A Narrative Inquiry into the Experiences of Point-of-Care HIV Testing Alongside People who were Tested while in a Correctional Facility or at a Bathhouse

by

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Abstract

With a call to increase the accessibility of HIV testing in Canada, point-of-care testing for HIV is being readily adopted. The World Health Organization (WHO, 2012) outlines the importance of protecting the human rights of those being tested through ensuring: informed consent, confidentiality, access to counselling, correct test results, and a connection to care. Little attention has been paid to the experiences of people being tested through HIV point-of-care (POC). Some testing environments, such as bathhouses and correctional facilities, promote testing for HIV among higher-risk groups. In this narrative inquiry study I explored the experience of people testing positive for HIV through point-of-care while at a bathhouse. I engaged with two men, David and Chris, over a period of several months, in two to three conversations between one to almost five hours at a time. The conversations were transcribed verbatim and analyzed for narrative threads. Field notes and observations were also collected and reflections have been incorporated into this study. Three narrative threads for reconsidering practice were identified: a) seeing complexities and understanding testing decisions in relation to time, place, and social context; b) recognizing the impact and significance of secret and silent stories; and c) tentative and tension filled connections to care. It is important to understand testing experiences across time, place, and in diverse social contexts. These experiences are embedded within larger life histories of people that further raise questions about adequate support, follow up and counselling when POC tests are administered in bathhouses. Listening to the experiences of David and Chris has also revealed that health policy and public health practices are shaped by neoliberal discourses.

Preface

This thesis is an original work by Shyla Genoway. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project name “A narrative inquiry into the experiences of point-of-care HIV testing”, No. Pro 00048596, July 28, 2014. Ethical approval was also obtained from The Northern Alberta Clinical Trials and Research Centre (NACTRC). Project name “A narrative inquiry into the experience of point-of-care HIV testing”, No. 25019, October 02, 1024; No. 25020, September 3, 2014; and No. 25021, September 3, 2014.

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Abbreviations

Abbreviation	**Unabbreviated**
AIDS	Acquired Immunodeficiency Syndrome
BBP	Blood Borne Pathogen
CD4	Cluster of Differentiation 4
ED	Emergency Department
HCV	Hepatitis C
HIV	Human Immunodeficiency Virus
IDU	Intravenous Drug Use
MSM	Men who have Sex with Men
NAAT	Nucleic Acid Amplification Test
PHAC	Public Health Agency of Canada
POC	Point-of-Care
STI	Sexually Transmitted Infection
STOP	Seek and Treat for Optimal Prevention
VSP	Vancouver STOP Project
WHO	World Health Organization

CHAPTER 1: INTRODUCTION

Narrative Beginnings

The first point-of-care (POC) test for human immunodeficiency virus (HIV) I ever performed was at a correctional facility in 2011. I was seduced by a technology that showed a preliminary HIV test result within minutes of performing the test. I was excited that more people might learn their HIV test results and I felt that this would be a better and more efficient way of connecting patients to care. I had been provided with training on how to respond to a positive preliminary HIV result and thought I felt comfortable with the procedure. I did feel comfortable with the first few hundred negative POC for HIV tests that I performed - until one day in May, 2012.

I was working for the local Sexually Transmitted Infections clinic (STI). My role was to perform testing, treating, contact tracing, and provide education about STIs and blood borne pathogens (BBPs) to offenders located in provincial correctional facilities in the local area. The day was unfolding like many days before, when into the clinic room walked a very tall, dark haired, heavy set, transgender male to female woman who I will refer to as Jen. She spoke so softly I could barely hear her. She appeared shy but very polite. She avoided eye contact but answered all of my questions very thoroughly. As part of the informed consent I explained that all results were preliminary and would require confirmation by standard testing. I also explained that there was a possibility the results could be incorrect. As with all patients, I drew standard serology first then proceeded to perform the POC HIV test. As I mixed the second chemical into the POC HIV kit I could see a positive result forming. My mind began to race, my heart began to pound, and my hands began to sweat. I added the third chemical, which was a decolourizer so the results appeared more clearly and more clearly a positive result was staring me in the face -

two blue dots. I knew Jen deserved the best care possible and in that moment I found myself very unprepared to provide it. I had to gather myself and gather my thoughts. I gave Jen a container and sent her to the bathroom to collect a urine sample while the POC HIV test kit remained on the table.

When she left the room I frantically called the clinic and spoke to our clinical development nurse. I was so glad he was around to talk to me, calm me, and reassure me. I had given patients HIV positive results in the past but never from a POC test. I had forgotten what to do next. I had roughly two minutes to pull myself together and figure out what I was going to say. Of course there was a possibility that the test results were incorrect but I wondered how likely that was given all of Jen's risk factors. She was a man who had sex with men, she used intravenous drugs, was incarcerated, worked in the sex trade, and checked almost every risk factor box. The phone call with our clinical development nurse ended just as Jen returned to the clinic room. I invited her to sit back down as I explained the results to her. I saw the anxiety, fear, hurt, confusion, and disbelief in her eyes. She remained very quiet. I reinforced that this was not a diagnosis and that standard testing was needed to confirm the results. I tried to provide her with the information that I felt was necessary without overwhelming her.

The tears fell from Jen's eyes even though she fought hard to hold them back. My mind raced again. How could I send her to sit in a holding tank while waiting to return to her cell with other people staring at her wondering why she was crying? People would make their own assumptions and her confidentiality would be destroyed. Everyone knew the nature of my nursing. Everyone knew I was the "STI nurse." How could I even think of sending her back to a cell to sit alone, without any supports? What kind of nurse would I be? What kind of person would I be? I invited her to remain with me for as long as she needed but we both knew that the longer she sat with me, the more assumptions would be made by those waiting to see me. Our hands were tied. How could I offer Jen the best support in a facility where “big brother” (security) and other offenders are watching you at all times while not breaching her confidentiality and trust? We decided together that speaking to a psychologist was probably the best option at that time. Jen granted me permission to share her story with one of the psychologists, who, in turn, was able to support Jen in a way that resembled an ordinary psychologist/offender interaction within the jail.

Although on that day I left the jail, Jen never left my mind. I thought about her every day until I saw her again. I thought about the impact of those events on my life and how much more they would have had an impact upon hers. I was able to leave the facility, go camping, and be surrounded by friends. Jen did not have any of those luxuries. She got to sit in a small, concrete cell with no supports and potentially no way to escape her thoughts, even temporarily.

The following Monday, the first thing I did was check for Jen’s results. No luck. They were not back yet. I checked for her results every day, probably twice an hour, until they were finally available. My jaw dropped when I read the negative results. I was overwhelmed with a mix of emotions. I was so happy she was negative as I had a sense about the impact of living with HIV, but I could not help but feel guilty and sad for putting her through this rollercoaster of emotions. I now had to tell her the results of the POC for HIV were incorrect and to explain the barriers of HIV testing and recommend she be retested in three months. All of these feelings came with a great deal of reflection on what kind of person and nurse I was for Jen. Did I provide her with enough support and information? Could I have done more? Could I have done things differently? I believe that this experience will change how Jen sees testing for HIV in the future. Maybe this experience has changed her life for the better, but maybe it has changed it for the worse. I still think of Jen all the time and wonder how she is. I wonder if and/or how her testing experience has affected her life. I would love to speak with her again and see how she is doing. There is an increasing demand for POC HIV testing yet no research has been done on how this experience affects patients and their wellbeing.

Less than three weeks later, I was again completing testing in a correctional facility. Through the clinic door walked a young, vibrant, talkative woman who I will refer to as Sarah. Sarah, too, had multiple risks factors. She was incarcerated, used intravenous drugs, and worked in the sex trade. She was so bubbly and full of life. She answered all of my questions and often provided additional stories. She too consented to POC HIV testing and her big, bright smile soon disappeared.

I remember the gut wrenching déjà vu as the second blue dot appeared in the testing circle indicating a positive result. I wondered whether this could be another false positive. I asked myself what the odds of it being another false positive were. I had learned from the first experience to send the person to the bathroom for a urine sample while the POC HIV test ran through. I was alone in the room when the result became visible. Again I felt my heart rate increase, my mind race, and my palms become sweaty. This time I did not call for support.

When Sarah returned to the room I explained to her the POC HIV results. She began to cry hysterically. She was so upset that she was unable to hear any information I was trying to give her, so instead I just sat quietly and allowed her to cry. It took everything to not cry with her. I felt overwhelmed. As Sarah became increasingly upset she began to struggle to catch her breath. At this point I felt I needed additional supports. A psychiatrist happened to be on site and had agreed to come and talk with Sarah. That turned out to be a mistake. The psychiatrist explained to Sarah that a positive POC HIV test was the same as a pregnancy test as it had to be confirmed by serology. This upset Sarah further as she did not understand how he could have compared an HIV test to a pregnancy test. I have to admit that I agreed with Sarah; they are not the same. Sarah requested to be returned to her cell. I was very concerned for Sarah's wellbeing and I wondered who would support her when she got back to her cell. I arranged for a psychologist to check in with her for the next few days.

As I did with Jen, I checked almost every hour until Sarah's confirmatory results were back. Again, the POC was a false positive. Again I questioned if the rollercoaster of emotions Sarah had just been on was worth the rapid result. When I told Sarah her serology came back negative she hugged me so tight it was hard to breath. She was overcome with a sense of relief. She was also concerned with how her partner would respond to the news as she had already told him that her rapid result was positive. Months later I found out that her partner did not believe Sarah was in fact negative. He thought she was lying to him and in turn terminated their relationship.

Looking back I cannot help but wonder where Jen and Sarah are now. So many questions run through my mind: how has their testing experience changed them? Have they been tested again for HIV since receiving the POC test? Some of my questions also centre on whether the test results have affected their lives overall: How have their stories changed over time as their situations changed and their stories were retold? I too wonder about the impact on my own practice as a nurse: Did I support Sarah and Jen enough throughout the testing experience? What could I have done differently? Was a correctional facility an appropriate place to perform POC testing for HIV? These experiences changed my comfort level with performing POC HIV testing.

Turning towards the Research Puzzle

The purpose of this study was to explore the experience of patients receiving POC HIV testing in public venues, particularly correctional facilities and bathhouses. Correctional facilities and bathhouses are both locations where patients present with higher risk factors. They are also both locations where confidentiality and discretion may be difficult to maintain, yet are no less important. Nurses often provide HIV testing in diverse clinical settings and want to ensure that the least amount of harm occurs to patients. Exploring the experience of testing in unique environments can help direct nursing practice and policies, create supportive environments, and ensure appropriate resources are available for patients, especially those who test preliminarily positive by POC and must await confirmatory results.

Literature Review

The following section provides background information on rates of HIV infection among men who have sex with men (MSM) at bathhouses, general rates and trends of HIV, and rates of incarcerations. This section provides background information on POC testing, the accuracy of POC tests, pre and post- test counseling for HIV, as well as the acceptability of POC as a testing method. I have also included previous research on the experience of testing positive by POC and the effects of misdiagnosis.

Rates of HIV Infection among Men Who Have Sex with Men at Bathhouses

In 2011, more than 60% of new HIV infections in Vancouver, British Columbia were among gay, bisexual, and MSM. This prompted the Vancouver STOP (Seek and Treat for Optimal Prevention) Project to target HIV testing in bathhouses and a variety of other outreach testing sites (Vancouver STOP Project [VSP], 2013). POC testing as well as nucleic acid amplification test (NAAT) testing for HIV was offered to patients of the VSP. The testing project found a 3% HIV- positivity rate (VSP, 2013). Of those who tested positive 64% were 35 years of age or younger and 27% were already eligible for treatment with a cluster of differentiation 4 (CD4) count of less than 500, and 18% had never been tested for HIV before (VSP, 2013). The nurses involved in the VSP indicated that their presence in the bathhouses provided an opportunity to normalize STI/HIV testing and to build relationships with the community and with patrons. There was, however, no mention of how the patrons or community viewed the testing in the bathhouses.

A report by the Centers for Disease Control and Prevention (2013) stated that in 2010, gay, bisexual, and other MSM represented 2% of the population of the United States, yet accounted for 63% of new HIV infections overall. They accounted for 72% of all new infections among persons aged 13–24, and the 13–24 year age group accounted for 30% of new infections among all MSM. At the end of 2010, it was estimated that 56% of all persons living with HIV in the United States were MSM or MSM- IDU.

A study looking at the determinants of recent HIV infections among Seattle - area MSM showed that those who tested HIV positive were more likely to use drugs (particularly methamphetamines) while having unprotected anal intercourse. There was also a strong association between meeting partners at bathhouses or sex clubs and acquiring HIV infection (Thiede et al., 2009). This was consistent with previous studies showing that drug use increased the likelihood of attending bathhouses and consequently engaging in higher risk sexual practices (Binson et al., 2001; Halkitis & Parsons, 2002). Grov and Crow (2012) found that men who used bathhouses as the most common place to meet sexual partners showed a 54% reduction in the odds of having sex while under the influence of drugs or alcohol than men who most commonly used the internet, and 73% reduction in the odds of having sex while under the influence of drugs or alcohol, compared to those whose most common place was bars/clubs, possibly due to the social environment of bars/clubs and the availability of alcohol. The odds of recent sex while under the influence were 2.21% higher in HIV-positive men. As well, a survey completed in Montreal, Quebec from 2008 to 2009 showed 61.2% of MSM surveyed reported being under the influence of drugs or alcohol while engaging in sexual relations with another man in the six months prior to the survey (PHAC, 2011). In that same survey, 42.1% of respondents met a sexual partner at a gay bar, 41.6% at a sauna, and 17.8% at a sex club or a bar with a back room (PHAC, 2011).

HIV Rates and Trends[1]

In 2013, there were 255 new cases of HIV diagnosed in Alberta. This was the third year in a row that the number had increased. Since the start of HIV reporting in Alberta, men continue to have higher rates of infection than women at a ratio of 2.2:1. The age at diagnosis ranges from zero to 64 years, with the highest rates in 25- to 49-year-olds (69.4% of the cases). Edmonton and Calgary accounted for the highest rates of new diagnosis at 8.8 and 6.3 per 100,000 respectively. The provincial rate was 6.3 per 100,000 persons.

Prior to 2003, intravenous drug use (IDU) accounted for the most important risk factor associated with acquiring HIV (Alberta Health, Surveillance and Assessment, 2012) but by 2013 it was the second most important risk factor after men who have sex with men (MSM). In 2013, 50% of all newly infected males reported that they had sex with other men, while IDU among males dropped from a high of 19% in 2005 to a low of 9% in 2013. For females, heterosexual sex with a partner from an endemic country accounted for 54.6% of newly diagnosed infections. IDU infections in females was at a high of 25% in 2005, then dropped to 6% in 2012 and began

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[1] All of the statistical data has been taken from Alberta Health, Surveillance and Assessment, Alberta Government. (2015). *STI and HIV 2013 Annual Report*. Unless otherwise referenced.

trending upward again with 12% reported in 2013. Aboriginal people are disproportionately affected by HIV. Up until 2006, Aboriginal people were the second largest group of known ethnicity to be infected with HIV. After 2006, Black people became the second largest group, while Caucasians continue to represent the largest ethnic group of newly diagnosed HIV cases. In 2013, Aboriginal people represented 19% of newly identified HIV cases, while Black people represented 31%.

Rates of HIV among incarcerated individuals are estimated to be 11 times that of the general population (Calzavara et al., 2007). A 2007 study in select remand facilities in Ontario, Canada between February 2003 and June 2004 was conducted to determine the HIV and Hepatitis C (HCV) prevalence rates and rates of co-infection among remanded offenders (Calzavara et al., 2007). The results showed a 2.1% prevalence rate among males and a 1.8% rate among female offenders (Calzavara et al., 2007). At that time, the estimated Canadian HIV prevalence rate was 0.8% (Calzavara et al., 2007). In 2008, of those serving federal time, it was estimated that 1.72% of offenders were HIV positive; approximately 1.60% of males and 4.71% of females (PHAC, 2012). One can only assume that these rates are higher now, as the rates of incarceration have increased (Dauvergne, 2012).

Rates of Incarceration

In 2010/2011, there was an average of 163,000 adult (18 years and older) offenders in correctional facilities in Canada at any given time (Dauvergne, 2012). Those serving time in the community (usually on probation) accounted for 77%, while those in provincial, territorial, and federal custody accounted for the remaining 23% (Dauvergne, 2012). There were over 332,000 admissions into correctional facilities (Dauvergne, 2012).[2] Of those sentenced to time in

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[2] An admission is counted every time a person in moved throughout the correctional system. For example, from remand to custody or into the community, each move counts as an admission (Dauvergne, 2012).

custody, 89% were males, 62% were single (never been married), and 24% were 25 years old or less (Dauvergne, 2012). A disproportionate number of incarcerated offenders were Aboriginal. Twenty-seven percent (27%) of provincial or territorial offenders were of Aboriginal descent and Aboriginals represented 20% of all federal offenders. That is seven to eight times higher than the proportion of Aboriginal people in Canada's adult population (which is approximately 3%) (Dauvergne, 2012).

Background Information on Point of Care Testing

Rapid or POC HIV testing was first approved by Health Canada in October 2005; the approved test (INSTI HIV1/2 Antibody test, bioLytical Laboratories) is considered a second-generation HIV test and screens for HIV antibodies (PHAC, 2007).[3] Standard testing in Alberta is conducted at the Provincial Laboratory for Public Health (ProvLab) on a serum sample using a fourth-generation HIV test which is more sensitive than second-generation tests. If no HIV antibodies are detected then the test is reported as negative (Alberta Health Services [AHS], 2011). The difference between POC and standard testing occurs if the initial antibody screen is positive. A positive antibody sample is then sent for confirmatory testing using the Western Blot and only then is the result reported to the testing clinician and shared with the patient (Alberta Health and Wellness, 2011). When a POC test is performed, a preliminary positive result is shared with the patient before the results of standard serological testing are available (AHS, 2011). This leaves the patient waiting for days (typically the turnaround time is up to 10 days) with the knowledge that his/her test may be confirmed positive or, alternatively, a false positive.

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[3] Definitions: Rapid refers to HIV results being available within < 30 minutes of testing. Point-of-Care (POC) testing refers to rapid testing done on site with the patient present and not in a designated laboratory.

Accuracy of Rapid HIV Tests

BioLytical Laboratories is the only company who produces and supplies rapid HIV test kits in Canada. They manufacture the INSTI HIV-1/HIV-2 rapid HIV test. Studies completed by bioLytical Laboratories show a sensitivity rate of 99–99.6% and a specificity rate of 99.3–100% (bioLytical Laboratories, 2012). BioLytical Laboratories did not discuss false results in their report. Invalid results were not included when calculating the sensitivity or specificity of the test kits.

A multisite pilot study was conducted across Alberta, Canada, to determine the accuracy of the INSTI HIV-1/HIV-2 test kits from April 2007 to November 2009. The study showed the sensitivity rate was 100% and the specificity rate was 99.9%, with a positive predictive value of 96% and a negative predictive value of 100% (Lee, Plitt, Fenton, Preiksaitis, & Singh, 2010). True POC testing (at the bedside) was not completed as serology was drawn and the rapid test was done at an on-site hospital lab while the standard testing (AxSYM as the initial screen followed by a confirmatory algorithm) was done at the Provincial Laboratory (Lee et al., 2010). One false positive rapid HIV result was noted (Lee et al., 2010). A limitation of both testing methods was the inability to detect acutely seroconverting patients (Lee et al., 2010). This study was unable to comment on patients' responses to rapid HIV testing, as patient response was not part of the study purpose or design. A questionnaire completed by staff showed satisfaction with the rapid testing and reported that true POC testing could enhance clinical practice (Lee et al., 2010).

Pre and Post-test Counseling

Counseling is important for patients having HIV testing. Pre-test counseling provides an opportunity to educate patients about HIV transmission and risk reduction. It also provides an opportunity to discuss test limitations and obtain informed consent. Traditionally, it has been argued that if pre-test counseling and informed consent are not obtained prior to testing it is a violation of Canadian human rights and contradicts the Canadian Charter of Rights and Freedoms (Canadian HIV/AIDS Legal Network, 2007). The WHO outlines that all test providers protect the human rights of those being tested by ensuring that "the 5 C's of good testing practices always apply; informed Consent, Confidentiality, Counselling, Correct test results, and Connection to care" (2012, p. 8). However, recent Canadian guidelines for HIV testing recommend "normalization" of testing with an increased focus on informed consent and less toward more traditional pre- and post- test counselling which has been perceived as a barrier to the provision of testing in the past (PHAC, 2013).

