Serwadda & Apisuk, 2008). The first five reported cases were confined to the gay and bisexual male population, leading to the widespread belief that HIV/AIDS was confined to this population (Merson et al., 2008). However, cases began to be reported in other populations, including but not limited to injection drug users (Merson et al., 2008). Since those first cases of HIV infection were reported, 78 million people worldwide have been infected with HIV, with 35 million people having died of AIDS (UNAIDS, 2016). Currently, 36.7 million people worldwide are believed to be infected with HIV (UNAIDS, 2016).

It is important to understand the potential routes of transmission to mitigate the spread of the virus. For an individual to contract HIV there must be a source of infection (someone already infected) and a means of transmission (Canadian AIDS Society, n.d.). HIV is transmitted through blood contact or sexual transmission. Blood is not often common during sexual transmission of the virus, however bodily fluids including semen, pre-ejaculatory fluid, vaginal fluid and rectal fluid may carry enough of the virus to allow transmission (Canadian AIDS Society, n.d.).
Society, n.d.). Additionally, HIV transmission can occur from mother to child in utero (though this is rare), during childbirth, or through breastfeeding.

In regards to the sexual transmission of HIV, some activities carry a higher risk of transmission than others. High-risk activities include insertive and receptive penile-anal intercourse without a condom and insertive and receptive penile-vaginal intercourse without a condom (Canadian AIDS Society, 2004). Although there are other low risk sexual activities for the transmission of the virus, having intercourse, vaginal or anal, without using a condom are the sexual activities where HIV is most likely to be transmitted.

Because an individual can contract HIV through infected blood, another high-risk activity is injection drug use. This activity is especially high risk if injection drug users share injecting equipment (Canadian AIDS Society, 2004). The sharing of injection drug use supplies is not restricted to sharing needles, but rather all injection drug use supplies including spoons, waters, cookers, filers and alcohol swabs. Additionally, using unclean equipment for piercing and tattooing is a low risk activity in terms of HIV transmission; however, there is the potential for HIV transmission, as the needles used for these activities typically come into contact with blood (Canadian AIDS Society, 2004).

2.2 HIV in Canadian Federal Penitentiaries

The burden of HIV in Canadian Federal Prisons is well documented, as the uptake for voluntary HIV testing is high: 85% of new inmates choose to be tested (OHTN, Inside Out Conference, 2014). This has produced a diagnostic yield of 2.4 cases per 100,000 tests in 2012, down from 15.3 cases per 100,000 tests in 2000 (OHTN, Inside Out Conference, 2014).
Additionally, the actual number of newly diagnosed cases of HIV in prison has decreased from 24 in the year 2000 to 10 cases in 2012 (OHTN, Inside Out Conference, 2014). This has produced a 2012 HIV prevalence rate of 1.24% in all CSC penitentiaries (OHTN, Inside Out Conference, 2014). The male HIV prevalence rate in CSC penitentiaries in 2012 was 1.19% and the female rate was 2.30% (OHTN, Inside Out Conference, 2014). Overall, the female inmates of CSC have had a higher prevalence rate from 2000-2012, as it has ranged from 2.30% to 6.02% (OHTN, Inside Out Conference, 2014). The male prevalence rate has remained much steadier; the prevalence rate has ranged from 1.19%- 1.99% from 2000-2012 (OHTN, Inside Out Conference, 2014). Although the prevalence rate of HIV in male penitentiaries is lower than in their female counterparts, it is still higher than the national prevalence of HIV (CSC, 2010), which is estimated to be 0.212% at the end of 2014 (Public Health Agency of Canada, 2015). It should also be noted that only 4.1% of all federal inmates are female, so the overwhelming majority of HIV-positive prison inmates in Canada are male (OHTN, Inside Out Conference, 2014).

In 2007, CSC conducted a survey of 3370 inmates from all institutions across Canada to obtain data on infectious diseases and their risk factors within prison (CSC, 2010). These risk factors including injection drug use and sexual risk behaviours. In prison, 16% of surveyed male inmates reported having injected drugs while in prison, 7% reported having shared a needle, and 5% reported that they knowingly shared a needle with someone who had HIV, hepatitis C or did not know their infection status (CSC, 2010). Additionally, of those male inmates surveyed, 5% reported having unprotected sex with regular partners, 2% reported having unprotected sex with casual partners and lastly, 2% reported having sex with someone who knowingly had HIV, hepatitis C or was unsure of their infection status (CSC, 2010).
In addition to the above individual-level risk factors, other factors related to the social determinants of health should be considered when investigating HIV among prisoners. One major consideration is race and ethnicity. Indigenous people, as well as visible minority groups in Canada, are over-represented in terms of both being incarcerated and being HIV-positive. These groups warrant special consideration when investigating HIV in Canadian Federal Prisons, which includes the need for tailored HIV resources and supports to address issues concerning being HIV and incarcerated.

As mentioned above, indigenous offenders are over-represented, as they make up approximately 23% of the Federal inmate population (CSC, 2017), yet make up only 4% of the general population (CSC, 2017). Prison-based HIV infection data stratified by race or ethnicity or indigenous status are not available, but in the community, people of indigenous backgrounds are 2.7 times more likely to contract HIV than are white Canadians (CATIE, n.d.).

Additionally, a report in 2013 by the Office of the Correctional Investigator shows that non-indigenous, visible minorities make up approximately 18% of the Federal inmate population (Office of the Correctional Investigator, 2013). This is important to consider because racialized minorities from HIV Endemic Countries make up 16.9% of all new HIV infections in Canada in 2011, even though they only make up 2.2% of the entire Canadian population (Public Health Agency of Canada, 2016).

Lastly, the 2010 survey conducted by CSC asked HIV-positive inmates if they were worried about experiencing HIV-related stigma and discrimination. The study found that over half of HIV-positive inmates who responded reported that they were worried about being stigmatized or discriminated against (OHTN, Inside Out Conference, 2014). As of the writing of this thesis, no studies have investigated why HIV-positive inmates in care of Canadian Federal
Institutions report being worried about stigma or discrimination based on their HIV status.

2.3 Canadian Prison Systems

In Canada, there are two prison systems, provincial and federal. There are two main differences in these systems. Firstly, the Provincial Prison systems are under the jurisdiction of each province and the Federal Prison system is under the jurisdiction of the Federal Government. The second difference is in the length of sentences that inmates serve within these two structures. To be classified as a Federal inmate and be placed within a Federal Penitentiary, an individual must receive a sentence of more than two years. Any sentence of two years or shorter is served within the provincial prison systems. This project was conducted within the Canadian Federal Penitentiaries within the Ontario Region, which covers as far west as Thunder Bay and includes Nunavut, though participants were only recruited from facilities within easy driving distance of Kingston.

Within all Canadian Federal Penitentiaries, there are over 15,000 incarcerated offenders in any one day (OHTN, Inside Out Conference, 2014). Of these, 4.1% are female and 22.8% are Aboriginal (OHTN, Inside Out Conference, 2014). Sentence length within the Federal system can range anywhere between two years and life imprisonment. In a 2013-2014 survey, CSC reported that 80% of inmates surveyed (N=5156) were serving sentences between two and five years in length and 14% were serving sentences between five and 10 years (OHTN, Inside Out Conference, 2014).

Under the Corrections and Conditional Release Act (CCRA), Section 86, CSC must provide all inmates with essential health care that is performed under professionally accepted
standards (OHTN, Inside Out Conference, 2014). The CSC’s Public Health Department has identified several strategic areas, including infectious disease prevention, disease control and management, health promotion and health education, and healthy environments. The overall goal of the CSC Public Health Program is to “provide services to federal offenders to prevent and control disease and promote good health within federal institutions” (OHTN, Inside Out Conference, 2014).

CSC provides voluntary screening for communicable diseases (HIV, hepatitis C, sexually transmitted infections, tuberculosis, and MRSA) when inmates are admitted into a correctional facility and periodically throughout the length of their sentence. This is in line with current guidance for HIV testing generally, which suggests that voluntary testing is preferable to mandatory testing. CSC has strong uptake with their HIV testing program upon admission to a CSC facility, with approximately 85% of new inmates being tested (OHTN, Inside Out Conference, 2014).

In addition to voluntary testing for HIV, CSC offers all immunizations and boosters and other regular preventive and diagnostic health care for a variety of conditions and illnesses, and all medical treatment is provided to inmates for free from medical professionals (OHTN, Inside Out Conference, 2014). CSC also offers harm reduction supplies consisting of condoms, dental dams, bleach, and opiate substitution therapy.

Lastly, CSC offers a Peer Educator Course (PEC) worker program in its facilities. This program involves fellow prisoners as educators and focuses on educating inmates on communicable diseases and mental health issues. Peer educators in prison have been shown to be an effective method of lowering the risk of HIV transmission (Collica, 2007), as inmate HIV peer educators have been shown to be more highly trusted by other inmates as compared to
prison officials or outside agencies (Collica, 2007). This trust of other inmates may be a result of coming from similar situations pre-prison sentence, being able to speak the same language, understanding what prisoners are going through in prison and being highly available (Collica, 2007). Not only are peer education programs beneficial for the general prison population as programs have been found to reduce HIV transmission factors post-release, it also has benefits for those inmates who are employed as peer educators (Collica, 2007). Being employed as a peer educator while incarcerated often leads to empowerment of the peer educator, which assists in a lower recidivism rate (Collica, 2007). Peer educators may also find paid employment in the HIV field upon release (Collica, 2007). Although peer education programs are beneficial to the inmates, they are also a cost-effective way of presenting HIV education (Collica, 2007). However, they may be met with hesitation because prisons may be wary of having inmates in high-status positions and inmates knowing sensitive information about other inmates (Collica, 2007).

### 2.4 Stigma 101

The word stigma originates from ancient Greek, and referred to any signs on the body that indicated there was a moral deficit within that person (Goffman, 1963). In the past, signs of stigma (discrediting traits) were often cut or burnt into someone’s body to signify that the person was a slave, criminal or should be avoided (Goffman, 1963).

Today, stigma is an attitude that society has towards individuals or groups who do not meet the standards of societal norms. To be stigmatized or experience stigma, one must have a discrediting attribute, which is deemed to be discrediting based on societal standards of what is
normal or acceptable. Additionally, people within society must feel some sort of negative emotions or evaluation of that trait. The negative evaluation of that trait must be widespread throughout society, so it becomes a social belief (Goffman, 1963; Deacon, 2006; Yang et al., 2007; Bos et al., 2013).

Stigma manifests itself through several different avenues. The first stigma pathway is known as enacted stigma (Bos et al., 2013). Enacted stigma is present when negative treatment occurs towards a person who is in possession of a stigmatized trait or condition (Bos et al., 2013; Chambers et al., 2015). For stigma to be enacted there must be evidence that the stigmatized person received negative treatment due to them having a discredited trait. This type of stigma pathway is sometimes referred to as discrimination, and in the literature stigma and discrimination are often used interchangeably or inconsistently. The Canadian Mental Health Association, for example, defines stigma as a negative stereotype, and discrimination as unfair treatment due to a negative stereotype (2016). Enacted stigma will be the term used in this study and will assume to include the unfair treatment that Canadian Mental Health Association describes as being discrimination. An example of enacted stigma is when a PLWH loses a job or housing because of the PLWH’s HIV status.

The second stigma pathway is known as felt stigma. This type of stigma occurs when the stigmatized person anticipates that they will be stigmatized, or believes that they have been stigmatized, due to having a socially discrediting trait (Bos et al., 2013; Florom-Smith & De Santis, 2012). An example of felt stigma could include a PLWH concealing their HIV status out of anticipation of negative treatment.

Finally, the stigmatized individual can also internalize stigma. The internalization of stigma refers to the stigmatized individual feeling a reduction of self-worth and the
accompaniment of psychological stress due to their condition (Bos et al., 2013). An example of internalized stigma could include a PLWH feeling like an unworthy member of society and consequently experiencing negative influences on their mental health and wellbeing.

The above three paths describe how individuals with a discrediting trait may experience stigma. There is an additional type of stigma known as stigma by association. This involves individuals who are associated with people with a stigmatized trait. Such people may also be devalued due to that association (Bos et al., 2013). Family members, friends and individuals who work with stigmatized populations such as counsellors and social workers can experience stigma by association. This type of stigma may also be related to a reduction of self-esteem and increased psychological distress for those who experience it (Logie & Gadalla, 2009).

In addition to the 4 categories of stigma (enacted, felt, internalized, and stigma by association), Loutfy and colleagues (2012) discuss the concept of layered or compounded stigma. This type of stigma refers to having multiple stigmatized traits or multiple stigmatized identities (Loutfy et al., 2012). Examples of layered stigmatized traits would be being HIV positive and belonging to the LGBTQ community. The concept of layered stigma is that each discrediting trait has a stigma attached to it. The stigma of each discrediting trait is then layered on one another increasing the likelihood that the person with the traits will experience stigma, or will experience greater amounts of stigma than someone with only one stigmatized trait.

2.5 HIV Stigma

Different cultures define their own discrediting traits since culture shapes personal understandings of health and illness and influences the perceptions of health and health seeking
practices (Airhihenbuwa et al., 2014). HIV, however, can generally be considered stigmatized universally, since all societies including Canadian society harbour some level of negative feelings and attitudes towards people who are or may be infected with the virus. HIV-related stigma has arisen because of fear of the virus, moralizing concerning the groups of people most likely to be infected with HIV, or moralizing concerning the most frequent modes of transmission including male same-sex sexual behaviours or injection drug use (Chambers et al., 2015).

In 2012, the Ekos Research Associate Inc. group conducted an attitudinal survey on HIV/AIDS with the Canadian population. To my knowledge this is the only survey of its kind in Canada. They found that HIV-related stigma is present within the Canadian society with 29% of survey respondents reporting moderate to high levels of stigma (CATIE, n.d.; Ekos Research Associates Inc., 2013). The researchers further found that 15% of respondents feel afraid of PLWH, 22% believe that HIV-positive people should not have the right to be sexually active, and 10% believed that HIV statuses should be made public, so people can avoid those who are HIV positive (EKOS Research Associates Inc., 2012). Although the majority of Canadians do not share stigmatizing beliefs about HIV-positive people, as 71% reported minimal or no feelings of stigma, HIV-related stigma in Canada is still existent and has consequences. This can be seen as 69% of Canadians surveyed believed that PLWH would be unwilling to disclose their status due to the stigma surrounding their condition (CATIE, n.d.).

Regardless of why society stigmatizes HIV, HIV-related stigma affects the health of those with HIV. HIV-related stigma may lead to poorer mental health among PLWH compared to the general population. PLWH are often diagnosed with anxiety, depression, PTSD, low-self-esteem, have suicidal ideations or experience isolation, which can negatively affect their quality
of life (Logie & Gadalla, 2009; Canadian Public Health Association, 2013; CATIE, n.d.; Chambers et al., 2015). The poorer mental health among PLWH could be a result of social exclusion due to stigma (Logie & Gadalla, 2009) and has been associated with internalization of stigma (Earnshaw et al., 2013).

HIV stigma not only leads to poorer mental health outcomes, but has potential to lead to poor physical health outcomes. The poor physical health outcomes may be related in part to healthcare provider stigma. This type of stigma may manifest itself by PLWH being segregated from the general population in different waiting rooms, by health care providers taking excessive precautions for routine procedures including double-gloving and gowning, and by placing warning labels on PLWH’s charts or fluid samples (Chambers et al., 2015). These types of stigmatizing behaviours assist in perpetuating the belief that HIV is transmitted through casual contact and the inclusion of warning labels may inadvertently disclose one’s HIV status without their consent (Chambers et al., 2015).

