

The Crosstown Clinic: An Inquiry into the Experiences of Staff

by

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Abstract

This study examined the experiences, perspectives and opinions of people who work at the Crosstown Clinic in Vancouver, BC, Canada. The Crosstown Clinic is the only program of its kind in North America, providing injectable heroin and hydromorphone to people with an entrenched opioid addiction. The study utilized a qualitative methodology, interpretive description, with an underlying critical social theory perspective. Twenty-two staff members participated in open-ended interviews. Thematic analysis revealed seven themes: from chaos to stability, putting patients at the centre, it's not all roses, stigma hasn't gone away, the clinic is life transforming, a little preparation would be good, and the patients have a story to tell. Three papers have been prepared from the findings of this study. The first paper outlines the first six findings from the study and discusses the implications of each. The second paper is a discussion about how the theoretical perspective, critical social theory, relates to the methodology, interpretive description. The third paper discusses the issue of informed consent for people who use opioids. The findings from this study are useful to nurses who are interested in learning more about harm reduction and its potential impact on patients as well as coming to a better understanding of how to care for this patient population.

Preface

This thesis is an original work by Jane McCall. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta ethics board, as well as the Providence Health Care/University of British Columbia ethics board. Ms. McCall was supported by a Banting-Best scholarship from the Canadian Institute of Health Research. This thesis includes three academic papers that have been submitted for consideration in peer-reviewed research journals. Jane McCall lead the theoretical development and writing for each of the three papers. The papers are:

McCall, J., Caine, V., Estefan, A., & Phillips, J.C. (submitted). The Relationship Between Critical Social Theory and Interpretive Description: A Focus on Nursing. *Canadian Journal of Nursing Research*.

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Dedication

We need to tell our own stories.
If we don't tell our own stories,
 People with power
 will tell our stories for us.
And we won't like what they say.
When we tell our own stories,
 we reach out to each other
 and build community.

Sandy Cameron, 2018.

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CHAPTER ONE

Summary of the Research

There have been numerous publications over the past two decades examining the lives of people who use illicit drugs (Costenbader, Zule & Coomes, 2007; Fischer et al, 2005; Millson et al, 2006). It is apparent from these publications that life for people who use illicit drugs is difficult. They are more likely to be poor and insecurely housed and to have mental and physical health problems. People who use illicit drugs also have less education, and lack familial and social support networks (Laudet, 2015; Matto & Cleaveland, 2016). In addition, they almost always experience a sense of dislocation or disconnection from their identities and their sense of personal power, wellbeing and spirituality (Alexander, 2008). Compared to the general population, illicit drug users experience significant disadvantage (Galea & Vlahov, 2002).

Despite sustained attention to these aforementioned issues, there is one topic that has rarely been discussed and that is the utility of opiate assisted treatment (OAT) as an alternative to methadone and suboxone for managing addiction in people who use opiates. OAT has been available in Europe for a number of years (Fischer et al., 2002) but has only recently become a model of care in North America. The Crosstown Clinic in Vancouver, British Columbia is the only center for OAT in North America. Crosstown provides injectable pharmacy grade heroin and hydromorphone to people with recalcitrant addiction in a controlled setting under the supervision of nurses and physicians.

In this study I inquired into the experiences of Crosstown clinic staff. I hoped to reach a broader appreciation of the intersecting factors that influenced the health and well-being of the patients from the staff's perspectives and come to a clearer understanding of what the staff deems as appropriate care and treatment. The knowledge gained from this study can be used to help

providers gain insights into the issues that shaped their experiences at the clinic. Specifically, the findings can help providers gain insight into how patients experienced the clinic, how the clinic transformed the lives of both providers and patients, and the challenges of working at the clinic. The findings of this research add to the growing body of literature that can be used to support changes in current policy and programs that affect the lives of people who use illicit drugs. I have cared for patients who use illicit drugs for my entire career and have long since developed an attitude that harm reduction is an important aspect of treatment and care for this population. OAT is yet another step on the harm reduction journey and constitutes an effective harm reduction strategy that can be considered.

Problem Statement

People who use illicit drugs have historically faced many challenges including economic and social inequities, criminalization and stigma (Degenhardt & Hall, 2012). Many people who use illicit drugs have difficulty in many aspects of their lives as a result of the adversities they have faced. The complex adversities and challenges faced by people who use illicit substances are interrelated and lead to vulnerability and marginalization. People who are vulnerable are unable to withstand the effects of a hostile environment and people who use illicit drugs are undisputedly subjected to a hostile environment. They are subjected to a significant degree of stigma, from both the general population and healthcare providers (Lovi & Barr, 2009; van Boekel, Brouwers, van Weeghel & Garretsen, 2013a). Marginalization is implicated in sustained social disadvantage. People who use illicit drugs are more likely to be poor, to be insecurely housed, to lack social supports, and are more susceptible to blood borne infections such as HIV and hepatitis C (Ahern, Stuber & Galea, 2007; Cheng, Wood, Nguyen, Kerr & DeBeck, 2014; Degenhardt & Hall, 2012).

Canadian substance use laws have worsened the position of marginalization that people who use illicit drugs find themselves in by criminalizing their behavior. In general, people who use or traffic illicit drugs are subject to the Canadian legal system, with subsequent fines, a criminal record and/or incarceration. The numbers of people in Canadian prisons with a drug offence is significant: 14% of inmates in federal prison are serving sentences for drug offences (Correctional Services Canada, 2015). One in twenty offences reported by police are drug related (Cotter, Greenland & Karam, 2013). Criminalization has led to the proliferation of an illegal black market and its attendant social pathologies including increased transmission of HIV and hepatitis C, corruption, violence, crime, destabilization of governments, destabilization of world markets, criminalization of youth, family breakdown, and disrespect for laws (Haden, 2002). People who use illicit drugs die prematurely, have poorer health, and experience difficulties in accessing timely medical care (McCoy, Metsch, Chitwood & Miles, 2001; McNeil, Small, Wood & Kerr, 2014; Merrill, Rhodes, Deyo, Marlatt & Bradley, 2002).

As a result of criminalization, illicit drug use is highly stigmatized in society affecting health and access to health care (Lloyd, 2010; Room, 2005). The idea that addiction is a moral failing or a lack of willpower is deeply embedded in society (Copp & Mullet, 2009). There is an additive effect in the stigma that people who use illicit substances experience because they are also usually struggling with poverty, lack of social support, HIV and/or hepatitis C infection, and mental illness. Multiple stigmas are a burden for this population and these burdens form a complex synergy of material and social disadvantage (McGibbon, Mulaudzi, Didham, Barton & Sochan, 2014). In addition, stigma and living conditions associated with poverty and homelessness play a role in the development of health inequities for people already at risk for poor health associated with substance use. Stigma is related to delayed help seeking, decreased

self-esteem and social adaptation, and social isolation (O'Connor & Rosen, 2008).

The stigma associated with drug use is nearly universal. Few patients generate as much hostility among physicians and health care workers as people with addiction issues (van Boekel, Brouwers, van Weeghel & Garretsen, 2013b). The criminalization and marginalization of drug users is part of a 'cultural script' and reflects a historical ideation in which certain illicit drugs have been branded as eroding morality (Pauly, Goldstone, McCall, Gold & Payne, 2007).

In this dissertation research I addressed the central problem of how to establish appropriate, responsive and accessible programs that will ensure that people who use illicit drugs receive the care and treatment needed to achieve a state of health and well-being that they themselves perceive as optimal. My work provides an opportunity for the voices of care providers to be heard. Care providers are often the last people who are consulted about how health care is delivered, but this study, with its emphasis on how care can potentially transform patients and care providers, how staff are challenged in terms of the physical space they work in plus their lack of educational preparation, and the continued issue of stigma, allows the voices of care providers to be amplified.

Purpose of the Study

I used an interpretive descriptive approach to identify the contextual and constructed nature of the workplace experiences of the clinic staff. The design of the study allowed for the generation of new knowledge, insights and understanding about the barriers, challenges and successes that the staff face in their daily work-life. The findings from this study will inform future research in this area and provide insight – from the perspective of the clinic staff – into how to design and deliver services to best meet the needs of people who use opiates in a compassionate, ethical and meaningful manner.

The research objectives that framed this study were to:

1. explore and understand the experiences and perspectives of the staff at the clinic;
2. gain an understanding of the intersecting formal support systems, including Crosstown Clinic, hospitals and other health care organizations and how the patients' lives are transformed by their participation in the clinic;
3. make recommendations for program design and policy development within the context of OAT.

A Review of the Literature

The lives of many people who use illicit drugs are characterized by poverty, powerlessness and disconnectedness. They bear a significant burden of ill health, premature death and marginalization (Degenhardt & Hall, 2012). The intersection of these factors in the context of the lives of people who use illicit drugs, the relationship of these factors to the vulnerability and stigma that they experience and related literature are described below.

The historical context of addiction.

There has been an interesting evolution in the concept of addiction over the past three centuries. People of a variety of ethnicities and cultures have been using substances since ancient times to reach profound spiritual experiences or to just have a feeling of well-being. It is only in the last three centuries that this use has been construed as addictive. Prior to this time addiction was seen as just another human passion such as smoking, gambling, greediness for profit or sexual excesses (Molintas, 2006).

Towards the end of the 18th century, substance users were assumed to have a will and their misuse of substances was assumed to be of their own volition (Levine, 1978). There was a widespread acceptance of drunkenness that persisted until the 19th century and the rise of the

temperance movement. There was a substantial literature in both Latin and English about the astonishing properties of opiates and they were widely prescribed. However, in the 19th century, the addictive properties of opiates in particular as well as alcohol, became commonly acknowledged (Parssinen & Kerner, 1980). It was at this time that physicians started talking about the disease of addiction. In the 19th century, with the advent of the temperance movement, people who used alcohol and substance users, in general, were conceptualized as having a disease of will. The temperance movement had tremendous influence over public perceptions of substance use and ultimately convinced government that the evil of alcohol, with its propensity to enslave users and create problems for society, needed to be addressed. Prohibition was the result. The notion was that an intoxicating substance could cripple self-control and cause bad behavior. Over the course of the 20th century, the concept of addiction as a disease took hold (White, 2000). At this point, people themselves were blamed for their addiction instead of the substance. This concept, which is outlined in the DSM-V substance use disorder diagnostic criteria, has been widely adopted (Reinarman, 2005). The DSM-V outlines 11 criteria that can lead to a diagnosis of substance use disorder. These criteria include:

1. The individual may take the substance in larger amounts or for a longer period than was originally intended.
2. The individual may express a persistent desire to cut down or regulate substance use and may report multiple unsuccessful efforts to decrease or discontinue use.
3. The individual may spend a great deal of time obtaining the substance, using the substance or recovering from its effects.
4. Craving is manifested by an intense desire or urge for the drug that may occur at any time but is more likely when in an environment where the drug previously was

obtained or used.

5. Recurrent substance use may result in a failure to fulfill major role obligations at work, school or home.
6. The individual may continue substance use despite having persistent or recurrent social or interpersonal problems caused or exacerbated by the effects of the substance.
7. Important social, occupational or recreational activities may be given up or reduced because of substance use.
8. Substance use may occur in situations where it is physically hazardous.
9. The individual may continue substance use despite knowledge of having a persistent or recurrent physical or psychological problem that is likely to have been caused or exacerbated by the substance.
10. Tolerance is signaled by requiring a markedly increased dose of the substance to achieve the desired effect or a markedly reduced effect when the usual dose is consumed.
11. Withdrawal is a syndrome that occurs when blood or tissue concentration of a substance decline in an individual who had maintained prolonged heavy use of the substance. (DSM-V, 2013)

The addiction as disease concept is problematic; yet it is the dominant orientation among addiction health care professionals. There is some evidence that this orientation weakens perceptions of agency in relation to problematic substance use and does not reduce feelings of stigma and shame (Wiens & Walker, 2014). In my nursing career, this is the orientation I usually witnessed among my nursing colleagues. It was my observation that for patients, this perspective often left them in a state of despair because they were left to feel that their addiction was out of

their control.

In Canada, the first recorded use of opiates was in the 19th century among Chinese settlers. Opium dens became a common feature of life in Chinese communities across Canada. Initially the governments of the day viewed opium consumption as an easy way to earn revenue so they imposed a tax on opium factories in 1871 (Dias, 2003). By the early 1900s however, the government became concerned about the growing numbers of opium users and in 1908 they enacted the opium act, which made it illegal to import, manufacture or sell opium. The advent of these anti-drug laws had more to do with anti-Chinese sentiment than any concerns over the drugs themselves (Dias, 2003). With the imposition of this act, a black market for opium began to emerge and governments responded by criminalizing opium use. The laws that were created in response soon included a number of prohibited drugs including morphine, cannabis and cocaine (Canadian Centre for Addictions, 2016). Although there have been updates in the laws since then, with the most recent iteration occurring in 1996 with the Controlled Drug and Substances Act, the essential philosophy remains unchanged - drugs are bad and drug users are criminals. The act does allow for harm reduction strategies but the focus remains on enforcement and punishment. This criminalization is at the bottom of most of the negative consequences that most illicit drug users face.