A quantitative study was conducted at the Hassle Free Clinic in Toronto, Ontario to see if patients receiving POC HIV testing as opposed to standard testing were more likely to receive results and post-test counseling (Guenter et al., 2008). The secondary purpose was to see if POC testing would be acceptable to patients and testing counselors, and whether any unforeseen issues arose; 1,468 patients were tested by POC (Guenter et al., 2008). This study concluded that 100% of rapid testers received preliminary results (Guenter et al, 2008.). There were 22 positive preliminary results. Of those, 18 were confirmed positive and four were false positive. Three of the participants with true positive results and one participant with a false positive result did not return to the clinic for confirmatory testing results (Guenter et al., 2008). Four people who were true positives and tested by POC returned for an in-depth interview. This study was not generalizable to the greater population. It is worth noting, however, that stress during the waiting period for confirmatory results was substantial and made manageable by having received compassionate post-test counseling (Guenter et al., 2008). There is no way of knowing what presumptive positive or inconclusive results had on the wellbeing, anxiety levels, or risk factors of those tested by POC who did not return for confirmatory results (Guenter et al., 2008).

Counseling sessions are important when testing by POC as there are fewer sessions, and when appropriate, arrangements need to be made for follow-up sessions. Counselors who are perceived by patients to be competent and confident, and who are sensitive to the emotional needs of the patient can enhance the patient's testing experience, especially when the results are positive (Hult, Maurer, & Moskowitz, 2009). As part of the counselling all risks of testing must be disclosed prior to testing. If nurses are able to foster a relationship of mutual respect, gain the trust of their patients, and provide important and factual information, patients are more likely to return for care (O'Byrne, Holmes & Roy, 2014). Conversation during the counseling period is a way to facilitate this.

Acceptability

Many qualitative and quantitative studies have been conducted to determine the acceptability of POC HIV testing for patients and staff. A cross-sectional study was conducted in an emergency department (ED) in Winnipeg, Manitoba (Becker et al., 2013). Everyone who presented to the ED, who was 18 years of age and older, and self-reported HIV negative were eligible to participate (Becker et al., 2013). Five hundred and one POC HIV tests were completed using the INSTI HIV-1/HIV-2 kit. Ninety-six percent of participants reported satisfaction with POC testing and 93% believed POC testing belonged in the ED. Ninety-six percent also stated that they would be tested by POC again. These results did not differ between those who tested positive and negative (Becker et al., 2013). The POC testing resulted in seven new HIV positive diagnoses, three of which reported no risk factors (Becker et al., 2013). This study shows strong evidence that there is a place in the ED for POC testing and that routine testing should be offered to everyone, not just those who identify risk factors. However, reporting satisfaction or willingness for repeat POC testing does not reveal much about the experience throughout the testing process.

A pilot was conducted to examine attitudes towards HIV testing and preferences for rapid versus standard testing among female patients at an urban primary care setting (Schwandt, Nicolle, & Dunn, 2012). The results showed 81.1% of the 95 participants would prefer rapid testing to standard testing and 53.5% reported they were more likely to be tested for HIV if rapid testing was available (Schwandt et al., 2012). No rapid or POC testing was ever conducted in this study. Patients were given a written paragraph on the testing procedures of rapid and standard HIV testing and asked to fill out a questionnaire while they waited in the waiting room (Schwandt et al., 2012). The information provided did not address the possibilities of false positive testing results or the limitations of testing. Since no actual testing was performed, results relied on what the participants would theoretically do. These findings are not generalizable to the general public and therefore further research would be needed to understand what “acceptability” of POC testing is and the experiences of those being tested by POC.

Patients are not the only ones affected by POC testing. MacPherson and colleagues conducted a very encompassing mixed methods study in 2011. Similar to the Becker and colleagues (2013) study, it showed that POC testing would be beneficial for patients, especially those who are marginalized or at higher risk. It provided evidence to incorporate POC testing into community settings as well as hospital settings (MacPherson et al., 2011). It also provided evidence that test providers supported POC testing and felt it gave them a better opportunity to reach out to patients, provide HIV education, and reach those who are not accessing care (MacPherson et al., 2011). The staff felt better quality assurance and communication with the lab is needed when confirmatory testing is required. It was felt that this period of "diagnostic limbo" had a negative impact upon provider-patient relationships (MacPherson et al., 2011, p. 5). Staff also raised concerns about the stress of having to give rapid HIV results and not feeling confident when dealing with complex cases (MacPherson et al., 2011). Giving POC results is stressful for the test provider. By exploring the experiences of those testing positive by POC in unique settings and how these experiences are situated in the complexities of the patients' lives, test providers can more accurately assess the needs of the patients as well as the training requirements of the test provider.

Experiences of Being Diagnosed with HIV and the Effects of Misdiagnosis

There is evidence that depression, anxiety, and fears are often felt upon initial diagnosis of HIV (Flowers, McGregor, Larkin, Church, & Marriott, 2011; Hult et al., 2009; Martinez, Lemos, & Hosek, 2012; Morrison et al., 2011). All of these authors showed in their studies that anxiety and depression decreased over time followed by an increase in adjustment and assimilation. Bhattacharya, Barton, and Catalan (2008) found that a misdiagnosis of HIV-positive resulted in stress associated with readjustment and psychiatric morbidities such as depression, anxiety, and panic attacks. The misdiagnoses in this study all occurred prior to 1996 and participants lived for years believing they were HIV positive before finding out they were actually negative. However, studies with women who have received false positive mammography results also show increased anxiety and depression (Hafslund, Espehaug, & Nortvedt, 2012; Olsson, Armelius, Nordahl, Lenner, & Westman, 1999). Olsson and colleagues found that women with a low educational level, women living in high density urban areas, and women with only one child or no children were especially at high risk of developing long-lasting psychological reactions to false positive mammography results. These are important factors to consider when performing POC testing with higher risk populations as additional supports may be needed to decrease long-lasting psychological effects of POC testing. Without similar studies, it is not valid to generalize these findings to those who test false positive on a rapid HIV test. However, the information obtained from these studies provides insight into the possible psychological effects of POC HIV testing, especially when the immediate result is positive.

Correctional Facilities

A report by Jürgens (2009) stated:

> even as increased funding for the response to HIV has become available, those most vulnerable to HIV and its impact continue to receive the least access to HIV prevention, treatment, care and support. Among them are prisoners, people who use drugs, men who have sex with men, and sex workers. (p. 6)

In 1987, the US federal government mandated that offenders test negative for HIV before being released from federal prisons. Offenders who tested positive were involuntarily detained, even after completing their sentences or meeting eligibility for transfer to a halfway house or transitional supervision programs (Starchild, 1989). This strategy turned out to be of no benefit to offenders who tested HIV positive and was shown to be more likely to destabilize their re-entry into communities and cause harm (Starchild, 1998). While the WHO continues to oppose mandatory testing, many correctional systems worldwide continue to enforce it (WHO, 2009). MacGowan and colleagues (2006) reported that close to a quarter of offenders in a correctional facility with mandatory testing did not report receiving HIV testing. This suggests that they were not made aware that testing was being performed, consent was not obtained, and offenders were not made aware of their results.

In the United States in 2009, 24 state correctional systems required mandatory testing for HIV upon admission or prior to release, with an additional five states moving to adopt a similar policy (Pope, 2009). This is occurring even as many organizations such as American Public Health Association, the National Association of People with AIDS, the American Correctional Health Services Association, and the National Commission on Correctional Health Care take opposition to it (Christensen, 2011).

Confidentiality and fear of its breach, as well as fear of the stigma attached to an HIV diagnosis, remain barriers to testing for HIV, especially in a closed setting (Braithwaite & Arriola, 2003). The most at-risk populations are more susceptible to coercion, discrimination, violence, abandonment, incarceration, and other negative consequences upon disclosure of HIV positive status (WHO, 2009). POC testing for HIV was shown to be of benefit to offenders when four health departments collaborated with jails across the United States in a study conducted between December 2003 and May 2006. Two hundred and sixty-nine (269) previously undiagnosed cases of HIV were identified out of the 33,211 offenders tested by POC. Over 99% of participants received their POC results (MacGowan et al., 2007). This study failed to discuss any supports that were in place or implemented when an offender tested positive, other than confirmatory serological testing by standard techniques being conducted on those who consented to it. The study authors did not mention if counseling services were in place or utilized by those who tested positive and whether community resources and links to care were made available. The WHO recommends that supportive social, policy, and legal environments accompany testing efforts in order to maximize positive outcomes and minimize the potential risks. The WHO also recommends that confidentiality is ensured and that the pros of diagnosis outweigh the cons and adverse social consequences that can be prevented.

South Carolina and Alabama are two states with mandatory testing policies in their correctional systems. When inmates test positive for HIV they are immediately placed in segregation on 23-hour lock-down. When a bed becomes available, they are moved to a maximum security HIV positive designated unit where they are not allowed to participate in activities or socialize with those who are HIV negative. Some institutions require HIV positive inmates to wear visible insignia (an arm band, badge or other visible marker), which leads to the widespread disclosure of their status (Human Rights Watch, 2010). This directly contradicts the WHO recommendations.

While mandatory HIV testing is not currently in place in Canadian correctional systems, policies need to be in place to ensure confidentiality, support, and resources are available for those who test positive for HIV, especially when using POC testing in a correctional facility. If these policies are not in place "it is time for the nursing profession to examine its role with regards to this specific form of testing and to ask how nurses can maintain a therapeutic relationship with prisoners if they actually engage in coercive practices," (Gagnon & Cormier, 2012, p. 152).

As I look back at my experience with Jen and Sarah, I cannot help but think about ways to improve confidentiality. As I have mentioned before, most staff and offenders knew me as the STI nurse, they knew that people saw me for very specific concerns, they knew how long each interaction routinely took, and they would question why someone would leave my clinic room in tears. I remember how Sarah was able to stop crying immediately before leaving the clinic room so that other offenders and staff would not see her tears. This not only shocked me but also made me sad. She was clearly distressed and had to hide her emotions. MacDonald (2006) recommended strong policies be in place to ensure the confidentiality of offenders' medical information, however, correctional facilities are small places with many eyes and ears. Policies about disclosing medical information may only prevent the transmission of information from medical staff to other professionals and offenders; it will not ensure that observations by other professionals and offenders are not being made and conclusions drawn based on experiences.

Bathhouses

A study completed by Grov, Parsons, and Bimbi (2007) examined risk behaviours of MSM as well as venues used by MSM to meet sex partners. Their study focused only on single men or non-monogamous partnerships. They found that of the 886 MSM surveyed, 40.3% reported meeting at least one sexual partner at a bathhouse in the previous three months, while 22.4% reported meeting at least half of their sexual partners in the previous three months at a bathhouse. Of those surveyed, 12.5% reported an HIV positive status with the proportion of those meeting sexual partners at bathhouses being 20.3%. MSM frequenting bathhouses also scored higher than average on the temptation for unsafe sex scale, and 39.2% reported unprotected anal intercourse within the previous three months, just slightly under the survey total in which 39.9% of all MSM surveyed reported recent unprotected anal intercourse. These findings were consistent with Grov and Crow (2012). Similar findings were found by Parsons and Halkitis (2002) that showed that men who met sex partners in commercial sex environments (for example, bathhouses and sex clubs) were more likely to engage in high risk sexual behaviours as compared to those who met partners at private sex environments.

A pilot project that considered the feasibility and field performance of dual use of POC syphilis testing and HIV testing in outreach settings was completed in Edmonton, Alberta (Bergman et al., 2013). Of the 1,183 participants, 635 (50.2%) were incarcerated at the time of testing, 339 (26.8%) were in inpatient addiction treatment facilities, while ten percent (n=126) were in community locations serving MSM. The highest acceptance and consent to POC testing was in the MSM population at the bathhouse site (91.3%), with the second highest being correctional facilities (80.0%). Reasons for declining POC testing were not examined in this study. One out of five men reported a history of same sex sexual contact. There were four newly diagnosed cases of HIV reported throughout the pilot, with three of them being MSM. All four cases reported previous HIV testing. This reinforces the need for regular routine testing. While this pilot highlights the importance of testing and potential POC testing among higher-risk populations in unique settings, it does not delve into the experience of those being tested. It did however highlight the importance of having supports in place.

Bathhouses are often frequented by MSM who wish to remain anonymous (Grov & Crow, 2012). A blogger wrote, “Silence is golden. Easy and quick sexual encounters are the name of the game and no one wants to have their fun spoiled with intimacy, disclaimers or any kind of recognition beyond basic physical need” (Japhet, 2007). Others attend bathhouses because they are “a sure thing” (Elwood, Greene, & Carter, 2003, p. 283). They are also places where men can go to be sexually free and do things that they would not normally do in a different setting (Elwood et al., 2003).

While there are many reasons MSM attend bathhouses, patrons reported a heightened sense of awareness around STIs and HIV as they assumed that anyone who frequented a bathhouse was more sexually liberated, took bigger risks, and had multiple sexual partners (Elwood et al., 2003). Interestingly, while there was an awareness of increased risk, levels of condom use still varied with men reporting an “intention” to use condoms but it not always being the reality (Elwood et al., 2003). Men also reported more willingness to have insertive anal intercourse without a condom verses receptive (Elwood et al., 2003). While men perceived their partners to be high risk, they often underestimated the risk of their own sexual practices (Mayer et al., 2012). The perception of bathhouses was acknowledged in the Elwood and colleagues (2003) study with MSM who frequented bathhouses reporting that bathhouses were often seen as "slutty or trampish" (p. 285) places to be. One patron reported leaving a bathhouse immediately if he saw an acquaintance, as he did not want to be seen as a bathhouse patron. This reinforces the desire for anonymity within the bathhouse. I have not found more recent studies that examined the experience of patients being tested by POC for HIV in bathhouses. It is a sensitive topic. While testing has been conducted for years at a variety of bathhouse locations around the world, it supports my stance that before testing through POC becomes widespread, the implications of testing need to be explored.

The literature shows that the risk of becoming infected with HIV is higher among incarcerated populations and MSM. It also shows that POC testing for HIV has been widely accepted when offered in various locations. Yet there is no literature available on the experience of being tested by POC or the practice implications POC testing may have for test providers. Exploring the experience of testing preliminarily positive by POC at a bathhouse or a correctional facility can provide insight into supports needed by patients and test providers and can shape policy around how POC testing is delivered in unique settings. Narrative inquiry as a research methodology allows for an in-depth exploration of the complexities of experiences and how they are shaped by time, place and social context.

Methodology

Narrative inquiry is more than just storytelling; it is a way of thinking about experience (Clandinin & Caine, 2013; Clandinin, Pushor, & Murray Orr, 2007). The purpose of this research was to gain a better understanding of the experience of patients receiving POC HIV testing. Receiving the actual HIV testing is only one piece of the puzzle. I wanted to know the context in which people received the testing. What was happening in the patients' lives that led them to testing? What was the testing experience like? How have their lives changed or remained unchanged since testing? Narrative inquiry allowed for the intimate and in-depth study of individuals' experiences over time and in the context of temporality, sociality, and place (Clandinin & Caine, 2013). Attending to experiences through these three commonplaces is what distinguishes narrative inquiry from other research methodologies (Clandinin & Huber, 2010).

Narrative inquiry provides no final story or one truth, and insight can be obtained through being open to change (Clandinin & Caine, 2013). Riessman (2000) stated, "Meanings of life events are not fixed or constant, but evolve, influenced by subsequent events" (p. 21). Narrative inquiry has the capacity to consider issues of social justice and equality (Clandinin & Caine, 2013). My goal is to influence policy and the disciplinary knowledge of nurses; especially those who are HIV care providers, particularly at a time of a push within Public Health to increase testing for HIV (PHAC, n. d.; PHAC, 2013).

Ontological and Epistemological Underpinnings

Until the day I met Jen, I was confident in my knowledge of HIV testing and my ability to provide competent care. My reality was turned upside down that day. My experience with Jen changed every experience I have had with POC testing since that day. My experience and story around POC testing changed again when I met Sarah. Narrative inquiry is based on the ontology that experiences are never ending and every experience grows out of a previous experience (Clandinin & Rosiek, 2007). Experiences and stories are ever changing through continuous interaction with personal, social, institutional, and material environments (Clandinin & Rosiek, 2007). "Narrative inquiry is an approach to the study of human lives conceived as a way of honoring lived experiences as a source of important knowledge and understanding" (Clandinin & Rosiek, 2007, p. 42).

Narrative inquiry stems from John Dewey's conception of experience (Clandinin & Rosiek, 2007) and learning through experience and interactions. It begins with experience as the fundamental ontological category from which all inquiry proceeds (Clandinin & Rosiek, 2007). It is from this conception of reality as relational, temporal, and continuous that reality can be known (Clandinin & Rosiek, 2007). I often wonder how Jen and Sarah's realities have shifted since their POC testing experience as they have moved forward in their lives. When I think about them, my mind is filled with questions for which I have no answers. Questions such as how did that experience change their testing story? How did it change their lived reality? Have their reality and story changed as they are storied and restoried again? How different would their testing realities have been if they were tested in the community and not in a correctional facility? A diagnosis of HIV represents an ontological crisis for the self (Flowers et al., 2011). It represents a time of questioning one's reality and his/her place within their new reality. Was my explanation of "preliminary results" enough to avoid this crisis? As I embarked down the path of narrative inquiry, I kept in mind that meaning is tentative and constantly changing. However, this was not a methodological problem to overcome; it was the purpose of the research (Clandinin & Rosiek, 2007).

World travelling

As I entered the testing room with Jen, I entered from my world as a nurse and from a world which could be considered privileged. Jen entered from a different world. She entered from a world of addiction and homelessness, from gender identity and incarceration. I only knew of her world what she told me and I did not share any personal details of my world with her. Our perceptions of each other were groomed by our experiences in the worlds in which each of us lived (Lugones, 1987). I cannot claim to know Jen's world, as I have never experienced it the way she has. I was able to leave the jail and I thought I was able to leave my world as a nurse and travel to my everyday world. I was able to go camping, but all the while I was wondering what was happening in Jen's world. I did not really leave my world as a nurse. I was stuck between worlds. My concern for Jen frequented my thoughts while I carried on with my life outside of my nursing world.

Narrative inquiry allowed me to travel to different worlds without being a *fluent speaker* (Lugones, 1987) in that world. I could be at ease in the world of participants by sharing history and experiences (Lugones, 1987). At one point I felt like a fluent speaker in my own world as a test provider, and now I no longer feel at ease. Jen and Sarah have changed my story and my perspective on POC testing for HIV. Traveling with participants to their worlds enabled me to understand their stories. I travelled with them from a place of loving perception (Lugones, 1987). A loving perception is not one that crosses ethical boundaries, rather one that is open-minded and nonjudgmental. My goal was not to conquer or erase their worlds, but to understand what it is to be in them (Lugones, 1987). I feared being stuck in the nurse world without understanding the world of the patient. At that point the human experience would be lost and my only goal would be to complete a task, yet:

> we are fully dependent on each other for the possibility of being understood and without this understanding we are not intelligible, we do not make sense, we are not solid, visible, integrated; we are lacking. So travelling to each other's "worlds" would enable us to *be* through *loving* each other. (Lugones,1987, p. 8)

Participants

The INSTI HIV1/HIV2 test was first approved in Canada in 2005 (PHAC, 2007). Not all test providers routinely offer HIV POC testing. The target population was anyone who had ever tested positive by POC HIV testing while at a bathhouse or a correctional facility. The inclusion criteria were: English speaking, at least 18 years of age, and tested positive for HIV by POC while incarcerated or attending a bathhouse since 2005, whether or not the results were confirmed positive by serology or confirmed negative. The exclusion criterion was anyone who was known HIV positive at the time HIV POC testing was performed. From personal experience with testing the field performance of the POC syphilis test kits, INSTI HIV1/HIV2 test kits were occasionally performed on those who were known positive. The target population was relatively small and hard to recruit, therefore, a convenience sample was used.