Because of the treatment and generally poorer mental health of HIV positive individuals, PLWH may be deterred from seeking treatment or utilizing health care options (CATIE, n.d.; Whetten et al., 2008; Canadian Public Health Association, 2013; Chambers et al., 2015). This can result in the use of informal medical care, avoidance of HIV-related health organizations and complete avoidance of treatment, which in turn can lead to a progression in the disease and a decline in physical health outcomes (Chambers et al., 2015). This suggests that HIV-related stigma not only negatively affects one’s mental health, but also has the potential to affect one’s physical health since PLWH may avoid treatment due to health care providers stigmatizing them.
2.6 Disclosure of HIV Status during Incarceration

Disclosure of HIV status in prison is often a complicated decision. HIV-positive inmates make one of three choices when it comes to disclosure of their HIV status. They may choose to fully, selectively, or not disclose their status, all of which are slightly different. Selective disclosure refers to disclosing of HIV status only to select individuals. Derlega and colleagues (2010) discovered that some HIV positive inmates disclosed their status to others who had severe medical problems. Full disclosure involved not concealing one’s HIV status to anyone. Derlega and colleagues (2010) discovered that when inmates were fully disclosed, they experienced a sense of relief. Lastly, inmates may also choose not to disclose their status, which would involve keeping it a secret from the prison population. Derlega and colleagues (2010) suggest, however, that when one discloses their status they may be able to live a happier life since they are no longer hiding a part of who they are. This suggests that for some inmates the perceived negative outcomes of being HIV positive while incarcerated may be more of a fear than a reality.

2.7 HIV-Related Stigma and Prison

No previous studies have investigated HIV-related stigma within a prison context in Canada. Three studies, however, have been conducted on HIV-related stigma in prisons: two in the United States and one in Indonesia. In 2008, Derlega and colleagues published a study that investigated stigmatizing beliefs among inmates in the United States about how HIV is spread. The research team discovered that inmates had negative beliefs about homosexuality and injection drug use. These beliefs were associated with the avoidance to being tested for HIV. The avoidance of testing could be detrimental to the prison population because inmates may be
unaware of their status and could spread HIV without knowing, which could result in higher prevalence rates of HIV.

In 2010, Derlega and colleagues investigated HIV-related stigma and the decision making process around disclosure of status while incarcerated in U.S. prisons. Derlega and colleagues (2010) found that inmates who chose not to disclose their status did so out of fear that something negative would happen to them. The fear of being treated poorly due to a positive HIV status was that HIV was linked to deviant, immoral or irresponsible lifestyles. This included the belief that if someone was a man who had sex with other men that they were homosexual and therefore HIV positive (Derlega et al., 2010). Additionally, these fears were only reinforced as the inmates reported that HIV positive inmates were often abused and treated poorly more often than HIV negative inmates. Derlega and colleagues (2010) reported that inmates believed that HIV could be transmitted through casual contact, like shaking hands. These beliefs attribute to HIV-related stigma because it reinforces the myth that a PLWH should be avoided because the virus itself is highly contagious and airborne.

Additionally, Culbert and colleagues (2015) found that the incorrect belief that HIV can be contracted through casual contact perpetuates social stratification in Indonesian prisons. In this case, inmates were socially excluded or placed in segregation units away from the general population of inmates. Lastly, inmates tended to mix the term HIV or AIDS with negative slang terms like ‘the bug’, or ‘the venom’, which perpetuates stigma within the prison environment. By giving HIV negative slang terms, a person who is HIV positive may be looked as someone who is poisonous and unclean and that should be avoided (Culbert et al., 2015). This suggests that if one had HIV it would be unsafe to disclose status in prison, given these beliefs that other inmates hold regarding HIV.
HIV levels in United States prisons have been reported to be five to seven times higher than that of the general population (De Groot et al., 2006). This high prevalence rate could be due to the issues that inmates face around disclosure of HIV status. De Groot and colleagues (2006) discovered that many inmates choose to not be tested due to fears around disclosure of a positive HIV status. One large concern for inmates relates to the confidentiality practices within the prison environment. Inmates have reported that they do not believe that their medical information is confidential and that if they were HIV positive they believed that their status would be spread throughout the prison population (De Groot et al., 2006).

In addition to issues of confidentiality, issues surrounding less than ideal treatment of HIV positive inmates, may be a reason for inmates not to know their status. De Groot and colleagues (2006) noted that HIV positive inmates face restrictions related to job assignments, housing sites, educational opportunities and conjugal visits. These issues that HIV positive inmates face may contribute to the higher rates of HIV found within the United States prison system, as being HIV positive may result in a number of negative outcomes. The restrictions HIV positive inmates face perpetuate the myth that HIV is transmissible through casual contact. HIV positive inmates are being judged on their disease status and not on other attributes such as their skills. In the case of restrictions on job assignments, not allowing someone to work due to status perpetuates the stigma surrounding that HIV can be transmitted through casual contact, which Delerga and colleagues (2010) point out is a belief by inmates. By restricting opportunities for HIV positive inmates, it does nothing to empower them, but rather puts them down and make them feel devalued in a society that already devalues them for being inmates.

In 2003, a study by Grinstead and colleagues focused on HIV testing by in-prison service providers. What the research team reported, validate the inmates fears about confidentiality (De
Groot et al., 2006), as in-prison service providers reported that there is no privacy in prison for inmates, which makes it extremely difficult for this HIV status to remain confidential (Grinstead et al., 2003). Additionally, it was found that many inmates may not want to know their HIV status, as HIV positive inmates are often segregated from the general population for their own protection (Grinstead et al., 2003). Often segregation can be very isolating and stigmatizing procedure, as the HIV positive individual is quarantined, which is the goal of stigmatization (Andrinopoulous et al., 2011).

As has been shown, there are numerous issues related to being HIV positive in prison. A major theme surrounding issues associated with being HIV positive while incarcerated is the stigma surrounding the disease among the prison population. My proposed study will take an in-depth look at HIV-related stigma within the Canadian Federal prison context. In addition to investigating HIV-related stigma, the study will also provide the opportunity for HIV positive inmates to provide suggestions for how to improve life inside prison for HIV positive inmates.
Chapter 3

Methods

3.1 Methodology

To investigate the lived experiences of HIV-positive Federal male inmates, I used the qualitative research method of semi-structured, open-ended interviewing. Qualitative methods were chosen over quantitative methods because I was seeking in-depth stories of the lives of HIV positive men in prison. I was seeking deeper answers to questions than would have been possible to elicit in a quantitative data collection method such as a survey. Furthermore, CSC conducted a quantitative survey with their inmate population that was published in 2010, and they specifically asked for this project to be qualitative because they were interested in knowing the ‘why’ behind some of the survey data. Specifically, they were interested in understanding why many of their HIV-positive inmates feared being discriminated against based on their HIV-status. In order to understand the ‘why’ to this question, the individual interview methodology was essential to elicit stories about discrimination experiences while incarcerated.

In-person interviews were chosen over other interview options (such as over the phone or via Skype) because of the ability of in-person interviews to allow a rapport and sense of trust to develop between the interviewer and interviewee. In-person interviewing was also the easiest way to provide confidentiality to the participants. Phone calls inside prison have the potential to be screened for security purposes, therefore the likelihood of being able to provide participants with privacy would be compromised. In-person interviews were chosen over Skype interviews because inmates in CSC do not have access to the internet. Additionally, interviews were chosen over focus groups due to confidentiality reasons as well. Many of the interviewees had not
disclosed to other inmates that they were HIV positive. Conducting focus groups would have potentially disclosed someone’s HIV status to a group of people to whom they may not have been comfortable disclosing. Lastly, in-person interviews allowed a greater opportunity for trust to be built between myself and the participant, increasing the likelihood of more in-depth telling of experiences.

To facilitate conversation with participants, semi-structured open-ended interview guides were developed. In total, four different interview guides were developed, one for each participant group (Appendix A through D). These open-ended interview guides allowed the conversation to flow naturally, but also assisted in re-focusing the interviews when they got off-track. The guides allowed me to have latitude to allow the conversation to flow onto topics not related, but still relevant, to the interview guide. The majority of the interviews flowed very well, however the flow of the interviews was dependent on who was participating. Some participants were eager to share their experiences, while others were more reserved in their answers to the interview guide questions and needed more prompting to expand on their experiences.

To prepare for the interviews, I conducted practice interviews with two recently released HIV positive inmates. These interviews were conducted at HARS in Kingston. The purpose of the practice interviews was to allow myself to practice my interviewing techniques, and to get feedback on the semi-structured interview guide. This included feedback on terminology, the style of question, and the structure of the interview guide. As a result, the semi-structured interview guides for the formerly and currently incarcerated HIV positive participants were slightly modified to assist in guiding the conservations to highlight key research objectives. The practice interview participants were given $20 in cash for their time.
3.2 Participant Groups

The results from this project draw on interviews from four different participant groups, each of which required their own tailored, semi-structured interview guide: Currently incarcerated HIV-positive men (n=10), incarcerated Peer Education Course (PEC) workers (n=4), formerly incarcerated HIV positive men (n=5), and formerly incarcerated HIV negative men (n=1).

PEC workers are current inmates who work for the health care department of their respective institutions and were included as a key informant interview group. Their role as a PEC worker is to be a peer educator, providing education on communicable diseases (HIV, HCV, STI’s, etc.) to fellow inmates, serving as a point of contact for those inmates struggling with mental health issues, referring inmates to the health care department or the mental health care department for further information and supports, and providing harm reduction supplies (condoms, bleach, and lube) to the general prison population. The inclusion of the PEC workers in the study was to provide an informed perspective of how HIV is perceived within the prison environment.

The formerly incarcerated participants had to have been incarcerated in and released from a CSC Federal within 5 years before the start of the study (Fall 2016). The inclusion of an HIV negative formerly incarcerated participant was meant to provide an outsider, but informed perspective of how HIV is viewed in the Federal prison environment.
3.3 Data Collection

3.3.1 Currently Incarcerated Participants

3.3.2 Prison Tours

To prepare for interviewing inside CSC Federal Penitentiaries, I was provided with a tour of four of the five selected institutions by nurses from each penitentiary. The tours were completed to allow myself to become more comfortable in a prison environment. They were also essential to have a cursory understanding of what prison life is like. Tours included visiting different housing units, health care departments, visiting areas, and cafeterias.

3.3.3 Recruitment

Recruitment for the currently incarcerated inmates occurred through the Regional Manager of Public Health for the Ontario Region of CSC. In order to assist with recruitment, the Regional Manager of Public Health for the Ontario Region of CSC contacted the infectious disease nurses at each of the selected institutions with the recruitment script and asked the nurses to speak to their HIV positive inmates, as well as their PEC workers about the project to gauge interest in participation. Once interest was shown by an eligible inmate, the infectious disease nurse would contact me or the Regional Manager of Public Health to set up interview times. This process was completely confidential, as names of participants were never exchanged over email. The only information shared over email was if the participant was an HIV-positive inmate or a PEC worker. This was necessary to make sure I brought the correct materials to each interview. The institutional locations for the currently incarcerated participant interviews are not being
disclosed in this report. This measure is being taken to assist in protecting the identity of the participants.

3.3.4 Consent

Prior to each interview, I read and explained the letter of information and the consent form to the participant, and answered any questions the participant may have had. Upon receiving verbal consent, the audio-recorder was turned on and the interview began.

The decision to use a verbal letter of information and obtain verbal consent was made for several reasons including confidentiality and to mitigate the risk of inadvertent disclosure. The verbal consent procedure involved reading the letter of information to the participants, which included the study protocols, risks, benefits, and withdrawal procedures. A physical copy of the letter of information was never given to the participants so that there was no paper trail of who was affiliated with the study, protecting the identity of the participant from the researcher and from CSC. Upon completion of the interview participants were provided with an information sheet with the mailing address of Queen’s GREB that was silent of HIV. This allowed the participants an avenue to contact GREB if they had any ethical concerns or questions after their interview. Reducing the risk of inadvertent disclosure due to references to HIV in study documents was vital, as many of the participants are not open with their HIV status to the prison population.
3.3.5 Interviews

For the two sub-groups of currently incarcerated participants, I interviewed 14 individuals. I interviewed 10 HIV positive inmates at five different Federal Institutions in the Ontario Region. The remaining four interviews were conducted with PEC workers. In accordance with CSC protocols, compensation was not provided to the participants of this portion of the research project. The interviews with the 10 HIV positive inmates took between 30 and 120 minutes to complete, while the interviews with the PEC workers ranged between 25 to 60 minutes. All interviews were audio-recorded with the permission of CSC and with the permission of all the participants. The interviews were transcribed verbatim, and then coded for thematic analysis.

3.3.6 Formerly Incarcerated Participants

3.3.7 Recruitment

Recruitment for these interviews occurred at four social service organizations that specialize in HIV, addictions work, and with clientele who are or have been in conflict with the law, and that therefore typically serve the desired participant population. A recruitment poster (Appendix F) and script (Appendix G) was sent to each organization as a means of primary recruitment. Below is a brief description of each organization and how recruitment was completed at each location.
**HARS**: Local to Kingston, HARS is an HIV/AIDS organization that provides comprehensive HIV/AIDS education and support programs, as well as some limited services related to Hepatitis C. Recruitment occurred through their Prison Support Worker, Diane Smith-Merrill.

**Salvation Army Harbour Light Centre**: Local to Kingston, and focused on residents of Eastern Ontario, Harbour Light is a residential program for men with chemical dependency issues. Recruitment occurred through a poster and script sent to the Program Manager.

**John Howard Society of Kingston**: John Howard Society focuses on working with individuals who are in or have been in conflict with the law. The Kingston Chapter offers a variety of programs including residential housing, court support, bail supervision, and employment counselling among others. Recruitment through John Howard occurred through a poster and script sent to the Manager of Justice Services for the Kingston Chapter.

**Kingston Parole Office**: This office supervises people released from federal penitentiaries on full parole, day parole, unescorted temporary absences, and statutory release. A poster was hung in the lobby of the parole office with approval from the office itself.

Interviews were conducted at HARS and the Salvation Army’s Harbour Light Centre and participants were given $20 Tim Horton’s gift cards for their time spent participating in the project. HARS was the most effective organization in recruiting for the community portion of the study, likely due to their programming which includes an explicit focus on serving incarcerated and formerly incarcerated people living with HIV/AIDS.
### 3.3.8 Consent

Participants were given a letter of information to read prior to beginning their interview. Additionally, I verbally explained the content of the letter of information, checked for understanding of the study protocols, and answered any questions that came up. Once participants stated that they did not have any questions about the study, they read and signed a consent form (Appendix H). Once the consent form was signed, the audio-recorder was turned on and the interviews began.

### 3.3.9 Interviews

Semi-structured interviews were conducted with both formerly incarcerated participant groups. The interviews with the HIV positive participant ranged from 45 to 90 minutes. The interview with the HIV negative participant took approximately 30 minutes to complete. All of the interviews were audio-recorded with the participants’ permission. Upon completion of the interviews, they were all transcribed verbatim and then coded for thematic analysis.

### 3.4 Project Ethics

#### 3.4.1 Ethical Considerations

This study posed several ethical dilemmas due to the marginalized and disempowered nature of the participants. When interviewing inside Federal Penitentiaries, there was an
immediate power imbalance between the participants and myself. This power imbalance was due to my freedom and the lack of freedom for the participants. The ability to leave and re-enter into society after each interview gave me power over the participants. To mitigate this power imbalance, the interviews were conducted in each institution’s health care department, a place that is not often associated with the security structures of the institution.