Criminalization.

The criminalization of drug use leads to unjust incarceration, an increased risk of blood borne infections such as HIV and hepatitis C, and interrupts access to prevention and treatment (Rubenstein et al., 2016). Due to Canada's anti-drug laws, imprisonment became the traditional response to the purchase, possession for personal use and use of illegal drugs (Loue, 2003). Compulsory treatment became a common strategy in the 20th century but evidence indicates that

it is seldom effective at ensuring ongoing abstinence. There are no randomized controlled trials or observational studies that have shown that people who are compulsorily treated have better outcomes than those who are not (Hall, Farrell & Carter, 2014).

More recently, drug courts have come into operation. Drug courts are predicated on the idea that drug usage is epidemic and that addiction is treatable (Loue, 2003). As with compulsory treatment, evidence has revealed that drug courts do little to reduce recidivism in substance users, with many lapsing back into substance use at the end of their programs. There is no evidence that drug courts produce outcomes that are superior or even equal to the outcomes achieved by voluntary treatment programs (Anderson, 2001).

The major issue with criminalization is the attendant damage it causes. There has been a substantial global increase in the population of drug using prisoners as a result of failed prohibitionist policies (Das & Horton, 2016). In the USA, Eastern Europe, central Asia and South and South East Asia most prisoners are detained for drug related offences (Das & Horton, 2016). Prison populations have a higher prevalence and incidence of HIV, hepatitis C and tuberculosis (Dolan et al, 2016).

Despite the burden of disease, people who use illicit drugs and who are imprisoned are less likely to receive optimal clinical care and treatment for their infections. Structural barriers such as lack of staff with an expertise in addiction and lack of harm reduction programs, stigma, and insufficient resources impede the delivery of adequate care and treatment (Rich et al., 2016).

Addiction.

As noted above in the section on the history of addiction, attitudes about the origins of addiction have changed over the past three centuries. In the early years, substance use was not seen as an issue but over the course of the 18th and 19th centuries societies came to view it as

problematic. The most common definition of addiction at present is that it is a chronic, relapsing disorder that is characterized by the compulsion to use one or more drugs, an inability to control drug intake, and a continued use of the drug despite negative consequences (DSM-V, 2013; Pierce & Kumaresan, 2006). In the past decade, there have been an increasing number of publications that propose that addiction is in fact, a result of a biochemical process in the brain that causes homeostatic dysregulation, alters the hedonic set point, and activates a biochemical switch that leads to chronic drug use, craving and relapse (Betz, Mihalic, Pinto & Raffa, 2000). Although different drugs affect different brain pathways they seem to have a common effect on dopaminergic pathways, enhancing dopamine release in either the nucleus accumbens, the prefrontal cortex, or both. Dopamine release leads to activation of the reward pathways in the brain and subsequent feelings of euphoria and pleasure. It is hypothesized that illicit drug users have a compulsion to continue their use to experience these positive feelings (Betz, Mihalic, Pinto & Raffa, 2000).

There is some evidence that addiction is heritable and Davis and Loxton (2013) propose that genetic and environmental risk factors play a roughly equal role in the development of drug addiction. Several studies explored how genetic variations in dopamine availability influenced a person's predilection for addictive behavior (Le Foll, Gallo, Le Strat, Lu & Gorwood, 2009; Volkow & Muenke, 2012). Some studies proposed that people have a propensity for addiction because of a deficit in the brain reward system (Noble et al., 1994; Rogers & Robbins, 2001).

Environment also plays a role in the development of addictive behavior. There are both broad societal and cultural context factors, and also factors that lie within individuals and their interpersonal environments which have been documented to contribute to addictive behavior. Contextual factors include laws and norms that are favorable to addictive behavior, availability of

the drug, extreme economic deprivation, and neighborhood disorganization (MacLeod et al, 2008). Individual and interpersonal factors include physiological factors such as sensation seeking and low harm avoidance, family alcohol and drug behavior and attitudes, poor and inconsistent family management practices, family conflict, low bonding to family, early and persistent problem behaviors, academic failure, low degree of commitment to school, peer rejection in elementary grades, association with drug using peers, alienation and rebelliousness, attitudes favorable to drug use, and early onset of drug use (Ducci & Goldman, 2012; Vink, 2016).

Adverse childhood experiences.

When the environmental factors that influence a person's addictive behavior are considered, there is increasing evidence that adverse childhood experiences (ACEs) possibly have the most impact. People who report ACEs are 7 to 10 times more likely to report illicit drug use. People who have ACEs account for one half to two-thirds of people with serious drug use problems (Dube et al., 2003). There are a number of variables that make up the constellation of ACEs including abuse, neglect and household dysfunction. There is an expanding body of evidence that early abuse and neglect results in early life stress which can lead to enduring brain dysfunction (Anda et al., 2011). Early stressors cause long term changes in multiple brain circuits and systems.

Early life stress is associated with a dysfunction in dopaminergic systems. Given the key role that dopamine plays in a number of brain functions such as cognition, reward, emotion and motor control it is unsurprising that ACEs have such an impact on the developing brain and on a propensity for addictive behavior (Rodrigues, Leao, Carvalho, Almeida & Sousa, 2011). It is theorized that the lack of dopamine that is a result of ACE is one of the reasons that people turn

to substances. (Cami & Farre, 2003). Using illicit substances stimulates the release of dopamine and leaves the user with a sense of euphoria.

Environmental cues play a major role in determining how neurons will differentiate, sprout dendrites, create synaptic connections and activate the final neural networks that allow us to think, feel and act (Perry, 2002). Being subjected to childhood stress such as abuse or witnessing domestic violence can lead to a number of negative health outcomes including substance abuse, suicide attempts and depressive disorders (Kendler et al., 2000).

Stigma.

Stigma is one of the most pervasive barriers to help seeking (O'Connor & Rosen, 2008). A growing body of evidence shows that people who use, have used, or are suspected of using illicit drugs, particularly when this intersects with visible markers of poverty, homelessness, or mental health issues, experience high rates of discrimination, stigmatization, and social exclusion in the health care sector (Lloyd & Lloyd, 2013; Room, 2005). In particular, nurses and other health care providers have been found to hold negative attitudes toward people who use illicit substances (Browne et al., 2011; Pauly, 2008; Smye, Browne, Varcoe & Josewski, 2011; van Boekel, Brouwers, van Weeghel & Garretson, 2013b). Stigma can be understood as a difference in power relations in which one group has the power to name differences, label, stereotype, and stigmatize another group on the basis of certain characteristics or behaviors (Link & Phelan, 2001; Link & Phelan, 2006). More recently, stigma has been conceptualized as a structural or macro-level process intersecting with broader social discourses, media representations, and public and legal policies that influence and are enacted during micro-level interactions, with serious implications for health and well-being (Link & Phelan, 2014). Structural stigma is defined “as societal-level conditions, cultural norms, and institutional policies that constrain the

opportunities, resources, and well-being” of people and groups who are stigmatized (Hatzenbuehler & Link, 2014, p.2). Thus, structural stigma can be understood as deeply embedded in health and social system culture and norms and enacted consciously or unconsciously during health care interactions.

Stigma in health care can contribute to delays in access to needed health care services, avoidance of health care, mistrust of the system, and other factors that constrain access to timely health care services (McNeil, Small, Wood & Kerr, 2014; Merrill et al., 2002; Pauly et al., 2007; Rachlis, Kerr, Montaner & Wood, 2009). To avoid the harmful effects of stigma and stigmatizing processes, people who use illicit drugs may avoid or delay seeking care until they are severely ill, or may leave hospital against medical advice without completion of treatment. Thus, resulting in missed opportunities to reduce and prevent health issues and the need for more intensive treatment and longer periods of hospitalization later or worse, death.

Socioeconomic consequences.

Social factors accompany and exacerbate the health consequences of illicit drug use (Galea & Vlahov, 2002). There are correlations between social factors and illicit drug use. There is some evidence that illicit drug use is more likely to occur in socially vulnerable communities. People who use drugs are more likely to exhibit markers of social disadvantage, including mental ill-health, unstable employment or unemployment, unstable housing, and lack of social supports (Lea, Bryant, Ellard, Howard & Treloar, 2015).

The health of drug users is related to their social environment (Galea & Vlahov, 2002). Social environments impact on drug use and drug use impacts on social environments. And although such things as homelessness and poverty are considered to be the consequence of drug use, it is also true that these issues are the circumstances that are responsible for shaping health

differentials among drug users (Galea & Vlahov, 2002). Social determinants of health directly impact risk behaviors (Palepu et al., 1999). For example, homelessness among illicit drug users directly influences sexual risk behaviour (Kral, Lorvick & Edlin, 2000). Poverty has a direct and linear impact on health. Rates of morbidity and mortality decrease directly and proportionately with an increase in income (Adler & Ostrove, 1999). People who use illicit drugs are statistically significantly more likely to be poor and homeless; it is estimated that they account for 10-20% of homeless people in the United States (McCarty, Argeriou, Huebner & Lubran, 1991) and in Canada, 150,000 street involved youth who used illicit substances were homeless (Krusi, Fast, Small, Wood & Kerr, 2010). The poverty experienced by people who use illicit substances has a direct and negative effect on their health. People who use illicit substances and who are HIV infected are more likely to experience treatment failure as a result of unstable housing, lack of transportation and food insecurity (Kalichman et al., 2015).

The intersection of inequities.

People who use illicit drugs face a powerful constellation of inequities that are inextricably linked with their social positioning in relation to the dominant society. They are at increased risk of poor health because of these intersecting issues, including: relatively low levels of education, poverty, homelessness, marginalization, stigma, and substance use. These issues are so tightly bound together that it is difficult to understand one without reference to the others (Collins, 2000). Intersectionality is an analytical perspective that considers the confluence of multiple identities within each individual and provides a means to understand the complexities of the lives of people who use illicit drugs (Hankivsky & Cormier, 2009).

There is a clear relationship between intersecting social forces and health. The social determinants of health are “humanly factored, socially influenced and unequal” (Lang, 2001,

p.162). There is a current discourse to account for differences between people as being a result of lifestyle choices, culture, chance or genetics but it is clear that it is more complex than that. “Class ... [and] social tension not only never went; they merely changed their clothes” (Lang, 2001, p.162). The social conditions that intersect to make life so difficult for people who use illicit drugs are a direct result of dominant societies’ attitudes towards this population. At the same time, it is important to understand the subjective realm of oppression if we are to understand the personal impact of structural relations of domination (Hulko, 2009).

Opiate assisted treatment (OAT) related literature.

Given the complexities of the lives of people who use illicit drugs it is interesting that virtually all of the published studies on OAT do not address the significant burdens of stigma, marginalization, intersectionality and ACE that this population faces. Virtually all of the studies focused solely on the appropriateness of OAT as an alternative harm reduction measure. Eighteen articles related to OAT were located. Sixteen of them were quantitative studies and two were qualitative. Four of the articles reported on the results of trials comparing methadone to diacetylmorphine (Blanken, Hendriks, van Ree & van den Brink, 2009; Demaret et al., 2015; Oviedo-Joekes, March, Romero & Perea-Milla, 2010; Oviedo-Joekes et al., 2009; Verthein et al., 2008). All of these studies reported an improvement in mental and physical health and a decrease in illicit drug use in the participants who received diacetylmorphine.

There were a number of other quantitative research reports that examined everything from crime to motivational status to effect on emotions as well as demographic factors. The existence of a OAT clinic had no impact on crime in the surrounding neighborhood (Lasnier, Brochu, Boyd & Fischer, 2010). Opioid dependent patients who otherwise may not have been attracted into existing treatment options were successfully retained in OAT, and OAT enhanced odds for

successful rehabilitation among patients motivated for treatment (Nosyk et al. 2010). Heroin dampens craving and negative emotions and increases positive emotions, specifically feelings of well-being. Heroin had a positive effect on emotional regulation (Blum et al., 2013).

Demographic factors associated with OAT included race/ethnicity, sex/gender, housing status, employment, access to health care and criminal history. Oviedo-Jokes et al., 2008 looked at the profile of participants in the North American Opiate Maintenance Initiative (NAOMI) trial. They found that that 72.9% of the participants lived in unstable housing, 70.9% were regularly unemployed, 94.4% had been charged with a crime, and half reported a significant, chronic health problem (Oviedo-Jokes et al., 2008).