Recruitment was done through staff at the local HIV clinics as well as the STI clinic. This was a way to reach participants who had tested and had been confirmed positive by POC and who were linked to care. The STI clinic staff had already established relationships with patients and was able to inform them of this research. No recruitment occurred within correctional facilities as permission to do so had not been obtained. Posters advertising the study were hung at outreach sites where POC testing was performed (which included a bathhouse) as well as at shelters, and centres with day programing.

Networking was used for recruitment. Potential participants were given my contact information or consented to have their information given to me. Consent was not signed until I had met with each participant in person at our first conversation. At that time each participant was made aware of all elements of the study, including time commitment, confidentiality, expectations, and the purpose of the study. As I was interested in the complexity and depth of the POC testing experience, the goal was to recruit three or four participants, however, recruitment was a challenge and only two participants were recruited. Two potential participants declined being in the study due to the depth of the study itself or not wanting to relive their story. This spoke to me about how secret people's lives are and how vulnerable one can be when sharing stories. It also spoke to the broader social aspects of HIV. To help with retention and to reimburse participants for their time, they were offered a meal and $20.00 cash at every interaction. With recruiting only two participants for the study, I was able to foster my relationship with each participant and spend more time engaging in deep, meaningful conversations.

Field Texts

I met face-to-face with each participant on two or three different occasions for one to five hours each. I met participants at a place of their choice where they were most comfortable, which usually was their own homes. I wanted to maintain the participants' natural setting where they could feel the most comfortable to increase the amount of information sharing (Streubert & Carpenter, 2011).

Conversations are the best way to listen to the experience of a participant (Nunkoosing, 2005). Participants led the conversations while I provided open-ended questions to clarify or get a deeper understanding, while keeping the goal of the research in mind (Streubert & Carpenter, 2011). Some of the important experiences I wanted to ensure were discussed with all participants were: what led you to obtain testing for HIV? Had you ever had HIV testing prior to being tested by POC? What was the testing experience like for you? Would you choose to be tested by POC again or by standard HIV testing only? Fostering relationships of mutual trust and respect increased the disclosure of personal information that may not have been seen as "socially acceptable" (Streubert & Carpenter, 2011). This increased the credibility and rigor of the study (Streubert & Carpenter, 2011). All face-to-face conversations were audiotaped and transcribed verbatim. With each of the two participants, the first conversation began by using annals to give a time line of their life. Annals are a way to organize memories, dates, or events to help narrate personal stories (Clandinin & Connelly, 2000). These annals were added to the field notes collected. This assisted them to tell their story.

Throughout each conversation I collect field notes that included what I heard, saw, thought, assumed, or experienced as well as questions for further inquiry (Streubert & Carpenter, 2011). These notes became part of the data analysis.

From Field to Final Research Texts

All audiotapes were transcribed verbatim. All field notes and annals were included in the data analysis. Moving from field text to interim and final research texts was a complicated process (Clandinin & Caine, 2013). Analysis began on day one of the research study. This is how narrativists learn which stories to keep exploring as well as which ones to clarify (Boje, 2002). Throughout the analysis process, participants were involved in the negotiation of text as they are co-composers in a narrative inquiry (Clandinin & Caine, 2013). Participants were co-composers of their narrative accounts. Composing the narrative accounts provided an opportunity to establish veracity and ensure credibility by giving participants the opportunity to challenge interpretations (Reilly, 2013) and ensure that these accounts reflected their experiences in ways that could be made public. Within these accounts are found poems. Found poems are taken out of transcripts and used to promote individual reflection, added emotion, organization and connectedness (Reilly, 2013). Rechecking with participants for clarity helped the credibility of the study as well as the accuracy of the interpretation (Streubert & Carpenter, 2011).

With the move from field text to interim research text, the participants and I reflected on the research experience and how it related to the initial "puzzle" or research question. This called forth the telling and living of additional experiences and field texts and the retelling and reliving of the research relationship (Clandinin & Caine, 2013). As part of the interim research texts, field texts were read and reread while paying simultaneous attention to the temporality, sociality, and place to move deeper into the meaning of the experiences (Clandinin & Caine, 2013). Attention to these three commonplaces identified disruptions, fragmentations, or silences in the stories (Clandinin & Caine, 2013). I paid attention to the events, times, and spaces in which the stories were told and asked, "What similarities are there? What resonates across all stories? What do they share?" This was done by continuously exploring the three dimensions of place, time, and social context and through the retelling of narrative accounts while looking for any narrative threads that emerged. I did not fracture the biographical account into thematic categories as is done with grounded theory coding, rather I interpreted it as a whole in a sequential order (Riessman, 2007). Focus was on the content of the analysis with minimal account of how it was communicated.

A central element in narrative inquiry is the need for three kinds of justification: the personal, practical, and the social justification (Clandinin et al., 2007). These justifications are demonstrated through attending to the following: first, narrative beginnings, which were completed prior to the study and also again towards the end (Clandinin et al., 2007). I had personal experience with providing HIV POC testing. I had my own assumptions and perceptions of what POC testing might be like for patients. I had seen the relief on the face of a patient who tested negative, the confusion of an invalid result, the grief and fear of a preliminary positive result, and the joy of a false positive result. I know what I felt like as the care provider and the range of emotions that I experienced. I made assumptions of how patients must have felt based on my own feelings. I needed to be aware of my biases before the study began, as well as continue to explore my biases as the study progressed. With narrative inquiry, personal experience and life context of the researcher are encouraged; however, they cannot overpower the meaning behind what the participants are trying to say (Clandinin & Caine, 2013). The personal justification in the autobiographical narrative inquiry outlined why the study was important for me as the researcher (Clandinin et al., 2007). Secondly, the practical justification provided insight into how the research could change my own and others' thoughts and practices (Clandinin et al., 2007). Finally, social justification set out to answer "so what?" and "who cares?" (Clandinin et al., 2007), points I address later in this dissertation.

In the final stages of analysis and written research text, I paid attention to the audience. By making the three commonplaces visible, the audience could see the complexity in the stories and begin to lay their own experiences alongside those of the participants (Clandinin & Caine, 2013). The final research texts were not meant for saturation or final answers, rather to engage the audience to reflect upon their own experiences and practices. Through these final texts the social significance of the work became evident as the questions of "so what?" and "who cares?" began to be answered (Clandinin et al., 2007).

Ethical Considerations

I obtained ethical approval from the University of Alberta and organizational approval from Alberta Health Services. Ethical approval with the University of Alberta was very challenging. I waited months for the final approval and had to adjust my original proposal that included those who tested negative by POC to only those who tested positive. The research ethics board challenged narrative inquiry as research methodology and questioned how research could be ethical if relationships are formed. My supervisor, Dr. Vera Caine and I had to defend the methodology as well as explain that narrative inquiry is a relational methodology and a relationship must be formed with participants in order to establish trust and open communication.

All participants were required to sign informed consent. This, too, was a relational experience. I shared my narrative and why the research was important to me as well as the impact I felt it would have on the provision of HIV care. I explained that I would like to meet face-to-face on multiple occasions over the course of the study, which spanned approximately one year. Participants were made aware that if they felt uncomfortable at any time throughout the research process, it was their right to withdraw from the study with no consequence. A written information sheet was provided to accompany the verbal explanation. Interactions were in a comfortable and convenient location for the participants. My supervisor was aware of my itinerary and location at all times when interactions with participants were taking place to ensure my safety.

To ensure the confidentiality of all participants was upheld at all times I changed their names and the names of any of the people mentioned in their stories. The creation of research texts was collaborative and I offered all writings to the participants for their feedback prior to sharing them with greater audiences.

Having the opportunity to have a voice and share experiences can be validating and empowering for some people; it can also be difficult and can stir up a plethora of emotions (Streubert & Carpenter, 2011). I had a list of counseling services readily available, as well as the information for the mental health and addictions crisis team. It was stressed that this was not a therapeutic relationship; however, I occasionally struggled with when to be a nurse and when to be a researcher (Streubert & Carpenter, 2011). This occurred particularly with the participant named Chris. He believed that a person could test positive for HIV if they had ever had a flu shot. While there is no scientific evidence to support his claim, it was hard for me to listen to his story as a researcher, without giving him the facts around HIV testing from the perspective of a nurse. This tension I felt also came into play when I worried about Chris's mental health. More on this tension will be shared in Chris's narrative account.

Relational Ethics

Responsibilities. Narrative inquiry requires a deep relationship between teller and listener (Clandinin & Caine, 2013). Throughout the inquiry I was working closely with the participants. There was no hierarchy of researcher and participant but rather a relationship of reciprocal respect. Both participants stated how comfortable they felt sharing their stories with me. The participants and I were co-composers and we negotiated stories (Clandinin & Caine, 2013). As co-composers, all interim research texts (narrative accounts) were negotiated with the participants. I took a stance of ethical care that called forth attention to equities and social justice (Clandinin & Caine, 2013). Being that this is a relational methodology, I realized that I will forever be part of the participants' stories as they will forever be a part of mine. While conversations are shaped by both the participants and myself, it was clear that they were not intended to be therapeutic, resolve issues, or answer problems (Clandinin & Caine, 2013).

Revisiting my Narrative Beginnings

Sound research has been conducted about HIV testing, the accuracy of rapid HIV tests, pre- and post-test counseling, and the experience of being diagnosed with HIV. Research has shown that POC HIV testing is considered acceptable by patients, however, evidence is lacking around patient experiences with POC testing and the psychological implications of that testing. Elliot and Jürgens (2000) stated:

> because the information about Canadian HIV testing and the counseling that accompanies it is so skimpy, impressionistic, anecdotal, and sporadic, an assessment of the potential benefits and harms of rapid screening has to be speculative and uncertain. If rapid screening is introduced, as the key testing strategy for HIV, the experience with it would need to be carefully investigated, evaluated, and monitored. (p. 140)

In 2000, the British Columbia Centre for Disease Control suggested that research be done to investigate patients' experiences of coping with positive preliminary results and then having to wait for confirmation, as well as the providers' experience of disclosing such results (as cited in Elliot & Jürgens, 2000). A report completed in 2010 by the BC Centre for Disease Control showed that there have been no studies examining the psychological impact POC testing has on patients (Gilbert, 2010), despite previous recommendations. There is a strong need to explore the experiences of people at risk for HIV being tested by POC in unique settings.

In this thesis I have included two chapters, each of which contains one of the two negotiated narrative accounts. The following chapter includes the paper submitted to the Journal of the Association of Nurses in AIDS Care for publication, which speaks to the analysis. The final and concluding chapter outlines the issues uncovered throughout this research project, the contributions to nursing practice and the recommendations for further research and policy changes.

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CHAPTER 2

Narrative Account of Chris

Arranging my first conversation with Chris was both nerve-wracking and exciting. I was nervous about meeting him and hearing his story, but I was also nervous that the meeting would never actually happen. I tried several times to arrange to meet with him and often he did not return those text messages, or our plans were cancelled. I did not want to be a "nag", but I also did not want to lose contact with Chris. Hearing Chris's story was important. I wanted to hear the experience of patients being testing through POC to ensure evidence informed practices. Where was the balance between being a nag, and showing interest? As I contemplated this question, I found myself relying on stereotypes for my answer. While I had never met Chris, I made assumptions about his life based on where he was tested. At this point all I knew is that he was tested at a bathhouse. I assumed that he might have a more chaotic life that may involve drug use and promiscuity. But why did I make those assumptions? I did not feel like I was judging him, and, in fact, I pride myself on my lack of judgement, but if I was making assumptions, then clearly I was not judgement free. This raised questions for me about my attitude towards patients who I see. How often do I not recognize my own assumptions? Do these assumptions influence my relationships with my patients? As I write this, tensions are starting to become apparent to me as I move into my role as a researcher; up until this point I have always been a practitioner.

When I finally spoke to Chris, we planned to meet up the next evening. I asked him if he wanted me to give him a reminder call. He absolutely did, he said he needed the reminder. The next day, I called him about an hour before we met. I was glad I persevered with meeting him. On our first meeting he explained to me, "Remember me saying about you'll understand better about just call me an hour's heads up? That was because I'm just used to people calling me and wanting me up in an hour, and I just knew that, I actually completely forgot that we were going to meet up and then you called me at five and oh yeah, perfect, I want to do that, I want to participate in this because if I can actually help somebody." As I came to hear Chris's story, these words made sense; he wanted to participate in this research.

that's pretty straight forward
for sure
I'm glad I can help
that's all good
for sure
I was the first person that ripped the phone number down
I think it'll be a benefit because it might help other people
I want to participate in this because if I can actually help somebody

As I pulled up to Chris's apartment I was again nervous. I thought to myself, are you ready for this? Is it safe? You are meeting a total stranger in his home. If Chris was someone who was tested in his doctor's office, would I be just as nervous about going to a stranger's home? It was a warm fall day, the sun was still shining and the leaves around Chris's apartment building were yellow, red and orange, and many had fallen to the ground. I stood in the lobby waiting for Chris to retrieve me. I definitely had butterflies in my stomach.

His apartment was well cared for, clean, and had the smell of a recently cleaned up, delicious meal. It was a small place with a lot of furniture crammed into it. Yet it was well organized and everything seemed to have its place. Hand painted art hung on the walls and a plump gray cat made his presence known by sprawling across my papers. Chris was well put together. He wore green army khakis with a matching top. His hair fell perfectly into place. He held the door for me and was polite. I immediately felt accepted and welcomed, like I had known him for a long time. There was a feeling of familiarity, like we had gone to high school together and were old friends about to catch up after not seeing each other in years. Everything has changed, yet nothing has changed. How could I feel this way with a complete stranger?

He immediately offered me a drink. I was surprised with how open Chris was about his sexuality, addictions and criminal past. As our conversations continued I saw a side of Chris that he himself did not seem to recognize. Chris described himself as "degenerate" and "self-absorbed." Yet what I saw in him was a caring man who seemed to lose his direction at times. I have seen this before in a family member of mine. Once an adventurous teen, jumping dirt bikes, now every day is a struggle to stay sober. He struggles to love himself, yet shows nothing but love to others. What happens to make that adventurous teen turn to substance use? Or was it substances that made him so adventurous to begin with? Were there warning signs that were missed? Was there pain that was left unhealed? Or health issues left uninvestigated? I say Chris lost his path in life, but what path was he on to begin with? At that time, I was just beginning to get to know Chris when he told me to his past boyfriend Carey.

I saw him as a target, somebody that I could use and abuse
I … got him addicted to drugs
He was marked
I'm more self-absorbed

When Chris was 21 years old, he met a much older man named Carey. "I met a guy who's born in the '50s, and I saw him as a target, somebody that I could use and abuse." Carey had gainful employment, a home, savings in the bank and his life on track. Chris describes seeing Carey as someone "who would help me pay for things 'cause I couldn't support myself." Carey was a "sugar daddy type thing." While Carey seemed to have his life together, he eventually started down the path of addiction with Chris, an addiction to crystal meth. Chris describes how he "got him addicted to drugs, and it's awful." Their relationship was monogamous for seven years, until Carey fell ill and told Chris to live his life and not worry about "babysitting" him. I wondered why a person would be monogamous for seven years to a man who was simply a target. Why would Carey want to not burden Chris if there was no love or respect among the two? Did Carey know that Chris would stay to care for him if he did not tell Chris not to? Did he see the loving side of Chris that Chris doesn't see in himself? I cannot imagine devoting seven years to a partner I did not love. When our conversations about Carey first began, Chris had only mentioned him briefly without detailing their relationship, but as our conversations progressed, Chris reflected on the seven years they spent together and how he learned to love Carey. Carey brought balance, safety, and acceptance in a world full of chaos.

After he and Carey parted ways, Chris was left to fend for himself. He was left to pay his own bills again: to makes his own money, and to support his own addiction. He was not used to having "a real job" as he describes it. He began hanging out with escorts and driving them around to their calls. "I thought it paid great. It's $40.00 to wait half an hour for this person to come back out. But the whole time I'm still on drugs and I don't wanna go back to my parents' house, so eventually I decided I'm gonna post an ad on the Internet too and try this escort thing." Chris describes how the money became really addictive and how he eventually met a client who would pay thousands of dollars every meeting. "I wonder where that guy is today and if he is doing okay…. He was supporting me of my art…every time I paint I think of the guy." While the escorting was a means of income, Chris again could not help but be concerned with those he met. I wondered about Chris's feelings; did he actually care for this man beyond an exchange of services for money. What role do meaningful connections play in his life? I wondered who defines what a meaningful connection is. When Chris spoke of these stories, he often had a straight face, would lean back in his chair but then quickly sit back up and carry on to the next story. Was he purposely leaving out details, were the details not important to him, or were they too important to talk about?

Loving is what I see in Chris. He loved Carey and he cares about those around him. When he agreed to be part of this narrative inquiry his motive was to help people. He never mentioned any personal gain from it, although he stated following our second conversation, “Thank you for listening to me, I’m glad that I called you. It’s kind of good to be able to tell your story in the sense. I keep forgetting the main topic of it all, but it’s nice to be able to actually tell somebody about yourself, and even how off-topic I seem to drag it sometimes, ‘cause I know I carry it kinda far sometimes. I appreciate it, I’m glad that I called.”

My second conversation with Chris was very much the same in my sense of feeling welcomed and the gentleness and kindness Chris extended to me. I again got that nostalgic feeling of meeting up with an old friend. However, from the first conversation to the second, which was a few weeks later, his life seemed more chaotic. His house was no longer well put together and organized. This time there was laundry in the living room, people were coming in and out moving furniture out of the apartment and Chris’s thoughts were fleeting and sometimes hard to follow. At one point I questioned whether he was high and whether he did drugs in the bathroom while I was there. He informed me that he needed to find a new place to stay by the end of the month.

With only two weeks left in the month I texted Chris to see how house hunting was going. His response reminded me of how laid back he was and how he was living life in the moment. It also reminded me of something he said to me in our second conversation. “I think I’m gonna start with even just thinking about even just getting a goal, ‘cause I don’t really have long-term goals anymore…I don’t have goals or things to aspire to, things like that, I don’t really think like that anymore." I question whether this was really true of Chris. Did he never think long term? Did he have no aspirations? While it may not be in a form of a long-term goal, Chris aspires to help people. He wanted to be part of this research so that he could help others and tailor the care provided to those being tested by POC.

After another two weeks had passed - and the end of the month had come and gone - I again texted Chris to ask if he had found a place to live. He had not. Yet again, he did not seem worried, while I was scared for him. I was concerned about where he was staying and whether he was eating. How is his mental health? Is he warm and safe? By now the fall weather was over and it was starting to feel very cold, especially at night. My heart was filled with sadness when I thought of him sleeping outside. There used to be a couple who made their bed by a hot air vent outside my apartment building every night. Almost every morning I watched so as not to hit them while I drove to work. Every morning I thought, "What a life, who can survive living on the streets in the winter?" Every morning I was saddened to see that humanity would leave people to sleep in the cold, by a dumpster, like they too were trash. Yet, every morning I drove by and did nothing. When I think of Chris without a home this is what I think of: him sleeping beside a trash bin... I never asked where he planned on going. Did he plan on returning to his family? Or was his family not an option? I just keep thinking of his statement, "But the whole time I'm still on drugs and I don't wanna go back to my parents' house." I wondered why he did not want to go back to his parents' house. Were drugs more important than a home? Or were the drugs not the reason at all? I again think of my own nursing practice, I cannot assume that drugs are more important than a home, and I also cannot assume that everyone has family that feels like family. If support systems are not in place, or someone is actively using, is it appropriate to test for HIV using a POC? Are they in a place in their lives where they are willing and able to hear the results of a 90 second test that could change their lives? How can I as a nurse accurately assess this readiness in a 20-minute interaction with a complete stranger?

While I saw Chris's life in chaos, dealing with homelessness and addiction, he showed a side of his character when he responded to my text about his wellbeing with, "I know I don't know you, but I am really proud of you." It brought tears to my eyes. While he had a lot of stressors, or what I would see as stressors in his life, he took the time to worry about me and tell me he was proud of me. What exactly he was proud of I do not know and I did not ask. I was so overcome with my own joy of someone being proud of me that I failed to continue the conversation past a "thank you." I feel proud of myself and I feel pride from my family, yet pride from Chris made me overwhelmed. It made me realize just how much small gestures of love and reaching out to another human can affect a person's life and wellbeing.