Although the qualitative research method of individual interviews was the best method for eliciting stories concerning experiences of being HIV positive in prison, it was also a challenging methodology to implement. One of the major issues with asking people to tell their stories, especially in the case of telling stories related to sensitive subject matter, is making sure the identity of the participants’ is kept confidential. To protect the identity of all participants, regardless of whether they were currently or formerly incarcerated, no names of participants were collected, unless the participant themselves stated their own name during the audio-recorded interview. If this occurred, during the transcription and analysis of the interviews, participants names were removed to mitigate the risk of inadvertently disclosing their identity during dissemination. Considering that the HIV-positive community both in the Kingston area and within CSC institutions in the Ontario Region is extremely small, any reference to specific quotes or experiences will use pseudonyms. This assists in the protection of the identity of all participants. To protect those currently incarcerated further, the institution names have also been removed.

Additionally, there was social risk for participating in this study. For both participant groups (currently and formerly incarcerated participants) there was a risk of their HIV status becoming known due to their participation in the study. In order to mitigate this risk, I went to great lengths to protect the identity of each participant. The location of the interviews was a key
step to protect their identity. When interviewing inside CSC institutions, all interviews were conducted in the health care department. The health care department provides greater levels of confidentiality because other inmates are not aware of why each inmate is in health care. Additionally, the letters of information, consent form, and debriefing letter were verbal scripts. The participants were not given any study materials that contained the word HIV. This was to mitigate the risk of another inmate finding the materials in their cell and connecting them with being HIV positive.

The majority of the interviews conducted in the community were completed at HARS. Although the act of entering HARS could disclose someone’s HIV status to the Kingston community, all participants that interviewed in HARS were clients there. The participants that were recruited from other organizations had their interviews conducted at the location of recruitment. This allowed those who were not comfortable with going to HARS for an interview, an opportunity to stay distanced from the organization and HIV itself.

The last major ethical concern with this project was that the interview questions were of a sensitive nature. The interview topics had the potential to make the interviews a stressful experience. To mitigate this risk while interviewing in prison, an infectious disease nurse at each institution was available (though not within the interview room) if any issues arose. In the event that the participant was in immediate distress, a protocol was established whereby the infectious disease nurse would refer the participant to the institution’s mental health services. No participants required such services as a result of participating in the interviews.

The protocol differed for the community interviews. When interviewing at each location, staff members from the organization were in close proximity (though not close enough to be able to see or overhear the interview). The staff members were available to assist if there was a need.
However, if the participant was in immediate distress and required assistance, the mobile crisis unit from KFLA-AMHS would have been utilized. Additionally, each community participant was offered a list of service providers in the Kingston community that could assist if they became distressed after the interview. Fortunately, in both CSC institutions and the community, there were no known issues with the interview questions causing distress to the participants that required intervention.

A final ethical consideration when interviewing the formerly incarcerated participants was whether to provide an incentive or compensation for the participant’s time and effort. Following CSC policy, no compensation was provided to incarcerated participants, as compensation may have unduly coerced participants into participating. For participants who were not incarcerated, compensation was small, a $20 Tim Horton’s gift card, and was given to each participant before the interview began. I thoroughly explained that if they chose not to participate, to skip questions, or to stop the interview at any time that they would not lose the compensation.

3.4.2 Queen’s University Ethics

Although both the community and in-prison aspects of this project received ethical approval from GREB at Queen’s University, the approval process for the in-prison interviews was a somewhat frustrating experience. Over the course of seeking ethical approval from GREB, there were times when GREB made suggestions that could be interpreted as unethical. One such suggestion included the requirement that I not introduce myself to the participants using my name, but that I should use a pseudonym when interviewing currently incarcerated participants.
The CSC Research Branch shared my concern that this request from GREB was unethical, as it was creating a power imbalance between the participants and me by assuming the participants were dangerous and would try to find me in the community upon their release. CSC stated that they had never received a request to use a pseudonym before and questioned why GREB made the request. In the end, GREB agreed to drop the inclusion of a pseudonym; however, this process took several months, and did not conclude until the CSC Research Branch specifically requested answers to why a pseudonym was necessary.

Additionally, issues arose when designing the contact information sheet to give to currently incarcerated participants after interviews. While incarcerated, inmates have limited access to contact people who are in the community, with their main methods of communication being letter mail or through the telephone. When working through the ethics process, GREB suggested that there be no contact sheet provided to participants and that the participants should have to ask the infectious disease nurse at each institution for GREB’s mailing address if they wished to contact GREB. In my opinion, this request was unethical. In prison, much of a person’s autonomy is lost. GREB suggesting that I put barriers in place to have participants’ concerns heard was another restriction on the autonomy of incarcerated people. However, upon discussion with CSC and with GREB, the project received approval to provide each participant with an information sheet including the mailing address of the GREB chair.

Overall, the experience of obtaining approval from GREB for the portion of the project conducted inside CSC institutions was challenging. During the process, I was made to feel like I was and should be in the ivory tower of academia, and the participants were beneath me. This lack of sensitivity to the needs and realities of currently incarcerated inmates by GREB is likely due to the dearth of student and other research projects by Queen’s researchers that take place in
prisons. In the future, with the possibility for more projects inside CSC institutions GREB should take steps to be more aware of the sensitivities necessary when working with population and the restrictions placed upon the researcher by CSC protocols and regulations.

3.5 Research Approval from Correctional Service of Canada

Upon obtaining approval of this project by my thesis committee at Queen’s University, I was required to obtain approval from CSC before beginning the project. The approval process through the Research Branch of CSC was slow and iterative. Although it was a long process, the Research Branch was forthcoming with information about the typical period for project approval. CSC stated that projects often take 6-8 months to approve, which was consistent with my experience with this project.

The first submission was sent to CSC in mid-to-late April of 2016. The Research Branch was receptive to the project and was willing to work with the proposal to get it approved. This receptiveness was likely due to the collaboration with CSC’s National Headquarters Health Department, who had recommended the project for approval. I had worked closely with the NHQ Health Department in the design of the proposal.

After the first submission, CSC requested a major edit of the proposal. This edit was required to improve the writing and to revise the methods and study protocols. The Research Branch was particularly helpful in this process. I was able to speak with a member of the review committee who had seen my proposal. She was able to offer insights into exactly what the Research Branch was looking for, and I was able to correct the proposal for re-submission. After the first and only re-submission to CSC in June, little was heard in terms of updates. I received
an email with three questions to clarify in July. After that point, I did not hear until I received the approval notice in November of 2016. Although I did not receive formal updates from the CSC Research Branch on the status of this project for months, I was able to obtain some informal updates from my contacts in CSC NHQ Health Care Department. Through these contacts, I was periodically updated on where the project was in the approval process. This assistance from NHQ was helpful in being able to stay on track to complete this thesis on time.

3.6 Data Analysis

In order to analyze the 20 interviews, I first transcribed all the interviews verbatim. Upon transcription, I began coding the interviews for thematic analysis, following the process outlined by Ritchie et al. (2014). I used the NVivo Pro 11 software package to assist with this process. The use of the software package allowed all data to be managed and stored in one location. The analysis was a lengthy process as I completed three separate codings of the data.

The first coding consisted of using line-by-line coding. This included developing codes that were close to the data. This allowed me to summarize small sections of the data in a short phrase or a single word. The second coding of the data consisted of looking at the list of codes developed in the first round and seeing the number of times each code appeared. This assisted in determining which codes were most prominent. This knowledge allowed me to re-code the interviews by combining some of the most frequently used codes into larger more abstract codes. The third and last coding consisted again of combining codes to create larger codes. These final codes consist of mostly one word and are the themes present in the research. The topics that will be discussed in the results sections of this manuscript are the theme names that were uncovered.
from the third and last step in the coding. The final codes that are represented in the results section closely follow the theoretical outline of stigma as presented in the literature review. This was not done intentionally such as by asking particular questions in the interviews, but it just so happened that the data I collected supported the stigma theory framework very closely.

3.7 Reflexivity Statement

My interest in conducting research with current and former inmates developed naturally over the course of my life. I grew up in a very rural community in central Manitoba, where people do what they need to survive. This ranged from working on family farms and working low skill, manual labour and customer service jobs, to consuming and selling illicit substances and alcohol. In my age group, the large majority of my peers consume illicit substances and alcohol recreationally. It is common with my peers that their substance use is often excessive. This early exposure to drug and alcohol use and misuse first got me interested in working in addictions.

The work that I have experienced in the addictions field has ranged from working in an abstinence-based Government Treatment Centre in my hometown, to working at a needle-distribution program. In my experience working for these organizations, I discovered that most of the clients have spent some time in the prison system. These prison experiences were often in both the provincial and federal systems. Additionally, as I grew up I became more aware of my family background. This background includes many people whom I am close with who have been incarcerated at some point in their life. Through knowing my family and working in addictions, I developed the mindset that not everyone who is incarcerated or who has been incarcerated is an inherently bad person. In fact, many good people end up in prison for making
mistakes. However, I am aware that prison exists for a reason and that many people inside prison are dangerous, but it is important to make a distinction that not everyone who is incarcerated or who has been incarcerated is inherently dangerous.

Although I am what I would call comfortable with the population I interviewed, I am still an outsider entering another world. I am aware that my biases as a privileged, white woman could affect my perception of the data. Additionally, I am aware that my position as an academic who had to seek approval from CSC before entering each institution could have affected the trust the currently incarcerated inmates had with me. This issue of trust was less of a concern when interviewing in the community. This lessened concern of trust in the community was likely due to the organizations recruiting their clients. This process likely allowed the participants to have some trust in me since a trusted worker was suggesting they speak with me.

In order to gain some trust from the currently incarcerated participants, after introducing the project and myself, I spoke about in detail about confidentiality. I spoke with each participant about who would have access to the data and what I was planning to do with the data. I needed to make it clear that although CSC approved my project, they would not have access to the raw data. I believe this made them more inclined to speak with me because I was able to make a clear distinction between myself and CSC.

Additionally, I believe their trust in me was fostered by my personality and my demeanor in the interview. I would describe my personality as being open-minded and relaxed. I find that I am typically able to connect with different groups of people and establish good working relationships. I believe this ability to connect and relate to people allowed trust to be gained during the interviews. I believe that my family background allows me to effectively relate to
currently and formerly incarcerated people due to my belief that not everyone inside prison is a danger to society.

I believe it was important that I felt comfortable during the interviews, as my comfort in the interviews both inside prison and the community led participants to also feel comfortable. I think if I was uncomfortable, I would have passed that onto the interviewees, and the data collected would not have led to a rich understanding of the lives of participants. Therefore, my being at ease in the interviewing environment allowed the participants to also feel comfortable in talking and sharing personal details of their lives with me.

For the most part, the participants shared freely about their lives with me. Others chose not to speak in detail about their experiences. However, regardless of the amount of information that each participant was willing to share about their experiences in prison, either as an HIV positive inmate, PEC worker or HIV negative inmate, all interviews and stories were of great value. I am truly honoured and privileged that I had the opportunity to hear the participants’ experiences and I am forever grateful for their participation.

In order to stay mentally healthy and ready to interview, I journaled throughout the duration of the project. Specially, I journaled about my interview experiences, along with the emotional toll the interviews were taking on me. The journaling about my emotional experiences was essential in being able to conduct these interviews. The content discussed was often heavy and difficult to hear. Journaling was a way for myself to stay mentally healthy and able to interview in a consistent manner. Additionally, journaling allowed me to be aware of what my preconceived notions were about the research, what I was hearing, and how I interpreted the interview content. In the remainder of the report, I am aware of the lens through which I look at
the data, based on my personal background and how I initially perceived and reacted to the 
stories of lived experiences I was hearing.

Additionally, journaling helped me understand that researchers are not non-neutral 
observers in research (Malterud, 2001). It is difficult in qualitative research to separate the 
researcher from the data because they are often immersed in the data (Malterud, 2001). In the 
case of this research project, the data refers to the personal lived experiences of quite 
marginalized people. I became intensely immersed in the data, as I conducted the interviews, and 
transcribed and analyzed all the interview data personally. Journaling helped me keep my 
preconceived notions, thoughts, and judgements in check throughout the project.
Chapter 4

Results

This chapter summarizes the results of the research project. No demographic information was formally collected during the interview process. Not collecting formal demographic data served to protect the privacy of the participants. However, during the interview process, approximately 5 out of the 20 participants self-described as indigenous, and 1 out of 20 self-described as a non-indigenous, visible minority in Canada. The remaining participants either described themselves as Caucasian or did not self-report a specific racial or ethnic group. Additionally, 2 out of 20 were self-described as gay males and 1 was self-described as transgender. Lastly, the age of the participants ranged with approximately 15 out 20 participants being between the ages of 35-65, with the remaining 5 participants being between the ages of 18-34. The HIV positive participants had all been HIV positive for 5 or more years.

A large number of themes emerged throughout the research and the majority of them fall under the following overarching categories: stigma experiences, disclosure experiences, life before HIV diagnosis, resiliency, LGBTQ in prison, supports available in prison and suggestions for how to address the issue of HIV-related stigma. Stigma experiences are categorized as enacted, felt, internalized, and stigma by association, as outlined in the literature review. Additionally, disclosure experiences are differentiated by the level of disclosure of HIV status, including non-disclosure, selective disclosure, and full disclosure. The majority of discussions on disclosure centered around disclosure of HIV status in prison; however, there were instances of discussing disclosure of HIV status in the community with the formerly incarcerated participants.
4.1 Experiences of Stigma

4.1.1 Experiences of Enacted Stigma

Every HIV-positive participant in the study reported experiencing some form of enacted stigma. Experiences ranged from violent physical attacks to discriminatory slurs and social exclusion or isolation. The participants also discussed the general perception of HIV inside Canadian Federal Institutions.

Many of the participants discussed that the general inmate population is uneducated on the topic of HIV. The participants report that the general inmate population frequently uses incorrect terminology when the topic of HIV is present, for example: “They said I got AIDS, not HIV… they’re not knowledgeable on the subject.” This experience was echoed by many participants reporting, “they don’t call it HIV, they call it AIDS.” Although these are only two examples, reports of ignorance about HIV/AIDS and the use of incorrect terminology was present in all the interviews, regardless of the participant group.

Concerning enacted stigma, many HIV positive participants reported witnessing or experiencing being ostracized. Again, these findings were consistent across all participant groups and security-level of the institutions. One HIV negative formerly incarcerated participant reported witnessing HIV positive inmates being ostracized in the prison cafeteria: “There’s two sides to the cafeteria, so the diseased ones go to the right and the good ones go to the left.” In this particular prison, there was a visual separation of worthy and unworthy identities when it came to a public space like the cafeteria.

Other experiences of enacted stigma show that the general inmate population in CSC subscribe to the myth that HIV is spread through casual contact, as illustrated with one experience about using a communal fridge: “I couldn’t put my chicken in the fridge because we
don’t want to catch your HIV… If they aren’t educated, it’s because they don’t want to be.”

Again, experiences like this were echoed throughout discussions with participants. One participant discussed not being able to use the same sporting equipment as the other inmates:

I do play sports and that. There’s some people that they don’t know the medication. They say I got to wear this equipment, why you putting it on, you’re HIV. I say you can’t get it from sweat. It has to be blood on blood. I mean blood hits the airs, it’s pretty well dead. – HIV positive medium security inmate

Fortunately, for this particular participant the social programs department at his respective institution was able to help by giving him a baseball glove that he could use every year, without having to share with the general inmate population.

Not all staff at CSC are willing or able to assist with helping to make life easier for HIV positive inmates. On several occasions, the participants spoke about issues with experiencing stigma from CSC staff. One HIV positive medium security participant reported: “some of the guards, are supposed to pat me down but they do a quick one cause they just… you’re treated like you’re some kind of disease.” This was echoed by other participants: “a lot of [stigma] from staff… like so and so spit at me, he’s HIV positive, I need 6 months off work and I need to be tested.” Participants report that not only does the general inmate population believe the myth that HIV can be passed through casual contact, some CSC staff members believe it as well.