Two qualitative articles were located. The first one examined staff concerns in OAT centers in Europe (Switzerland, Netherlands, Germany and the UK). Staff, mainly nurses, were interviewed. Staff reported few problems and few conflicts with patients. They did have some concern about patients' injecting behaviors but in general they were in support of the program and worked hard to convince the interviewer that OAT was rigorous and feasible (Demaret, Lemaitre & Ansseau, 2012). The second article (Jozaghi, 2014) examined the experiences of patients with the Study to Assess Long Term Opiate Maintenance Effectiveness (SALOME) trial in Vancouver. The participants revealed that their lives had changed in many positive ways including a reduction in criminal activity, sex work and illicit drug use. Many had been able to reconnect with their families. Health and social functioning had also improved, with some participants acquiring work or volunteer positions. One of the gaps of this study is that it did not explore how participants' use of substances had changed since they had started the program. Nor did it specifically examine how their mood and possible mental health issues had changed or improved. There was also no discussion about how this program had potentially changed their

experiences of stigma.

There is a dearth of literature that examines the experiences of patients and staff in relation to OAT. Although there is one qualitative study that examined the experiences of patients with SALOME there has been no study that has looked at the ongoing changes that have potentially occurred since this program has transitioned outside of the research field. It would be interesting to understand how the lives of the participants have changed since the Supreme Court of British Columbia (BC) ruling established the OAT program in Vancouver as an ongoing treatment option for people addicted to opiates. The Supreme Court of BC ruling recognized that the risks faced by people addicted to opiates, who acted as plaintiffs in the case would be reduced if their physician was allowed to prescribe heroin. In addition, the court recognized that the exemption requested by patients did not constitute a material harm to the government (Lupick, 2014). It would be interesting to discover, as a result of this research, whether the Supreme Court of BC ruling changed the sense of stigma that patients face in accessing this program.

With the exception of the Demaret, Lemaitre and Ansseau (2012) article cited above, there was no literature on staff or clinical care provided in relation to OAT. The authors of that article noted that staff were primarily concerned with two things: patients receiving their heroin when they were already intoxicated and the potential for patients smuggling heroin out of the clinic. Nurses reported few problems and few conflicts with patients (Demaret, Lemaitre & Ansseau, 2012).

There are some articles about nurses involved in supervised injection sites. Nurses in these sites spend much time providing safer injecting education to their patients (Wood et al, 2008). As they observe clients injecting their drugs, nurses provide health teaching and health assessments and provide assistance with a variety of health concerns. Because these nurses are

often the first point of contact with the health care system, they are in a position to provide primary nursing care, as well as work with community partners to ensure that their clients get the referrals they need. Possibly the most important part nurses do is to focus on building a therapeutic relationship with clients (Lightfoot et al, 2009). This provided an impetus for exploring the care providers' perspectives in this study. Looking at the care providers' perspective, the methodology chosen for this study is described in the next section.

OAT: Treatment or Harm Reduction?

OAT has historically been defined as treatment as opposed to harm reduction, but the results of numerous surveys and opinion pieces would indicate that it is reasonable to call it a harm reduction approach. Strang, Groshkova and Metrebian (2012) note in their report that the utilization of OAT leads to improvements in health, reductions in blood borne infections and improved social circumstances. An organization called Shatterproof (2018), which aims to reduce the stigma of addiction, states that OAT is an essential part of any harm reduction program. Nadelmann and LaSalle (2017) call it a novel harm reduction approach. People who participate in OAT programs have access to sterile injecting equipment and supervision, and are not at risk of using heroin that is contaminated with fentanyl, which puts them at a far lower risk of overdose. OAT is a treatment, but it is also harm reduction.

Methodology

In this section, the research design is outlined. The theoretical underpinnings, methodology, study design, research setting, sampling strategies, data collection methods and procedures, data analysis, ethical considerations, and scientific quality are discussed. Front line nursing and allied staff have historically been excluded from the research process. Steps were taken to ensure that the research methodology and methods allowed participants to attain a degree

of participation and control over the research process, and opportunities were sought to share findings with participants and related organizations with the goal of promoting dialogue and planning future directions of care for and with people who use substances.

Theoretical underpinnings.

Allen (1999) pointed out that cultures and cultural differences are constructed and unless this construction is adequately articulated, social inquiry will inevitably create an 'other', an 'outsider', a 'not us'. In order to minimize the potential for exclusion, a critical social theory perspective informed the research approach of this study (Sumner & Danielson, 2007).

Critical social theory is a school of thought that stresses the reflective assessments and critique of society and culture. It is used to explore and question discourse and the social world (Sumner & Danielson, 2007). The underlying standpoint of critical social theory is that dialogue is value laden and that norms are contextual depending on the situation and the participants. Critical social theory presents a way of understanding the political and social agendas that influence people's lives. Critical social theory is an important tool for uncovering the complexities of the social world and how its discourses affect people. It is particularly useful to consider marginalization because critical social theory is about power - who has it and who doesn't. Critical social theory can be used to examine power relationships and dynamics to determine who benefits from power and who is marginalized (Sumner & Danielson, 2007).

Critical social theory is especially relevant when looking at the experiences of people who are marginalized (Sonn & Quayle, 2013). It allows questions to be raised about what is taken for granted, what norms are unchallenged, what works and for whom (Sumner & Danielson, 2007). Critical social theory is useful because it allows researchers and participants to identify the systemic oppression that is at work in society as a whole and in our health care systems. It also

allows us to identify the power structures that are at work (Sonn & Quayle, 2013). Critical social theory helps us to understand the why of social oppression (Leonardo, 2004).

Critical social theory arose from resistance movements that were against social conditions such as fascism, racism, exploitation of women and prejudice against various groups such as people of color and the LGBTQ¹ community. Critical social theory is grounded in definitions that came from peoples who were oppressed themselves as opposed to theories about them or on the assessment of outside experts (Mooney & Nolan, 2006). This is important because a crucial consideration when working with people who are marginalized is to ensure that they have opportunities for empowerment. In an interesting study by Fulton (2007), the author noted that nurses conceptualized empowerment as the freedom to make decisions with authority and to have choices. In order for the research participants to be empowered, it is important to involve care providers in the research process so that their issues and concerns remain paramount. A collaborative approach is essential if empowerment is to take place. I have a long history with the clinic as the former nurse educator for the staff and my ongoing relationship with the staff supports collaborative efforts.

When a critical social theory lens is used, people have an opportunity to question, understand and come to terms with their position in order to enable them to act on behalf of themselves (Mooney & Nolan, 2006). Although front line staff in hospitals are not generally considered to be marginalized, there is some literature that addresses the issue of powerlessness that front-line staff experience (Brathwaite, 2018; Hart, 2015; Hutchinson & Jackson, 2014). It is important that frontline staff be given an opportunity to exercise power and control over the research process.

¹ This abbreviation is a representation of the complete variety of gender orientation and expression.

Intersectionality focuses on the importance of paying attention to the multiple, intersecting identities and relevant social positions such as gender, race, class, sexual identity and lifestyle along with associated power dynamics. People can be members of different social groups at the same time and consequently will have unique experiences with privilege and disadvantage as a result of these intersections (Rosenthal, 2016).

Methodology.

Theory and research in the social sciences are increasingly emphasizing everyday life experience, the significance of multiple constructions of reality, and the complexity and ambiguity that are inherent both in everyday life and the research process (Mjosund et al., 2017). Interpretive description (ID) is a qualitative methodology that acknowledges the constructed and contextual nature of human experience while at the same time it allows for shared realities (Thorne, Reimer Kirkham & O'Flynn-Magee, 2004). This approach is grounded in and appropriate for the generation of nursing practice knowledge. It offers practical solutions to the problems that the health professions present (Teodoro et al., 2018). ID enables the development of knowledge to support nursing practice. Its emphasis on examining the constructed and contextual nature of everyday life makes it a good fit with the critical social theory perspective that frames this project. ID provides a grounding for the concepts and their linkages that become apparent when one attempts to locate the specific in the universal, the state within the process, and the subjectivity of experiences within the usual conventions that current health care contexts represent as the temporal and symbolic location for health and illness (Thorne et al., 2004). Three philosophical criteria underpin the design of interpretive description:

1. Reality is constructed, complex and subjective and can only be studied holistically.
2. The inquirer and the participant interact to influence one another and meaning must be

constructed through negotiation with research participants as opposed to the researcher imposing meaning on the findings.

3. Due to the probable emergence of multiple realities from the findings, theory must emerge or be grounded in the data.

I anticipate that reality will be different for each participant. A critical social theory perspective will aid in understanding how the complexities of intersectionality impact on the findings.

(Thorne et al, 2004)

Study design.

This study focused on examining the experiences and perspectives of staff who worked at the clinic. Human experiences are complex and rooted in a contextualized and constructed reality. Interpretive description focuses on uncovering knowledge about how and what individuals think and feel about the situations they find themselves in (Thorne, 2000). It is a way of systematically reducing the complexity of information that is collected in order to arrive at generalized explanations (Ganapathy, 2016). It is oriented towards an understanding of cases as opposed to variables, and towards discerning the particulars presented by each piece of data.

ID is a qualitative research methodology that can be used to enhance our understanding of how people experience health and illness as well as to understand how health care staff navigate their workplace (Thorne, 2008). It is generally utilized for investigating a clinical phenomenon of interest (Thorne et al, 2004). The product of ID “is a coherent conceptual description that taps thematic patterns and commonalities believed to characterize the phenomenon being studied” (Thorne et al., 2004, p. 7), as well as account for individual variations.

An ID design with thematic analysis was well suited to the research objectives of this study. Thematic analysis is a flexible approach that can be used across a wide range of

epistemologies and research questions. Braun and Clarke (2007) argue that it provides an accessible and theoretically flexible approach to analyzing qualitative data. Their phases of thematic analysis were utilized to understand this study's data. These phases included familiarizing myself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report.

Research setting.

This study sought to broaden understanding about the experiences and perspectives of the health care staff who worked in the clinic. This setting was convenient for the participants. Most of the staff were regular full time or part time employees who worked at the clinic on an ongoing basis. I have a long history with the clinic, having provided a number of inservices for staff. I know the staff well and have observed and talked to many of the patients during numerous encounters. At the same time, I am no longer employed by the health authority that oversees the clinic, which limits the potential for perceptions of coercion.

Sampling strategy.

Qualitative data collection and analysis is demanding and the sample size must be selected with a view towards being neither so large as to inhibit deep, case-oriented analysis nor so small that a richly textured understanding cannot be achieved (Ritchie & Lewis, 2003). ID, with its emphasis on eliciting the constructed and contextual nature of human experience whilst allowing for shared realities, generally builds from relatively small samples (Thorne et al, 2004). In general, it is recommended that qualitative studies that are directed towards discerning the essence of experiences should include a relatively small number of participants. As a general rule of thumb, qualitative samples for a single study involving individual interviews usually include fewer than 50 participants (Ritchie & Lewis, 2003). If the sample size gets much larger, it starts

to get difficult to manage in terms of the quality of data collection and analysis that can be achieved (Ritchie & Lewis, 2003). With this in mind, purposive sampling methods were utilized to recruit 22 participants, including 18 nurses, two social workers and two clinic peer workers.

Information sessions were held at Crosstown Clinic to inform the staff about the study. Flyers and posters were created that described the study (Appendix One) and were posted and distributed throughout the clinic. The clinic manager also sent out an email to all the staff notifying them about the study and asking them to contact me directly if they wished to be involved.

I approached the staff individually to determine who wanted to participate in the study. I also conducted an information session with the staff before the study began to determine their level of interest. Because this study proceeded with approval and support from the administrators of the program I needed to ensure that the staff understood that their participation was voluntary and had no bearing on their employment status or continued employment at the clinic.

Data collection methods and procedures.

Qualitative researchers generally believe that people who have lived with certain experiences are usually the best source of knowledge about those experiences (Thorne, 2008). Data for this study were collected via the use of in-depth, semi-structured interviews, which were audio taped and transcribed verbatim. A private room at the clinic was utilized for the interviews. Interview questions were broad based trigger questions that are intended to stimulate conversation (Appendix Two). The participants' responses were used to generate more in-depth exploration of a particular area during the interview and informed lines of inquiry for later participant interviews. The goal was to encourage participants talk freely about themselves. As part of the strategy to encourage participation and empowerment, it was important that the

participants have a sense that their stories are important and valuable. After data collection, transcription and preliminary analysis I returned to the clinic to review the findings with the participants in a focus group setting. Focus groups were recorded and transcribed and field notes taken.