It was Christmas and I again texted Chris, "Merry Christmas and happy birthday!!!" He responded, "Thank you! Happy holidays." That is where our conversation stopped. I really wanted to know if he had a place to stay, if he was alright, if he was sharing a meal with family or friends. Did he celebrate Christmas or is that another assumption I have made? But I did not ask and I wonder now why. Perhaps it was distance or because I did not know how to help if his answers were not the ones I was hoping for.

While his physical safety was a concern of mine, his mental health was too.

Did therapy from grade 5 to 8
Never on any medication or anything
I went mental
The Morgellons thing is really freaky
I get these awful sensations in my body that there is something coming out of my body

You feel like there is a string thing you can pull out of yourself?

I put one in a pop bottle and it continued to grow with no air, nothing

The first time I met Chris I was intrigued by his mistrust of the health care system, the government and the world at large. When he first mentioned his interests in conspiracy theories, I questioned in my head "why?" I have had patients in the past with fascinations with conspiracy theories and they all experienced mental illness and/or addiction. My entire career has been working with people affected by mental illness and/or addictions. I also had to question why I thought his theories were related to mental illness or addiction. There are many conspiracy theorists in the world, and I still wonder whether they can all be wrong. As he shared his story, he said that his fascination with conspiracy theories started at a young age. He stated, "I became conspiracy theory person and started reading about things like that." He described when he was treated as a contact of someone who had gonorrhea, "And they gave me this intramuscular shot for that…Yeah, and that sure freaked me out, I don't think I would have gone then 'cause I thought it was pills. But they said because it's a special shot for gay men… Yeah, that freaks me out, that added to my conspiracy thoughts." I wonder how many other patients have these same thoughts or fears and this makes me think about the time I spend explaining treatments to patients and why a certain drug or route is required for a certain condition. Does my ignorance to the individual needs of my patients leave them feeling fearful and mistrustful? I began thinking of ways to individualize the education I provide to my patients, even when it comes to something that is non-life threatening, and what I may not perceive as "a big deal."

Chris was immunized as a child but as he grew older he became sceptical. "I began reading about big pharmacy companies and stuff like that, and how they have suppressed other technologies and stuff like that that have ever emerged. Because they're all about medications and the route they see fit." While getting a routine screen at the STI clinic Chris received a vaccination. He recalled how his sister had told him to never get vaccinations and how he is not even sure why he did, since he already had theories about pharmaceutical companies. What made Chris receive that immunization if he was against it? I wonder if Chris felt the medical staff knew best so he did not question it or stand up for himself. I wondered if the paternalistic approach to health care left him feeling forced. I have had patients in the past who apologise for asking questions about their own health or who tell me they trust me to do what is best. These are statements that make me uncomfortable. Everyone has the right to question health care practices and everyone has the right to be involved and informed about their medical care. Chris believes that was when his health started to decline. He said, “This is gonna sound bizarre in the aspect in that I was reading about that there’s 80 some other conditions that can make you test positive for HIV. Things like if you’ve ever had a flu shot or there’s all these different conditions, and I started thinking that maybe I have one of these things.” My scientific knowledge about HIV and HIV testing, as well as immunizations, is different than the information that Chris had just stated. I found myself biting my tongue. I wanted to provide Chris with education about HIV, HIV testing and immunizations in that moment but I also wanted him to feel free to speak his mind and his truths. I did not want to say something that would hinder our communication or jeopardize the relationship we had established. How often do I correct the information of patients and hinder our communication? Do I often say what I know to be the latest scientific facts and in turn diminish the thoughts and fears of my patients? I chose to continue wearing my researcher hat, in hopes to continue our communication while respecting and not judging what Chris had to say. With science constantly evolving and new findings emerging from research, maybe the information I am providing today will turn out to be inaccurate too.

These comments really made me wonder about how Chris perceived his HIV positive results. I asked him, “At this point do you believe you are HIV positive?” He responded, “I believe that the tests have come back and said that I have HIV, of course.” His answer was interesting to me. Does Chris believe he is HIV positive and actually carries the virus? Or does he believe that the test was positive but that the root cause was not the HIV virus at all? Testing positive for HIV can alter a person’s sense of self and identity. It can also alter how a person identifies with the virus. In health care, we often believe we know what is best for our patients’ but I do not think we pay enough attention to our patients concerns. Chris once described his experience of attending an HIV clinic, “And I was tryin’ to tell them about my thoughts about what I was saying about the documentaries and my different perceptions of it now, they wouldn’t hear it. Except for one younger girl, she was listening and wrote it all down…but I never saw her again.”

As a health care provider I must ask myself if I am doing what is in the best interest of patients. Am I doing enough to calm their fears, or answer their questions? By disregarding their beliefs and ideas, I am creating a wedge in our relationships and fostering distrust. Distrust is something that can have detrimental outcomes, especially if a person is already sceptical. To this day, Chris remains off medication. He uses alternative forms of treatment like drinking what he believes is colloidal silver and using was he called “electrification”. I found this treatment intriguing so I looked for any evidence of it as a valid treatment. I could not find any scholarly articles or research on this treatment. All I found were websites selling the devices and a website claiming that the electrification did not kill HIV but destroyed the protein layer of the virus, inhibiting it from completing reverse transcriptase (Adachi, 2000). There was no evidence that the device worked.

I will never forget when he showed me the electrification device. It was 2 electrode pads that were placed over the veins in his wrists. The pads were attached to a 9-volt battery. “Just zaps the blood as it goes through, and you wear it for seven minutes, take it off for 12, another seven minutes. It’s just like a cycle that you do and they say that it kills all the viruses, pathogens, and any parasite in your body.” Chris completes this treatment about once a month. He started using it about nine months before he was diagnosed with HIV. He started using it originally “cause I thought I can help all of these people, I’m gonna go cure HIV on people, think that I could do this. Well, people don’t believe you, they don’t wanna hear about, they think you’re a conspiracy, and you’ve gone crazy when you talk about this sort of stuff, so I kinda kept it to myself and put the machine away.” While I did not ask Chris at the time, I do wonder if the treatment works; how did he become infected with HIV? He was using the treatment before he was ever diagnosed. He had HIV testing that was negative in those nine months prior to his diagnosis. On the other hand, while lacking scientific evidence, maybe Chris knew something. I expressed my curiosity to see how his home treatments have impacted his viral load and CD4 count. Chris agreed with my curiosity and he too was curious, but since his initial appointments at the HIV clinic, he had never returned for follow up. I do hope he will return for follow up care one day. I think it is the choice of the individual as to whether or not they take medications for HIV but I also think that the choice should be informed and based on scientific evidence. As a registered nurse, I care for the health and wellbeing of my patients and it is hard for me to not say something if I think they are not doing what is in their best interest, but who am I to judge what is in their best interest. Do I do this when offering POC or not offering POC testing to patients? Do I make that judgement for what is in their best interest? Or does policy drive what I believe is in their best interest?

Chris also described to me how he makes the colloidal silver. “Well, if you take two pure silver rods and hook them up to the wall, the left-right and plug it into the wall, put it in distilled water, a cup will turn into 7% or 12%, I can’t remember exactly which one it is, with silver solution in the water. And as long as it isn’t exposed to air, light and you put it in the dark bottles then you can save it and drink it, you can apply it topically and everything like that, it’s really good shit.” At this point I expressed my concern for his physical safety. Chris assured me that he was safe. Again I also expressed my curiosity about how this may have affected his viral load and CD4 count. He replied, “for sure, I’m kind of excited about going back, you just reminded me that I wanted to do that, I forgot.” I wonder if Chris had indeed forgotten, or if all it took was someone listening to his ideas to get him interested in care. This reinforces to me that connections that I make to patients can change the direction of their health care and potentially their health outcomes. All patients I see have a story. They have reasons for why they are being tested and why they are choosing to be tested in an environment such as a bathhouse. It is up to me as the health care provider to ensure that the context of the lives of each patient is considered, the spaces we share are safe and the relationship we build is respectful.

Chris’s distrust of the health care system goes beyond vaccinations and feeling like he is not being heard. Before testing positive for HIV by POC, Chris had a positive HIV test in the past. It was back in 2010, during the same visit to the STI clinic when he received the vaccination. It was by standard serology, not POC. “Right, no it wasn’t rapid. I was just going in there to get tested because you think it’s your duty is what I was thinking right.” What an interesting word he used, “duty.” Duty, to me, implies an obligatory action and a feeling of responsibility. Did Chris feel a responsibility for the health of his past and future partners or was it just an extension of the care and concern he shows to others? Is it a personal responsibility or does he feel the pressure to be tested from what he was taught around sexual health as a child? Chris described how scare tactics were used to teach him sexual education. “It seems life-altering ‘cause they taught us in school if you don’t use condoms you are going to get HIV and die, that’s kind of what they told us right.” I fear that scare tactics are still being used to educate on sexual health as well as testing for sexually transmitted infections and blood borne pathogens.

When I asked Chris for more details about the positive HIV result, he was unsure. I wondered if he had a positive antibody test followed by a negative Western Blot, which would require follow up serology. Chris said, “I’m not sure, they never gave me any of the details about it. It really was alarming for a week and a half or however long it was. I wasn’t expecting that phone call.” This left me questioning nursing practices and policies once again. Was Chris truly not informed of the details around this result? Or was it not explained clearly? Was the shock enough the information that was provided to him was not absorbed?

When Chris first learned of the positive result, before learning that he was actually HIV negative, he described how he did not leave his house for days. He was shocked by the results. “I got depressed and upset but then eventually I just woke up one morning, smiled anyway, got out of bed and just motored on, because there is not much you can do about it is what I figured.” He still had not heard that the results were in fact negative, but he made the conscious decision to carry on with his life. “I was still thinking that there was a potentiality that I’ve got HIV now.” As our conversation continued I asked if he had any doubt in his mind that the results could be negative. His response was, “No, I was convinced for sure it was a positive test. Then again, my thoughts about it all now were never there. I didn’t do any research, I didn’t know about undetectable, all that sort of thing, I didn’t know how it all worked whatsoever. It’s kind of funny in retrospect.”

I realize that pre-test counselling does not involve many details about HIV infection, but maybe it should. Or at least while confirmatory results are pending, more information may need to be provided. His experience of false positive results by standard testing really makes me consider the consequences of POC testing and the information that should be provided to clients while confirmatory results are pending. I wonder what supports need to be in place to ensure the safety and well-being of patients.

I could not help but wonder what emotions and thoughts were going through Chris when he found out the results were ultimately negative at that time. He responded, "I thought wow this is stupid I can't believe they did that to me. Does this happen a lot? People should be warned this can happen to them, I don't know if it happens a lot but it makes me kinda wonder now if that test had anything to do with me getting HIV, maybe they messed it up again or something, so maybe I was positive back then, you know you never know I guess." I tried to put myself in Chris's place, would I trust the test after that? Would I question if I were positive all along? Would I trust the system enough to ever be tested again? Would Chris trust the system again? His answer was, "Yeah, that was probably the beginning of me thinking that they don't know what they're doing 100%." Instead of being jaded, Chris took the attitude of wanting to help others so they never have an experience similar to his. "I want to participate in this {research study} because if I can actually help somebody." Chris wanted to do his part to ensure better care for others. As he told his story I could see his facial expressions change from smiling to flat. From relaxed to concern. While he remained very calm and collected, his posture changed from leaning forward and engaged to leaning back into the couch, shoulders wide, in a more defensive position as he spoke of the false positive. When he discussed his desire to help others, he again leaned forward in a less defensive posture.

While Chris's false positive experience was with standard testing, and all of the details around the testing are not clear, his emotions and response were very clear. I can ensure that false positive results are not given by standard testing, however, that is not an option with POC. The result is within seconds to minutes and the confirmatory results can take a week or more. I need to ensure that it is clear to patients that the POC results could be a false positive. I wonder if it is possible to ease their fears while waiting for confirmatory results.

I asked Chris what he thought test providers need to do to when someone tests positive for HIV through POC and is waiting for confirmatory results. He said, "They never explained to me that there is a potentiality that I would still be negative, anything like that, it was just come in for more testing and this is why and then yeah, OK, thank you, and then if you don't hear from us that's good news type thing. And then it is just sort of like what, you are just kind of left alone type thing. Maybe they did explain it to me but I guess I didn't have the understanding of how it actually played out." The more Chris offered the more I thought about policy. Chris said that maybe the nurse explained things to him and he did not understand. Maybe his learning should have been assessed further. Maybe the policy of "no news is good news" should not apply in these situations. Maybe I need to be more accountable and make that phone call with those negative results so I can then educate patients again, and answer questions that may not have been asked in the initial testing phase.

Chris mentioned that since he tested false positive by standard testing, he still continued to go for periodic testing after that. "I'd done rapid testing the whole time, every couple of months… so I was familiar with the process of it." I wondered if he was familiar with the way the test worked and what the results meant. Or was he familiar with the actual physical steps of the testing process. Because he was tested by POC so frequently, did the testers assume he knew what to expect. Between his false positive result by standard testing and his positive result by POC, Chris had been tested, “probably like 8 times or something … I guess because it was there. I didn’t even know it existed first of all and then I was like I’d just like to find out too. And you sit there and they’re telling you it’s gonna be that rapid, so it really is like 90 seconds of questioning it, doubting it, what am I gonna do, and then it came back positive I guess I wasn’t shocked. I guess I had expected something to happen at that point. After being around, going around as an escort, you know what I mean? But you do your best to play safe with people and I know that sounds really fucked up but it happens when you don’t.”

I was interested in Chris’s comment, “so it really is like 90 seconds of questioning it.” What were his questions? What were those 90 seconds like for Chris? “Yeah, it’s like you bite your nails. Why am I doing this, do I really wanna know if this is happening? No, this is a good thing, you’re like this is something you’re supposed to know, and this is the way society is today, everybody goes and gets tested is what I was thinking to myself.” I found his thoughts interesting. It is almost as if he went from mistrust and questioning “why” to convincing himself that it was the right thing to do. If someone needs to convince themselves during that 90 seconds of waiting for the results, were they ready to be tested at all? Or was he ready up until the moment the testing began and in that moment he no longer felt prepared. While I have not had a patient change their mind as the test is running through, what if that situation arose? What if they no longer wanted the rapid test? What if I had already seen the result by that time? Is it ethical for me to withhold that result at that time and wait for standard testing, or no testing at all if that is what they chose? Is it ethical to not give that result to a patient? Is it ethical to give it to someone who no longer wants it? How does knowing or not knowing affect the psychological wellbeing of patients? His comment, “everybody does and gets tested” sounded like a commercial. I wonder if these were his thoughts or “society’s” thoughts of perceived obligation.

I asked Chris what his life was like from the time he tested positive by POC and when he received confirmatory results. I wanted to know what those 10 days were like for him. He answered, “Yeah, right after I left there, it took me probably a day to shake it off and then I was still kinda uh, I probably had a good six hour breakdown before I fell asleep. And then when I woke up I remembered what had happened and then just grabbed my computer and started looking and reading.” His response made me reflect on my own experience of testing patients by POC in correctional facilities. A place where many people want to cry, but few people actually do. A place where a six hour cry would leave a person too vulnerable in their surroundings; in a place where they cannot grab a computer and start looking information up. Inmates do not have access to outside information or supports and they have to rely solely on what information and support the nurse can provide.

Chris described what he meant by “breakdown.” “I guess what you do to yourself mentally. Let’s say when you fail the test or you just don’t make the grade, or you have a break-up from somebody, the different mental shit that you go through, tell yourself and treat yourself, or you start crying and get sad and upset and angry, and rip shit up and punch something … like you aren’t good enough, like what are you doing with yourself, and look what you did … disappointment in yourself or that you would disappoint others … No, I guess, in myself. I guess I don’t really ever think about other people much. I’m more self-absorbed.” I wonder if Chris feels he is a disappointment in relation to others and if he is worried he is a disappointment to others then this is in fact outward thinking that contradicts his message of being self-absorbed. I wonder if he sees himself as self-absorbed because it is easier than feeling like he is a disappointment to others.

Chris's feeling of self-disappointment and wanting to "rip shit up and punch something" makes me think of my incarcerated patients and the supports available when they are having negative self- thoughts. What would happen to them if they expressed their emotions through anger and ripping things up or punching something? I asked Chris if he ever felt a loss of self-identity. He responded, "No, not really, 'cause I guess I felt I had a support system."

Chris said his results came with disbelief. "I honestly do believe that there's a high probability that like whatever it is that they call HIV, that I've got it. But I also do believe that thinking outside the box that there's a possibility that other factors come into play. So like it makes me wonder, I guess obviously I always have doubts." As I explored this disbelief further, Chris explained that it is not necessarily that he believes it is not HIV that he has but something else, it is that he wants to believe it is something else. Chris also explained that his disbelief in the results had nothing to do with being tested by POC versus standard testing, "it wouldn't have mattered, there'd be that sense of disbelief."

All of these thoughts and emotions were flooding through Chris in the time between receiving the results of the POC and receiving his confirmatory results. "I guess I wasn't thinking, I felt like a robot, just like do, do, do, they tell you, wake up at nine, go home at five, you know what I mean? I'm just functioning without any thought behind it, following everybody like those people that drive in trains, you can just speed around them, people like that, almost like robot kind of thinking … Just like numbed right out."

I was curious to know if he responded to the confirmatory results with the same emotion as the POC results. He said, "No, I guess I'd already accepted what they said, but not accepted it at the same time." Chris explained that part of his doubt stemmed from his first false positive experience. "That was another part of the thing too, that's another one of the reasons why I didn't trust it." I honestly could not blame Chris for having doubts.

I again reflected on my testing experiences in correctional facilities. I had two patients who tested positive by POC but then negative by confirmatory testing. They were false positives. I could not help but think of them wanting to break down but not wanting to show weakness. I remember one patient crying so hard she was hyperventilating, only to shut off all emotions when it was time to leave my clinic room and return to her cell. I was both surprised and saddened by this defense mechanism. Had this patient learned that it was not okay to cry and show emotions at various stages in her life, so now it was just another one of those times? How can a person filled with so much emotion be expected to hold it in? She returned to her cell without a phone call home, and without a support system, only armed with the information I had provided to her, but was that information enough to get her through those next 10 days? I did explain to her that there was a possibility of it being a false positive and that POC was not a diagnostic test and a diagnosis by standard testing would need to be done to confirm any findings on POC. I explained this before testing commenced and after the positive POC result was given. When her emotions were running so high, could I really expect her to hear and absorb anything I had said? Did she see risk factors in her life that would make her believe that a false positive was impossible? As the test provider, I did not think it was possible. What could I have done to make this experience better for her?

I asked Chris to reflect on what he thought health care providers could do to make the testing experience better. He replied, "Honestly, I'm not even really sure that there's any sort of thing that they could implement to make it more comfortable of an experience, or anything like that because it's such a hit and miss, and you have to initiate it yourself. I really do think that they're doing a great job for what they're doing; they're effective. If there was more supports, I'm not so sure that other supports could be initiated or anything like that." As we discussed this topic further, I shared my experiences of testing in correctional facilities. Chris has been in a correctional facility in the past and he knew the environment and the climate. He said, "I guess one of the main difference between me and them per se, not to pertain to your question but there's a huge difference I'd say to me and those people that are incarcerated, is the freedom factor. 'Cause even if they add pamphlets or they're given an extra hour or something, people to chat with, or shown that they have support networks, that they might not even pursue them because other people would be able to figure it out right away. You come back from medical, you took that extra hour, huh? You can only imagine how that would go for them. But thinking about myself, I guess the support things, there's not really much more that there can be, it's all about how you're gonna deal with it yourself, it's how can you handle it. I don't think there's much more that the medical people can do for you."

Chris's comment raised so many concerns. My own assumptions plagued my views once again. I assume that everyone would want supports, but as Chris mentioned, even if supports were in place, who is to say that patients would want them. If confidentiality could be maintained, would people access supports if available? Or is it an individual's responsibility to cope with their results on their own. Chris's experiences with the health care staff were good, yet, are there other things we can do to address some of the concerns he mentioned earlier.