Experiences of enacted stigma did not stop at HIV positive inmates being ostracized and having to cope with negative comments from other inmates and staff. Sometimes enacted stigma led to violence. Many participants reported having to switch housing units or ranges due to being
unwanted by the other inmates in their housing units. One reports, “Sometimes, 15, 16 guys want you off the range cause you’re HIV. Get the fuck out of here… They never got me out.” This was echoed by another participant reporting.

It’s never one guy. One guy will approach you. If that don’t work, 2 will come, 3 will come, 4 will come, 5 will come and if that don’t work and they see that you can’t be intimidated they will threaten to cause bodily harm. – HIV positive medium security inmate

In addition to being run off the range, which refers to being made to leave one’s housing unit, issues arose when participants were in communal housing settings. Some institutions have inmates living in communal houses, where they cook their own food and live together. One participant who was open with his HIV status reported not being allowed to cook his own food when he first moved into the housing unit, “I had a guy that was going to cook for me cause the guys didn’t want me around the knives. Eventually as they seen how I carry myself and look after myself… now I’m able to cut my own veggies… It just had to work itself out.” – HIV positive medium security inmate

4.1.2 Experiences of Felt Stigma

Experiences of felt stigma were rare with the participants, with it being reported only by those who were non-disclosed about their HIV status.
One participant described being non-disclosed with his HIV status due to fearing how he will be treated if he discloses his status. He described his life in prison as going well, and that he did not want to rock the boat.

Another participant described in detail why he is non-disclosed and what he fears if he would disclose:

Well probably get booted off camp (minimum security prison) or probably even beat up, for sure talked about. Less people would hang around with you, cause everyone would assume that other person hanging out with you is gay or something.- HIV positive minimum security inmate

Outside of these two experiences, the majority of participants were at minimum selectively disclosed, so experiences of enacted stigma were more common.

4.1.3 Experiences of Internalized Stigma

Experiences of internalized stigma were most common immediately after finding out one was HIV positive. This type of stigma often manifested itself with participants discussing attempting suicide and becoming depressed. These experiences are discussed in length in the section below entitled Reactions to HIV Diagnosis. However, one quote that rang true for the majority of participants was made by one participant who compared himself to being a maggot:
“I was more like thinking of myself like a maggot cause they had me thinking like that. Now I’m stronger in the head.” - HIV positive medium security inmate

This idea of believing oneself unworthy and undesirable due to being HIV positive was central to many participants’ experiences upon receiving their HIV diagnosis. This manifested itself in numerous accounts of depression post-diagnosis and the majority of participants reported attempting suicide multiple times.

4.1.4 Experiences of Stigma by Association

Stigma by association was mentioned briefly by PEC workers. One newly hired PEC worker reported the office being associated with HIV from inmates who passed by:

“I work in the PEC office for health care… so you know I can hear whispers to people like he’s working in there? He’s in the HIV office or it’s the AIDS office” – PEC worker

minimum security inmate

Although this was the only direct comment on the PEC office being associated with HIV, some participants commented on the usefulness of the PEC office and program due to this association. Other participants commented that the program was valuable and necessary in the prison environment.

One participant reported that during his incarceration, he rarely sees inmates going to the PEC office: “I don’t see too many guys going down there… they just don’t want people knowing
their business.” The inmates wanting to keep their medical issues confidential was echoed by others: “Some people don’t want to go in there cause they feel if I’m seen here, somebody might think I have this and have that.” – HIV positive medium security inmate

Stigma by association affects the effectiveness of the PEC program because inmates may avoid the program all together to avoid being associated or presumed to have HIV.

### 4.2 Experiences of HIV Criminalization

Out of the 15 HIV positive participants I interviewed, 4 reported being incarcerated under HIV non-disclosure convictions. All 4 were currently incarcerated at the time of the interviews. During the course of the interviews, the topic of HIV criminalization came up in regards to disclosure of HIV status while incarcerated. All four discussed their trials as being publicized in the news, so once sentenced, the inmate population at their prison were aware of who they were and that they were HIV positive. One participant simply described his HIV status being known to the inmate population: “Yeah, a lot of people know about me. I was in the newspaper. I was on TV.” Another participant reported: “People know because well, when you’re publicized on the news it’s kind of hard to say oh no… and then you just sound like a liar.” These two participants conveyed that regardless of whether or not they wanted to share their HIV status with the general inmate population, the population knew because of details concerning their trials including their photos being publicized.

Although these particular participants did not talk about receiving any backlash due to their HIV non-disclosure charges, one HIV positive participant who was incarcerated for other
offences not related to HIV non-disclosure described in detail that those who are incarcerated for HIV non-disclosure are not welcomed into the prison environment:

In today’s prison, the only people that are not welcome, seriously not welcome, is if you knowingly have HIV and have purposely had unprotected sex and it’s in the newspaper and you can, and your name or your picture is splashed all over the place. And you go into prison… that person’s not getting anything. It doesn’t matter. He could be getting stabbed and I wouldn’t get him a Band-Aid. – HIV positive formerly incarcerated inmate

Overall, those incarcerated for aggravated sexual assault due to HIV non-disclosure may be classified as being more unworthy than just a regular inmate who is HIV positive. One HIV-negative formerly incarcerated inmate describes HIV positive inmates as being on the same social level in prison as the skinners, which refers to those incarcerated for rape and sexual crimes against children. As mentioned in the above quote from an HIV positive inmate, he wouldn’t give someone who is incarcerated for HIV non-disclosure a Band-Aid, suggesting a more unworthy identity than just being an HIV-positive inmate.

Outside of worrying about being stigmatized for HIV non-disclosure laws in prison, the four participants worried about being stigmatized upon being released because of the nature of the law:

I didn’t know you get charged for aggravated sexual assault and now I’m on the sex registry list for life. I can handle the HIV, being on that list is the worst feeling ever… and the reason why it falls under that is because it’s a weapon. HIV’s a weapon… How
am I going to explain that I wasn’t charged with rape, but I’m charged with HIV. – HIV positive minimum security inmate

Currently those who do not disclose their HIV status before engaging in unprotected sexual intercourse may be charged with aggravated sexual assault. When publicized, news outlets may report that it is aggravated sexual assault due to HIV non-disclosure or not, which is what this particular participant is speaking about. His worry is that once released that how is he going to explain that he was charged with aggravated sexual assault, but that he did not commit rape.

4.3 HIV as a Protective Factor during Incarceration

One interesting, but unexpected, theme was HIV as a form of protection from physical violence while incarcerated. As reported above, HIV positive participants experienced violence due to their HIV status and them being unwanted in housing units. However, some participants reported believing that being HIV positive may be protective from physical violence due to the fear of contracting HIV during a physical altercation on the part of a would-be perpetrator. One minimum-security participant reports, “If a person is angry at somebody and they know he’s HIV positive, the person is going to back off more, rather than just giving him a punch and hurting them bad. They will not do that cause they don’t want to get it.” This was echoed by other HIV positive participants saying, “What I realized is people don’t like to get into conflicts with people who have HIV because they’re afraid of the virus” and simply, “you don’t want to be fighting with him cause he’s got HIV and you don’t need it.”
This was not a consistent belief among all 20 interview participants. One participant speculated that physical altercations with HIV positive inmates may be more violent than with an inmate who is not known to have HIV because of the perpetrator not wanting to be involved in hand-to-hand combat where there could be an increase risk that both members of a fight would get cut. One participant reported:

Guys are scared of [HIV]. You know when they find out, they want to pretty much avoid a person. If you’re in a higher institution unlike a minimum-security, if there was ever a threat of violence it tends to get more violent quicker because it’s not a fist fight. Its guys bringing weapons in, like a bat or a knife because they don’t want to end up flopping around and dealing with blood. The perception a lot of the time is hands off… the plague… the big ‘A’ (AIDS). – HIV positive minimum-security inmate

There is obviously debate between inmates whether HIV is a protective factor against physical violence, or if it leads to even more severe forms of physical altercations.

4.4 HIV Transmission: Risk Behaviours during Incarceration

During discussions about risk factors for HIV transmission, some participants spoke about risk behaviours in prison. These discussions focused mostly on needle use inside prison for both injection drug use and tattooing purposes. One participant spoke about the re-using of needles inside due to a lack of access to clean needles:
A lot of guys use dirty needles, well used needles, because of the lack of needles. They are forever finding them though. Guys, they’ll chop a needle down to make it smaller and they’ll hide it in their butt, it’s just not safe! –PEC worker medium security inmate

One PEC worker when asked about harm reduction supplies reported that the condoms and bleach that he supplies are always needing to be re-filled: “I mean in prison, people do use drugs. I mean I give out condoms and bleach and stuff like that and they go pretty fast.” Beyond the comment about giving out condoms, no PEC workers could definitively report that other inmates engage in sex with other men.

One participant who was incarcerated at the time in a minimum-security institution offered an explanation for why inmates engage in risky behaviours that may lead to the transmission of communicable disease:

You don’t have as much freedom, so the tendency is to lose yourself in some way. It is far higher in the medium (medium-security institutions) than it is here (minimum-security institution)... I think if you want to counter the HIV and any STDs around, that’s something they (CSC) should be looking at providing some form of escapism… You got probably 4 options: watching TV, playing cards, playing chess, or reading, or doing absolutely nothing. Those are your 5 options when you’re in a medium.

This particular inmate is suggesting for higher security institutions where there is less freedom to provide more substantial options for inmates to do when they have free time. He went on to describe that in his experience, he has options in minimum-security prison to spend his time in the leather shop, woodworking shop, and other programs that have the potential to be
fulfilling. He also described that in his experience in a minimum-security prison, that he hasn’t seen issues with drug use.

4.5 HIV Status Disclosure: Experiences during Incarceration

4.5.1 Experiences of Non-Disclosure

A small number of participants reported being non-disclosed of their HIV status to the general inmate population. Each participant provided reasons for why they did not want to disclose their HIV status to the population. These reasons ranged from fearing being stigmatized to reasoning that if they were not putting anyone at risk they had no reason to disclose a personal medical issue.

Reasons centered around fear were common for those who chose not to disclose their status. One minimum security participant reported when asked why he was not disclosed: “I’m afraid about how I’ll be treated here.” This fear was echoed by others.

I didn’t for a second feel bad about protecting my HIV status. I saw too many people ostracized. A lot of stigma, a lot of blatant ignorance around people with HIV. I saw people in the Federal System be shunned, ostracized and just the stigma of being HIV positive in prison, you do become a leper in a lot of aspects. – HIV positive former inmate

One participant reported fearing being inadvertently disclosed due to practices with the healthcare department:
If I’m paged to healthcare and I know of somebody else in here who is also HIV and if we’re both paged to healthcare at the same time it raises questions. Because this person is very vocal in their condition and I’m not. So you kind of get lumped in together and that’s the fear you get sometimes- HIV positive minimum security inmate

When asked for more detail, this inmate explained that in situations when this happens, at the end of the day when he goes back to his housing unit, people ask why he was called to healthcare and why he was called with a particular inmate. He mentions that inmates can put things together and presume that if you are always called to healthcare with certain inmates, then you probably have the same disease they have.

Outside of fear of discrimination one participant reported that he is non-disclosed with his HIV status because he feels that is no one’s business, since he is not putting anyone at risk of contracting HIV:

I try not to share that information… there’s no reason for it… there’s no reason cause I don’t put him at risk so why should I tell him. There’s no risk, I’m not going to put him at risk, no need to know. It’s on the need to know basis.- HIV positive minimum security inmate

These participants who report being completely non-disclosed described their experiences in prison with less detail than those who were selectively- or fully- disclosed. Experiences of selective and full disclosure will be disclosed in detail below.
4.5.2 Experiences of Selective Disclosure

The majority of participants reported being selectively disclosed during incarceration. Those who were selectively disclosed spoke about telling those inmates who they were close with. They also spoke about being nervous to disclose their HIV status, even if they were telling their inner circle of friends:

My inner circle pretty much [knows]… with everybody individually I’d be afraid. I don’t know what they’re capable of or what they think about it. A lot of times getting people to talk about stuff like that first and say oh… yeah I’m positive, but I take care of myself and tell them a little bit about [HIV]. – HIV positive medium security inmate

This participant spoke about gradually disclose his HIV status to his friends, by broaching the subject first before disclosing to gauge his friends’ reaction and so the conversation is already flowing.

A separate participant spoke of why he was selectively disclosed instead of fully disclosed. He spoke of the importance of having to live in harmony with the rest of the inmate population:

“Maybe if I was Superman I wouldn’t care, but you have to live. My friends, the friends I’ve made in my lifetime, I just know I would trust every one of them.”– HIV positive former inmate
In contrast to the above experiences of participants trusting their friends with disclosure of their HIV status, two participants spoke about experiencing issues with disclosing their HIV status. The major issue was their HIV status not staying confidential with the inmate they disclosed to. One medium security participant reported: “Tell one inmate and everyone in the unit knows.” Additionally, a formerly incarcerated participant reported: “I only let certain people know and they never treated me any differently. If someone else got wind of it, which someone did, they were ignoring me.”

Although some participants report trusting their inner circle and preparing their friends with the news of their HIV status before actual disclosure, it is evident that disclosing of HIV status to close friends does not guarantee that one’s HIV status stays confidential.

4.5.3 Experiences of Full Disclosure

Some participants reported being fully disclosed to the general inmate population in regards to their HIV status. Again there were a variety of reasons for wanting to be fully disclosed ranging from wanting to educate the population on HIV to just accepting that being HIV is a part of who they are.

One participant spoke about the importance of educating the inmate population as a reason why he is fully disclosed:

If anybody asks me, I’ll let them know. It’s also my responsibility to. I mean I would rather have people more aware of what HIV is and what it’s not. A lot of people think
you share a spoon or something, like they think the same thing as Hep C, so a person you
know gets in my face and says I don’t want to… I say listen this is what HIV is, this is
what Hep C is, totally different. I educate them. So it’s good to educate people rather than
have them talk behind your back or feel uncomfortable.- HIV positive medium security
inmate

Others have accepted that HIV is part of who they are and that they will likely always
have HIV as reasons for being fully disclosed. This is evident in reports from several participants
stating, “everybody knew. I was very open about. I had nothing to hide” and “I’m pretty blunt
with it. All the people I talk to, everybody knows.”

A minimum security participant spoke about his time before he was fully disclosed. He
described being stressed out and always concerned about if other people knew and were talking
about him behind his back. This is why he described becoming open with his HIV status upon
incarceration: “I can’t go around and be like every time somebody’s whispering be like oh my
god! Are they talking about me?” He described the experience as being unhealthy for him to be
non-disclosed.