Detailed and accurate field notes are essential for the success of a qualitative study. Field notes were recorded immediately after the interviews or focus groups. There are four purposes to the field notes. Operational notes provided an objective description of the event and the conversation. Coding notes allowed me to reflect on the interview process and provided instructions and reminders for the conduct of subsequent interviews. Analytical notes provided a beginning interpretation of the meanings of the interaction. Reflexive notes helped me to reflect on my own feelings during the interview process (Birks, Chapman & Francis, 2008).

As a researcher I brought my own understandings and prejudices to the process. I have a long history of working with this population and I had a number of preconceived ideas about what I was likely to find. Reflexive notes helped me to reflect on my own assumptions and feelings during the interview process (Birks, Chapman & Francis, 2008). It was important to keep track of these impressions because it was essential to account for them as analysis proceeded. I needed to mitigate the effects of my expectations by identifying them and determining how they coloured my perceptions as I proceeded with analysis.

Data analysis.

The purpose of data analysis is to extract meaning from the data set and rebuild and present the processed data set in a thematic or conceptually relevant whole. Data analysis in interpretive description involves moving beyond the theoretical framework towards an abstracted interpretation that will illuminate the phenomenon that is being investigated in a novel and

meaningful fashion (Thorne et al., 2004). In qualitative work such as this, the stages of analysis are non-linear, with data collection and analysis occurring concurrently. Data analysis in the interpretive descriptive tradition requires an immersion in the accounts of the participants to develop themes within each account and through constant comparison, a description of the patterns between and among the narratives (Irwin et al., 2002). The two main tasks in data analysis utilizing interpretive description are the identification of themes within coding categories and identification of themes across coding categories (Gillespie, 2002). The aim is to work upwards towards broader levels of abstractions and to connect the themes to generate a theoretical or conceptual model (Ganapathy, 2016).

As the data were collected, the interview transcripts were read repeatedly to identify recurring, converging and contradictory patterns of interaction, key concepts, emerging themes, symbolic examples from the data, and possible connections to the underlying theory. As the data was reviewed, emerging concepts and themes were developed and used to categorize and code the data. As each transcript was coded, I compared them to identify similarities and differences. It is important to check for discrepancies because they identify areas for further exploration and possible development of new coding categories (Anderson et al., 2003). As coding progressed, categories were expanded or collapsed to reflect the developing picture. Emerging themes and categories were reviewed and compared and taken to a higher level of conceptualization with the aim of developing broader theoretical constructs. It is at this point that the findings were taken back to the participants at the clinic. The insights and feedback from the participants were incorporated as analysis continued. It is important to have the input of participants in the construction of meaning as an essential component of ID (Thorne et al, 2004). It is important for the researcher to have an explicit awareness that their role is as an interpreter of the stories told

by the participants (Thorne et al., 2004). It is important that the participants themselves verify the findings as they develop.

The field notes were invaluable in aiding me to develop distance as the analysis progressed and alternate themes and concepts arose. It allowed me to reorient the analysis to focus on constructing the knowledge from the perspective of the participants. Because I have a long history of working with this particular population of patients it would be easy for me to make assumptions about the challenges the participants faced. Utilizing field notes helped me maintain some distance and resist interjecting my own meanings into the data. In addition to the field notes, checking my findings with the participants also helped me to understand how my own assumptions impacted the analysis.

Ethical considerations.

The use of face-to-face interviews made anonymity impossible to ensure for the participants. For this reason, every effort was made to ensure that identities remained confidential and that the use of context embedded descriptions within the report of the findings did not allow for identification. Specific strategies to protect the participants' identities included the use of a unique code number for each person on all data sheets, avoidance of identifying participants on transcripts and analytic memos, and the use of fictitious names in public writings. The memory sticks, codebook and all transcribed interview data are maintained in a locked file cabinet. All electronic data is password protected. In accordance with university policy, they will be retained for at least five years after the conclusion of the study. If the data is disposed of after that time, all paperwork will be shredded and the memory sticks will be wiped and/or destroyed.

Written consent was obtained from all participants prior to the interviews (Appendix Three). The consent form was reviewed by the participant and myself, and understanding of the

study, its implications, and possible effect on the participant was verified prior to the participant providing informed consent. Consent should be viewed as an ongoing and transactional process (Pollock, 2012). With this in mind, consent was verified verbally and on an ongoing basis with participants as the interviews progressed.

Asking participants to discuss issues related to addiction has the potential to unmask feelings of guilt and trauma. The plan was that staff who needed support would be referred to the staff support program that is provided by Providence Health Care. As it turned out, no staff required this service.

Ensuring quality.

The production of quality research can only occur within the context of validity or trustworthiness (Whittemore, Chase & Mandle, 2001). Whilst it is commonly accepted that qualitative research must achieve the benchmark of validity, what is less clear is the validity criteria that are utilized to attain this benchmark (Whittemore et al., 2001). Qualitative research uses an interpretive perspective as opposed to a positivistic approach and this has led to continued discussion and dispute about what constitutes sound validity criteria. It is important to remember that the field is not neutral. It is a negotiated site of historically located yet shifting researcher and researched subjectivities (Reimer Kirkham et al., 2002). Although ultimately the evaluation of research is a matter of judgment on the part of the reader (Sandelowski, 2015), evaluating scientific quality in qualitative research necessitates making a decision on using a set of established criteria.

For this study, a contemporary synthesis proposed by Whittemore et al. (2001) was utilized. They propose that validity is illustrated through the explication and differentiation of primary criteria, secondary criteria, and techniques. Primary criteria are necessary to all

qualitative inquiry and include credibility, authenticity, criticality, and integrity. Secondary criteria are more flexible and differ depending on the particular investigation but for a study such as this, which portrays an emic perspective within a social and political culture the secondary criteria of sensitivity, explicitness and vividness should take precedence. Techniques refer to the methods that are used to demonstrate or assure specific validity criteria. Underpinning all of this is the concept of reflexivity, which is considered integral to qualitative studies (Berger, 2015).

Credibility.

Credibility is attained through a conscious effort to establish confidence in an accurate interpretation of the meaning of the data (Cope, 2014). This study utilized a number of methods to enhance credibility. Concurrent, comparative analysis allowed for the ongoing checking of the representativeness of the data, coding categories, and emerging consistencies and discrepancies. Validating the findings by going back to the participants enhanced and expanded the construction of meaning. An audit trail was maintained throughout the conduct of the research, documenting my decisions and assumptions. An audit trail is a key strategy to enhance the credibility of qualitative research (Ryan-Nicholls & Will, 2009).

Authenticity.

When a study presents the descriptions and interpretations of a human experience in such a way that they are recognized by people having that experience as their own it is considered authentic (Cope, 2014). It is essential to remain true to the phenomenon under study (Whittemore et al., 2001). In studies that utilize an interpretive perspective, there is an inevitable, and in fact, necessary interaction between the researcher and the researched. It is important to appreciate the influence of the researcher on the ability of the participants to speak authentically. There are a number of ways to address this issue. Field notes were kept for the duration of the study that

allowed me to reflect upon and respond to issues that arose during the conduct of the study as well as to achieve a clearer understanding of how my positioning impacted on and influenced the findings. Going back to participants with preliminary findings was key in checking and validating the findings and ensuring that the participant's voices were heard and adequately portrayed without distortion or bias.

Criticality.

Evidence of critical appraisal is necessary for a sound research design (Whittemore, 2001). During the process of data collection and analysis, I needed to be critical in the search for alternative hypotheses, negative instances, and the explicit accounting of biases (Thorne et al., 2004). Concurrent, comparative analysis was used to identify similarities and discrepancies that arose in the findings. Reflexive field notes were used to quickly identify underlying biases that I brought to the study. Observational and methodological field notes were useful for establishing a definitive trail that explicated the process of collection and analysis. A responsible and substantiated scientific process is integral to the demonstration of criticality (Whittemore et al., 2001).

Integrity.

Qualitative research is subjective and the unique interpretation that the researcher brings to the data is an essential ingredient in the process, but integrity must be evident to assure that the interpretation is valid and grounded in the data (Whittemore et al., 2001). It is important for the researcher to be self-critical and to seek integrity at each stage of the inquiry to ensure that uncritical verifications and dogma are averted. As with criticality, integrity is represented through recursive and repetitive checks of interpretations (Whittemore et al., 2001). In this study, it was addressed through the use of constant comparative analysis, follow-up interviews, and field and

reflexive notes.

Secondary criteria.

Sensitivity was demonstrated by ensuring that the study was not only based on sound ethical principles but that the results will provide benefit to the participants. I have shared the findings with the participants and will continue to engage in dialogue with them to further determine how the findings can inform their practice. Explicitness was determined by ensuring that there was an auditable trail that accounted for methodological decisions, interpretations, and investigator biases. Vividness was ensured by the presentation of rich data that allowed others to personally understand and experience the phenomenon or context which was described (Whittemore et al., 2001).

Reflexivity.

Reflexivity is a tool for analyzing how subjective and inter-subjective elements influence the researcher (Finlay, 2002). It involves a process whereby the researcher engages in an explicit and self-aware analysis of their role in the study. This personal analysis needs to be purposeful and primarily focused on the participants and the data as opposed to being a navel gazing exercise (Finlay, 2002). The ultimate goal is to capture the connections and influences that the researcher and the participants have on each other and an awareness of how meaning is constructed within this context. It is important for the researcher to give voice to the participants in a way that addresses the social, political, and economic context in which they live without setting them apart as the 'other'. In this study, reflexivity was enhanced by a process of data collection and analysis that was framed within the theoretical perspective that underpins the study, a consideration of the existing knowledge that was revealed in the literature, and the use of field notes to aid me in locating myself in relation to the participants.

Conclusion

The remainder of this dissertation consists of three papers that were written for publication, as well as a final chapter outlining the implications for nurses. The findings from this study are directly relevant to nurses and provide a direction for culturally safe, patient centered care.

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CHAPTER TWO

Exploring the Experiences of Staff Working at an Opiate Assisted

Treatment Clinic: An Interpretive Descriptive Study.

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Abstract

There have been many advances in harm reduction over the past three decades. One of the newest approaches is the provision of medical grade heroin to people with opiate addiction, known as opiate assisted treatment (OAT). There is one clinic in North America which provides this service. The goal of this study was to uncover how the clinic staff provide care to what is generally considered to be a challenging population, their perspectives on how the clinic program has impacted on them and their patients, and their opinions about the program itself. This was a qualitative study with an interpretive descriptive methodology underpinned by a critical social theory perspective. Convenience sampling was undertaken with a resultant sample of 22 participants – 18 nurses, two social workers and two peer support workers. Thematic analysis was undertaken to identify recurring, converging and contradictory patterns of interaction, key concepts and emerging themes. The study location was the OAT clinic, which is located in the downtown eastside of Vancouver, BC. The findings were organized around six themes reflected in the interview data: from chaos to stability, it's not all roses, a little preparation would be good, putting the patient at the centre, the stigma hasn't gone away, and the clinic is life transforming. Taken together, these themes indicate the complexities of working in this environment.

Keywords: opiate addiction, harm reduction, heroin assisted treatment, patient centered care, critical social theory, interpretive description

Exploring the Experiences of Staff Working at an Opiate Assisted Treatment Clinic: An Interpretive Descriptive Study

There is a long history of addiction in human culture. Humans have had a taste for psychoactive substances for as long as there have been written records and abnormal patterns of substance use have been described since antiquity (Crocq, 2007). Illicit substance use is associated with harm. There is the harm that occurs as a result of intoxication and violence (Miller et al., 2005) and the harm that occurs as a direct result of using illicit drugs, including higher rates of HIV and hepatitis C, as well as injection related infections such as endocarditis, cellulitis and osteomyelitis. It is in consideration of these harms, as well as the long term, enduring nature of substance use that the concept of harm reduction has arisen over the past three decades. Initially, harm reduction consisted of needle and syringe exchange and the provision of methadone, but it has come to embrace a variety of interventions, including supervised injection sites and opiate assisted treatment (OAT).

There have been significant advances in the provision of harm reduction in British Columbia, Canada. A notable example is the establishment of a clinic that provides OAT. This clinic was created to conduct a study called NAOMI or North American Opiate Maintenance Initiative. The NAOMI study was a quantitative study that compared injectable heroin to optimized methadone. The results of that study showed that heroin was clearly superior (Oviedo-Jokes et al., 2009) A follow-up study called SALOME or Study to Assess Longer Term Opioid Medication Effectiveness, determined that there was no difference between patients receiving injectable heroin and patients receiving injectable hydromorphone (Oviedo-Jokes et al., 2016).