"I'm curious, if you could go back would you choose to be tested by Point of Care testing again?"

Chris: “Yes… There’s less wait time…that was the number one thing. I absolutely would because of how rapid it was.”

“The rapid was the best part.”

Chris: “Absolutely.”

I am curious to know, if Chris would have the same outlook on POC testing if he had tested positive while in a correctional facility. As we further discussed his experience with testing, Chris mentioned more details that also got me thinking. Chris tested positive by POC in October but stated, “I didn’t go and get tested for sure to know until December.”

“So they didn’t draw your serology at the same time as doing the rapid test?”

Chris: “They did but I lied about my name.”

“Oh.”

Chris: “Cause you can go in and do it anonymously. ‘Cause I started freaking out about all these things, like my past.”

“Up until this point when you’d been tested at {the bathhouse}…did you use an alias as well?

Chris: “No.”

“So you used your real name and then this time you used an alias.”

Chris: “Yeah.”

“So what made that decision? What were the kind of things going through your head?”

Chris: “I could have a gonorrhea infection, or get called for a gonorrhea infection and not even actually have symptoms of it. So I started thinking about things going on in the background and all these people I know being tested positive for HIV… … and so it was kind of alarming.

At an early part of our conversation Chris also mentioned, “Then I started doing the research in that time and then so many people around me were telling me that they were positive or they were just diagnosed and stuff. But they didn’t seem unhealthy or anything like that.” This conversation really made me reflect on what HIV “looks like.” What is the common face of HIV? Do people picture clean cut Chris, with gelled hair, and a white smile? Do people not see themselves at risk for HIV so a POC test may not hold any fear at all as they do not anticipate a positive result?

I asked Chris what he felt when he saw those two blue dots become visible on the POC test. “It was kind of heart dropping, but I guess at the same time it was somewhat expected. It’s something that… … thought to say is that even though I’d never actually prepared myself for something like that, I had also prepared myself for it. You know what I mean? Like doing what I do and the lifestyle that I’m living, it made me think about that is, that this could eventually happen to you one day, right. And then it turned out that it did, it’s kinda weird. But it really does make your heart sink because it made me realize I’m on some government leper list now.”

The words “some government leper list” made me cringe inside. This made me reflect about stigmatization in relation to HIV. How does having HIV influence policies such as medical coverage, health and life insurance, and the ability to travel freely? In Alberta, a person cannot receive publicly funded medical care for HIV if their real name is not reported to Public Health and in turn a positive result linked to their provincial health care number. Yet, testing under an alias is offered. Many patients may not know prior to testing that their real name will need to be provided if they test positive. How can a medical condition have such power to influence policy? How can a medical condition have so much influence on the Criminal Code of Canada? At this time, people can still be charged criminally for non-disclosure of their HIV positive status (Canadian HIV/AIDS Legal Network, n.d.). Chris's use of "leper list" brought up a whole new aspect of POC testing that I had not considered before. I knew that 90 seconds can be life changing, but maybe I did not realize just how life changing. I asked Chris what he meant by "leper list" as my thoughts may have been different from his.

He replied, "Well you know what I mean by lepers, right? Like the shunned, you know, the ostracized sorta thing. There's definitely a stigma." While I assumed that stigma still existed from what I have read in the literature or the things that I hear people say, I had no idea it was so bad that someone would feel as though they were on a "leper list." What do I need to do as a registered nurse to start decreasing stigma further? I feel I was very naive in my thinking. I asked Chris if he had ever experienced stigma first hand and he replied, "Just from other people in the scene…..my family and everybody like that, they're all good and everything, the ones that I've enlightened." I wonder if he would have felt stigma, even from those closest to him if he had not "enlightened" them. Chris also describes facing stigma from his clients when he tells them he is HIV positive, "I have gotten everything from it doesn't change anything to your disgusting, get the fuck out, so it's all over the map." Chris also describes the personal stigma he felt. "What they tell you in school is that if you don't use condoms you're gonna get HIV and die from AIDS, and shit like that. Then my whole conspiracy thing kicks in again but it's, yeah, I'm not even really sure, it's a personal stigma mostly."

I was still intrigued by Chris's choice to use an alias, so I asked him again, "did you have an event occur that might have made you feel more at risk, or did something change in your life, or in your body, in your sense of self?" Chris's response again made me think of his mental health. "The April prior to that {testing} I started noticing this really bizarre feeling in my body. It was really weird to me and I have no idea, I've come to more knowledge about what the potential of what it could be, but it started off with this weird feeling like a biting at my skin. So I started thinking oh my god, I've got scabies or something … And then it turned into a deeper feeling. So I went and I bought medication for that, and it didn't do anything, and the guy who I was with at the time was like oh you're going crazy, don't worry about it. And then it started happening to him about two weeks afterwards, and it's been progressive for him since. I could crack off more about what I think that is and stuff like that, but that was one of the main turning points of my life lately, my mind doesn't work in any other way, it's changed my thought patterns, I'm slow, I don't have memory, it's messed my body right up. And I wonder if that's when it happened to me, I do question it, there's a whole bunch of different things that basically ever since that last April, not this last, but the prior April is when my life completely up roared and changed 100% ... That's the thing that stands out the most."

I asked Chris if he thought these changes to his body, such as memory loss, were directly related to HIV or from other factors such as drug use that may alter brain activity. He answered, "It could potentially be that as well. I'm not sure if you ever heard about it before, or if anybody ever told you about it, like a skin disorder that has been becoming more prominent in people lately, it's called Morgellons or that's what they're calling it. Have you heard of it before? That's what I think that it all stems back to. I've actually hospitalized myself a couple of times over these different machines and stuff that I bought and stuff, homeopathic treatments and stuff if you will. It messed my electrolytes up and all this sorta stuff. I did a number on my body." Chris stated that he originally turned to homeopathic treatments such as the drinking colloidal silver and the electrification as a way to deal with the Morgellons, the treatment for HIV came later. Chris explained how he used a variety of different homeopathic treatments such as a magnetic pulser and a biotuner that he would clip onto his ears and it would "tune" him to the "Schumann frequency or something like that, the frequency that the earth runs on." He also said he tried ionic foot cleansers that were only to be used twice a year and he used "30 times in a month."

Chris's use of homeopathic treatments worried me. What damage could he be doing to his body, especially if he was using them in excess? I was happy when he said the only treatments he continues to use are the electrification and silver, but even those worry me. When clarifying all the treatments he tried Chris said, "there's a whole bunch of things that I did, I went mental. Because the Morgellons thing is really freaky." His words "I went mental" stuck with me. What was his description of going "mental"? Did he feel a loss of control? Did he feel overwhelmed? Did he feel a tension between reality and what was going on in his thoughts?

It was Chris's sister who introduced him to some of the homeopathic treatments. She especially turned him away from eating genetically modified or processed foods. "I'm really paranoid scared of food and stuff like that. I think that's probably the reason why maybe on top of everything that's why I've lost so much weight lately as well, is because I'm freaked out about eating genetically modified food … I can't eat it … I really pay the price later … My body rejects it and stuff like that and my body doesn't digest fruits and vegetables and stuff anymore, it's messed up, my body's completely 100% different." I began having more tensions between my role as a nurse and as a researcher. I was concerned that Chris's weight loss was not due his food choices but to his untreated HIV. Should I take this time to provide education around HIV disease process? Do I express my concerns for Chris's physical and mental health? Or do I just listen to his story? I chose the latter at this time.

Chris described how eating canned, boxed or processed foods made him feel. "I get this tingling weird sensation in my body, and it really is gonna make me sound like I lost my mind here, but I get these awful sensations in my body that there's something coming out of my body, almost like a long string type thing, and I can feel it pulling from different points in my body and stuff." I asked him if this feeling only corresponded with foods or if it ever corresponded with anything else, like meth use. He said, "there's a possibility of that, I have sleep psychosis, could have a part to do with it." He described how drug use, paranoid thoughts, and different tastes in his mouth, trigger different thoughts. At this point I asked if Chris had ever gone to a support group and I referred him to one in his area. While the researcher in me wanted to know more, it was the nurse in me that wants him to feel supported, to feel safe, and to be able to sleep without paranoid thoughts. Again I wondered if he was having neurocognitive changes related to his HIV.

As we further discussed Chris's paranoia, the conversation again went back to the strings that he can pull out of his body. "It's not even a hallucination, I've even had other people confirm it to me like these strings, they're almost like micron thin, and they almost look like hairs, you can see them sometimes when they're wet, or in the right sunlight. And they're like micro thin, they're really weird. And sometimes they get really thicker, like an actual hair. Comes out and I mean like I'll take my clothes off and find this big long white, or dark hair under my clothes that I could feel earlier that day. And I took one out and put it in a pop bottle, and I'm very aware of how these stories and stuff make me sound but I'll continue anyway. Is that I put one in a pop bottle and it continued to grow with no air, nothing, I put it up on the top of the cupboards for 2 months and it got longer and bigger. It's messed up, I don't know, it's something to do with I think that the government's trying to make me sick and stuff in the sense of the pharmaceutical companies, I know they make money off of you if you're not healthy, right? ... And I notice also that my body's become super sensitive to magnetic frequencies, like if somebody walks into the room the frequency changes and I can feel it. Or if your phone rings or we turn the TV on, any of that, it changes and I can feel it."

I was beginning to feel a little overwhelmed by what all I was hearing. Has drug use caused Chris to have hallucinations? Has HIV lead to neurocognitive changes? Has mental health been a factor from the start? What could be other explanations for the way Chris is feeling and seeing the world around him? Even though Chris makes comments like, "I went mental" or "I'm very aware of how these stories and stuff make me sound," does he see himself as having a mental illness? Is his paranoia preventing him from being healthy? When I talk to Chris he does not seem to be hallucinating. He can speak clearly, he makes eye contact when he talks, he seems aware of his surroundings and what is real and what is not. While his stories often go off on tangents, he is always aware of when he has gone off topic. Then he tells me about his experiences and I wonder about the complexities surrounding one's life. About how others experience the world around them that may differ so greatly from how I experience mine. Who am I to say that my experiences are the right experiences or the "normal" way to experience life? Every patient I see will experience his/her world differently. I need to listen to my patients' thoughts, beliefs and concerns so I can help shape a positive POC testing experience that does not leave them with paranoid thoughts or conspiracies.

I can remember every person I have ever given a diagnosis of HIV positive to. When I look back, I reflect on my empathy and compassion that I showed each person. I reflect upon the information and education I provided them; I felt like I was non-judgemental and that patients felt comfortable in my care. I can also say that I did a good job with contact tracing, public health follow up and informing people of their duties and legal obligations. As I reflect, I realize that I did a lousy job of assessing the needs of my patients. I have always referred patients to a practitioner for treatment and follow up, but that was because of policy and what I thought was best for the patient. I have never actually asked a patient if they wanted follow up and treatment. I have never asked them how they felt about being on medications. I have never asked if they had any indications that HIV was in their body, other than possible feelings of the flu after initial infection. Maybe more people feel like Chris. Maybe a lot of people fear pharmaceuticals and pharmaceutical companies. I have always assumed that people would want to take medications and have a viral load as low as can be. But how many people do not? Chris was very open with me about his experiences, but if people feel like what they are saying will sound "crazy" to others, why would they say it?

Chris's comments about the government and pharmaceutical companies lead me to clarify if he was currently on meds. I was quite certain he was not, but then why would he think the government and pharmaceutical companies were trying to control him? How did he think they were doing it? I asked, "You aren't currently on any medications, right?

Chris: "No, nor would I take them I don't think … No medications whatsoever."

"Ok, and is that simply because of your feeling around pharmaceutical companies?"

Chris: "That's a huge part of it as well as I think that there's probably, I know that my diet is fuckered to begin with, and my nutrition I know, for the last however long has been not the best. So I think that could be maybe a huge part of what's going on in my mind and stuff, why I probably seem a little bonkers. But I think that there's other ways to cure and fix other ways, and things to look at it, you know what I mean, rather than the pharmaceutical company. I just think that they're so quick to cut and chop at the body, they cut the wires to the alarm bells and not turn off the alarm. I guess that's why I've always had an aversion to them."

I appreciated Chris's openness and his willingness to let me in on a side of his life he often hid from others because they thought he was "crazy." "My mom thinks I'm crazy about this too but I used to be able to pick up radio stations on my teeth before I had the silver taken out. And then after they took the silver out of my teeth I wasn't able to hear them anymore, I used to be told I was crazy over that one. It changes, the electromagnetic frequencies, even LED lights or laser beams and shit, I can't handle those being on around me, at all, it really sucks. Fluorescent light bulbs too, I don't like it." I asked Chris if he had ever seen a psychiatrist or a mental health practitioner of any form, even as a child. That is when he told me, "I was going through therapy from grade five to grade eight every Friday but I don't know of any diagnosis, I was never on medication for it or anything."

Chris had told me that his sister had gotten him into meth, and I wondered if meth was a way of dulling all the feelings and sensations Chris was having. I wondered if drug use was a way of self-medicating. Were these feelings the reason for his drug use, or have these feelings gotten worse since starting the drugs? I have previously worked with many patients who turned to drug use as a way to cope with their mental illness, even if their mental illness was not acknowledged or known at the time.

Chris responded, "I don't think they're related, mind you, the only times that I've been clean in the last 12 years has been when I went to [a different large city] for four months, when I was in jail for three months, and when I went to treatment for three weeks two years ago. That's the amount of time I've been clean, the longest bouts I've been clean. And it doesn't matter, it's been like an everyday thing."

Throughout our conversations, Chris mentioned his family but never in great detail. While he always described them in a good light, I felt a sense of disconnect. That disconnect carries over into my writing as I know his family is important to his narrative, yet I do not know where to put them in his story.

My parents couldn't tell me what was going on
I came out of the closet
My dad came up with some crackpot theories about it
My sister, she was my idol growing up
She got me into smoking crystal meth
I don't blame her for anything other than just a bad introduction
I lied to my probation officer
She's like you're still young enough, and I talked to your parents, they do like you they want to have you back, so guess what?
I kind of kept up doing fraud
And then I realized that crime is kind of like a clock, you have to get in and out before your time's up

When I first met Chris, the first story he shared with me was when he moved to a different city when he was 16. "Basically I decided that my parents couldn't tell me what was going on. I got kicked out of high school, and then I didn't want them to tell me what was going on, so then I just bought a plane ticket [to a different city] and not knowing anybody there I just decided to set up shop there." I think of myself as a 16 year old, barely old enough to drive, trying to navigate a city. Barely old enough to get a job; still too young to be expected to take care of yourself. I wonder what that was like for Chris.

Just after Chris turned 17, his parents offered to pay for his driving training so he could get a drivers' license if he moved back home. That is when Chris told them he was gay. "It was actually kind of really cool because the way that they took it, they're both accepting of it, and it was no problem. I was emotional about it and they were all good. They both told me we already knew anyway ... Actually, my dad came up with some crackpot theories about it, he's like I think the reason why you're gay is because we used to make you play baseball when you were a little boy and you didn't wanna play. And he's like, we'd throw the ball to you and you'd just cry because you didn't wanna play baseball, but we made you play anyway. And that's why you're gay. Just weird things like that, it was bizarre." As Chris told this story, he smiled when he shared that his family was accepting of his sexuality, and laughed about his dad's "crackpot theories." I cannot imagine what a relief that must have been for him to be accepted by his family. While we did not discuss his sexuality much further, I wonder what it was like for Chris as a teenage boy before he came out.

Chris described how after he got his driver's licence he moved back to a different city and shortly after his sister followed. They started working together at a marijuana grow operation. When he speaks about his sister he describes her as, "she was my idol growing up, she's the closest sibling." She was also the person who introduced him to smoking crystal meth. "She was doing hard-core drugs, and she got me into smoking crystal meth … It's kinda shitty 'cause she's all clean and stuff like that now and she's preachy about it. I completely understand, and I don't blame her for anything other than just a bad introduction." More of Chris's laid back demeanor was showing through. At no point did he ever try to put blame on others for his decisions in life. He always took responsibility for his actions. This is something I find to be quite admirable about him, and I cannot always say the same is true for myself.

About a year and a half into his addiction, Chris moved to yet another city for a new job. "I only lasted out there for three months. 'Cause I wanted to get high again and I was like I gotta get outta here. So I just moved back again… and then I ended up going to jail there…It was only for three months though." After his three months in remand charged with fraud, Chris's probation officer arranged for him to move back in with his parents to serve his house arrest. "I lied to my probation officer and said oh yeah, I don't talk to my parents and she's like you're still young enough, and I talked to your parents, they do like you, they want to have you back, so guess what?" The way Chris told this story, made me laugh a little. His face was animated and he used his hands as if to say "surprise!" when he describes his parole officer talking to his parents. I could not help but keep wondering why Chris was so against living with his parents, when he describes them as being so open to having him there. Even when Chris described telling his family he had HIV, he described their response in a very supportive and loving way.

After moving back with his parents, Chris continued committing fraud for "probably five years … I was going around stealing mail … luckily I didn't catch any court cases or anything, so I lucked out. And then I realized that crime is kind of like a clock, you have to get in and out before your time's up." That is when Chris met Carey and his life began to have some stability, even if it was only for a while.

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CHAPTER 3

Narrative Account of David

I am always nervous before meeting a participant for the first time. My heart races and my hands get clammy. The drive to his house felt long with that constant voice in my head telling me not to go. It was the middle of winter, it had been snowing all through the night, and the roads were slippery. It was the perfect excuse to avoid the -25^{o}C air and head back home. But I could not. I had to keep driving. I had to meet David. I had to hear his story. His story left my head filled with thoughts of secret lives, silent stories and mental health.

My first phone call to David left me feeling unsure. Unsure if he was going to participate in the research. Unsure if he was willing to tell me his story. He seemed very nice on the phone but through his questions and silences, I was wondering if he was ready for me to hear his story, or for him to tell his story for the first time. When he agreed to meet with me face-to-face for a no-obligations conversation I was ecstatic.

I pulled up in front of his home, and again thought to myself, "Are you ready?" I trudged through the fresh snow, up his long walkway to his door. I knocked and immediately heard a dog barking. "Oh great!" I thought to myself. I love dogs and it was an easy way to break the ice. David opened the door and before me stood a middle-aged man with salt and pepper hair and a mustache much like my father's. He wore clean jeans and a sweat-shirt. He reminded me of a construction worker or someone who is not afraid to get his hands dirty. He invited me in and offered me a drink. The home was much like any other family home I have been in. Family pictures of his wife and children hanging on the wall, a blanket folded on the couch and dog toys in the living area. We sat at the oak wood kitchen table and started to chat. Conversation flowed smoothly other than interruptions from the very friendly dog, looking to be petted or to sneak me a quick kiss. David initially seemed uneasy, sitting back in his chair with his arms folded across his chest. I explained the research once again and told him he was under no obligation to participate. He agreed to take part, and while he did not say it, I felt that knowing he could withdraw at any time may have made signing the consent easier. As we wrapped up the paper work he said, "I have no idea where to start." While I got the impression he was worried about focusing his story to meet the objectives of the study, I also felt that maybe he had never told his story before. Was David a person who kept to himself? Did he never feel the need to tell his story? Or did he not want others to know his story?

As David started telling me his story I was amazed by how adventurous he was. When he was 15 years old he quit school and started traveling the world. He attempted to hitchhike across the USA at 16 years old before backpacking through Europe at 17. He described himself as having "no fears." "There's a few people in the world that have no fear at all, like they put a gun in their face and they don't get scared and stuff. I'm not like that but not very far, never been scared of anything." His comment shocked me. Is it possible for people to have no fear? Even if physical events do not scare a person, are emotional situations scary? I wonder if showing no fear was a defence mechanism for David.

Around the time David's fears began to dwindle, his personality and mental health were changing. "At 12 years old I remember still that I wanted to die, you know, because I have been depressed all my life you know, and I was a very sensitive person and stuff so at 15 I put that all aside and I became a hard person to hide all those … [4] When you're 12 years old and you are thinking suicide, something's not right with your brain and stuff like that." His words were hard to hear. My heart broke for that 12 year old boy. What was it like for him to have such powerful

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[4] When pieces of the transcript have been removed it is indicated as "…"
When there is a pause for thinking it is indicated as "… . .. …"

feelings at such a young age? I wonder who he turned to for support. I began to think of my 12 year old self. I was just getting into make-up and boys. I was heavily involved in sports and loved laughing with my friends. Suicide was never a thought that crossed my mind. As I look back, I wonder how many of my peers felt as David did.