The participants who were fully disclosed reported fewer fears of being stigmatized by
the general population. They also were more likely to discuss ways that they had fostered some
resiliency in their lives, and that their HIV status was not going to negatively affect them once
they were released from prison.
4.5.4 Inadvertent Disclosure by Healthcare Department

Participants who were non-disclosed spoke of being concerned about being inadvertently disclosed due to practices in the healthcare department. One of the biggest concerns about inadvertent disclosure is also related to inmate housing practices. This concern is centered around medication practices. It is standard to give inmates their medications in a blister pack for a month. The blister pack format is standard for HIV medication. When discussing medication practices, participants spoke about concealing their medication, so other inmates do not find them and figure out that the participant is HIV positive:

Well in my case, every room has a desk. And the way I conceal them is I put them in my desk drawer. I don’t leave them out in the open. Even when I have to renew my medication I kind of time it, so that I get it with something else if I have to. So that way I can put my antidepressant on top of it and that way if anyone were to be nosy they would see just the antidepressant, not the other medication. - HIV positive minimum security inmate

One participant reported only being concerned about inadvertent disclosure due to medication when he is in a double cell or roomed with another inmate:

“I try to put them in the drawer and cover them cause I’m in a single. But when I’m in a double it’s a big concern.” - HIV positive minimum security inmate
In one conversation with a participant he mentioned not being worried about inadvertent disclosure due to medication until he was picking up his HIV medication prescription at healthcare. When the participant suggested an alternative way of receiving his medication to mitigate the risk and protect his privacy, health care did not oblige:

“I wasn’t worried until health care said people know what that bottle is. I suggested putting them into one of those things, the pill packs. They wouldn’t do it. So you’re putting me at risk now.” - HIV positive medium security inmate

This risk of inadvertent disclosure was only discussed in detail with participants who had not disclosed their HIV status to the general inmate population. Those participants who were selectively or fully disclosed did not report being worried about inadvertent disclosure due to healthcare practices.

4.6 Life Before HIV Diagnosis

4.6.1 Experiences of Childhood Traumas

Experiences of childhood trauma were common for the formerly incarcerated participants. The currently incarcerated participants did not discuss their lives as children in detail, other than to say, for example, “I had an unhappy childhood” without going into more detail even after prompting.

The formerly incarcerated participants discussed being abused by members of their families from a young age. One particular participant discussed his mother’s new husband abusing him as a young, 4-6 year old child: “He came home from the honeymoon and that night
at dinner when we were eating, he stabbed me through the hand with a knife for holding a fork wrong.” Unfortunately, for this particular participant abuse did not end as he grew up. He discussed several traumatic experiences of sexual abuse at age 13. One of these experiences he encountered was at an adult drug and alcohol rehabilitation centre where he was a patient as a young teenager. “Some guy tried to molest me in that place [rehabilitation centre] and I ended up stabbing him in the side.” This experience was mild in comparison to his reported second experience which also ended in self-defence: “I got kidnapped by a child molester when I was on the street [at age 13]... I had to plan a way out… I grabbed a knife and put it behind a pillow… I stabbed him once and I killed him.” This particular participant discussed the new step-father as the reason for beginning to use drugs, as he was trying to escape the abuse experienced in the home and the rehabilitation centre that his step-father sent him to, which lead to him leaving the home and becoming a street-involved youth leading to the kidnapping and murder.

Others described trauma experienced as children as a reason that led to them contracting HIV:

Because of the way I was told, the sexual abuse, the verbal, the mental abuse, I went through growing up, I’ve sold myself on the street because I didn’t know what to do anymore. I needed to supply my drugs. I think it was my way of saying, what am I? Should I be with a male, should I be with a female, should I be with a shemale, should I have a sex-change, or just commit suicide and say the hell with it. –HIV positive former inmate
These examples demonstrate the abuse suffered as children by some of the participants. In these instances, the participants spoke about their unhappy childhood leading them to engage in risky behaviours such as drug use and unsafe sexual behaviours, which eventually led to their incarceration.

4.6.2 Risk Behaviour: Illicit Drug Use

During the interviews, many participants spoke about drug use behaviours as the means of contracting HIV. In these cases, all participants spoke about contracting HIV while in the community and not while incarcerated. They may, however, have been diagnosed while incarcerated due to being tested upon admission.

One common practice among participants was the sharing of needles for injection drug use purposes. One participant stated that he was not concerned about sharing needles and contracting HIV, because at that time HIV was believed to only affect gay men.

I was a heroin junkie… I heard it maybe once or twice cause we were sharing needles. They were saying, watch it, you can get that new thing around there, the HIV. At the time, they were calling [?] it the gay virus. If you were HIV, you were a fag at that time.

–HIV positive former inmate

Two other participants speak of female companions using their needle without their knowledge. One participant in particular speaks of his female companion infecting him with HIV on purpose in order to prolong their relationship.
I got HIV out in Vancouver. Up to that point, yeah I shared needles, cause not a lot of people knew about [HIV] back then… I was fooling around with this girl… she put blood in the cap of my rig. She gave it to me on purpose, so we could be together. –HIV positive former inmate

Another instance of sharing needles leading to infection was reported in the following way:

Actually, I had a hit made up. I had it in my end table and I let this female use my room and she went into my drawers and did the hit, filled it with water and didn’t tell me. I went in there and did the hit and yeah, that’s how I got it. –HIV positive former inmate

These are only a few examples of needle sharing related by the study participants. There were many more instances. There were also, however, reports of participants taking precautions when engaging in injection drug use.

When I was using, because I’m a heroin addict, I was an intravenous drug user. I knew all about it (HIV). I took precautions to make sure that anything I used was mine. So when I was finishing using, it was put away. I only used my syringes once. I disposed them. I broke them. I put them in one of those yellow hazard type containers. –HIV positive former inmate
Additionally, one participant spoke of his persistence in not sharing needles despite the difficulties he and other injection drug users faced obtaining clean needles when he was an active injection drug user:

I took a lot of precautions… because I grew up in an era where we just shared syringes, and syringes were harder to get than heroin as matter of fact at some points… I started demanding, you know people started practicing a little safer… I was really careful. –HIV positive former inmate

Although many of the participants spoke of contracting HIV through injection drug use in the community, they also spoke of practicing harm reduction techniques before needle exchange programs were available. The harm reduction techniques they spoke of was destroying their old needles so they were unusable, disposing them in biohazard bins, and purchasing new needles.

4.6.3 Risk Behaviour: Sexual Health

In contrast to those participants who spoke of injection drug use as their means of contracting HIV, others spoke about contracting HIV through engaging in unsafe sex. Some participants spoke about their experiences in detail, others spoke about it in passing only reporting, for example: “I’ve played with unsafe sex.” One participant spoke in more depth about his experience contracting HIV from his sexual partner:
We took precautions, got tested. Stopped using protection. We didn’t see each other for 6 or 9 months, we started seeing each other again and didn’t use protection. She told me she got tested and the tests came back positive. I got tested and came back positive. –HIV positive former inmate

The contraction of HIV from a sexual partner was echoed by two other participants. However, the two other participants disclosed that they identified as a gay male and were not surprised when they tested positive. One participant describes finding out his HIV status after his partner tested positive:

When I found out that he had it and I got tested. I found out on my birthday that yes low and behold, I’m positive too. It was a little devastating, but I had kind of prepared myself. By preparing myself for him.- HIV positive minimum security inmate

In contrast to contracting HIV from a partner, other participants spoke about engaging in prostitution as a means to support themselves and their drug habits. The participants who spoke about these experiences, also spoke about engaging in drug use and were often unclear of their means of contracting HIV. However, it is still important to note that engaging in prostitution at a young age may have led to contracting HIV.

Two participants spoke of contracting HIV while incarcerated. One describes contracting HIV in the ‘bucket’, which refers to a provincial jail where people are held before trial and sentencing:
A guy I met in the buck on the first manslaughter charge, we didn’t have condoms back then. He wanted to use a bag or saranwrap… we ended up still going at it… I said to him, do you have anything? I went and did it with him and next thing you know about 8-12 months later, after he was transferred, all of a sudden, I’m breaking out in boils. –HIV positive medium security inmate

Additionally, another participant spoke about contracting HIV during an unwanted sexual encounter while incarcerated in a Canadian Federal Penitentiary:

They placed me into a double bunk with another inmate. That night, while sleeping, that inmate thought it was okay to crawl up there and well, have sex with me while I slept. All the noise and that woke everybody up and the guards caught him in the act and basically, I got sent to healthcare. They did some checking here and there, did some blood work and a couple months later, I was told I had HIV. – HIV positive medium security inmate

Experiences with unsafe sex, both consensual and non-consensual were common for the participants, with some of those unsafe sexual encounters leading to the contraction of HIV.

4.7 Reaction to HIV Diagnosis

During discussions of the process of being diagnosed with HIV, many participants spoke about their reaction to the diagnosis and how they handled it and how it affected them. Many of
these discussions focused on the mental health of the participant post-diagnosis with many describing increases in instances of depression and suicidal ideations and attempts.

One formerly incarcerated participant describes his dive into depression after his doctor disclosed his HIV test results to his partner over the phone without his consent, “I went into a depression because people started turning their backs on me as soon as they found out. Family, Friends. I was trying to commit suicide. I tried suicide by police.” This was not his only attempt at suicide. He describes additional suicide attempts due to not knowing who he was after his HIV diagnosis. Another formerly incarcerated participant describes forming a suicide pact with another inmate by way of drug overdose during incarceration. He recalls waking up after attempting to overdose to find that his friend had died. Attempts at suicide were common when discussing reactions to finding out their HIV diagnosis.

Other participants describe not dealing with learning their HIV status in healthy ways. One participant in particular describes that his injection drug use became more intense in the years following his diagnosis, as he did not know how to cope with being HIV positive.

Participants also described becoming violent and reclusive after becoming HIV positive. One participant speaks about wrecking his room in the hospital after finding out he was HIV positive, and then once released from hospital, not speaking to anyone for several months, including his family. Another participant speaks of becoming violent to distance himself from people upon diagnosis:

After I got HIV, I was more or less being violent to keep people away from me and not be disrespectful to me about this… Cause I have an ego problem about someone
disrespecting me when it’s none of your fucking business. – HIV positive medium-security inmate

Lastly, another participant spoke of an increase in anger issues, and how they now cope with the anger concerning being HIV positive:

I didn’t really talk about it for the first 3-5 years cause I was devastated and I think my anger issues went up drastically after that… I was slashing back then, so I had a lot of mental breakdowns over that… my whole arms are messed up… now I started writing poetry to help with the pain. – HIV positive minimum-security inmate

While the majority of participants experienced some decline in their mental health, many of the participants eventually became resilient and developed ways to cope with the reality of being HIV positive. The writing of poetry was only one coping method discussed. Others included disclosing their HIV status to friends and family, joining support groups, and upon release accessing community HIV organization.

4.8 Resiliency: Post HIV Diagnosis

Participants spoke of becoming accepting about their HIV status over time. Some describe it taking years to accept their reality. However, participants who spoke about this, formed a theme of resiliency, a becoming comfortable with who they are as an HIV positive person. Each of these ideas of resiliency take different forms, as each participant has a different
story and a different background which led to their becoming HIV positive and to their becoming incarcerated.

One participant described contracting HIV in the early 1990’s, but how he did not believe that HIV was going to kill him. He described being determined to fight the virus and that now 26 years post-diagnosis he remains healthy:

I didn’t take it that hard because I understand what it could do and it was a death disease but in my mind I refused to let that get to me. That wasn’t killing me. I did everything in my power to make sure. I went and I played hockey, I played soccer, all these sports. I ate proper and I listened to the doctor… I just thought that, if I’m going to go down, I’m going to go down fighting.- HIV positive medium security inmate

Another participant who was incarcerated for aggravated sexual assault for HIV non-disclosure describes how upon release he wants to be able to tell his story and speak with his local HIV/AIDS organization to help spread awareness about the HIV non-disclosure law:

“I have no problem telling my story. I’m not embarrassed. Yeah, I went to prison for it. Is it going to ruin my life? No.” – HIV positive minimum security inmate

This theme of finding a voice and telling one’s story was echoed by another participant. This particular participant was one who was not incarcerated for HIV non-disclosure, but one who described not telling him family about being HIV positive for 17 years:
“I’ve sort of found my voice when it comes to being a spokesperson around HIV. That voice gets reinforced time and time again, because I’ve never felt anything but support from people around me.” – HIV positive former inmate

One participant who reported attempting suicide multiple times describes fighting for his rights, when faced with a tuberculosis specialist who was advising medication that could have negative interactions with his HIV medication:

“It’s my life I’m fighting for! Yeah, I screwed up by doing my drugs and booze and working the streets. But it’s my life that’s on the line!” – HIV positive former inmate

Many participants found self-acceptance and became resilient in their HIV diagnosis, as one can see above including fighting for their rights, and being able to tell their story and express their experiences with both being HIV positive and being incarcerated.

4.9 HIV Association with MSM

When discussing the perception of HIV in prison, many participants reported that HIV has remained associated with the gay male population, even though it is clear that it is not confined to those who are men who have sex with other men (MSM). One report that was echoed frequently was: “I think there’s a lot of them that think it’s a gay disease. They stereotype it. It has to do with being a homosexual and that’s where it’s going to be transmitted.”
One participant who contracted HIV through heterosexual sex described his experience of being assumed to be gay and how he tried to educate other inmates that HIV is not confined to the gay community:

At first, there was a couple people were like, you’re gay, you’re a fag. But then there were people when I told them kept asking how did I get it. I got it through sex (heterosexual)… some were okay and some were like stay away. – HIV positive medium security inmate

This presumption of sexual orientation was echoed by another participant who also reported contracting HIV through heterosexual sex. This particular participant discussed how the gay community in prison now approaches him to engage in MSM due to this presumption of sexual orientation based on him being HIV positive:

“There’s been a lot of stigma… I’m supposedly part of the subculture of homosexuals here.”- HIV positive medium security inmate

This perception was also echoed by HIV negative PEC workers. The PEC workers also noted that HIV positive inmates may also be assumed to be injection drug users:

Mostly onto the gay aspect of it or the drug user. They automatically assume the guy is a drug user or whatever. They first jump towards him being gay, that’s the only way he got it… cause they still believe it’s a strictly gay disease.- PEC worker medium security
After hearing these accounts of HIV being immediately associated with those who are MSM, when asked if being MSM in prison is a respected identity, it was clear they were not an accepted population for the most part:

“You can tell it’s a big no, no in prison. Cause it’ll be back to okay you’re gay. That’s a big thing in prison.” - HIV positive medium security inmate

This association of HIV with MSM is an important result to consider because four of the participants self-disclosed being a member of the MSM community.

4.10 Experiences of LGBTQ+ Participants

Of the four MSM participants, two identified as being gay males, one identified as being transgender, and one identified as engaging in MSM while incarcerated, but was also married to a woman. These four participants spoke openly about how their sexual orientation affected their lives in prison.

The participant who participated in MSM despite being married to a woman described how prison has changed over the years, as he has been in prison on and off for the past 2 decades. He described that in the early days being associated with what he called a ‘queen’, or someone who may be transgender or a cross-dresser, as a status symbol. He described how having a ‘queen’ made you recognizable as one of the toughest inmates in the prison. However, he spoke of that dynamic being unwelcome in today’s prison environment.
Both of the two self-identified gay males were non-disclosed with both their HIV status and their sexual orientation. One minimum security inmate did not discuss his sexual orientation in detail only to say, “no I’m not open with that at all… it’s my decision.” However, the other participant described being HIV positive and gay as being two unworthy identities in prison:

I think if you’re straight and HIV positive, and if you’re sort of a bad boy, it’s probably a lot easier for them. But I know being gay and HIV positive is a little different… all of a sudden you suck dick and the other one doesn’t… you’re the devil.- HIV positive minimum security inmate

The transgender participant spoke in length about issues at their particular prison in regards to their gender identity and what supports they have access to:

There’s discrimination because I’m a queen right. The black guys’ like using their language and they’re literally ignorant. Calling us fags and they don’t say it to our faces, you can hear what they’re saying cause its broken English.- HIV positive medium security inmate

Although stigma is present due to their gender identity, this participant talks about the supports that are in places at their prison, including a LGBTQ+ support group:
“Well we got that group which helps. It helps people meet people for one. We talk about a lot of things, being trans or gay in an environment like this. How people feel about it.” - HIV positive medium security inmate

They have meetings for trans like me. There’s two of us here. Then there’s other ones that are like in the closet trans. I think they’re gay. Another guy that just left here, he’s a lifer, he just turned into a trans. And he’s already getting hormone therapy and he’s seeing a doctor. Here we don’t even have a doctor.- HIV positive medium security inmate

The support groups are helpful because there is a space within the prison environment that is welcoming and supportive of sexual and gender identity. However, issues surrounding access to a doctor that is specific for those who are transgender is one that this participant holds dear to their heart:

The thing is here we don’t have a doctor for trans. That’s what I’m trying to work on. I’m trying to get on the hormone. I can have the surgery. I just got told by my elder that they approved us for that as long as I have gender identity dysphoria or gender identity disorder and I was diagnosed with that.- HIV positive medium security inmate

Supports for inmates who are LGBTQ+ are dependent on the prison. Some prisons offer support groups for the community, while others offer access to a doctor who specializes in transgender medicine and hormone therapy. Experiences for LGBTQ+ inmates who are also HIV positive are influenced by the supports available in their prison.
4.11 Supports Available during Incarceration

Outside of support groups for those inmates who are LGBTQ+, the participants also discussed supports available to them in prison that are specific to being HIV positive. One of the types of supports they spoke of as being important was having access to local HIV/AIDS organizations. This included having access to prison support workers from these organizations that can assist with support while incarcerated, but also assist during pre-release planning and support once released into the community.