One issue with these studies was that patients were unable to access heroin after the study was completed. Given how well they were doing this became an ethical problem. Providence

Health Care took the federal government to the Supreme Court of British Columbia and won a ruling that essentially stated that denying patients access to heroin was denying them access to health care (Lupick, 2014). At this point, the ongoing OAT program was born. The OAT clinic operates out of an aging building on the downtown eastside of Vancouver, which is considered by many to be the epicenter of the drug epidemic in British Columbia. This is a neighbourhood with an extremely marginalized population and the patients that attend the clinic reflect this demographic.

Although OAT programs have been well established in Europe for a number of years, there is a dearth of qualitative research that explores the experiences of both staff and patients. Qualitative research allows the researcher to study the social interactions of humans in naturally occurring settings. The researcher is able to gather data and make sense of the phenomena that are observed and revealed. Qualitative research considers questions that involve the “what” and “why” of human behaviour (Lichtman, 2014). As such, qualitative research can deepen understanding of the complexity of social interactions and the meanings that participants themselves attribute to those interactions (Marshall & Rossman, 1999).

Overview of the Study

The objectives that guided this exploratory, descriptive study were to explicate the experiences, observations and perspectives of the staff who work at the clinic. Specifically, the goal was to uncover how the staff provide care to what is generally considered to be a challenging population (Dodge, Brady & Maguire, 2006; Press et al., 2016), their perspectives on how the clinic program has impacted on them and their patients, and their opinions about the program itself.

There is a lack of qualitative research about the experiences of staff in OAT centers. Only one study that used a qualitative approach to talk to OAT clinic staff was located (Demaret, Lemaitre & Ansseau, 2012). Interpretive description was selected as the approach to this inquiry because it calls attention to human experience in both its constructed and contextual nature, whilst allowing for shared realities (Thorne, 2008). Interpretive description captures themes and patterns and allows the development of broader understandings that can inform practice. Interpretive description is a non-categorical, inductive method that is driven by a clinical problem that is approached thematically. It allows the researcher's interpretive lens to be accessible and visible throughout the research process (Thorne, Reimer Kirkham & O'Flynn Magee, 2004). Thematic analysis was undertaken to identify recurring, converging and contradictory patterns of interaction, key concepts and emerging themes.

Critical social theory (CST) served as a theoretical perspective to this research because it allows us to understand the political and social agendas that influence people's lives. CST is an important tool for uncovering the complexities of the social world and how its discourses affect people. CST is about power – who has it and who does not. Power is not a neutral term. Power encompasses racism, marginalization, micro-aggressions and stigma. From a nursing perspective, CST is important because it allows them to question what is taken for granted, what norms are unchallenged, what works and what does not (Sumner & Danielson, 2007). CST focuses on transforming the world rather than simply explaining it. The goal of CST is to intentionally attend to and disrupt oppressive sociopolitical contexts and processes (D'Arrigo-Patrick et al., 2017).

The OAT clinic staff is composed of nurses, social workers, pharmacists, peer support workers and physicians. Front line staff, including nurses and social workers, do not generally perceive themselves as having power. Nursing is an oppressed group (Fulton, 1997). In a study

by Katriina and colleagues (2012) nurses rated themselves as having little power in relation to environmental forces, resources and communication competency. Social and structural factors in both the activities and organization of nursing work implicitly communicates to nurses that they have less value than other members of the health care team (Hart, 2015). Social workers also experience a sense of powerlessness when dealing with team members who are perceived to have more power. Power inequities affect the voice and contributions of social workers. They feel that they get talked over and lost by more powerful members of the health care team (Ambrose-Miller & Ashcroft, 2016).

When a CST lens is employed, people have an opportunity to question, understand and come to terms with their position. In doing so they have the opportunity to reflect on power and how to access it (Mooney & Nolen, 2006). When nurses use a CST lens to engage in critical reflection, they can develop insights into the central values of nursing. A CST approach allows nurses to probe the historical assumptions of professional nursing and how those assumptions influence practice (Sumner & Danielson, 2007). It also allows them to understand power, how it is distributed and how they can access it.

Ethical approval was obtained from the University of Alberta and Providence Health Care. Purposive sampling was utilized to recruit participants. All of the staff received an email communication about the study with an invitation to participate. The staff were excited about the project and independently approached the researcher asking to be included. Informed consent was obtained and an honorarium – a \$20 gift card – was provided. Identities were protected by the use of initials in the transcripts and pseudonyms in all reports of the findings.

Twenty-two staff members at the clinic participated in interviews for this study. This is considered a reasonable number for a qualitative study where the focus is on sample adequacy as

opposed to sample size (O'Reilly & Parker, 2012). The participants ranged in age and experience. Four of the participants had worked at the clinic for less than a year whilst three of them had been with the clinic since the beginning of the first study. Eighteen of the participants were nurses, two were social workers and two were peer support workers.

Data were collected using in-depth, semi-structured individual interviews lasting 30 to 45 minutes. Interviews were audiotaped and transcribed verbatim. The interview guide consisted of open-ended questions that allowed for broad and unstructured responses. Interviews started with a discussion of the participant's work and life experiences and then turned to focus on their experiences, perceptions and observations about their working life at the clinic. Two follow-up focus groups were held at the clinic to obtain staff feedback on the preliminary findings.

Findings

Analysis of the participants' stories revealed that their experiences at the clinic were multifaceted and provided both challenges and opportunities. It became apparent that their work life provided many occasions for pleasure but also some frustrations. The findings were organized around six themes reflected in the interview data: from chaos to stability, it's not all roses, a little preparation would be good, putting the patient at the centre, the stigma hasn't gone away, and the clinic is life transforming. Taken together, these themes indicate the complexities of working in this environment. Unlike the qualitative study cited above (Demarat, Lemaitre & Ansseau, 2012) concerns about diversion and overdose were not the primary issues raised by the staff in this study.

From chaos to stability.

The participants in this study told many stories about how the clinic had changed their patient's lives for the better. Having access to medically prescribed heroin took away one of the

challenges of living with addiction which is having to search for access to illicit substances several times a day. Elizabeth talked about how “people are reconnecting with their family that they haven’t talked to for years.” Michael related that it was impressive:

seeing people get unionized jobs as front desk workers... It’s pretty amazing because you look at these people, they were having to sell their bodies, you know, crime, whatever to get their next fix. And now they’re able to have some stability, they’ve got, you know, a routine going on in their life.

Vanessa mentioned that “I’ve seen a few that like some of them have taken classes. And there’s a young man who’s gotten to like cooking school and he’s got a job.” Julie brought up something more basic but still important: “I think the biggest thing for me is I always love, we’ve had so many patients lately that have, have gotten dentures.”

David summed it up by saying:

with stability not having stability in their addiction, not having to search for their next drug, lower amount of crime. Being able to do other things like live a life whether it be to find a place to sleep permanently like housing, having food, like they spend their money on food, clothes, entertainment, going back to school some of them. Being able to maintain part time work because a lot of them have employers that can work around or they work part time right so shorter hours so they can work around their hours.

The staff observations are directly supported by the findings of the various quantitative studies that have been conducted. According to Blanken and colleagues (2009), OAT is associated with stable physical, mental and social health. Verthain and colleagues (2008) also noted that physical and mental health improved and street heroin use declined. Another study by Verthein, Schafer and Degkwitz (2013) showed that social integration improved. A Vancouver study by Oviedo-Jokes and colleagues (2010) showed that OAT participants had a significant reduction in drug-related HIV transmission risk behaviour. It was apparent that the stability achieved by the patients was important and significant for the staff. David noted that “...it makes

everything worthwhile.” It was clear that patients’ outcomes validated the staffs’ work at the clinic.

It’s not all roses.

It would be easy to assume that a clinic such as this, which is providing a unique service in the North American context, is doing everything right. The clinic is very busy. It is treating around 140 patients, which is the most it can handle given the physical constraints of the location. However, the staff indicated that there are a number of challenges related to working at the clinic. The most significant of these is space or the lack thereof. The staff repeatedly brought up this issue. Rebecca noted that “...it’s a very small space with a lot of big personalities.” Tabitha talked about how:

the biggest challenge I would say with [the] clinic is the, I would say the facility itself, it’s very old, it’s very run down. There’s exposure to asbestos, to mold, the roof is leaking, many things like that. I think a lot of that is around the fact that we are in a very small space. And people don’t have the space they need pre and post injection.

Alison talked about how she

...would love to have a new space, a larger space so we could actually fit more people comfortably so that half the people don’t have to stand and like hang out. Or that there’s enough chairs for everybody if people want to stay and do activities. It’s like a space that would accommodate like more time and more people so I think that would be good.

These comments bring up a lot of issues around the idea of space. It is in fact, place, not space, which frames our behavior. Place isn’t just about space. It is about human experience and interpretation (Stedman, 2003). Place is not just physical, it is socially constructed. Place has an impact on people, materially, cognitively and in terms of their social interactions (Fletcher, 2006).

One of the most significant impacts of place constraints was the potential for conflict. A number of the staff members mentioned this. Stuart talked about how the lack of space

contributes to instances of conflict. “We have all these people crammed into this little space right? And some of our patients are high on crystal or whatever. The lack of space really contributes to the potential for conflict.” Natasha noted that “...a bigger part of it is because of the space right?”

Lack of space also contributes to the staff’s inability to provide comprehensive care for their patients. Many of the staff felt that the clinic should provide more comprehensive care, including primary care but the lack of space precludes this. Melissa talked about

funding, more money because with more money we could get a bigger space, cleaner space – do more for the clients – take on primary care. We could take on more clients, help more people. I mean even if out of the two thousand some people in two years have died from fentanyl if we could have even taken on fifty more.

Melanie mentioned that it is difficult to provide basic care:

space that’s literally it. We have a very small space here and we don’t have all of the space that we would like in terms of being able to treat the clients with their wound care and those sorts of things.

A little preparation would be good.

There have been numerous publications examining the issue of staff preparation in caring for people who have an addiction. A publication by Marcellus (2007) noted that healthcare professionals continue to lack education about substance misuse. Murphy-Parker (2013) noted that the nursing literature indicates that there is a negligible amount of substance misuse education within schools of nursing in more developed countries.

The registered nurses in particular verified these findings. Marcelle stated “It’s not part of it at all...when I was in nursing school we didn’t even really talk about mental health and substance use at all.” The nurses all felt that what they had learned about addiction and mental health they had learned as a result of working at the clinic. Paul said “It’s more on the job...there were a lot of things I had to learn on the go...I’d make a lot of mistakes.” The registered

psychiatric nurses and social workers seem to be better prepared for the work in the clinic. Julia indicated that “as a psychiatric nurse...mental health and substance use is a big component of our education.” What seems to be critical to increasing the understanding of health care workers about issues of addiction is ensuring they have access to and understand the latest research on addiction. Treatment, education and policy decisions need to be implemented using facts instead of anecdotal or prejudicial information (Erickson et al., 2003).

An issue that the staff identified was that the lack of educational preparation had an impact on staff turnover. They noted that at times a newly hired person would only last a short time before they left. Paul stated that “you see people coming that, that just don’t fit and they just don’t last because it, it’s too hard and people that get uptight and take it personally...” Jane indicated that “...it wasn’t what they expected and they leave the clinic fairly soon.” It is difficult to know without speaking to them why the staff left, but lack of educational preparation could be a contributing factor.

Putting the patient at the center.

Patient centered care is an oft-cited value in nursing, but there is some evidence that practitioners only pay lip service to the concept. Peterson (2001) noted that practitioners frequently discount the experiential knowledge of their patients. Knowing the patient or understanding the patient’s reality, is an important component of patient centered care (Mantzorou & Mastrogiannis, 2011). Incorporating shared decision making into clinical practice continues to be a challenge (Legare & Leduc, 2014).

The staff at the clinic, however, have embraced the concept of patient centered care. They spoke in a way that made evident that they consider this an important strategy in caring for their patients. Alison spoke about how it is important to “...give [patients] that respect and make sure

to treat them like they're, they're an adult and they can make educated decisions.” Jody talked about “...getting to know the kind of stories, finding out where they came from and how they ended up where they are. Building close relationships with them and having breakthrough and seeing improvements in their lives.” And Peter spoke of how you need to “...make sure the patients feel heard and make sure their concerns are validated.” Melinda spoke about how it was “...extremely rewarding...” to gain the trust of the patients and watch them grow. A number of the staff spoke about how the relationships with the patients were the reason that they kept working at the clinic. Alison said “That’s a definite reason for me staying as long as I have.” Interestingly, although the term client is generally preferred by community, public health and mental health nurses, the staff at the clinic preferred to use the term “patient”.