It did not take long for David to begin to open up to me and sharing different aspects of his life and his experiences. He would first share only a few details but as our conversation progressed he opened up more and more. David said he felt comfortable with me, but I also wonder if he was opening up because he finally had the opportunity to tell his story. “Most of my problem is because I hated my dad so bad in those years that I wanted to do bad things to make him look bad … If I would have succeeded my dad would’ve been happy. So to displease him to … . .. … every time I was gonna succeed I would fuck it up but because I started to do that around 15, 14 too because I was mad at my dad because I thought he was bad to my mom … so every time I was starting to get better unconsciously I was doing stuff to fuck it up.” As David told me this story he paused multiple times, maybe to collect his thoughts, but maybe to reword things to avoid telling the whole story. As our conversation progressed the pauses and silences were filled in.

“I have an uncle that abused a girl and this, like that was all over the place with the Catholic Church, the abuse, and me, I saw that at 12 years old, they forced me to go and do my confession. You know when you … . .. … had to, and I said why would I want to be in a religion, and I’ve been abused by a brother in the summer you know, and things like that … and then my cousin [name], his dad and my uncle … . .. … He phones home and his dad came and got him but my dad wouldn’t come and get me, and that’s when I started to be really mad because I felt he was responsible for what was happening to me, and they were hiding all the bad shit and stuff you know and then yeah I got really, really mad and then I was … . .. … Still I was 28 years old and then I did my therapy you know and then I understood that religion has nothing to do, it's the man behind you know that's the problem … Maybe that's what made me so depressed, and then it escalated … Twelve years old and I already knew I thought the world is fucked up … I discovered pot around 15 ... but then at 17 got into cocaine and then drinking in 19 and then by 21 I was just a mess … You know sometimes I think did I become mental, crazy because I did drugs, or did I do drugs because I was mentally sick?"

As David told this story it reminded me of the many of times I have heard similar stories of abuse, mental health and addiction. This is a story that has been shared with me throughout my years as a registered nurse when I worked in correctional facilities and as an STI nurse. It was also a story I encountered in my years as a teacher. This story runs through all walks of life, all income levels, all ethnic backgrounds, both genders and all age groups. It is a story that makes me sad and angry. It stirs my emotions. I question how as humans we can do such terrible things to one another, and to children who are looking to adults to protect them, not hurt them. I thought about how often I have heard of these "secrets" not being dealt with but forced into silence instead. How that silence festered into sadness, depression, drug use and crime. The silence and secrets that can cause a person to have walls built around them for protection, and addictions necessary to ease the pain. I wonder what I can do to give these secrets and silences a voice. I reflect on past patients, and I hope I did enough to let them know that I was willing to give voice to their silences.

When David shared his story of summer camp with me some of the pieces of his life puzzle began to make some sense. His hatred of his father, his severe depression and extreme mania, his addiction, the anger he described as a teenager and his lack of fear. "In '89, '90 when the Hell's Angels were moving quite a bit on our turf there and I had been the guy [drug dealer] for 10 years … so Hell's Angels wanted me to work for them. I didn't want to work for them … But a good friend of mine close to the Hell's told me because they were going to kill me to make an example to scare the others to get them to fall … I said come on, killing people for drugs? Just friggin' ridiculous, and not being scared of anything … A striker got into a fight and beat the shit out of some guy and then I said I don't fuckin' care. But then [a friend] came and told me, Dave she said, don't sell not even a five dollar bit to help a friend because they'll know and then I got out." David described his history of drug dealing and how he got out of the trade so nonchalantly. I cannot imagine what it would be like to know that a group of people wanted me dead and for me to not care.

David described the person he used to be as uncaring, yet some of the stories he told proved otherwise. At one point in his life, to escape his chaotic life of drug dealing and addiction he drove to a South American country where he volunteered his painting skills at a local orphanage. He recalled, "that was a big change in my life because I saw really people that had nothing, not even a bucket and so poor but still smiling." He fights for social justice and for everyone to feel loved and accepted. "I trust too many people in my life … I always give people the benefit of the doubt … You know if you want to talk bad about others, clean your yard you know? That's as simple as that. Now you see how I get like I hate prejudice, I hate … . .. … you know generalization, like it's totally contrary to my intelligence … Stigmatization, it just makes me crawl." He also described how he came to peace with his father. "At 28 I did my therapy, I understood that … .. ... earlier, my dad gave me what he thought was right. That's it. He was raised in that way, and he thought that was the way, take your belt out, put the pants down and you know. But he got so mad. And then some day you realize that he just gave me what he thought was, he can’t give me things he didn’t know about.” David has such a compassion, understanding, and acceptance for others. I wonder if this acceptance comes from being the victim of generalizations and from experiencing injustices.

He told me a story about the time he broke his leg and had to stay with his parents for two months. During these two months he had the opportunity to spend time with his dad and get to know him a little better. “Dad said you know it’s almost a good thing you broke your leg because we didn’t know each other anymore. So I got to spend that summer with my dad … Yeah, and he was quite happy that I had succeeded because I was a black sheep you know and stuff and then I ended up with five kids and good company. So he was happy.”

Could I forgive someone that I felt so hurt by? Do I put myself in the shoes of others as David does? How often do I catch myself generalizing and stigmatizing others? What assumptions did I make about David before, during and after our conversations? One assumption that I made about David is that the decision to get testing for HIV was not an easy one to make and that mental health is one of the biggest drivers in his life. “You know, every morning getting up and you just wish you wouldn’t wake up. Like you wake up in the morning and you’re scared and have panic attacks, just like you can barely function but you still have to function because you got all these people you’re looking after, you know, the kids to feed and the one that’s in school. Then you just keep thinking you’ll be strong enough you’ll get through it.” It would be exhausting to have to pull from your deepest inner strengths every day just to get through. David and I had a conversation that left my mind filled with questions.

> David: In ’09, ’08, and I’m depressed by then, I was being safe, like I was quite happy when I got only hep C. You know like I was a junkie during the AIDS epidemic and all that. I have friends that died from it. So that’s why in ’98 I thought I should get checked,

and then it came out I only had hep C and I thought holy shit I'm lucky you know because we shared needles, and from the early '80s to '84, '85. So I was really very careful and stuff, but then being all depressed and stuff it's like you almost wish to get sick to die.

You just didn't care anymore?

David: Months at the bathhouse I didn't use protection and all sex. So that's why, like I didn't go often I think maybe twice a year ... Then I saw that you guys were doing testing there … Then a few months later I told myself next time I go I'll get myself checked.

What changed your mind?

David: I didn't want to infect my wife … My wife don't know by the way that I'm bisexual. She doesn't know I was at the bathhouse and that I got tested.

So, was there like a sense of a responsibility to her?

David: Yeah, oh yeah, that was definitely that because not that we had sex very often, you know, but, oh and things were getting better, you know, and I was getting better too mentally, finally I read so much about that manic stuff, and then finally, I was starting to have a better handle on it … and finally, it's like I stopped being out of breath 2 years ago about … and I stopped being mad at myself … I understood that mental health is a disease, and then I understood so many things all my life. It seems like I had been out of breath since about 14, 15 years old, … . .. …. Even still, I have a little bit of hard time to stay sane … Yeah so, the reason I went for the test that's why, I didn't want to even if I was really scared … . .. …, I have to, like I can't just risk to infect my wife.

David described a time in his life when things were not going well with his wife. At one point they did not have much money, his father had passed away, and he was very manic. “So by then that’s when I was kinda like everything falling apart and then you know. I had never went to the bathhouse and stuff and that’s when I started to go to the bathhouse.” It is so easy to just hear the portion of David’s story where he was having sex at the bathhouse without his wife’s knowledge, but when you hear the whole story, it is harder to pass judgement for me.

David’s responsibility for his wife was his motivation for testing. Did he want to know his status for his own well-being or was it solely for his wife? What changed that he stopped feeling mad at himself? I found his words “I stopped being out of breath” to be very powerful. As a nurse I need to recognise when my patients are feeling out of breath and needing support. David’s words, “Like you almost wish to get sick and die” also resonated with me. What is it like to want to get sick and die? David saw HIV as a slow suicide. I was curious why David felt dying of HIV would be more acceptable than dying through another form of suicide. Do other people see HIV as a means of dying like David did? I make the assumption that people would not want to become infected with HIV but my assumptions are wrong. I need to be more mindful of my assumptions and how the lives of my patients cannot be assessed based on how I think their life should go. I question my practice and how often I think I know what is best for my patient. I also question my assumptions about how HIV is viewed in the world, feared or not feared, prevented or even sought. I cannot help but question my assumptions that no one would want HIV, that everyone would want to prevent it and that everyone would want to be on treatment. While David seemed to not fear it for himself, he did feel a sense of the consequences of living with HIV as his main concern was protecting his wife. David’s mental health was a motive in his risk behaviours, but how often is mental health not incorporated into testing practices?

While David's motivation for testing was his wife, the choice to be tested at the bathhouse and by POC was one based on anonymity, convenience, and access to rapid results. He did not receive anonymous testing, as he used his real name, however, he did not want to see his family doctor and the bathhouse was a good alternative for him. "I mean like I didn't have to see my family doctor … a new family doctor I had here and small town you know and the thing is there too that they had the results right away." When David realized testing was offered at the bathhouse he thought, "gosh, that's a good place, you know. I thought that was a brilliant idea actually … Because most people at risk are there and those people like, you don't tell anybody that you go there. Lots of gay, but there's lots of bisexual men, married men and stuff like that, you know, so I thought, hey, if you're serious about your health or like me, it was for my wife, I thought that's the right place. Because you go see your family doctor it's a little more difficult." I asked David if POC had not been offered, would he still have been tested. He responded, "No … if I would have had to wait, the reason I chose that is so I could know right away. Then you can try to lie to yourself because it could be a false test, but that is stupid." I thought this was an interesting statement. My experiences with actual false positives were overwhelming for me the test provider. In both instances, I would have never thought the tests were indeed a false positive. I'm not sure that the patients would have thought so either. There were so many risk factors in both cases. When people test positive for HIV through POC do they have a sense that the test could be wrong? I know I include the possibility in my pre-test counseling but I wonder if anyone ever actually believes me. A positive preliminary result by POC is just as real as a positive result through standard serology. For David the result was just as real.

I asked David what those moments were like when the POC was positive. “Yeah she [the test provider] was talking and like I wasn’t there anymore … I saw it in her face … A face of a person that sees a positive test … A little bit shocked, yeah. Because I’m sure she doesn’t want to see that, you know … Sadness. That’s mostly what it is … Yeah I sat through and then you know she’s telling me. I’m trying to remember now like I can barely … . .. … there’s two of them. And then she has to give me some paperwork and stuff and I left. I’m trying to see, I can barely remember.”

“So after the POC came back with two blue dots, you said you felt sad.”

David: “Then scared, like scared to shit.”

It was interesting that David could not remember what happened in the moments immediately following the POC considering he is such a good historian. As a test provider, David’s inability to recall pieces of those moments spoke volumes to me. What information are my patients actually hearing? Maybe I should not bother providing information or education in those moments and provide support in the way of silence, holding their hand or giving them a hug instead. I can only relate it to the feelings I had when the doctor first told me he thought I had lymphoma. I know that HIV and lymphoma are not the same thing, but both are very life altering. My mind went blank, I do not remember feeling anything but fear. I do not remember hearing any information or asking any questions. I do not remember if I felt supported in that moment. I asked David if he felt supported from the health care team. He said, “But actually when I walked out that room there I felt like alone. Like I was like alone yeah, and I was like a zombie. Like I took my things and walked outta there and, like I said I drove my car back here and looking at that truck and maybe I should just fucking drive into it.”

"Did you feel like a zombie for the whole time between POC and getting the final results or was it just a couple of days?"

David: "No, it was a couple of days. You know I came home and like holy shit and the like … . .. … fuck you know I'll just deal with it."

"*What helped you get through that zombie mode?"*

David: "I don't know … I probably just did the usual, just went to work and just hate myself I'd say, he did it again."

"Did you feel a loss of identity at any point, like who am I, what does this mean for who I am? Did you ever question that aspect of it or was it, 'cause you were saying that you had some kinda negative self-talk after. Like why did I do this, why did I make those choices and those kinda things."

David: "Yeah, like it's, yeah you don't like yourself."

David's zombie mode reminded me of Chris who described those two weeks as living like a robot. Going through the motions of a daily routine but not actually feeling like he was living his life. David also described how he felt supported by the health care staff in the testing room but the minute he walked out he felt alone. I wonder if a person living with HIV had been present to provide David with peer support if he would have still felt alone, and if he would have still contemplated driving head on into a semi-truck.

David described the two weeks he waited for confirmatory results as "long." He waited to tell his wife he had tested positive until it was confirmed. "Yeah, even if you expect it's like it's still, and you go into a mode of shock I suppose … . .. … And then I was like in a dream kinda … . .. … kinda like, lots of sadness mostly that. Because I knew I could avoid that. I should have known better. I had Hep C, I've been so sick and I beat Hep C. I got two friends that died from it. I'm like shit, what's wrong with me, why? But then I knew it, it was like a suicide in slow motion … And I couldn't go back you can't. There's no way you can make it disappear now. So you start thinking about stuff and your kids and your family and mostly my wife … When two weeks later they confirmed it. Then I was driving back to here and I was crying and then quite like distraught I suppose you know. I'm driving I'm looking at big truck coming and I'm just thinking I should just drive in front of that truck and just put an end to that."

"*What made you not?*"

David: "My kids … . .. … Then when I had this thought start in my head was I didn't want my kids to say my dad committed suicide when I was a kid. So that's what kept me always to not do it mostly … I was telling myself well maybe that's the end of it. Like [my wife] will leave me and then I'll just end my life you know. But, no I wasn't thinking about that, but if I would get support … . .. … pissed off at me. And then I when I come from it, I'm driving then finally I phoned [my wife]."

"*And how did she take it?*"

David: "'We'll get through it' [said his wife]. Well I phoned her and then I'm kinda crying too and then I said you're not gonna want to see me ever. Like she was why, because I done something really bad. But she said that can't be that bad. And finally I told her I tested positive for HIV, and she goes well we'll get through it. We got through other stuff before."

David had always described his wife as a wonderful woman but as he told the story of her unconditional love and support the more I felt connected to her. I have never met her, yet I feel like I know her. As I looked around their home, there were pictures of her, a sweater on the chair, and her shoes by the door. I felt her presence in the house, but also her love in the words David spoke. How would I have reacted if I had been in her situation? How lucky David was for that support. And not just luck as I saw it but luck that he acknowledged as well. What made her react so calmly and supportively? Is it that she recognizes him as a good man and partner? What made her not ask more questions? What about their relationship allowed her to feel comfortable not asking those questions? It brought me back to thinking of secrets and silences. Is this a silence in their story? Is it unwavering trust, or is it that the secrets are not really secrets? Does she have knowledge that David is a bisexual male and accepts him the way he is? Does she think it is related to his previous drug use? How has what David told her impacted her life? As I think about his wife, it reinforces that HIV impacts more than just the person who tests positive. There are so many other people, variables, contexts and spaces in a persons' life that are all affected by HIV.

David and his wife are the only two who know he is positive. When I asked if his children knew, he responded, "Definitely not my kids. They don't know and I don't want them to know. They don't need to live that…I don't want them [his kids] to know because I know they wouldn't judge but they don't need to have to live that. I mean it's not gonna give them anything more in their life, I'm more like worried about my youngest one that's 19. You know like they deal with stuff … . .. … why would my dad do something like that. Like they know the story, they know I was a junkie and they knew I had Hep C and all that. I suppose it's more for me than them … Yeah, I went through all that shit and got out of it and then my life was finally and then bang I got myself HIV. It's like a failure. So it's probably more that like you know I don't wanna see me as a failure."

I could not help but wonder if a "failure" is how David fears his children will see him or is it how he sees himself. David is trying to protect his children from living with the fact that their father is HIV positive. While there is still a stigma around HIV, I am curious if David is more afraid that his children will ask more questions than his wife did? Questions he may not be ready to answer yet.

David told me the story of the time he almost told his children. "I almost did … . .. … around Christmas there we were playing that game and then a bunch of cards and then you know kids they still make fun of gay and stuff and then I thought to tell them because of that but I thought no but they don't have prejudice my kids mostly … But they would question it. They would question it, and why give them that? It's not gonna make them happier … . .. … It wouldn't solve nothing for them, and then even make them sad, so there's no reason for them to have that … As you grow older, you realize yeah there's things that are better not being said. They don't serve a purpose."

> *"Do you hear people talk and do you feel that there's a stigma around both being gay or bisexual as well as HIV, do you hear it?"*
>
> David: "Oh yeah. They think HIV is an old disease. The kids today they don't think that has anything to do with them … [Referring to playing a game with his kids] What came out to me he was like you're stupid if you get HIV today with all the information that's out there there's no reason. You're frickin' dumb you got yourself HIV? That's what they think. So it's more of an older people disease."

HIV is not just an "older person disease." If the message is being sent that because information on HIV is available, that people are no longer at risk, then it is the wrong messaging. HIV has many associated complexities and for David his mental health played a huge factor in his infection. It is not fair to say he is "stupid" for getting HIV. I could not help but feel compassion for David and wonder if those words were hurtful to him.

David was aware of my experiences with false positives POC while working in correctional facilities. David has been in jail in the past. Even though he was not in jail at the time he was tested by POC, he could speculate on what testing positive by POC in a correctional facility would be like. He said, "Yeah, you might as well not let them know what they have because they don't have any supports … There's too many in jail too that has mental health problems you know." David's comments made me reflect on my own experiences and the fact that I felt my support was not enough for my patients. Even if I inquire about supports or ask how a person thinks they might react to a positive POC prior to testing, can a person really predict how they would react?

David has been experiencing stigma his whole life around his sexuality. "Yeah like I had men, you know every 2,3 years."

> "*Up until this point had you ever identified as a bisexual male.*"
>
> David: "Yeah, but I was with my woman like you know. But I would say when I was like 17, 16 you know in the early 80's, like free sex in [province], and I had experience with other guys. I supposed I could've choose to be gay but I really didn't want to and I didn't want to be a gay person there's too much prejudice and stuff like that."

David could foresee the complexities of living as a gay man at a young age. I do not remember a single person in my high school that was openly gay. There would have been gay and bisexual peers in my school. I recall when a high school peer came out to his friends as being gay when we were in our 20's and he was accepted. Would he have had that same experience if he had been openly gay in high school?

I feel lucky to have met David and lucky that he chose to share a portion of his life with me. He provoked my thoughts and self-reflection.

CHAPTER 4

Publication

Point-of-Care testing for HIV in bathhouses:
A narrative inquiry into the experiences of receiving a positive preliminary result.

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Key words: bathhouse, HIV, narrative inquiry, point-of-care, qualitative, testing

In 2013, it was estimated that 35,000,000 people were living with HIV worldwide (World Health Organization [WHO], 2014). There are approximately 1,200,000 people living with HIV in the United States of America (USA) (Centers for Disease Control and Prevention [CDC], 2015). Men who have sex with men (MSM) account for approximately four percent of males in the USA (CDC, 2015). In 2010, MSM accounted for 78 percent of new HIV infections in males and 68 percent of all HIV infections (CDC, 2015). In 2011, 54 percent of all people living with HIV in the USA were MSM (CDC, 2015). Similar trends are seen in Canada (Public Health Agency of Canada [PHAC], 2012). It is estimated that 20 to 24 percent of MSM living with HIV are unaware of their status (PHAC, 2012). This has led public health officials to push for increased HIV testing, including point-of-care testing (POC) for HIV at unique locations such as bathhouses. The purpose of this study was to better understand the experience of people receiving positive preliminary results by POC testing for HIV while at a bathhouse.