The other support system that was discussed at length was the availability to access Cell Count, which is a newsletter for people who are HIV in prison produced by Prisoners’ HIV/AIDS Support Action Network (PASAN). At one point Cell Count was banned in prisons due to its content. However, when speaking with the participants several spoke of Cell Count’s importance as a support for several reasons. One was it was a way to get information on new medications for HIV. This allows inmates to be educated when speaking with prison doctors and the HIV specialist, such as being able to ask informed questions about the newest line of medication:

“PASAN and Cell Count, it helps me become educated because they tell me what the line of newer meds coming out is, like what they’re studying and so on.” – HIV positive medium security inmate

Additionally, several participants spoke of Cell Count as a means of communication between Federal Prisons and a way of understanding about how HIV positive inmates are treated at certain institutions:
That’s the way we (HIV positive inmates) basically communicate with each other. We write what’s going on with each prison, and others get to see if its positive here and that way people can tell where they’re going to, cause if you’re going to go to a place where there’s no help, there’s no groups, you’re not going to want to go there. – HIV positive medium security inmate

Support that are external to the prison, but accessible while incarcerated were frequently described as the most important due to the availability of continuing supports once one is released from prison.

4.12 Suggested Improvements to Current CSC Programs

4.12.1 Reception Awareness Program / Orientation

A significant portion of the interviews involved evaluating programs related to HIV that are offered in prison. The participants provided insight into the effectiveness of programs. One of the programs most frequently discussed was the Reception Awareness Program. The remarks made about the current program suggest improvements may be warranted:

“When I was in reception, they had this lousy video that they do. It wasn’t really informative. I didn’t find it very factual.” – HIV positive medium security inmate

Other participants spoke of developing a more in-depth orientation program. At one particular prison the PEC workers put in an application to be involved in running an orientation for new inmates:
They need an orientation. That’s what we actually tried to submit a request that the PEC workers should do that. Every week or whenever 10 guys come in, we do a little orientation we show them a bit of this and that. I don’t know where that’s going, but it would be nice. – PEC worker medium security

This sentiment was echoed by other PEC workers reporting: “There used to be an orientation where inmate committee, heads of different departments, this is who I am, this is what we do, any questions, feel free to ask. That would be a great thing. I’d be happy to be involved with that you know.”

One last suggestion to improve the Reception Awareness Program was discussing extending the program by one day to include a more in-depth curriculum on infectious disease prevention and education:

The way the system is set up now is they go through Joyceville Assessment and during that, there’s about a 2-week period people go into classes and get their assessment done and wait to find out where they’re going. If there could be one mandatory day and you catch everyone as they come in and they would all know that just a little bit more about the situations and what CSC can do to help. – HIV positive medium security inmate

Improvements to the Reception Awareness Program or the addition of an orientation program once inmates are sent to their home prisons were common suggestions from both the
HIV positive participants and the PEC workers. It is important to note that the PEC workers suggest that they be involved in the implementation of such a program.

4.12.2 Peer Education Course

Additionally, participants suggested that improvements could also be made to the current PEC worker program. One participant suggested not having an inmate in the position due to fears surrounding confidentiality:

[The] PEC positon… that becomes a problem because if you go to that person and you start asking them questions and you started divulging, you could be shunned within the prison community. That’s an issue I have. And I think it’s a valuable position, but I don’t know if it’s being used properly… I think the best thing is that should be somebody from an HIV organization or somebody neutral… outside the facility or from medical. But to have an inmate, it’s just that inmates talk with inmates. If you disclosed to somebody, you’re not guaranteed any confidentiality. – HIV positive minimum-security inmate

When discussing why the PEC position should be run by someone who is seen as neutral and preferably someone who is not associated with the prison, participants spoke of the benefits that these individuals could bring:

It just seems they come in with a different mindset. They come in from the road and people in here, like the staff, it’s kind of like the same thing. But when people come from outside, they offer something different. – HIV positive minimum-security inmate
The PEC workers also spoke of desired improvements to the program. These improvements were more focused on management of the prison:

The PEC office needs to be more aware to the guards. The guards don’t seem to know what we do. They don’t understand, there needs to be awareness amongst the staff. Cause it’s fairly new, the PEC, so there needs to be awareness because they don’t know what’s going on. They belittle us, and we want to help the population. – PEC worker medium security

Although the majority of participants saw the PEC program as valuable in the prison environment, it was not without scrutiny. Suggestions for improvement were mentioned by HIV positive participants, as well as the PEC workers.

4.12.3 HIV Educational Programming

Outside of the PEC program and the Reception Awareness Program, the majority of participants discussed needing to improve the education program surrounding HIV inside the prisons. The need and want for further education was driven by the belief that education would help to destigmatize HIV:

I think more education would be better to help those people to have them feel more comfortable and those that don’t less likely to get it and know that and to destigmatize so
people would be more vocal to getting tested for these things. – HIV positive medium security inmate

The participants provided innovative solutions to improving the accessibility of the education program. The importance of offering creative solutions to educate the general inmate population was discussed since the inmate population is described as being hard to reach and unengaged:

You got to get creative, cause you’re trying to reach out to people that, they’re sort of a lot of them are negative to being with… It’s tough to reach out to people or educated when they don’t really want that. – HIV positive medium security inmate

Several participants suggested taking advantage of the prison TV channel to put a social marketing campaign related to HIV education and awareness, as a potential avenue to develop a widespread education initiative:

A lot of people don’t want to go to the PEC office, they don’t want to do the peer health course, but if there was a video that could be shown though the joint channel that they could watch, they might say well, I don’t have to go there, I might want to watch that. They could get educated without having to be there… I’m just thinking we could promote more widespread because that way we could cover more people. – HIV positive medium security inmate
The concept of developing a series of workshops on communicable disease was suggested frequently as an avenue to increase education and awareness. The other resounding theme was that the workshops should be open to the entire inmate population. Some suggestions included enlisting the PEC workers to hand out flyers to individual housing units, but to also put the flyers on the prison TV channel. Other suggestions focused on the location of the workshops as being important:

They could make workshops here. If you have a more open thing in the gym and someone comes in and actually speaks about it and explains it. If you were going do to it in the gym like an open health day where people could ask questions, it would make more sense.- HIV positive minimum security inmate

The last suggestion to improve education and awareness on HIV was to institute a speaker series. The series would include members from community organizations entering prisons to give talks on different aspects relating to prison health, which would include HIV. The participants discussed these events to be open to the entire inmate population and should take place in a large area like the gymnasium.

4.12.4 Remaining Participant Suggestions

The participants also spoke briefly about instituting a staff sensitivity training that is centered on HIV and other communicable disease. Participants spoke about prison staff being insensitive to the needs of HIV positive inmates. However, they mentioned the staff that are currently coming out of the staff college to be better educated on HIV and are generally more...
sensitive. They did not provide any details about how they would like to see a staff sensitivity program formulated, but did suggest that it exist.

On another topic, many participants wanted to discuss ways to mitigate the risk of transmitted HIV in the prison environment. The participants focused on having access to clean needles for injection drug use and re-instituting the safe tattooing program. Having access to these programs was a common theme for participants, even if they would not use the services themselves.

Overall, participants suggested many different types of programs with several innovative ways to implement programs that they believe would be effective in the prison environment. The opportunity for the participants to provide ideas to mitigate HIV-related stigma was met with enthusiasm.
Chapter 5
Discussion

The results found in this study support those results of studies conducted in the United States of America by Derlega and Colleagues, as well as the study in Indonesia by Chambers and colleagues. The results from this project support that those HIV positive inmates who are open with their HIV status, report a more fulfilling prison life. These results also support that being HIV positive is an unworthy prison identity and is often linked to being a gay male or being an injection drug user. Although this study supported the results found in American and Indonesian studies, it is novel for the Canadian Male Federal Inmate population. Additionally, the study included the experiences of HIV-positive male inmates who were incarcerated for HIV non-disclosure laws. To my knowledge these experiences have not been included in any previous research on HIV-related stigma among incarcerated HIV-positive men. Although this study did not focus solely on these experiences these findings are important because approximately half of the 10 currently incarcerated HIV-positive inmates in this study reported being incarcerated for HIV non-disclosure laws.

The results of the study were clear that HIV-related stigma does exist in Canadian Federal Prisons in the Ontario Region, and that enacted stigma was one of the most common forms. The participants gave many opportunities for areas of improvement to help combat this, with the most common being instituting a widespread education program. Suggestions for educational programs took on many forms, suggesting that a multi-faceted approach would work best. The participants described the general inmate population as uneducated on all facets surrounding HIV. To begin to curb the false beliefs, such as the central beliefs that HIV is exclusive to the gay men’s community and that it can be transmitted through casual contact, I am
recommending that the Reception Awareness Program be altered. The participants described the current program as being non-standardized as there was a range of experiences from not experiencing the program, to experiencing if fully, to the nurse who was running the program fast-forwarding through the video tape. Currently, the program is designed to educate inmates in infectious disease prevention, while creating awareness of diseases that affect the inmate population (CSC, 2015). There was some skepticism among the PEC workers about its effectiveness, however, as the majority expressed interest in being a part of the reception awareness program or at a similar orientation program at their respective prison. The inclusion of the PEC worker in this program may serve to increase the effectiveness of the current PEC worker program as they may not be solely associated with the ‘HIV office’.

A second proposal for the revised education program is to use the prison TV channel as a means of social marketing to debunk HIV myths. Participants suggested this program could be potentially effective because inmates could watch from their cell, room, or shared living space, without having to approach the PEC office for that information. They believed this would be effective because people tend to avoid the PEC office for fear of being associated with being HIV positive. This social marketing campaign on the prison TV channel should be utilized to supplement education received through other established means such as the Reception Awareness Program. These videos could be developed by healthcare and be standardized across the country, meaning each inmate who watches the video receives the same information. These videos, if well received, could be expanded from HIV to other health topics included hepatitis C, needle cleaning, mental health diabetes, exercise, and many other topics.

In addition to suggesting improved inmate education, participants suggested improving staff sensitivity to those with HIV. There were reports of the security staff being insensitive and
spreading misinformation around HIV. The participants noted that this was most common with the older guards, not the ones who have recently graduated from the staff college. The participants suggested a sensitivity training for the staff. It was not clear what they would like to see in a program, but one part would be educating staff members on how HIV is and is not transmitted. It would not be enough to address this issue in staff college currently because the issue reported is with older staff members. A mandatory staff training for all would be ideal. This would help ensure all staff members receive this training, either in the staff college or on the job professional development training.

A multifaceted education program suggested by the participants would be one that is most effective in their opinion in changing the perception of HIV and HIV-positive inmates. However, it was not the only suggestion brought up by the participants. Many participants brought up disease transmission for not only HIV, but hepatitis C as an issue that is important to them. Two suggestions were common, one being the development of a clean needle program and the other being the re-introduction of the safe tattooing program. In Canada, clean needle programs in any form are not currently allowed in Federal Prisons. However, there is an ongoing lawsuit between the government and the HIV/AIDS Legal Network and other organizations to permit clean needle programs into Federal Penitentiaries to decrease hepatitis C or HIV transmission (HIV/AIDS Legal Network, 2017). Speaking with the HIV/AIDS Legal Network and CSC, a decision on the lawsuit appears to be coming in the later months of 2017. At this stage, it is unclear what the outcome of the lawsuit will be.

The second suggestion is to reinstitute the safe tattooing program that was previously available in 6 Institutions across Canada. The program consisted of education and then a tattooing program, with dedicated equipment and spaces at each Institution (CSC, 2015). The
program was reported to increase awareness of blood borne infectious in the inmate population, along with increasing opportunities for inmate employment, and the program start-up costs were low in comparison to the potential benefit of the program (CSC, 2015). Unfortunately, due to budgetary cuts, the program was phased out by the previous federal government and has yet to return even though CSC reported it to be beneficial. The inmates interviewed were asking for the re-introduction of the program because they reported that tattooing in prison is common. When I inquired about this program through my local Member of Parliament, Mark Gerretsen, he reported that to his knowledge there have been no discussions at the federal level concerning bringing the program back.

5.1 Study Limitations

Although this project answered the research questions and objectives that it started out with, as with any study there are areas where the study is limited. This study focused on male inmates incarcerated Federally in the Ontario Region of CSC. This may limit the generalizability of the findings as, for example, not applicable to female inmates. They may experience different types of stigma more frequently, and may have different risk factors that led to the contraction of HIV. Future studies may want to focus on investigating HIV-related stigma in female only Federal Penitentiaries, since the prevalence rate is higher than in male only penitentiaries.

Additionally, generalizability may be restricted as the study only focused on Ontario Region Prisons. There is potential for different experiences from HIV-positive inmates who are incarcerated in Pacific, Prairie, Quebec, or Atlantic regions of CSC. However, due to time and budget constraints, the opportunity to travel and interview HIV positive inmates in these regions
was not possible. Future projects may want to expand to collect data in other regions of Canada to ensure that these results extend to other regions.

Not knowing the exact demographics of the interviewed population further limits the generalizability of this research. The lack of formally collected demographic information stems from wanting to maintain the privacy of all participants. Although some participant disclosed demographic information that included age, ethnicity, length of incarceration, such disclosure was not consistent across all 20 interviews. Future research may want to consider using an anonymous demographic questionnaire to ensure this data is consistently collected across all interviews.

One last limitation could be that these interviews were self-report in nature, which might bring the trustworthiness of the data into question. However, I took several steps in order to increase the rigour of the study. One method I used was to involve a critical friend as I completed the data analysis. I turned to a colleague who worked in the prison system when I had questions about terminology or at other points in the analysis when I was stuck. Additionally, I took my time through the analysis of data. Finally, when I was unsure of the process I spoke with my supervisor and sometimes other faculty members to increase my understanding of how I was analyzing the data in order for me to stay on track. Having a critical friend, taking my time with the analysis, and reaching out to faculty members to talk through my analysis, allowed the data collected in this study to be trustworthy.

### 5.2 Future Research Directions

Throughout the course of the interviews many of the participants mentioned issues for which I lacked sufficient time to thoroughly probe and discuss. This has led to unanswered
questions and topics that may be of interest for future research projects. One of these questions relates to those HIV positive individuals that are incarcerated for HIV non-disclosure laws. Potential future research could investigate how these individuals are received by the general, non-HIV infected inmate population. This type of question could be investigated by way of quantitative survey to get an understanding of the views of a large number of participants. To supplement the quantitative data and to obtain a deeper understanding of the issues, interviews could be conducted with a random sample of survey respondents. Such a study would have the potential to better explain why those incarcerated for HIV non-disclosure in Canada were described in this current study as being stigmatized.