The stigma hasn't gone away.

Addiction is highly stigmatized. There is a plethora of literature and an ongoing social conversation that supports this. Stigma is not just an experience for the patient with the addiction issue, it is also an experience for the staff. A number of the staff members talked about how their choice of job impacted their interactions with family and friends. Natasha noted that “...from friends and family there’s always – it’s always very – it’s never fully embraced.” Peter talked about how “You’re always having to back that statement up with evidence.” Melissa spoke about how you are “...being constantly questioned like why are you working there – when are you going back to the hospital as if I should be doing something different and something better in their terms.” The experience of stigma made the staff cautious about who they talked to about their work. It also made them much more sensitive to the stigma their patients experienced. Melanie noted that “it’s something we need to be aware of. I feel like I need to protect them.”

Nurses who cared for patients with HIV infection experienced stigma, which resulted in mental health issues and a loss of job satisfaction (Phillips, 2009) and mental health nurses are stigmatized “by association” (Harrison, Hauck & Ashby, 2017). Careworkers who deal with incontinence feel stigmatized by other members of the team and the public (Ostaszkiwicz, O’Connell & Dunning, 2016). No literature was located that dealt specifically with the stigma experienced by health care workers who care for people with addiction issues but it was clearly an issue in this study.

The clinic is life transforming.

Happily, despite all the challenges, the staff related that working at the clinic has been life transforming. Melanie said:

Working at [the clinic] has given me a lot more patience and understanding in the sense that – how do I – I mean people come here with a lot of issues and, you know, you’ve really got to be understanding and give time to, you know, hear people out and their frustrations... made me think more about advocacy and things that we need to do for our communities.

Melanie talked about how she was compelled to talk about her work with her friends, family and acquaintances in an effort to increase their understanding of her patients and their intrinsic value to society. Jody related that:

I think having a more personal understanding of the level of trauma that these folks have experienced in their life and how that has contributed to their addicted lifestyle. It’s just allowed me to be more compassionate about it, that, that’s the biggest thing. I mean I know all these things on paper . . .

Peter stated that “my work gives me hope.” Natalie spoke about how “...every day I cherish what I have and who I have in my life...” And Natasha spoke about how “I get paid to actively practice compassion on a daily basis.” For Natasha, the opportunity to pursue active compassion means not just talking about it, but doing something. The staff often talked about the things they

did for patients, from listening to building relationships to providing them opportunities for accomplishment and change.

Life changing experiences for nurses often seem to occur in the face of adversity, whether it is the experience of nurses working at ground zero in New York after the terrorist attacks on September 11, 2001 (Fruiterman, 2006) or nurses who work in impoverished areas of Africa (Daniels & Servonsky, 2005). Adversity is also a common element in the addictions field, where workers constantly battle public perceptions about people who have an addiction issue. It is apparent from the participant's stories that adversity is a common experience at the clinic. Overcoming this adversity contributes to the staff's sense of achievement.

Discussion

The intersecting issues that the staff experienced as a result of working at the clinic clearly had an impact on their working lives and their perceptions of the work that they do. This study revealed a number of issues that have both positive and negative implications for the staff at the clinic. On the negative side, the clinic's physical environment is clearly an issue for the staff. The built environment has an impact on social determinants and health inequities (Gelormino et al., 2015). Space confers power (Gieryn, 2000) and lack of space can be seen as a symbol for the lack of power of the staff that need to work within it. Space is socially produced and constructed and it could be said that space "...keeps people in their place." (Kitchin, 1998, p. 343). From a critical realist perspective, space impacts on agency. As Putnam (1999, p. 76) suggests, "...our words and our life are constrained by a reality not of our own invention..."

A number of researchers (Lancman, Mangia and Muramoto, 2013; Makinde, Bjorkqvist and Osterman, 2016) support the concept that lack of space leads to conflict, Kilcoyne and Dowling (2007) also observed that the lack of space leads to moral distress and burnout for staff,

who are unable to provide the care that they believed patients deserve. Space can also be seen to have a causal relationship on institutional effectiveness (Fugazotto, 2009). Fugazotto contends that it is important to be strategic about space because it has an impact on how well the program operates. Space also has communicative value, lending validity to the program that operates within it.

The staff indicated that they felt powerless to change their working environment, one person stated “we can’t do anything about it.” Neglecting the material forces that impact on clinical practice is to neglect the potential for clinical learning and practice (Fenwick, 2014). Space is central to the production, organization and distribution of cultural power. An appropriately resourced workplace is not only functional, but it also confers power and status (Paliedelis, 2013). The difficult environment that the staff had to work in (and the patients had to be in) is illuminated by the philosophical approach of critical social theory, which highlights the complex social and political agendas that are inherent in the environment. Poor working conditions in the clinic reveal a lack of concern and lack of priority from decision makers. It is difficult to understand where this lack of priority comes from although it could just be an issue of addiction not being considered a priority in the health care system. Stigma is pervasive at all levels. There is research that reveals that people with addiction issues feel unworthy, different, excluded and powerless when accessing health care (Brondani, Alan & Donnelly, 2017). The clinic design reflects this.

The lack of educational preparation is also an issue. There is some evidence that educational preparation can change the attitudes and skills of nurses and other staff who are working with addicted patients. Gerace, Hughes and Spunt (1995) observed that educational interventions were influential in improving nurses’ confidence in caring for substance misusing

patients. On the other hand, Ford, Bammer and Becker (2009) revealed that workplace education was not enough on its own but needed to be accompanied by role support in the field to provide advice and assistance.

Addictions education in and of itself can play a pivotal role in preparing health care providers to care for populations with substance use issues but a focus on attitudes is also important (Warner et al., 2013). Addiction is a problem that cannot be addressed with education alone (Vandermause & Townsend, 2010). Education needs to be combined with a problem-based learning approach and site specific support. Workplace experience was found to be an important factor in addiction competence (Krokmyrdal & Andenaes, 2015). For this reason, in addition to pre-licensure educational programs, staff need ongoing education and support in the work setting.

It is important for nurses to take a critical social theory perspective to their work, as it will make visible the complexities of the social world and the discourses that impact those who seek care (Summer & Danielson, 2007). This in turn will help them understand the strategies they need to utilize to better care for their patients and, hopefully, have a better connection with them. This will help them create therapeutic relationships and potentially leave them happier in their work. Therapeutic alliances are important for patients with addiction issues. There is evidence that therapeutic alliances are a predictor of engagement and retention in treatment (Meier, Barrowclough & Donmall, 2005).

The experience of stigma is well documented in relation to people who use substances but there is virtually no literature that discusses the stigma experience of health care workers who work with this population. However, as this study revealed, stigma is an issue for care providers who work in addictions. Stigma is generally seen to have negative social, political, economic and psychological consequences (Crocker & Major, 1989) for groups who are marginalized and

oppressed. This is not necessarily the case for health care workers. However, health care workers may choose to remove themselves from social situations where they think stigma is likely. For this reason, ongoing public education and the implementation of interventions that address stigma around addiction is an important strategy to minimize this issue. For many members of the public, including nurses, addiction remains a moral rather than a public health issue. Yet, there is some evidence that when the public sees addiction as treatable and people with addiction as having positive attributes they are more likely to view addiction in a positive light (Barry et al., 2014; Livingston et al., 2011).

The finding that the staff routinely put patients at the center of their care is encouraging. Patient centered care is a goal that is not always realized but in the case of this clinic it seems to be the norm. It is clear that a majority of the staff take a critical perspective to their work and understand the social and political challenges that their patients face. Some research suggests that patients want their practitioners to provide patient centered care (Little et al., 2001). Patient centered care should incorporate the following principles: getting to know the patient as a person, enabling the patient to make decisions based on informed choices, shared decision making, providing tailored information, supporting the patient to assert their choices and ensuring that care and services are appropriate for each individual patient (Manley, Hills & Marriott, 2011). It is clear from the stories that the staff shared that they embrace these principles.

It is important for patients to feel safe when they are accessing care and patient centered care is an important strategy for achieving this. Culturally safe care focuses attention on power imbalances, institutional discrimination and inequity (Pauly et al., 2015). As a result of their effort to provide patient centered care, the staff ensured that the patients had power and a more equitable relationship with their providers.

The life changing aspects of the clinic program, for both the patients and the staff, were remarkable. The staff descriptions of the changes they saw in their patients were compelling and the staff's own experiences were also noteworthy. The staff were excited when they talked about the changes in their patients. It was clear that this was a central reason that they continued to work at the clinic. A number of them mentioned that they found the positive changes in their patients inspirational.

There is evidence that experiencing life changing events "...opens hearts and minds" (Callister & Cox, 2006, p. 95), which is reflected in the experiences of the staff. Given the positive way the staff talked about the patients it was evident that their hearts and minds were open to their patients at the clinic. Another study by Johansson and Lindhal (2012) revealed that when nurses feel that they are part of something momentous it increases their commitment to the patients. Being immersed in work at the clinic meant that the staff were immersed in the culture of their patients, which is different from their own. Being immersed in this way led to a change in thinking, including increased compassion, accepting differences and recognizing societal ills. It also changed the way the staff engaged in care. The staff were committed to providing the patients with holistic, patient centered and supportive care. The experiences of the participants highlighted the art of caring, which is particularly important in nursing (Levine, 2009).

Conclusion

The findings from this study are intended to highlight and make visible the work of staff at this OAT clinic. It is clear that the work that the staff engaged in is complex and challenging but provides many instances of achievement and satisfaction. An unfortunate limitation of this study was the inability to interview patients due to issues raised by the ethics board. Hearing from the patients would have added another layer of complexity and cohesiveness to the findings.

Future qualitative research in OAT clinics should include patients' perspectives. Future research should also examine staff experiences more thoroughly, including the issue of stigma and how it impacts on practice. This OAT clinic is the first of its kind in North America but it is clear from this study that careful attention needs to be paid to issues of physical space, stigmatization, and the educational preparation of staff. This study also revealed the importance of patient centered care, which should be central to any caregiver who works in this field.

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CHAPTER THREE

The Relationship Between Critical Social Theory and Interpretive Description: A Focus on Nursing

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Abstract

This paper is an examination of the methodological and theoretical perspectives of a study entitled *The Crosstown Clinic: An Inquiry into the Experiences of Staff*. This study utilized an interpretive descriptive approach to methodology with a critical social theory perspective. This paper examines and discusses how the relationship between critical social theory and interpretive description enhanced the primary study. Examples from the study are presented to clarify the relationship.

Keywords: Interpretive description, critical social theory, harm reduction, opiate assisted treatment

The Relationship Between Critical Social Theory and Interpretive

Description: A Focus on Nursing

Researchers use theoretical perspectives to determine how to design and conduct research as well as to make claims about knowledge. Theoretical perspectives inform the choice of methodology, whether or not the researcher explicitly understands that a choice is being made (Liu & Harrell, 2015). Researchers often make a choice about methodology based on a hunch about what will work well (Lloyd-Walker & Walker, 2015). They may not clearly consider how their theoretical perspective informs their choice but it is necessary to have a clear ontological, epistemological and axiological stance in order to defend a research approach (Lloyd-Walker & Walker). It is also important that a clear connection exists between the theory, the problem or phenomenon being studied and the methodology and methods (Connelly, 2004). In this reflective essay we draw on the experiences and knowledge gained while conducting a qualitative study examining the experiences of staff in an opiate assisted treatment clinic. In this study we utilized a critical social theory perspective and an interpretive descriptive methodology. Reflecting on the primary study, we critically examine and discuss how the relationship between critical social theory and interpretive description enhanced the primary study.

What is Critical Social Theory?

Critical social theory (CST) is a school of thought that stresses the reflective assessments and critique of society and culture. It is used to explore and question discourse and the social world (Sumner & Danielson, 2007). The underlying standpoint of CST is that dialogue is value laden and that norms are contextual depending on the situation and the participants. CST presents a way of understanding the political and social agendas that shape, constrain and influence people's lives. CST is an important tool for uncovering the complexities of the social

world and how its discourses impact people. It is particularly useful in looking at the process of marginalization because CST addresses power, which is one of the social dynamics. CST can be used to examine power relationships to determine who benefits from power and who is marginalized and how the processes of marginalization shape both people and practices.

CST is especially relevant when looking at the experiences of people who are marginalized; it allows questions to be raised that explore what is taken for granted, what norms are unchallenged, what works and for whom (Sumner & Danielson, 2007). CST is useful because it allows people to identify the systemic suppression that is at work in society as a whole and in systems of health and social care. CST in particular helps to identify the power structures that are at work within society.