Background Information

Bathhouses[5] are often frequented by MSM who wish to remain anonymous (Grov & Crow, 2012). Others attend bathhouses because they are “a sure thing” (Elwood, Greene, & Carter, 2003, p. 283). They are also places where men can go to be sexually free and do things that they would not normally do (Elwood et al., 2003). While there are many reasons MSM attend bathhouses, patrons reported a heightened sense of awareness about STIs, including HIV, as they assumed that anyone who frequented a bathhouse was more sexually liberated, took bigger risks, and had multiple sexual partners (Elwood et al., 2003). While there was an awareness of increased risk, levels of condom use still varied with men reporting an “intention” to use condoms, yet this was not always the practice (Elwood et al., 2003). Men also reported a

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[5] A gay bathhouse is a commercial space where men can engage with men in sexual encounters, not all men who utilize bathhouses identify as gay. Occasionally bathhouses have dedicated times for women.

greater willingness to have insertive anal intercourse without a condom (Elwood et al., 2003). While men perceived their partners to be high risk, they often underestimated the risk of their own sexual practices (Mayer et al., 2012). MSM who frequent bathhouses reported that bathhouses were often seen as "slutty or trampish" (Elwood et. al., 2003, p. 285) places to be. One patron reported leaving a bathhouse immediately if he saw an acquaintance, as he did not want to be seen as a bathhouse patron; this reinforces the need for anonymity within the bathhouse, which is no less true when POC HIV testing is being offered on site.

Rapid or POC HIV testing was first approved by Health Canada in October 2005; the approved test (INSTI HIV1/2 Antibody test, bioLytical Laboratories) is considered a second-generation HIV test and screens for HIV antibodies (PHAC, 2007).[6] Standard testing in Alberta is conducted at the Provincial Laboratory for Public Health (ProvLab) on serum samples using a test that screens for HIV antibodies and p24 antigen; this test is a fourth-generation HIV test which is more sensitive than second-generation tests. If no HIV antibodies are detected then the test is reported as negative (Alberta Health Services [AHS], 2011). With standard testing, a sample with a positive antibody on the screening test is then sent for confirmatory testing using the Western Blot and only then is the result reported to the testing clinician and shared with the patient (Alberta Health and Wellness, 2011). When a POC test is performed, a preliminary positive result is shared with the patient before the results of standard serological testing are available (AHS, 2011). This leaves the patient waiting for up to 10 days with the knowledge that his/her test may be confirmed positive or in fact be a false positive.

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[6] Definitions: Rapid refers to HIV results being available within minutes of testing. Point-of-Care (POC) testing refers to rapid testing done on site with a patient present.

A quantitative study was conducted at the Hassle Free Clinic in Toronto, Ontario to see if patients receiving POC HIV testing were more likely to receive results and post-test counseling than those undergoing standard testing (Guenter et al., 2008). The authors concluded that 100 percent of participants who were tested by POC received their preliminary test results and post-test counseling (Guenter et al., 2008). There were 22 preliminary positive results. Of those, 18 were confirmed positive and four were false positive. Three of the true positives and one of the false positives did not return to the clinic for confirmatory testing results (Guenter et al., 2008). Four people who were true positives and tested by POC returned for an in-depth interview. It is worth noting that stress during the waiting period for confirmatory results was substantial and made manageable by having received compassionate post-test counseling (Guenter et al., 2008). There is no way of knowing what presumptive positive or inconclusive results had on the wellbeing, anxiety levels, or risk factors of those tested by POC who did not return for confirmatory results (Guenter et al., 2008). In this current study we are interested in the experiences of MSM who have received a positive preliminary POC test result while being tested in a bathhouse.

Methodology

Narrative inquiry is a relational methodology that explores the experiences of participants and requires an ongoing relationship between teller and listener (Clandinin & Caine, 2013). Of particular interest are the experiences of participants over time, in social context, and in specific places; this is also referred to as the three-dimensional narrative inquiry space (Connelly & Clandinin, 2006). While conversations were shaped by both the participants and researcher, it was clear that they were not intended to be therapeutic, resolve issues, or answer problems (Clandinin & Caine, 2013). For Connelly and Clandinin (2006),

> People shape their daily lives by stories of who they and others are and as they interpret their past in terms of these stories. Story, in the current idiom, is a portal through which a person enters the world and by which their experience of the world is interpreted and made personally meaningful. Narrative inquiry, the study of experience as story, then, is first and foremost a way of thinking about experience. (p. 375)

Participants were recruited through the local STI clinic's outreach team in Edmonton, Canada. Posters were displayed in the local bathhouse, other community organizations that catered to the MSM population, as well as HIV/AIDS service organizations. Participants had to be at least 18 years of age and had tested positive by POC while at a bathhouse. Those excluded were anyone who may have already known they were HIV-infected when the POC testing took place. POC testing first became available in the recruiting area in 2012 when a pilot study was launched looking at the feasibility and field performance of dual use of POC syphilis testing and HIV testing in outreach settings (Bergman et al., 2013). At the time of that study, some participants who were already known to be HIV-infected, had a POC for HIV performed, and therefore, those participants did not meet eligibility criteria for this study. The STI outreach team routinely offered POC testing for HIV following the completion of the study.

Even though a small sample size was anticipated for this current study, recruitment was still a challenge. Overall, there was only a small number of people who had tested positive by POC in the catchment area. One of the reasons for declining participation in the study, given by potential participants, was that it was too in-depth and that they were not ready to share their experiences. Two men were recruited for this study and engaged in two to three conversations that lasted from one hour to almost five hours. Conversations took place in a location chosen by the participants, which included their homes or at the local university. Participants were offered a meal and $20.00 at each interaction.

Participants used annals[7] to document significant past events to help tell their stories. Each conversation was audiotaped and transcribed verbatim. The annals and audiotapes were used as field texts, in addition to extensive field notes. Based on field texts, narrative accounts were written for each participant; the accounts were then negotiated with them. Composing the narrative accounts provided an opportunity to establish veracity and ensure credibility by giving participants the opportunity to challenge interpretations and to ensure that these accounts reflected their experiences in ways that could be made public. Analysis was undertaken by reading and re-reading the field texts and narrative accounts. The analysis focused on identifying resonant narrative threads while paying particular attention to the three dimensional narrative inquiry space and the personal, practical and social justifications that are key to narrative inquiry (Clandinin, Pushor, & Murray Orr, 2007).

Ethics approval was obtained from the University of Alberta Health Research Ethics Board and organizational approval from Alberta Health Services. Participants were offered written and verbal information about the study. Written informed consent was obtained. To ensure confidentiality all names and identifying information have been changed.

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[7] In narrative inquiry annals are sometimes used to initiate data collection (Connelly & Clandinin, 1990). There is no expectation that events unfold chronologically or that the record of events is exhaustive. Events that are recorded might also not necessarily be connected.

The Lives of the Participants

As part of this paper we share parts of the narrative accounts negotiated with participants [I in these accounts refers to Shyla Genoway, the first author, who engaged directly in conversation with participants].

Chris

Despite wanting to participate in this study, Chris was challenging to meet up with and it took several attempts to connect with him in person. I met Chris for the first time at his house and was immediately drawn in by his personality – he was polite and talkative. Chris had been tested multiple times through POC while using his real name, yet at the time he tested positive, he used an alias. Recalling the moments waiting for the POC results Chris said, "*you sit there and they're telling you it's gonna be that rapid, so it really is like 90 seconds of questioning it, doubting it, what am I gonna do, and then it came back positive I guess I wasn't shocked. I guess I had expected something to happen at that point. After being around, going around as an escort, you know what I mean? ... Yeah, it's like you bite your nails. Why am I doing this, do I really wanna know if this is happening? No, this is a good thing, you're like this is something you're supposed to know, and this is the way society is today, everybody goes and gets tested is what I was thinking to myself."* Chris went from mistrust and questioning *"why"* to convincing himself that it was the right thing to do.

Following his positive POC Chris described having a *"breakdown"*. *"I guess what you do to yourself mentally. Let's say when you fail the test or you just don't make the grade, or you have a break-up from somebody, the different mental shit that you go through, tell yourself and treat yourself, or you start crying and get sad and upset and angry, and rip shit up and punch something ... like you aren't good enough, like what are you doing with yourself, and look what you did ... disappointment in yourself or that you would disappoint others ... No, I guess, in* *myself. I guess I don't really ever think about other people much. I'm more self-absorbed ... It was kind of heart dropping, but I guess at the same time it was somewhat expected. It's something that [pause] thought to say is that even though I'd never actually prepared myself for something like that, I had also prepared myself for it. You know what I mean? Like doing what I do and the lifestyle that I'm living, it made me think about that is, that this could eventually happen to you one day, right. And then it turned out that it did, it's kinda weird. But it really does make your heart sink because it made me realize I'm on some government leper list now."* Chris' voice was serious when he talked about the *"leper list"*; I wondered how he had come to learn about this list and if any health or social care practitioner had done anything to interrupt this.

David

My first phone call to David left me feeling unsure about whether he was willing to tell his story and whether he was going to participate in the research. He was polite on the phone but through his questions and silences, I also wondered if he was ready for me to hear his story. Eventually he agreed to meet with me face-to-face for a conversation.

I pulled up in front of his home, and asked myself, "Are you ready?" as I trudged through the fresh snow, up his long walkway to his door. I knocked and immediately heard a dog barking. David opened the door and before me stood a middle-aged man with salt and pepper hair and a moustache. He wore clean jeans and a sweatshirt. He invited me in and offered me a drink. The home was much like any other family home I had been in. Family pictures hung on the wall, a blanket was folded on the couch, and dog toys lay on the floor in the living area. We sat at the oak wood kitchen table and began a conversation that would last almost five hours.

As David started sharing his experiences with me, I was amazed by how adventurous he was. When he was 15 years old he quit school and started traveling. He attempted to hitchhike across the USA at 16 years old before backpacking through Europe at 17. He described himself as having *"no fears*". *"There's a few people in the world that have no fear at all, like they put a gun in their face and they don't get scared and stuff. I'm not like that but not very far, never been scared of anything.*"

Around the time David's fears began to dwindle, his personality and mental health were changing. *"At 12 years old I remember still that I wanted to die, you know, because I have been depressed all my life you know, and I was a very sensitive person and stuff so at 15 I put that all aside and I became a hard person to hide all those."* Mental health has been a constant battle in David's life. He experienced extreme mania followed by deep depression. At 28 years of age, he went to therapy to try and understand himself better. Therapy provided him with *"tools"* as he described it to help cope with his mental illness and the secret stories of his life. *"At 28 I did my therapy, I understood that [pause] earlier, my dad gave me what he thought was right. That's it. He was raised in that way, and he thought that was the way, take your belt out, put the pants down and you know. But he got so mad. And then some day you realize that he just gave me what he thought was, he can't give me things he didn't know about."*

David's decision to get testing for HIV was not an easy one. *"You know, every morning getting up and you just wish you wouldn't wake up. Like you wake up in the morning and you're scared and have panic attacks, just like you can barely function but you still have to function because you got all these people you're looking after, you know, the kids to feed and the one that's in school. Then you just keep thinking you'll be strong enough you'll get through it."*

David said, *"In '09, '08, and I'm depressed by then, I was being safe, like I was quite happy when I got only hep C. You know like I was a junkie during the AIDS epidemic and all that. I have friends that died from it. So that's why in '98 I thought I should get checked, and then it came out I only had hep C and I thought holy shit I'm lucky you know because we shared* *needles, and from the early ‘80s to ’84, ’85. So I was really very careful and stuff, but then being all depressed and stuff it’s like you almost wish to get sick to die.”* David’s experiences continue to stay with me, and I keep thinking about the many silences in his life.

Findings: Resonant Threads

Narrative threads are a way of looking at experiences as a whole while not fragmenting experiences into themes (Riessmen, 2007). These threads are composed around plots or subplots in the stories that make up experience. Narrative threads are often complex and difficult to disentangle (Clandinin & Connelly, 2000). Three narrative threads resonated across David and Chris’s accounts.

Resonant Thread: Seeing Complexities

Within the narrative thread of seeing complexity we recognized that it is important to consider the past and future, the role mental health plays, and also the significance of the testing environment.

Considering the past and future. The first time Shyla met Chris she was intrigued by his mistrust of the health care system, the government and the world at large. He had been captivated with conspiracy theories since a young age. He recalled a time he was named as a contact of someone who had tested positive for gonorrhea. He was given an injection of Ceftriaxone instead of the Cefixime pills. He recalled getting, “*a special shot for gay men.*” He said, “*Yeah that freaks me out, that added to my conspiracy thoughts.*” Following this experience, he mentioned a time he tested false positive for HIV by standard testing methods. While Chris was not clear on all of the details, it seemed he had received a positive enzyme immunoassay (EIA) followed by a negative Western Blot. Chris described his reaction to the false positive result, “*I thought wow this is stupid I can’t believe they did that to me. Does this* *happen a lot? People should be warned this can happen to them, I don't know if it happens a lot but it makes me kinda wonder now if that test had anything to do with me getting HIV, maybe they messed it up again or something, so maybe I was positive back then, you know you never know I guess ... Yeah, that was probably the beginning of me thinking that they don't know what they're doing 100 percent*."

Chris's past influenced his POC testing experience, as well as how he interpreted his surroundings, the health care team, the meaning of his results as well as his connection to care. Bhattacharya, Barton, and Catalan (2008) found that a misdiagnosis of HIV resulted in stress associated with re-adjustment and psychiatric morbidities such as depression, anxiety, and panic attacks. Testing positive for HIV by POC is more than a single moment in time, it is an experience that is shaped by previous experiences and an experience that continuous to shape future experiences.

Mental health. David has experienced bipolar disorder since he was 12 years old; he experiences severe highs and lows. He once said, "*At 12 years old I remember still that I wanted to die… When you're 12 years old and your thinking about suicide, something's not right with your brain.*" David described a time in his life when things were not going well with his wife. At one point money was really tight, his father had passed away, and he was very manic. "*So by then that's when I was kinda like everything's falling apart and then you know. I had never went to the bathhouse and stuff and that's when I started to go to the bathhouse.*" When the mania ended, the depression began. That is when he stopped practicing safer sex at the bathhouse. He said, "*being all depressed and stuff it's like you almost wish to get sick and die ... Months at the bathhouse I didn't use protection for all sex. So that's why, like I didn't go often I think maybe twice a year ... Then I saw that you guys were doing testing there ... Then a few months later I told myself next time I go I'll get myself checked ... I didn't want to infect my wife.*"

So many of the complexities of David's life shaped his testing experiences. He wanted originally to get HIV and die only for his deep depression to remit, and then he started to worry that he might infect his wife. When he received the preliminary positive result through POC, he contemplated driving his vehicle head on into a semi-truck, only to not follow through for the sake of his family.

Chris has also battled mental health although he did not recognize it the same way that David did. Chris once mentioned the "*string type things*" that he can pull out of his body. He said,

> *They're micro thin, and they almost look like hairs, you can see them sometimes when they're wet, or in the right sunlight. And they're like micro thin, they're really weird ... And I took one out and put it in a pop bottle, and I'm very aware of how these stories and stuff make me sound but I'll continue anyway. Is that I put one in a pop bottle and it continued to grow with no air, nothing, I put it up on the top of the cupboards for two months and it got longer and bigger. It's messed up, I don't know, it's something to do with I think that the government's trying to make me sick and stuff in the sense of pharmaceutical companies, I know they make money off of you if you're not healthy, right?... And I notice also that my body's become super sensitive to magnetic frequencies, like if somebody walks into the room the frequency changes and I can feel it. Or if your phone rings or we turn the TV on, any of that, it changes and I can feel it.*

Chris would often make statements like, "*I'm very aware of how this stories and stuff makes me sound*," yet he did not identify as having a mental illness. Chris stated, "*My mom thinks I'm crazy,"* and she sent him to therapy starting in grade five. Sending him to therapy happened after he began picking up radio frequencies with his teeth.

Mental health and substance use are a struggle for both David and Chris. They both experienced feelings of self-hatred following their diagnosis of HIV, and David contemplated suicide. These feelings seem to resonate across many research studies (Miles et al., 2011; Flowers, McGregor, Larkin, Church, & Marriott, 2011; Hult, Maurer, & Maskowitz, 2009; Martinez, Lemos, & Hosek, 2012; Morrison et al., 2011).

Testing environment. The environment in which testing is provided impacts the testing experience. David and Chris both thought testing in the bathhouse was an appropriate location. They said that the reason they were tested in a bathhouse was because a rapid preliminary result was available. Had it not been, neither was confident that they would have been tested. David liked that he did not have to see his primary care provider, while Chris took the opportunity to be tested using an alias. Using an alias comes with ethical concerns. While HIV is not a legally notifiable disease at the national level in Canada, most provinces and territories voluntarily report cases to the Public Health Agency of Canada (Hancock & Gustafson, 2014). In Alberta, Canada, although testing can be conducted under an alias, it is then required to report a legal name (Alberta Health, 2015).

Both Chris and David have spent time in correctional facilities. Although they were tested in the bathhouse, they expressed concern with POC testing in correctional facilities when asked. Chris said he could not imagine not having immediate access to support systems like family and friends. He also was concerned by the potential lack of confidentiality and lack of information available regarding HIV. Confidentiality and fear of its breach, as well as fear of the stigma attached to an HIV diagnosis, remain barriers to testing for HIV, especially in a closed setting (Braithwaite & Arriola, 2003). David was able to cope with his diagnosis because he was able to access information through the Internet immediately following his positive test result. David was also concerned with the lack of support in a correctional facility. David's wife was very supportive when he told her he tested positive for HIV she responded by saying, "*We'll get through it... We got through other stuff before.*" Being able to talk with his wife following POC testing was important to David. While both men were concerned with the potential lack of confidentiality with POC testing in correctional facilities, neither mentioned it in relation to POC testing in bathhouses.

Resonant Thread: Recognizing Secret and Silent Stories

Silent stories are the ones we leave untold or that are silenced because they are never heard. While silent stories resonated throughout both Chris's and David's narrative accounts, the secrets and silences in David's life stood out the most. As David chose to share stories with Shyla, silences were slowly voiced. At first he just mentioned "*I hated my dad*", as the conversation continued Shyla learned that when he was a boy at summer camp he was sexually abused and his father refused to come and pick him up. He felt the abuse was his father's fault. As Shyla's relationship with David grew, she came to know a life that seemed so full of secrets. The secret that he was abused at camp, the secret of the pain and anger he kept locked away, the secret that he was a bisexual man and the secret that he is living with HIV. David has always known he is bisexual but that is a secret that no one else knows.

David continues to live new secrets as well, as no one except his wife knows he is living with HIV and how he became infected remains a secret even from her. He described hearing his kids use the saying, "*Oh that's gay*" and how they expressed that if a person becomes HIV-infected nowadays it is because they are *"stupid."* As Shyla listened to David she could not help but think about how hurtful those words must have been to him. He said he would never tell his children he is living with HIV as he does not want it to burden them and that they would have too many questions. His status is both a secret and a silent story. The fear of stigma and discrimination from others has led many people living with HIV to live in secrecy. These secrets lead to emotional strain and the erosion of support systems (Miles et al., 2011).

Chris's secrets and silences were the opposite of David's. Chris is very open about his sexuality and that he is living with HIV. His secrets and silences are heard in relation to his mental health. Chris would often make statements like, "*I'm very aware of how these stories and stuff make me sound*," yet he did not identify with having a mental illness. Chris stated, "*My mom thinks I'm crazy,"* and she sent him to therapy starting in grade five after he had said that he was picking up radio frequencies with his teeth. Chris stopped sharing his stories about conspiracy theories, being able to pull strings out of his body or picking up radio frequencies because he was tired of people calling him *"crazy."* He stopped sharing stories that others may interpret as *"crazy"* or delusional, yet he lives this reality every day. Mental health is the product of a complex interplay between genes and environment, and between the individual and society (Lewis, 2013). When Chris tried to voice his experiences, the reactions of others, including health care professionals, silenced him. Chris's experiences have silenced his ability to address his mental health and have left him distrustful and subsequently disconnected from care for his HIV.