A second topic that came up in the course of discussion was access or the lack of access for transgender identifying inmates to appropriate medical care. Appropriate medical care includes access to medical professional who specialize in hormone therapies and gender re-assignment surgeries, as well as mental health professionals to assist with transitioning. Although I only interviewed one transgender inmate, it was clear through our discussion that this issue not only affected her, but that she spoke on behalf of other transgender inmates at her respective prison and other prisons in Ontario. Perhaps a study to investigate what services are available to transgender inmates and what exactly is lacking at different prisons. This participant mentioned that access to appropriate medical professionals was only available at certain prisons in the Ontario Region. In addition to investigating access to appropriate medical professionals, a study could look into placement of transgender inmates and how gender is defined within the culture of CSC.

A third topic for future investigation is why HIV negative inmates have negative misconceptions about HIV, how it is transmitted, and the individuals that are HIV positive. In
order to attempt to change culture inside Federal Prison it may be helpful to know why there are negative misconceptions around HIV. Having this insight may allow for better developed programs to address HIV-related stigma within this unique population.
Chapter 6

Conclusion

Although the research study answered the research questions and objectives it set out with, the study left me with questions. I believe that CSC is making strides to address false beliefs surrounding HIV within their inmate population and with their staff. However, in saying that I think there are areas for improvement. The frequency of reports of enacted and internalized stigma are cause for concern because HIV-positive inmates are not seen as a worthy identity to the inmate population or to the HIV-positive inmate themselves. Accessibility of mental health supports for HIV-positive inmates seems to be limited as the participants rarely spoke of mental health supports located in the prisons. Although prevention and improved harm reduction programs need to be implemented in order to deal with the increased prevalence rates of blood borne infections in Federal Penitentiaries, it may not be the most important need. The need to empower not just HIV-positive inmates, but all inmates to become ready for re-integration into society is, in my opinion the most important. Without empowerment, recidivism will continue to occur. This empowerment can relate to working with inmates who experience previous traumas to assist them in coping with those traumas. The theme of childhood trauma(s) was common, with the majority of interviewees reporting experiencing multiple traumas before beginning drug use, prostitution, and eventually incarceration. CSC has made strides to improve testing and access to healthcare through their public health strategy, however this is just the start and work must be done to create a more educated, understanding environment for inmates who may have a stigmatized identity, such as being HIV-positive.
Afterword

As I finish writing my manuscript and begin preparing for thesis defense, I have taken some time to reflect on this project and what it means to me. The project was anything but easy to complete. There were many times that I did not believe that the project would be approved by Queen’s University Ethics, and the Research Boards of CSC. There were many days after conducting interviews and listening to often times heart-breaking stories from the participants that I worried about how I would successfully write those stories in the hopes of affecting change. Now as I write this reflection, I have concluded that there is an immense amount of research and work left to do on this project. This project is preliminary in the sense that it was meant to provide some understanding into the current state of Canadian Federal Penitentiaries for HIV-positive males. Whether that work is done by me or by someone else, what is clear is that more needs to be done. The stories that I have heard over 20 interviews have inspired me to want to continue working in this field. Whether that be in research, pursuing further education, or beginning work in the HIV field or correctional field, or simply volunteering in the field should life take me down a different employment path, I believe I will continue to be involved in this work. I sincerely hope that someone picks up this research manuscript and develops programs to combat research, completes evaluations of current offerings, or investigates new research questions that this project has uncovered. I believe it is essential to keep working, and that is what I will do after I successfully finish this degree. It has been a privilege to hear and write these experiences and I am forever grateful to the participants for allowing me to do so.
References


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Appendix A

Interview Guide: HIV Positive Incarcerated Participants

The interviewer will make a note of what institution each participant is from, only for quantitative purposes. No identifying information will be collected such as name or inmate number. Age will be collected and then reported as an age-range. This will help describe the population being interviewed.

1. Could you tell me a little bit about yourself? (looking to build a sense of trust and rapport)
2. What is your age?
3. When were you told you have HIV? (looking for: a timeperiod/year/age)
4. Where were you told you have HIV? (community or CSC)
5. Let’s talk a bit about your life before your diagnosis.
   a. Were you afraid of getting HIV?
   b. Did you think you were at risk of getting it?
6. Tell me about how you were told you have HIV.
   a. What did the provider say?
   b. How did you feel?
   c. What is the best way to tell someone they have HIV?
7. How has HIV affected your life
   a. in prison?
   b. in the community? (if applicable)
8. Have you ever been afraid to tell someone that you have HIV?
   a. If yes, why?
   b. If yes, is there something that can be done to make you feel safer?
   c. If no, why?
9. Have you told anyone that you have HIV?
   a. If yes, how did they react?
   b. If yes, how did you feel?
10. Have you at any point felt that you were discriminated against in CSC for having HIV?
    a. If yes, how were you discriminated against?
11. CSC has a number of programs in place to prevent HIV, including screening and testing, counselling, substance abuse programs, methadone, harm reduction, and treatment.
    a. Have these been helpful to you?
    b. Do you think they are working to help prevent HIV and other infections like hepatitis C?
    c. Did you feel that they played a role in reinforcing stigma associated with HIV in CSC?
12. Do you have any suggestions on how to improve the information offered to HIV positive inmates in CSC?
13. Lastly, do you have anything else to mention about your experience living with HIV while in prison that would be important to know?
Appendix B

Interview Guide: PEC Workers

The interviewer will not report what institution each PEC worker participant is from, so the participant will not be identifiable. No identifying information will be collected such as name or inmate number.

1. Could you tell me a little bit about yourself? (Looking to build rapport and trust)
2. Could you please describe what your role as a PEC worker is? (looking for background and training)
3. Have you received any specific training on HIV?
   a. If yes, could you please describe that training?
4. Do inmates come to you with questions about HIV?
   a. If yes, what questions?
   b. If yes, did you feel like you were prepared to answer them appropriately?
5. How did you perceive risk of HIV before becoming a PEC worker?
   a. How do you perceive risk of HIV now, as a PEC worker?
6. How do you believe an HIV positive inmate is perceived by their fellow inmates?
   a. What makes you believe this? (based on what their response to 5 is)
   b. Have you ever seen acts of discrimination against HIV positive inmates?
   c. If yes, what did you see?
7. Has anyone told you that they have HIV?
   a. If yes, how did you react?
   b. If yes, how did you feel?
   c. Describe the experience overall?
8. CSC has a number of programs in place to prevent HIV, including screening and testing, counselling, substance abuse programs, methadone, harm reduction, and treatment.
   a. What is your opinion of these programs? Do they work?
   b. If yes, why?
   c. If no, why not?
9. Do you have any suggestions on how to improve the information offered to HIV positive inmates in CSC?
10. Lastly, do you have anything else that you would like to mention about HIV in prison that you think would be important to know?
Appendix C

Interview Guide: Formerly Incarcerated HIV Positive Participants

No identifying information will be collected such as name. Age will be collected and then reported as an age-range. This will help describe the population being interviewed.

1. Could you tell me a little bit about yourself? (looking to build a sense of trust and rapport) (prompt: How old are you?)
2. Could you tell me about your prison sentences?
   a. Where in CSC have you been incarcerated?
   b. How long have your sentences been?
   c. How long has it been since your release?
3. Tell me what it was like being told you have HIV? Prompts:
   a. When were you told you have HIV? (looking for: a timeperiod/year/age)
   b. Where were you told you have HIV?  (community or CSC)
4. Tell me about how you were told you have HIV.
   a. What did the provider say?
   b. Do you wish anything was different about the experience of being told you were HIV positive?
      i. If so, what?
      ii. If not, why not?
5. Let’s talk a bit about your life before your diagnosis.
   a. Were you afraid of getting HIV?
   b. Did you think you were at risk of getting it?
   c. What did you know about HIV before diagnosis?
   d. What information, if any, did you have?
6. What is it like having HIV in prison? How has your diagnosis affected your life
   a. In prison?
   b. In the community?
   c. Are there any big differences between being HIV positive in prison compared to the community?
      i. If so, why?
      ii. If not, why not?
7. What has it been like telling other people you have HIV? Are there some people you don’t want to know about your HIV? Have you ever been afraid to tell someone that you have HIV?
   a. If yes, why?
   b. If yes, is there something that can done to make you feel safer?
   c. If no, why?
d. Are there any differences between telling someone you are HIV positive in prison vs. someone in the community?
e. Why have you disclosed?
f. Why haven’t you disclosed your status?
8. Have you told anyone that you have HIV?
   a. If yes, how did they react?
   b. If yes, how did you feel?
   c. Were you afraid of telling that person?
      i. Why or why not?
9. When you were in the community were you ever discriminated against for having HIV? Did you ever worry about being discriminated against for having HIV?
   a. If yes, why?
   b. If no, why not?
   c. What happened? What did you experience?
   d. What about in prison? Have you ever been discriminated against for having HIV? Do you worry about being discriminated against for having HIV?
   e. If yes, why?
   f. If no, why not?
   g. What happened? What did you experience?
10. CSC has a number of programs in place to prevent HIV, including screening and testing, counselling, substance abuse programs, methadone, harm reduction, and treatment.
   a. Do you think inmates are aware of these programs? Do many inmates use them? Have you used any of them? Which ones? Have they been helpful to you? How could they be better?
   b. If you have used these programs, would you use them again?
      i. Why or why not?
   c. What does CSC do well in these programs? What are the good aspects?
   d. Have you ever found any of the programs offered at CSC to be stigmatizing or discriminating around HIV?
      i. If so, why? What could be improved?
      ii. If not, why? What is good about them?
11. What suggestions do you have about how to improve the information and services offered to HIV positive inmates in CSC?
   a. Testing?
   b. Counselling?
   c. Treatment?
   d. Release into community?
12. Lastly, What would you recommend to make life better for people living with HIV/AIDS in prison?
Appendix D

Interview Guide: Formerly Incarcerated HIV Negative Participants

The interviewer will make a note of what institution each participant is from, only for quantitative purposes. No identifying information will be collected such as name or inmate number. Age will be collected and then reported as an age-range. This will help describe the population being interviewed.

1. Could you tell me a little bit about yourself? (looking to build a sense of trust and rapport) (prompt: How old are you?)

2. Could you tell me a bit about your time in prison?
   a. What CSC institutions have you been incarcerated in?
   b. How long have your prison sentences at CSC been?
   c. How long has it been since you’ve been released?

3. Let’s talk a bit about HIV in general.
   a. Have you ever been afraid of getting HIV?
   b. Do you think you have ever been at risk of contracting HIV?
   c. What do you know about HIV?
   d. Have you ever received any information about HIV while incarcerated?
   e. What information, if any, did you receive?
   f. In prison, what would you say is the general perception of HIV?
      i. Why or why not?

4. What is it like being in prison?
   a. What is the general prison culture?
   b. If you have been in different security levels, does prison culture change?

5. Has anyone ever told you that they are HIV positive?
   a. If yes, how did you react?
   b. If yes, how did you feel?
   c. If yes, where did this disclosure occur?
      i. Prison or the community?
      ii. Could you talk about the experience in general?

6. When you were in prison did you ever experience (see, hear, be a part of) anything that was discriminating against an HIV positive inmate?
   a. If yes, why?
   b. If no, why not?
   c. What happened? What did you experience?
   d. In prison, what do you believe in the general perception of HIV positive inmates and HIV in general? (looking to see if it is associated with any other types of stigmatized traits [injection drug use or men who have sex with men])
e. What about in the community? Have you ever experience any type of discrimination towards an HIV positive person?

f. If yes, why?

g. If no, why not?

h. What happened? What did you experience?

7. CSC has a number of programs in place to prevent HIV, including screening and testing, counselling, substance abuse programs, methadone, harm reduction, and treatment.

a. Do you think inmates are aware of these programs? Do many inmates use them? Have you used any of them? Which ones? Have they been helpful to you? How could they be better?

b. If you have used these programs, would you use them again?
   i. Why or why not?

c. What does CSC do well in these programs? What are the good aspects?

d. Have you ever found any of the programs offered at CSC to be stigmatizing or discriminating around HIV?
   i. If so, why? What could be improved?
   ii. If not, why? What is good about them?

e. Do you think these programs are effective in preventing the spread of HIV, Hepatitis C or STI’s?
   i. If yes, why? (experiences?)
   ii. If no, why not?

8. What suggestions do you have about how to improve the information and services offered to HIV positive inmates in CSC?

9. What would you recommend to make life better for people living with HIV/AIDS in prison?
Appendix E
Queen’s University GREB Approval Letters

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Kingston, ON, K7L 3N6

GREF Ref #: GSKHS-221-16
Title: ‘GSKHS-221-16 Human Immunodeficiency Virus (HIV) and Stigma among Male Inmates in Canadian Federal Penitentiaries: A Snapshot of the Ontario Region’

Dear Ms. Gushulak,

The General Research Ethics Board (GREB), by means of a Full Board review, has cleared your proposal entitled "GSKHS-221-16 Human Immunodeficiency Virus (HIV) and Stigma among Male Inmates in Canadian Federal Penitentiaries: A Snapshot of the Ontario Region" for ethical compliance with the Tri-Council Guidelines (TCPS 2 (2014)) and Queen’s ethics policies. In accordance with the Tri-Council Guidelines (Article 6.14) and GREB’s Standard Operating Procedures (405.001), your project has been cleared for one year. At the end of each year, the GREB will ask if your project has been completed and if not, what changes have occurred or will occur in the next year.

You are reminded of your obligation to advise the GREB of any adverse event(s) that occur during this one year period (access this form by signing at http://www.queensu.ca/traq/signon.html; click on “Events”; under “Create New Event” click on “General Research Ethics Board Adverse Event Form”). An adverse event includes, but is not limited to, a complaint, a change or unexpected event that alters the level of risk for the researcher or participants or situation that requires a substantial change in approach to a participant(s). You are also advised that all adverse events must be reported to the GREB within 48 hours.

You are also reminded that all changes that might affect human participants must be cleared by the GREB. For example, you must report changes to the level of risk, participant characteristics, and implementation of new procedures. To submit an amendment form, access the application by signing at http://www.queensu.ca/traq/signon.html; click on “Events”; under “Create New Event” click on “General Research Ethics Board Request for Amendment of Approved Studies”. Once submitted, these changes will automatically be sent to the Ethics Coordinator, Ms. Gall Irving, at the Office of Research Services for further review and clearance by the GREB or GREB Chair.

On behalf of the General Research Ethics Board, I wish you continued success in your research.

Yours sincerely,

John O. Freeman, Ph.D.
Ms. Riesne Gushulak
Master’s Student
School of Kinesiology and Health Studies
Queen’s University
28 Division Street
Kingston, ON, K7L 3N6

Dear Ms. Gushulak:

RE: Amendment for your study entitled: GSKHS-221-16 Human Immunodeficiency Virus (HIV) and Stigma among Male Inmates in Canadian Federal Penitentiaries: A Snapshot of the Ontario Region; TRAQ # 6017643

Thank you for submitting your amendment requesting the following changes:

1) To change the title to: “Human Immunodeficiency Virus (HIV) and the Lived Experience of Male Inmates in Canadian Federal Penitentiaries: A Snapshot of the Ontario Region”;

2) For the Principal Investigator to use her first name, as opposed to a pseudonym, during data collection;

3) Revised Recruitment E-mail (v. 2016/09/30);

4) Revised Verbal Script Debriefing – Inmate Participants (v. 2016/09/30);

5) Revised Verbal Consent Script – PEC (v. 2016/09/30);

6) Revised Verbal Consent Script – Inmates (v. 2016/09/30);

7) Revised Verbal Letter of Information – Inmates (v. 2016/09/30);


By this letter you have ethics approval for these changes, and the file has been updated accordingly.