CST has an interesting history. It arose from Marxism and was first defined by Horkheimer of the Frankfurt School of Sociology in 1937 (McLaughlin, 1999). In the 1960s, a new generation of theorists including Habermas, Foucault and Freire proposed that CST was a scientific inquiry which described distortions and constraints that impeded free, equal and unconstrained participation in society (Fulton, 1997).

CST arose from resistance movements where scholars spoke out against social conditions such as fascism, racism, exploitation of women and prejudice against various groups such as people of color and the LBGTQ community (Hall, 1999). CST is different in that oppressed people themselves define the issues that marginalize them as opposed to outside experts. This is important because a crucial consideration when working with marginalized people is to ensure that they have opportunity for empowerment (Sumner & Danielson, 2007). When a CST lens is used there is an opportunity to engage people who are marginalized in the issues that affect them.

CST is especially important in the care of people who are marginalized because it can illuminate the issues they face. Nurses work for health care systems that marginalize patients and it is important for them to question whether they owe their allegiance to the system they work for or to the patients they care for and to find a balance between the two (Stevens & Hall, 1992). Nurses need to focus on their patients' everyday concerns and the problems that patients identify. Yet, while nurses attend to immediate concerns there is also a need for nurses to reflect and ask themselves how the oppressive conditions of the patients they care for have developed and what they can do to alleviate them. It is important for nurses to identify how issues of race, class, gender identity, lifestyle, sexual orientation and medical status influence their patient's chances for a healthy life. A CST approach can help nurses critique existing conditions in an effort to enhance individual autonomy and responsibility (Wilson-Thomas, 1995).

Nurses' capacities to engage in critical reflection and action upon that reflection are constrained by the fact that nurses are often marginalized themselves. In many instances nurses working alliances with particular clients extends stigma and social exclusion to them. This has been documented particularly when nurses work with patients with high levels of stigma, including people living with HIV or people who use substances (Phillips, 2009).

Historically, within the healthcare system, nurses have rarely held positions of power. Nurses often see themselves as an oppressed group, within a system that relies on them, yet rarely values their input in developing policies and structures that determine their practice. Nurses rate themselves as having little power in relation to environmental forces, resources and communication competency (Katriina et al, 2012). Social and structural factors in both the activities and organization of nursing work implicitly communicates to nurses that they have less value than other members of the health care team (Hart, 2015).

CST provides a worldview that is helpful for researchers as they decide how to conduct their research and as they negotiate the many steps of the research process with participants. By using CST as a theoretical perspective, researchers seek to understand the world through the perspectives of their participants. The goal is to make sense of the meaning others attribute to the world (Cresswell, 2006) and to identify social conditions that shape those meanings. CST is also about making change based on the meanings that are identified.

What Is Interpretive Description?

ID is a qualitative methodology that acknowledges the constructed and contextual nature of human experience while at the same time it allows for shared realities (Thorne, Reimer Kirkham & O'Flynn-Magee, 2004). All inquiry entails description and all description entails interpretation. Qualitative description is especially useful for researchers who want to know the who, what and where of events (Sandelowski, 2010)

Interpretive description (ID) provides useful and accessible guidance in elaborating a coherent research design, orients the research process toward the clinical context and the generation of practice-relevant findings, and draws attention to disciplinary biases and commitments (Hunt, 2009). ID is grounded in the idea that research should have an actual practice goal and that there is a need to understand what we know and do not know on the basis of existing empirical evidence. It allows researchers to go beyond the self-evident – in other words, beyond assumed and established knowledge, to see what else might be there (Thorne, 2008). ID is designed to account for the clinical context of research in applied health disciplines. The explicit relationship between ID and clinical practice orients data analysis toward the development of findings that will assist health care professionals in their practice (Hunt, 2009). ID is appropriate for the generation of nursing practice knowledge (Thorne, 2008). Its emphasis on

examining the constructed and contextual nature of everyday life makes it a good fit with a CST perspective. ID provides a grounding for the concepts and their linkages that become apparent when one attempts to locate the specific in the universal, the state within the process, and the subjectivity of experiences within the usual conventions that current health care contexts represent as the temporal and symbolic location for health and illness (Thorne et al., 2004).

Three philosophical criteria underpin the design of ID:

1. Reality is multiply constructed, complex and subjective and can only be studied holistically.
2. The inquirer and the participant interact to influence one another and meaning must be constructed through negotiation with research participants as opposed to the researcher imposing meaning on the findings.
3. Due to the probable emergence of multiple realities from the findings, theory must emerge or be grounded in the data. (Thorne et al, 2004)

There are similarities between these philosophical criteria and CST. CST is contextual and is based on the complexities of the social world, giving it a subjectivity that is similar to ID (Sumners & Danielson, 2007). CST is contingent on understanding definitions that come from oppressed persons themselves as opposed to outside experts which is similar to the concept of negotiating with research participants as opposed to imposing meaning (Stevens & Hall, 1992). CST is also grounded in data in that it illuminates the issues that people struggle with (Stevens & Hall).

Thorne (2008) contends that ID, unlike most qualitative methodology, is not reliant on a theoretical fore-structure, but instead, is located within a disciplinary orientation, which is appropriate when researching a clinical problem or population. In nursing, there has been a history of thinkers being divorced from doers (Wilson-Thomas, 1995). However, there is a place for theory to influence practice. Theory helps nurses to “understand, examine, illuminate and facilitate empowerment for people who are interacting with the health care system” (Wilson-

Thomas, p.572). CST can be knowledge generating in this respect and Thorne does acknowledge that no human being is immune from theoretical influence. What is important is ensuring that inductive reasoning is conducted with integrity so that the findings are well grounded within the data.

Overview of the Study

This study, *The Crosstown Clinic: An Inquiry into the Experiences of Staff*, was a qualitative study utilizing an ID methodology. The first author has extensive experience with the clinic as a nurse educator and was interested in having a greater understanding of what motivated the staff to work in what on the surface would seem to be a challenging environment. The Crosstown clinic is a novel concept in the North American context. While there are a number of clinics that provide opiate assisted treatment in Europe, this is the first clinic of its kind in North America.

Twenty-two staff members were interviewed, including 18 nurses, two social workers and two clinic support workers. Staff experience with the clinic ranged from 6 months to more than 10 years. An open-ended interview questionnaire was used to talk with staff and understand their perspectives, opinions and experiences. Seven findings were uncovered including from chaos to stability, putting the patient at the centre, it's not all roses, the stigma hasn't gone away, the clinic is life transforming, a little preparation would be good, and the patients have a story to tell. Three of these findings are relevant to this essay and are discussed below.

Putting It Together

CST is a philosophical position that works well in ID. What researchers name as data is really our constructions of other people's constructions of what they are up to. The choice of theory is subjective but it provides one of the ways in which data can be analyzed (Walsham,

2006). A worldview or paradigm, informs the development and implementation of theory in an ID study (Jackson, 2015). In the case of this study, the theory chosen was CST, which reflects the first author's worldview. A worldview is a fundamental cognitive orientation which reflects an individual's knowledge and point of view. We embrace a social justice perspective about the world, which means that we believe in an equitable distribution of resources and opportunities. Additionally, as a nurse, the first author has worked for over 30 years at an inner-city hospital. She has had first hand experiences with the inequities with which her patients struggle. The other authors are nursing faculty and have had similar experiences in the populations with whom we work and research. A social justice perspective is congruent with CST and often arises when understanding processes of marginalization.

Findings from this study reveal how a CST perspective elevated the analysis to a higher level. Taking a CST approach to ID allows for a research design that encourages the negotiation of meaning beyond a descriptive level (Lather, 1986). What is important is for meaning to transform practice. For Lather (1986), the connection between theory and practice was praxis, which was concerned with the development of emancipatory knowledge. As Freire (1970) pointed out, people need to reflect and act upon the world in order to transform it. Freire believed that humans have a capacity for historical, cultural and linguistic praxis and that people produce history and culture, even as history and culture produce them. People see their reality as presenting concrete problems as well as opportunities for transformation (Glass, 2001).

One of the study's findings, from chaos to stability, described how the patients achieved stability as a result of being able to receive legal heroin in a medical setting. But it wasn't just about stability. As a result of being able to access heroin without fear of arrest, incarceration or public shaming, the patients found power. Power to make decisions about their lives and power

to make their treatment objectives known to the staff. The issue of power is a central idea in CST. CST attempts to lay bare the social sources of oppression (Leonardo, 2004). In the case of the patients, their experiences reveal how their change in social status as a result of being able to access legal heroin has enabled them to gain power. A number of the participants commented on the changes they saw in the patients in relation to this and they attempted to assist their patients in making the most of their unfolding experiences of having power.

The second finding, it's not all roses, revealed that the clinic location was deficient in terms of space. Many of the participants talked about the challenges of working in inadequate space. The staff was concerned about the space, which was prone to mould, water leaks and overcrowding. Space confers power (Gieryn, 2000) and when the staff lack space they in turn lack power. Space is socially produced and constructed and it could be said that space "keeps people in their place" (Kitchin, 1998, p. 343). From a CST perspective, space impacts on agency. Lack of space makes it difficult for the staff to do their work in the way they would like to do it. As Putnam (1999) suggests, "our words and our life are constrained by a reality not of our own invention" (p. 76). Space is fundamental to any exercise of power (Soja, 2003). The limitations of the clinic made it difficult for the staff to engage in reflective practice. It is important for nurses to question how oppressive conditions have developed and what they can do to relieve those conditions because as much as the lack of space is an issue for the staff, it is also an issue for the patients.

When space becomes an issue, it affects peoples' ability to do their job. A study by Kasule (2015) revealed that the quality of the work environment has a direct effect on job performance. A CST and Foucauldian perspective indicates that the dominant reality imposed by the clinic's design inhibits the nurse's ability to practice (Mantzoukas & Jasper, 2004).

Another finding that is relevant to this discussion is that of stigma. Stigma is a social process that is rooted in social space (Yang et al., 2007). Stigma is associated with CST in that stigma sustains existing social hierarchies (Poteat, German & Kerrigan, 2013). Stigma is both a product and an enactment of power. Participants talked at length about the experience of stigma, both for themselves and their patients. Participants had experienced a lack of understanding and support for their job choice from friends, family and acquaintances, and they reported that the patients were fearful of accessing healthcare outside of the clinic due to the stigmatizing responses they received from healthcare workers. Stigma has negative political, social, economic and psychological consequences (Crocker & Major, 1989). From a CST perspective, stigma is a marginalizing discourse that is a tool of oppression.

Reflections on CST and ID

Utilizing CST reveals the complex political and ideological agendas that influence people's lives. In the context of this study, it takes the experiences of stigma and power to a higher level of understanding. When one looks at stigma and power through the lens of CST, it becomes apparent that there are complex issues of marginalization, oppression, racism and gender discrimination that are at work.

From a philosophical standpoint, ID assumes that it is impossible to attain objective knowledge through empirical analysis (Thorne, 2008). This is why a CST perspective is a good fit. CST helps to uncover the complex political, ideological and social agendas that impact on people's lives. Realities are local, experientially based and contingent on the persons who hold them (Hunt, 2015). The goal of ID is to inform clinical practice (Hunt, 2015), which is reliant on an understanding of patients – where they come from and what they believe. Nursing's goals in relation to patients and our social and moral mandates for practice are inherently emancipatory

(Browne, 2000), yet they are not always acted upon. In this current study, the research provided knowledge that can leverage change and as such be emancipatory. As Thorne (1997) contends, an emancipatory perspective shifts human inquiry away from straightforward knowledge acquisition towards a domain of generating practical knowledge, disrupting the patterns of power and participating in socially transformative activities that lead towards justice, equity and freedom. However, practice cannot exist without theory. In fact,

What is required is a dialectical unity of theory and practice so that theory guides and informs practice and practice guides and informs theory. Practice without theory is mindless activity, but theory without practice is verbalism (Lantholf & Poehner, 2014, p. 203).

A CST approach helps bridge the gap between theory and practice through the process of reflection on practice (Manias & Street, 2000). This process of reflection is the first step towards advocacy, which is an important consideration for researchers and participants. CST not only accepts the reality of oppression. It also assumes the possibility of a less oppressive condition. For the nurses in this study, a less oppressive condition would be to have a voice that is heard and acted upon and to minimize the stigma that they experience as a result of their job choice. CST does not surrender the search for emancipation but qualifies it as an unending process of liberation and multiple emancipations (Leonardo, 2004). Taking a CST perspective means undertaking a conscious remaking of the world (Freire, 1998).