Resonant Thread: Connections to Care

Both Chris and David have been connected to care at some point, yet neither is currently on medication. Chris went to the HIV program once and never went back again. He has conspiracy theories about health care and pharmaceutical companies. At one point he said, "*I believe that whatever they call HIV I have it.*" This was surprising to Shyla, who wondered: Did Chris identify with his diagnosis? Does he think he has been told he has HIV so the pharmaceutical companies could make money off him? Over time Shyla learned that Chris chose to do his own form of treatments. He attaches electrodes over his veins on each of his wrists and plugs them into a battery. The electricity is supposed to cleanse his blood. Chris makes and drinks what he believes is colloidal silver. When Chris received his preliminary positive POC results, his perception of health care and western medicine influenced how he viewed his HIV diagnosis. Chris also viewed his diagnosis as placing him on the governments *"leper list"*: a list of outcasts. Chris's experiences with the health care system have led him to not seek further treatment. When he went for his first appointment at the HIV clinic, he felt like he was not being listened to and his concerns were not being addressed.

David is connected to care. He attends regular appointments but chooses not to be on ARV medications due to the possibility that the medications could affect his mental health. He finally feels mentally stable and is afraid the medication will disrupt this.

Discussion

The narrative threads that resonated across David's and Chris's narrative accounts are: (a) seeing complexities, understanding testing decisions in relation to time, place, and social context; (b) recognizing the impact and significance of secret and silent stories; and (c) tentative and tension filled connections to care. While these narrative threads resonate across the accounts, it is also important to recognise that David's and Chris's experiences are shaped by public health policies that reflect the influences of neoliberal discourses in HIV prevention, care, and treatment. Testing for HIV in Canada is voluntary and there are clear benefits to early diagnosis, including a modification of behaviours that would limit HIV transmission and the option to access care and treatment. Chris strongly feels a societal expectation that his HIV status is "*something you're supposed to know"*. While Chris does not specifically refer to the MSM population in this statement, it is of interest to note that POC testing offered in bathhouses reflects a practice whereby "a neoliberal actor specific target community is identified, one that warrants more aggressive and advanced surveillance" (Gagnon & Guta, 2012, p. 479). Targeted screening is not unique to the MSM population. It is also seen in prison populations and with individuals from HIV endemic countries who are at higher risk for HIV and with reported higher HIV prevalence (PHAC, 2012). This approach of targeted testing links risk or risky behaviours with a need for surveillance in particular populations and places, and an onus on taking personal responsibilities. Here the only interest in practice is in identifying infected bodies, or bodies at risk. As seen in David's and Chris's experiences, there is little to no interest in their individual identities or life histories. In their experiences, the central focus is to identify contaminated bodies: bodies at risk for infecting others.

Chris subjects himself to repeatedly being tested, using both real names and an alias. David wanted the anonymity and lack of connectedness that POC testing in the bathhouse offered him. Both Chris and David perceived themselves as being "at risk" and it shaped why they engaged in POC testing. Neither of them voiced any expectations of care that reflected recognition of their narrative identity. Instead, they both live their story of being at risk silently. Even as Chris doubted his choice of engaging in the test, he did not turn back or walk out as the test was being performed. This called into question whether he was adequately prepared to undertake the test and if there was a real opportunity to re-consider the test. We are, like Gagnon and Holmes (2008) stated, troubled "with the violence of so-called rational knowledge that manipulates the individual to conform with diagnostic practices such as routine HIV testing" (p. 272).

Looking backwards across their lives, David and Chris took responsibility for being members of at risk communities; they situated their risk in their personal behaviors and hence felt an obligation to engage in testing. Neither of them voiced concerns about their own understanding of risk that "shape their lives according to a moral code of individual responsibility and community obligation" (Miller & Rose, 2008, p. 105). Interestingly, it has been identified that "HIV testing is the most important technology through which the virus is personified in an epidemic that is as infectious as it is political" (Gagnon & Holmes, 2008, p. 272). Neither David nor Chris raised any political questions as they recounted their experiences. While Chris was uneasy during the testing period and doubted that his engagement in POC testing was meaningful, he also had a sense that he was a good person by engaging in POC testing. For David it was important that others saw him as deserving; undergoing the test indeed affirmed that he cared about those with whom he engaged in sexual relationships, irrespective of his HIV status or sexual choices.

As the Public Health drive to reduce undiagnosed HIV infections through increasing rates of HIV testing continues, it is critical that the individual and his/her psychological and social needs are not forgotten (Flowers et al., 2011). In 2000, the British Columbia Centre for Disease Control suggested investigating patients' experiences of coping with positive preliminary results and then having to wait for confirmation, as well as providers' experience of disclosing such results (Elliot & Juergens, 2000). A report completed in 2010 by the BC Centre for Disease Control showed that there have been no studies examining the psychological impact POC testing has on clients (Gilbert, 2010), despite previous recommendations. Chris's and David's experiences show the depth of psychological impact of a positive POC test. David thought about suicide immediately after leaving the bathhouse where he was tested, while Chris was clear that he was now placed on the "*leper list.*" Both David's and Chris's reactions may also be called forth by standard HIV testing, yet access to resources such as counselling may be more challenging in settings such as a bathhouse. David and Chris teach us that testing cannot ignore their larger social vulnerabilities and experiences. Listening to their experiences closely, the link between fear, stigma, and the social environment becomes evident. For David this reinforces and shapes his secret and silenced stories, while for Chris it reinforces his conspiracy theories and ultimately his choice to engage in non-western medical care.

While there is a Public Health push to identify HIV-infected bodies by targeting the MSM population, health care professionals cannot ignore the long standing support for POC testing from the MSM community themselves. Both Chris and David expressed that they received testing specifically because a rapid result was available. Neither was sure that they would have been tested for HIV if POC were not an option. Acceptance for POC testing in the MSM population was found to be exceptionally high in the Bergman and colleagues (2013) study, where acceptance and consent to POC testing was 91.3 percent in the MSM population at the bathhouse.

David's and Chris's experiences are embedded within life histories that raise questions about adequate support, follow up and counselling when POC tests are administered in bathhouses. As we contemplate David's and Chris's experiences we wonder whether communities are willing to invest additional resources in HIV care, treatment, and prevention, or whether interest extends only to identifying, containing, and managing "risky bodies". Moore and Fraser (2006) argue in relation to harm reduction that, "neoliberal discourses downplay material constraints on individual human agency, divert policy and practices away from structural issues, limit the conception of effective strategies for harm reduction and ignore alternative formulations of the subject" (p. 3035). HIV POC testing practices appear similar; perhaps more troubling, however, is the "generalised move by educators and doctors into a regime of self-surveillance, discipline, and punishment" (Holmes & Federman, 2010, p. 70) in the field of HIV. We are reminded of Chris's talk about being placed on a "*lepers list"*. This is reminiscent of the early days of HIV where words such as plague and discourses of contagion were prevalent. These discourses are damaging to MSM communities who engage in bathhouses and may increase the public's fear of communities that are marked publicly as being different. This notion of being different triggers ongoing surveillance, while ignoring the experiences of those who engage in POC testing in bathhouses.

Recommendations for Practice

For both David and Chris the bathhouse was an appropriate place for POC testing, appropriate because of the anonymity and convenience it offered. However, instead of just identifying "risky bodies" through POC testing, care providers also need to acknowledge the ongoing life contexts, vulnerabilities, and experiences of clients. In part, this can be achieved when providers who engage in POC testing ensure that "the 5 C's of good testing practices always apply; informed Consent, Confidentiality, Counselling, Correct test results, and Connection to care" (WHO, 2012, p. 8) are in place.

It is critical to assess clients' support systems and their personal needs as part of anticipating a positive POC. Neither Chris nor David mentioned community or peer support being present or readily available to them in the bathhouse. When Chris reflected on what he thought health care providers could do to make the testing experience better, he replied, *"Honestly, I'm not even really sure that there's any sort of thing that they could implement to make it more comfortable of an experience, or anything like that because it's such a hit and miss, and you have to initiate it yourself. I really do think that they're doing a great job for what they're doing, they're effective. If there was more supports, I'm not so sure that other supports could be initiated or anything like that."* While Chris was unsure if further support would be of value, peer[8] support was shown to empower people newly diagnosed with HIV (Peterson, Rintamaki, Brashers, Goldsmith, & Neidig, 2012). David recalls feeling supported while in the

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[8] "Peer" refers to a person living with HIV.

testing room but the minute he left, he felt alone. While AIDS Service Organizations are currently involved in the delivery of POC testing in the bathhouse, their role could be more pronounced. Given David's and Chris's tentative connections to care, perhaps early connections to peer support could enhance stronger links to care.

Study Limitations

Narrative inquiry provides no final story or one truth, and insight can be obtained through ongoing inquiry (Clandinin & Caine, 2013). Narrative inquiry is not meant to generalize, but rather it allows for the intimate and in-depth study of individuals' experiences over time and in the context of temporality, sociality, and place (Clandinin & Caine, 2013). Chris and David have unique challenges and are not necessarily representative of the greater MSM population who receives positive POC testing results in a bathhouse. Chris's paranoid and sometimes delusional thoughts have greatly affected his testing experience. David is a bisexual, married man who is "closeted," allowing his life's complexities to also influence his testing experience.

Conclusion

With a call to increase the accessibility of HIV testing in Canada, POC testing for HIV is being readily adopted and supported by at risk communities. The WHO (2012) outlines the importance to protect the human rights of those being tested. Bathhouses promote testing for HIV among higher-risk groups. In this paper we show that it is important to understand testing experiences across time, place, and in diverse social contexts. These experiences are embedded within life histories of people that raise questions about adequate support, follow up and counselling when POC tests are administered in bathhouses. It is also important to understand that POC testing is influenced by policy and public health discourses that are shaped by neoliberal agendas. To work in constructive ways with these influences, it is important to further engage communities at risk, such as the MSM community.

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CHAPTER 5

Conclusion

In this chapter I will build on the narrative threads and highlight the personal, practical and social significance of the research I undertook. Attending to these three justifications is key to any narrative inquiry and helps to answer the questions "so what?" and "who cares?" (Clandinin, Pushor, & Murray Orr, 2007). Recommendations for future research will also be provided.

Looking Backwards

Since engaging in this narrative inquiry, I have reflected on my own nursing practice often. I have personal experiences with providing POC testing in correctional facilities and I have had to work through having two patients test false positive by POC. Recognising the challenges many people face when living with HIV, I was glad that neither patient had confirmed positive test results. At the same time, I could not help but feel guilty for the emotional rollercoaster each one of them experienced during the diagnosis and wait time for a confirmatory diagnosis.

Meeting with David and Chris as part of this inquiry taught me a lot about the testing experiences. Among the most significant learning for me was to understand both of them in their complexity and to see testing as only one of many of their experiences. Their lives have been shaped by experiences over time and their current experiences will continue to shape their future experiences. By attending to David and Chris, I learned what Dewy (1938) has meant by his criterion of continuity – recognizing this, I am more mindful of how the testing experience shapes future engagement in care. David's and Chris's lives are complex with many secret and silent stories. In my past practice, I have been less attentive to these silent and secret stories. I did not ask or consider how these experiences shape people's engagement with POC testing and subsequently with care.

I too still think about how different the motivation for testing was for David and Chris from the assumptions I had carried of why people engaged in testing. For David this motivation was connected to the care he had for his wife, who did not know that he was bisexual. I wonder how David continues to make sense of telling his wife about his HIV diagnosis, yet not disclosing so many other aspects of his life. I wonder what questions his wife carries. While knowing David's motivations to engage in testing were important to his stories of testing, I too was deeply concerned when he told me that he had considered driving head-on into a semi-truck after he received his preliminary results. I am aware that knowing David's story will make me attend differently to the patients I will see in my practice. I will wonder if they like David, are devastated by their diagnosis and will contemplate self-harm.

Being alongside David and Chris has opened up new ways of understanding for me. I now look at the people who are close to me and wonder about the stories we share freely and the experiences each one of us holds silent. In close conversations with Chris, I realized that I hold preconceived notions of care and what that might look like in our lives. I worried about him and I was struck how much it meant to me, when he said he was proud of me. For the first time I considered that patients also care for us as people. Who I am and am becoming in their unfolding stories matters, and it too matters in my own professional and personal life. David challenged me to see beyond the ordinary and how life sometimes evolves in unexpected ways. It was perhaps David's wife who made me think about unconditional love and how significant others are to our experiences.

Re-considering Practice

This section is divided into two subsections which are: 1) testing environments; 2) testing using an alias.

Testing environments. The environment in which testing is provided affects the testing experience. David and Chris both thought testing in the bathhouse was an appropriate location. They both also said that the reason they were tested is because a rapid preliminary result was available. Had it not been, neither was confident that he would have been tested. David liked that he did not have to see his primary care provider. He did not want his primary care provider to know that he was bisexual or sought sexual engagement in a bathhouse.

Both Chris and David have spent some time in correctional facilities and expressed concern with POC testing in correctional facilities. Chris said he cannot imagine not having immediate access to support systems like family and friends, as well as access to information regarding HIV. He was able to cope with his positive POC results he received in a bathhouse setting because he was able to access information through the Internet. He described feeling like a "robot" in the days following his positive POC. He was also concerned by the potential lack of confidentiality in correctional facilities. This is similar to findings in the Miles, Isler, Banks, Sengupta, & Corbie-Smith (2011) study where one participant who had tested positive for HIV while in prison said, "So you keep your mouth shut. If you tell, you'll be ostracized and left alone. If you don't tell you are alone" (p. 494).

David was also concerned with the lack of confidentiality and support in a correctional facility. When he received his positive POC result he described feeling "scared" and like a "zombie". He also expressed concern with the number of people in correctional facilities who have mental health concerns that may not be addressed and make it more challenging to cope with a positive POC test result. If additional and more extensive supports are not in place, correctional facilities may not be the best option for POC testing. Considerations of confidentiality and support directly affect nursing practices. As I listened to David and Chris I realized how important it is to ask what confidentiality and support mean to clients and that we cannot possibly know all that needs to be in place prior to testing for POC.

While I was unable to recruit people who tested positive by POC in prison settings, research is urgently needed to explore the experiences of being tested by POC in correctional facilities. This research is necessary so that appropriate support systems are in place and confidentiality is maintained. Confidentiality and support are of utmost importance for a person when testing positive for HIV (Miles et al., 2011). The WHO recommends that testing efforts must be accompanied by supportive social, policy, and legal environments to maximize positive outcomes and minimize the potential risks (2009). The WHO also recommends that confidentiality is ensured and that the pros of diagnosis outweigh the cons and adverse social consequences that can be prevented.

While both Chris and David stated that maintaining confidentiality in correctional facilities is important, neither mentioned concerns about their confidentiality in regards to their testing experience in the bathhouse. In more recent times, some bathhouses have ensured that POC testing is done in rooms or buildings adjacent to bathhouses and not directly in bathhouses, to decrease any possible visibility or stigma towards those who chose to be tested within this environment. Both Chris and David appreciated the convenience of being tested in the bathhouse. Chris used an alias while David was thankful he did not have to go to his family physician for testing. They also both expressed the desire for the rapid results although Chris described how he had to convince himself throughout the whole process that he had made the right decision.

A push for integrating POC testing in diverse environments is so more people know their HIV status and can be connected to care (Flowers, McGregor Davis, Larkin, Church, & Marriott, 2011). While knowing one's HIV status is critical, it still calls forth the question as to whether people want to be connected to care. Chris does not trust western medicine and is no longer connected to care because he felt that medical staff was not hearing his concerns. As nurses, we must work with the values, understandings, and assumptions Chris brings to the medical system and this work is also necessary prior to, during, and after POC testing. We need to ensure that people who test positive are able to remain connected to care and feel respected in their choices; this would mean that we broaden what I currently see as a very medicalised understanding of care. David chooses not to be on ARVs as he is afraid they may cause mental health problems.

Testing using an alias. Chris took the opportunity to be tested using an alias for his POC test. Although Chris could not recall his reasons for using an alias, I wondered if he was aware of the implications of using an alias. Interestingly, while considering the implication of using an alias, I began to wonder about how using an alias shapes the care of people who test positive. I also became aware that a person cannot have health care coverage unless a positive result is reported to public health under their legal name. This raises new considerations for my practice as a nurse, such as the ethics behind allowing aliases to be used if legal names must be provided for treatment. It also reinforces the need for pre-test counseling so patients can be made aware of this policy prior to testing if they choose to be tested using an alias. I was unable to find a policy or best practice on what information must be provided in advance of using an alias to ensure patients know that if they test positive, their legal name must be given in order to receive treatment. Within this context, I reconsidered the following statement made by the HIV Legal Network of Canada: "It would be a great mistake to dismiss the importance of respecting people's rights and the risk of discrimination, and it would be imprudent to rush the implementation of coercive measures when treatments are not accessible for many of those living with HIV" (Jürgens, 2006, p. 9).

Currently the province of Newfoundland and Labrador also has ambiguity around reporting practices when anonymous testing occurs (Hancock & Gustafson, 2014). A lack of health care insurance has also been shown to be a stressor for those who are HIV positive (Miles et al., 2011). There is a need to impact policy around POC testing so each person, situation and testing environment is adapted to meet individual needs. If we cannot meet the needs we may need to re-consider the technology and the contexts in which this is implemented.

The Social Context of HIV

As I engaged in this research project many questions of the social significance of POC testing in a bathhouse or correctional facility remain unanswered. What happens to the social relationships when testing is completed in a bathhouse? Does it send the message that because testing is there, that everyone is safe? When a person tests negative by POC do they understand that the test may present a false negative if they are seroconverting (PHAC, 2007)? Or is a negative test permission to not exercise safer sex practices? Is the technology seducing the provider and patient and offering a false sense of security and safety (Almerud, Alapack, Fridlund, & Ekebergh, 2008)? Are people forced to lie when they test positive and as they leave the care environment? What other mechanisms could we use to target this population? Does fear promote stigma or does a lack of fear promote transmission? A study by Miles and colleagues (2011) found that successful treatments of people with HIV supported an attitude of avoidance and denial as people infected with HIV were no longer visibly ill. As this current study did not include those who tested negative by POC, research needs to be conducted to understand the message a negative POC test sends when preformed at a bathhouse.

In 2000, the British Columbia Centre for Disease Control suggested that research be done to investigate patients' experiences of coping with positive preliminary results and then having to wait for confirmation, as well as the providers' experiences of disclosing such results (as cited in Elliot & Jürgens, 2000). A report completed in 2010 by the BC Centre for Disease Control showed that there have been no studies examining the psychological impact POC testing has on clients (Gilbert, 2010), despite previous recommendations. There is a strong need to explore the experiences of people at risk for HIV being tested by POC in unique settings. As the drive to reduce undiagnosed HIV infections through increasing rates of HIV testing continues, it is critical that the individual and his/her psychological and social needs are not forgotten (Flowers et al., 2011) or eclipsed by the brilliance of effective technology. Elliot and Jürgens (2000) state:

> because the information about Canadian HIV testing and the counseling that accompanies it is so skimpy, impressionistic, anecdotal, and sporadic, an assessment of the potential benefits and harms of rapid screening has to be speculative and uncertain. If rapid screening is introduced, as the key testing strategy for HIV, the experience with it would need to be carefully investigated, evaluated, and monitored. (p. 140)

Registered nurses in Canada are bound by a code of ethics that includes: providing safe, compassionate, competent and ethical care; promoting health and well-being; promoting and respecting informed decision making; preserving dignity; maintaining privacy and confidentiality; promoting justice; and being accountable (Canadian Nurses Association, 2008). In order to ensure these core values are met, all test providers need to reflect upon the uniqueness of the site at which they are providing POC testing. If appropriate resources are not available, an assessment of whether or not a rapid test should be completed needs to be done. Thinking about how different both Chris and David were in this study, I realize that not all patients have the same needs or wants and individual assessments need to be completed. For both Chris and David pre- and post-test counselling was important. Just because the test is rapid, does not mean that the counseling should be rapid.

Conclusion

While the results of this study are not generalizable to all testing environments, it is important to consider the questions that were raised and the understanding that the experience of engaging and receiving a positive POC test is distinctive and unique for everyone. No matter the environment, testing positive for HIV is never just a single moment in time. It is not just one point of time in one's life, rather it impacts subsequent and ongoing experiences. These experiences are also shaped by ongoing societal stigma and values, and are shaped by the environments in which they occur.

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