Good luck with your research.

Sincerely,

[Signature]

John Freeman, Ph.D.
Chair
General Research Ethics Board

c.: Dr. Stevenson Fergus, Supervisor
Ms. Rianna Guzmans 
Master's Student 
School of Kinesiology and Health Studies 
Queen's University 
28 Division Street 
Kingston, ON, K7L 3N6

GREB Ref #: GSKHS-233-16; TRAQ # 6019128 

Title: "GSKHS-233-16 Human Immunodeficiency Virus (HIV) and Stigma: A Descriptive Study of Recently Released Canadian Federal Penitentiary Inmates"

Dear Ms. Guzmans,

The General Research Ethics Board (GREB), by means of a delegated board review, has cleared your proposal entitled "GSKHS-233-16 Human Immunodeficiency Virus (HIV) and Stigma: A Descriptive Study of Recently Released Canadian Federal Penitentiary Inmates" for ethical compliance with the Tri-Council Guidelines (TCPS 2 (2014)) and Queen's ethics policies. In accordance with the Tri-Council Guidelines (Article 6.14) and Standard Operating Procedures (SOP) (65.001), your project has been cleared for one year. You are reminded of your obligation to submit an annual renewal form prior to the annual renewal due date (access this form at http://www.queensu.ca/traq/signon.html; click on "Events"; under "Create New Event" click on "General Research Ethics Board Annual Renewal/Closure Form for Cleared Studies"). Please note that when your research project is completed, you need to submit an Annual Renewal/Closure Form in Romeo/traq indicating that the project is 'completed' so that the file can be closed. This should be submitted at the time of completion; there is no need to wait until the annual renewal due date.

You are reminded of your obligation to advise the GREB of any adverse event(s) that occur during this one year period (access this form at http://www.queensu.ca/traq/signon.html; click on "Events"; under "Create New Event" click on "General Research Ethics Board Adverse Event Form"). An adverse event includes, but is not limited to, a complaint, a change or unexpected event that alters the level of risk for the researcher or participants or situation that requires a substantial change in approach to a participant(s). You are also advised that all adverse events must be reported to the GREB within 48 hours.

You are also reminded that all changes that might affect human participants must be cleared by the GREB. For example, you must report changes to the level of risk, participant characteristics, and implementation of new procedures. To submit an amendment form, access the application by at http://www.queensu.ca/traq/signon.html; click on "Events"; under "Create New Event" click on "General Research Ethics Board Request for the Amendment of Approved Studies". Once submitted, these changes will automatically be sent to the Ethics Coordinator, Ms. Gail Irving, at the Office of Research Services for further review and clearance by the GREB or GREB Chair.

On behalf of the General Research Ethics Board, I wish you continued success in your research.

Sincerely,

John Freeman, Ph.D.
Appendix F

Recruitment Poster: Formerly Incarcerated Participants

Human Immunodeficiency Virus (HIV) and Stigma: A Descriptive Study of Recently Released Canadian Federal Penitentiary Inmates

Research study to explore HIV-related stigma. The study will require you to complete a 60-minute audio-recorded interview. To participate in the study you must answer YES to the questions below:

1. Have you ever been incarcerated in a Correctional Service of Canada (CSC) institution?

2. Have you been released within the past 5 years (2011)?

If so and you are interested in helping to potentially inform future CSC policies, please contact Rianne at rianne@queensstudy2017@gmail.com.

For your time, you will receive a $20 Tim Hortons Gift Card!
Appendix G

Recruitment Script: Formerly Incarcerated Participants

To whom it may concern (several different social service organizations in Kingston),

My name is Rieanne Gushulak and I am a Master’s of Science student specializing in Health Promotion at Queen’s University under the supervision of Dr. Stevenson Fergus in the School of Kinesiology and Health Studies. I am writing to inform your organization, that I will be conducting research with formerly incarcerated men, focused on investigating stigma associated with HIV inside and outside of the Canadian Federal Correctional System. The research will involve a 60 minute in-person, audio-recorded interview to discover experiences of stigma inside federal penitentiaries and in the community.

To be eligible for the study, a potential participant must have been incarcerated in a Canadian Federal Penitentiary, and not have been released more than five years ago. I am looking for HIV positive participants, as well as HIV negative or undisclosed participants, as I am looking for multiple view points on the topic. I am looking to interview approximately 20 participants.

I am asking if your organization would be willing to post a poster, or send a Facebook status or Tweet advertising this study to your clientele or informing clients of the study when meeting with them.

If this is possible please let me know. I have attached to this email a copy of the research poster, and also a copy of an example of a Facebook update that could be posted. All questions can be forwarded to myself, Rieanne Gushulak, at either my email qustudy2017@queensu.ca.

Thank you for assisting in this research study,

Looking forward to hearing from you,

Rieanne Gushulak
MSc. Candidate 2017
Health Promotion
School of Kinesiology and Health Studies
Queen’s University
Appendix H

Letters of Information and Informed Consent

Verbal Script Letter of Information for Inmate Participants

“Human Immunodeficiency Virus (HIV) and the Lived Experience of Male Inmates in Canadian Federal Penitentiaries: A Snapshot of the Ontario Region”

Background
The purpose of this research is to explore issues related to stigma among those living with HIV in CSC. This means we will explore how your HIV status may have affected your life, in and out of prison, and if you at any time felt discriminated against. We hope the results of this study will help CSC to create and/or maintain a safe and accepting environment for HIV positive inmates. Do you have any questions about this?

Methods
This study requires an in-person interview with the researcher. It will take roughly 60 minutes, will be held in health care, and will be audio-recorded with your approval. The interview will take place at a convenient time for you and the researcher. Do you have any questions about this?

Risks
There is some risk that you will feel uncomfortable answering questions of a personal nature. There is some social risk with this study, as your HIV status may be known through your participation in this study. The researcher has gone to great lengths to keep your HIV status unknown, by scheduling this interview as a medical appointment in the health services department. If you experience stress during or as a result to this interview, please go to health services and speak with a nurse. Do you have any questions about this?

Benefits
This study may not have immediate benefits. The hope is that it may inform CSC future policies and programs regarding HIV prevention, HIV treatment and HIV counselling. Do you have any questions about this?

Participation
Your involvement in this interview is voluntary. Please answer the interview questions as honestly as possible. However, you may choose to not answer any questions and you may withdraw from the study at any time during the interview by telling the interviewer that you do not want to continue with the interview. If you withdraw, the interviewer will delete the audio file before you leave the room. Withdrawal from the study is not possible after the interview ends. In order to participate you must consent to the interview being audio-recorded. Do you have any questions about this?

Confidentiality
Your interview will be kept private; your name will not be collected. The consent form will not contain your name. All forms and tapes will be stored in a locked desk, in a locked room. The findings may be published in a report, professional journal, or presented at conferences, but any direct quotes used will not allow you to be identified. Should you be interested, you can request a copy of the findings. Do you have any questions about this?

If you have any questions or concerns about study participation they may be directed towards the Chair of the General Research Ethics Board by mail at the following address: Chair, General Research Ethics Board, Queen’s University, Fleming Hall-Jemmett Wing, 78 Fifth Field Company Lane, Kingston, ON, K7L 3N6.

Again, thank you. Your interest in participating in this research study is greatly appreciated. This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and Queen’s policies.
Verbal Script Consent Form- Inmates

“Human Immunodeficiency Virus (HIV) and the Lived Experience of Male Inmates in Canadian Federal Penitentiaries: A Snapshot of the Ontario Region”

1. You have been read the letter of information, and have had any questions answered.
2. To participate in the study, you will be asked to complete an in-person, audio-recorded interview and answer the questions honestly.
3. Your participation in this study is voluntary. You may withdraw at any time during the interview, but not after the interview is completed. Every effort will be made to maintain my privacy now and in the future. Only Queen’s University researchers will have access to the interviews. The data may also be published in a report, journal or presented at a conference, but any quotes will not be able to identify you. You are allowed a copy of the findings.
4. If you have any questions, concerns, or complaints, you may contact the Chair of the General Research Ethics Board at Queen’s University by mail at the following address: Chair, General Research Ethics Board, Queen’s University, Fleming Hall-Jemmett Wing, 78 Fifth Field Company Lane, Kingston, ON, K7L 3N6. I will provide you this contact information again, after the interview.

You have read the above statements and freely consent to participate in this research:

Verbal Consent Given: ___________________________ Date:__________________
Verbal Script Letter of Information for Peer Education Course Workers (PEC)

“Human Immunodeficiency Virus (HIV) and Stigma among Male Inmates in Canadian Federal Penitentiaries: A Snapshot of the Ontario Region”

Background
The purpose of this research is to explore issues related to stigma among those living with HIV in CSC. This means we will explore how being HIV positive may affect the lives of HIV positive inmates, and if you at any time have seen an inmate discriminated against based on their HIV status. We hope the results of this study will help CSC to create and/or maintain a safe and accepting environment for HIV positive inmates. Do you have any questions about this?

Methods
This study requires an in-person interview with the researcher. It will take roughly 45 minutes, and will be audio-recorded with your approval. The interview will take place at a convenient time for you and the researcher. Do you have any questions about this?

Risks
There is some risk that you will feel uncomfortable answering questions of a personal nature. If you experience stress during or as a result to this interview, please go to health services and speak with a nurse. Do you have any questions about this?

Benefits
This study may not have immediate benefits. The hope is that it may inform CSC future policies and programs regarding HIV prevention, HIV treatment and HIV counselling. Do you have questions about this?

Participation
Your involvement in this interview is voluntary. Please answer the interview questions as honestly as possible. However, you may choose to not answer any questions and you may withdraw from the study at any time during the interview by telling the interviewer that you do not want to continue with the interview. If you withdraw, the interviewer will delete the audio file before you leave the room. Withdrawal from the study is not possible after the interview ends. In order to participate you must consent to the interview being audio-recorded. Do you have questions about this?

Confidentiality
Your interview will be kept private; your name will not be collected. The consent form will not contain your name. All forms and tapes will be stored in a locked desk, in a locked room. The findings may be published in a report, professional journal, or presented at conferences, but any direct quotes used will not allow you to be identified. Should you be interested, you can request a copy of the findings. Do you have questions about this?

If you have any questions or concerns about study participation they may be directed towards
the Chair of the General Research Ethics Board by mail at the following address: Chair, General Research Ethics Board, Queen’s University, Fleming Hall-Jemmett Wing, 78 Fifth Field Company Lane, Kingston, ON, K7L 3N6.

Again, thank you. Your interest in participating in this research study is greatly appreciated. This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and Queen’s policies.
Verbal Script Consent Form- Peer Education Course Workers (PEC)

“Human Immunodeficiency Virus (HIV) and Stigma among Male Inmates in Canadian Federal Penitentiaries: A Snapshot of the Ontario Region”

1. You have been read the letter of information, and have had any questions answered.
2. To participate in the study you will be asked to complete an in-person, audio-recorded interview and answer the questions honestly.
3. Your participation in this study is voluntary. You may withdraw at any time during the interview, but not after the interview is completed. Every effort will be made to maintain my privacy now and in the future. Only Queen’s University researchers will have access to the interviews. The data may also be published in a report, journal or presented at a conference, but any quotes will not be able to identify you. You are allowed a copy of the findings.
4. If you have any questions, concerns, or complaints, you may contact the Chair of the General Research Ethics Board at Queen’s University by mail at the following address: Chair, General Research Ethics Board, Queen’s University, Fleming Hall-Jemmett Wing, 78 Fifth Field Company Lane, Kingston, ON, K7L 3N6. I will give you this contact information again after the interview is completed.

You have been read the above statements and freely consent to participate in this research:

Verbal Consent Given: ___________________________ Date:__________________
Letter of Information

“Human Immunodeficiency Virus (HIV) and Stigma: A Descriptive Study of Recently Released Canadian Federal Penitentiary Inmates”

Background
The purpose of this research is to explore issues related to stigma among those living with HIV in CSC. This means we will explore how your HIV status (positive or negative) may have affected your life, in and out of prison, and if you at any time felt discriminated against. We hope the results of this study will help CSC to create and/or maintain a safe and accepting environment for HIV positive inmates.

Methods
This study requires an in-person interview with the researcher. It will take roughly 60 minutes, will be held in a convenient place for both you and the researcher, and will be audio-recorded with your approval. The interview will take place at a convenient time for you and the researcher.

Risks
There is some risk that you will feel uncomfortable answering questions of a personal nature. There is some social risk with this study, as your HIV status may be known through your participation in this study. The researcher has gone to great lengths to keep your HIV status unknown, by scheduling this interview in a location that is private. If you experience stress during or as a result to this interview, please contact one of the mental health service providers from the counselling services sheet that you will be given by the interviewer.

Benefits
This study may not have immediate benefits. The hope is that it may inform CSC future policies and programs regarding HIV prevention, HIV treatment and HIV counselling.

Participation
Your involvement in this interview is voluntary. Please answer the interview questions as honestly as possible. However, you may choose to not answer any questions and you may withdraw from the study at any time during the interview by telling the interviewer that you do not want to continue with the interview. If you withdraw, the interviewer will delete the audio file before you leave the room. Withdrawal from the study is not possible after the interview ends. In order to participate you must consent to the interview being audio-recorded

Confidentiality
Your interview will be kept private; your name will not be collected. The consent form will not contain your name. All forms and tapes will be stored in a locked desk, in a locked room. The findings may be published in a report, professional journal, or presented at conferences, but any direct quotes used will not allow you to be identified. Should you be interested, you can request a copy of the findings.
If you have any questions or concerns or comments you may contact Master’s student Rieanne Gushulak at 1gr2@queensu.ca or project supervisor Dr. Stevenson Fergus at ferguss@queensu.ca or by calling 613-533-6000 x78656. If you have any ethical concerns about this research please contact the Chair of the General Research Ethics Board by phone at 613-533-6081.

Again, thank you. Your interest in participating in this research study is greatly appreciated. This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and Queen’s policies.
Consent Form

“Human Immunodeficiency Virus (HIV) and Stigma among Male Inmates: A Description from Released Canadian Federal Penitentiary Inmates”

Name (please print clearly): _________________________________

1. I have read the letter of information, and any and all question have been answered to my satisfaction.

2. I understand that by consenting to participate in the study “Human Immunodeficiency Virus (HIV) and Stigma: A Descriptive Study of Recently Released Canadian Federal Penitentiary Inmates”, that I will be required to participate in an in-person interview and answer honestly to the best of my abilities.

3. I understand that my participation in this study is voluntary and I may withdraw at any time. I understand that every effort will be made to maintain the confidentiality of the data now and in the future. Only experimenters named Rieanne Gushulak, and Dr. Stevenson Fergus will have access to the data collected from the interviews. This data will be managed securely under lock and key for five years, as is standard in the QUFA collective agreement. No access to the hard copies of the data to anyone except the researchers. The data may also be published in a response report, professional journals or presented at scientific conferences, but any such presentations will be of general findings and will never breach individual confidentiality. Should you be interested, you are entitled to a copy of the findings.

4. I am aware that if I have any questions, concerns, or complaints, I may contact Graduate Student, Rieanne Gushulak at 1gr2@queensu.ca; project supervisor, Dr. Stevenson Fergus at (613- 533-6000 x78656); ferguss@queensu.ca, or the Chair of the General Research Ethics Board (613-533-6081) at Queen’s University.

I have read the above statements and freely consent to participate in this research:

Signature: _______________________________ Date: __________________