There is a contention that CST is not inherently practice driven. Browne (2000) contends that an indiscriminate reliance on CST as a framework risks favoring the collective over the individual and general over particular knowledge. It is difficult to agree with this contention. It is apparent from the findings in this study that taking a CST perspective allows the researcher to understand the complexities and context of the experiences of the nurses. CST is a means for

creating different methods of knowing and understanding relationships, which are inherently individualistic (Wilson-Thomas, 1995).

It is important to consider the subjective reality of each and every individual we encounter in clinical practice. CST has the potential to advance nursing science towards socially relevant and progressive emancipatory possibilities (Browne, 2000) but care must be taken to engage in a reflective process that ensures that prevailing norms and accepted truths are challenged. It is important to attend to what is most important, which is the social, political and structural conditions that impact on the lives and experiences of both patients and caregivers.

Conclusion

It can be a difficult task to determine the direction of research. Formulating a plan, selecting a methodology, determining a prospective sample and deciding on an analytic strategy can all be fraught. It is important to connect research methodologies with theoretical concerns and commitments (Lather, 1986). Having a clear understanding of the researcher's worldview and their theoretical perspective can help inform choices that ultimately shape the knowledge that is created.

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CHAPTER FOUR

The Patients Have a Story to Tell: Informed Consent for People who use Illicit Opiates in a Qualitative Research Project

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Abstract

This paper discusses the ethical issues that arise when seeking informed consent from people who use illicit opiates. There is a significant discourse in the literature that opines that people who use illicit opiates are unable to provide informed consent due to withdrawal symptoms and cognitive impairment as a result of opioid use. This paper outlines the ethical issues that have been discussed in relation to this issue, reviews the findings of a study in which staff were asked their opinions about their patients' ability to provide informed consent and discusses the issues that arise when patients are not allowed to consent to research.

Keywords: informed consent, addiction, heroin assisted treatment, ethics

The Patients Have a Story to Tell: Informed Consent for People who use Illicit Opiates in a Qualitative Research Project

It is an ethical and legal requirement for healthcare professionals to obtain informed consent from patients and research participants. The concept of informed consent is rooted in the value of autonomy, and in the context of standard medical research, obtaining informed consent is a quintessential and obligatory practice. In order for informed consent to be considered valid, voluntariness and comprehension are required. When it comes to people who are addicted to opiates however, the issue of informed consent becomes fraught for some research ethics boards (REB) in Canada. Because there is a potential for prospective participants to be intoxicated or experiencing acute withdrawal, ethical issues have been raised. This paper discusses the ethical issues that were raised in the conduct of a study that examined the experiences, opinions and perspectives of staff at the Crosstown Clinic. Crosstown is a clinic that provides injectable medical grade heroin and hydromorphone to people with an illicit opiate addiction.

Ethical Issues in Substance Use Research

A research participant is considered competent to consent when they can understand the material information, judge the information based on their values, understand both the expected and potentially adverse outcomes, and are able to communicate their views to researchers. The primary elements of informed consent are the participant's ability to understand what is being asked of them and that their decision about participation in the study is made voluntarily (Smith, 2007). Voluntarism has been defined as embodying respect for the person as a human being, as a person with their own history and values and as a moral agent with rights and privileges (Geppert & Bogenschutz, 2009a). Voluntariness depends on a person's beliefs about their options and their

motivation for action (Henden, 2013). In the case of people who use heroin, their choice is constrained by the wider social and psychological circumstances of their addiction.

A number of ethicists have raised concerns about the ability of people who use heroin to provide informed consent. Levy (2016) states that addiction adversely affects the autonomy of users. Addiction has such an adverse impact socially, economically and psychologically that it casts considerable doubt on the ability of substance users to provide informed consent (Levy, 2016). The ability of individuals who use opioids to make decisions has been called into question due to the impact of intoxication and withdrawal and the potential long-term consequences of drug use (Anderson & McNair, 2018). Steel, Marchand and Oviedo-Joekes (2017) stated that researchers should assume opioid dependent people are incompetent to provide informed consent unless proven otherwise.

People who use opioids are vulnerable as a result of their marginalization, their social positioning, their criminalization and their addiction (Anderson & DuBois, 2007). Smith (2007) contends that the capacity of people who use opioids to exercise autonomy and protect their own interests is impaired by their vulnerability. Vulnerable participants present researchers with ethical and moral dilemmas that need to be addressed as part of the research process (Nordentoft and Kappel, 2011).

There seems to be a general consensus that people who are addicted to opioids have problems with providing informed consent. There is concern that coercive factors, whether that be the provision of medical grade heroin or cash honorariums, influences decision making by people with addiction issues (Caplan, 2006). In addition, there is a potential for people who use illicit opiates to be cognitively impaired or in withdrawal, which can also impact their ability to make an informed decision.

The Psychosocial Positioning of Heroin Users

People who use illicit opiates are subject to a significant degree of stigmatization, both by the general population and health care providers (Lloyd, 2010; Neuman et al., 2013; Room, 2005). People who use substances experience multiple layers of stigma. They are stigmatized because of their drug use but also because of issues of poverty, unemployment and homelessness. In addition, because they are more likely to be infected with hepatitis C and HIV, they are subjected to the dishonor that is associated with these conditions. People who are marginalized and discriminated against are overrepresented in the population of people with addiction to opioids (Hemsing et al, 2016).

There is a clear link between trauma and addiction (Wiechelt & Straussner, 2015). A recent study by McCall et al. (2018) revealed that people with HIV infection who had a history of childhood sexual abuse had a significantly elevated risk of being addicted to substances. Trauma has profound impacts on development that can leave a person at risk for addiction due to their inability to practice self-protection. A pathological environment of abuse also leaves individuals at risk for developing psychiatric symptoms and aberrant behaviors such as anxiety, agitation, somatic symptoms including tension headaches, GI disturbances and abdominal pain, and personality changes such as distortions of relatedness and identity (McCall & Lauridsen-Hoegh, 2014). Heroin addiction is associated with depression, anxiety and other psychological disorders (Henden, 2013). Multiple studies have revealed that people with substance use disorders were twice as likely to experience mental illness (Anderson & McNair, 2018). People with heroin addiction often experience feelings of powerlessness, hopelessness and despair (Henden, 2013).

Stigmatization and its political expression in discrimination have an adverse effect on all aspects of addiction care from diagnosis to treatment and from education to funding (Geppert &

Bogenschutz, 2009a). This has been the case in the health care setting, where stigma towards substance users is rife. There is a wealth of literature that outlines the experiences that people who use illicit substances have with the health care system (Browne et al., 2011; Natan, Beyil & Neta, 2009; Strike, Myers & Millson, 2004). Nurses report that they have difficulty caring for members of this population (Browne et al., 2011; van Boekel, Brouwers, van Weeghel & Gerretsen, 2013). Nurses often use marginalizing and dehumanizing terms that reflect embedded stigma and judgment such as referring to illicit substance users as “addicts”, “junkies” and “drug abusers”. These are highly marginalizing and dehumanizing terms. Nurses have negative attitudes towards people who use substances that reflect societal stigma (Natan, Beyil & Neta, 2009). Nurses tend to see patients who use substances as dangerous and immoral, which reflects the attitudes of society at large (Strike, Myers & Millson, 2004).

The stigmatizing attitudes that nurses hold extends to their perceptions of pain control in general, but especially for, members of this population. Nurses hold disturbingly inaccurate beliefs about pain control and addiction for people who use substances including the belief that people who use substances are drug seeking. Krokmyrdal and Andenaes (2015) found that a majority of nurses that they surveyed believed that patients who have addiction issues exaggerate their pain, are dishonest when describing the effect of their pain medication and misrepresent their pain experience. These authors among others make it clear that nurses are ill prepared to care for member of this population. Most nurses receive little in the way of training in addiction care (Campbell-Heider et al., 2009).

The Story of a Study

The Crosstown study was initially envisioned and federally funded as a qualitative study where the first author would interview both patients and staff about their experiences, opinions

and perspectives about the clinic and its program. The Crosstown Clinic provides injectable opiate assisted treatment to people with long standing opioid addiction who have tried and failed with standard treatments such as methadone and buprenorphine. The study was approved by the university where the first author is completing her PhD but the university and health authority where the study is located withheld approval. It became quickly apparent as the proposal proceeded through the review process that the local REB had reservations about including the patients in the study and ultimately they made their opinion plain, stating that “there are ethical concerns with the consenting and interviewing of individuals under the influence as they cannot give proper informed consent.” The clinic staff however had other ideas. As part of the interview process, the staff were asked what they thought of the REB’s position and they were unanimous in stating that they were in disagreement.

Melanie stated, “Point blank, that’s bullshit. [They are] fully capable...they are smart. Just because they use heroin they’re not stupid, they’re smart.” Many of the staff members felt that the REB decision was stigmatizing. Joan commented that it was “incredibly judgmental.” Peter stated “that’s bias and backward thinking.” Kathy said “I think there is a bit of discrimination in that.”

A number of the staff made the point that the patients were not impaired. Natalie pointed out that “they might be on heroin but a lot of them are fully functional. The amount that we give them isn’t supposed to get them high it’s just supposed to help maintain.” Mike noted that

it seems weird to say but they kind of seem like a little bit more themselves after their dose versus before their dose. When they come in especially like with their first one – I mean people are sick², they’ve been gone for like eight to whatever, however many hours they’ve been gone. And, you know, so when you’re sick, you’re a little edgy, you’re a little moody, you’re a little grumpy. But afterwards like after hanging out with them in that twenty minute post time they’re laughing, they’re talking, they’re telling jokes.

² Describing yourself as “sick” is a street term that opiate users use to describe withdrawal symptoms.

Shelley said “our clients are not in a diminished capacity because they’ve taken a medication that, you know, stabilizes them.”

The staff also talked about how the program had helped their patients stabilize. Penelope noted how “they go to work right after this so they’re able to function.” Scott talked about how “a lot of our clients work paid jobs so, you know, like to be able to do that you, you have to kind of have yourself together.”

Some of the staff also noted that the patients often talk to the media about the clinic. Judith talked about how “lots of our patients have given extremely well put together interviews for media.” David mentioned that they needed consent for media interviews. “A lot of the individuals who are part of this clinic they do that media and that media is consent based.”

The staff also observed that the REB did not have a problem with approving the two quantitative studies associated with the clinic. The first of these studies, the North American Opiate Maintenance Initiative (NAOMI) compared injectable heroin to methadone. The second study, called the Study to Assess Long Term Opioid Maintenance Effectiveness (SALOME) directly compared injectable heroin to hydromorphone and ultimately the efficacy of oral hydromorphone. In both of these studies the participants were provided with either injectable heroin or hydromorphone. Dierdre noted that “they had to sign a consent for the NAOMI (North American Opiate Maintenance Initiative) study. I don’t see how that was safer than this [study].”

Possibly the most important finding that came out of the staff interviews in relation to this question was the idea that the patients should have a voice in the research that is conducted for their program. Shelley stated that many of the patients “would just love to participate in this study.” Alison said “the patients have a story to tell.”

Discussion

Excluding vulnerable people from research over concerns about their ability to provide informed consent may have the unintended consequence of being discriminatory and also denies them the opportunity to contribute to society through research. The absolute dictum to disallow vulnerable people from giving informed consent excludes people in disadvantaged groups who do not have the power to exercise this right equally (Smith, 2007). There is the potential for the needs of vulnerable people to be neglected and thus, the principles of justice and beneficence would be violated (Shrems, 2014). The end result of this positioning is that research activity is diluted, with limits in the assumed benefits of research to specific social groups and society (Smith, 2007).

A number of researchers have taken exception to the generally held position that people who use heroin are incompetent. Levy (2016) noted that addicts do not just react, they act. Their movements are flexible and intelligent responses to the situations they find themselves in. Levy (2016) also noted that people with addiction issues are not in autonomy limiting states (craving, withdrawal, intoxication) most of the time. It is never right to assume that individuals cannot provide informed consent just by virtue of using illicit opioids (Anderson & McNair, 2018). Even for substance dependent individuals, choices are not predetermined or illogical. Rather, they are dependent on the “constellation of rewards and negative consequences in any specific situation.” (Geppert & Bogenschutz, 2009b, p. 56). In consideration of this, their choices are not incompatible with informed consent. Interestingly, informed consent does not seem to be an issue in studies involving people with an addiction to alcohol, even though they are just as likely to be impaired or in withdrawal at the time of enrollment. Several studies were located (Hamalainen et

al., 2018; Hodgins & Kim, 2016; Mihai et al., 2006) that examined issues related to alcoholism and none of these studies indicated any issues with the consent process.

Informed consent assumes that the potential participant has autonomy. Autonomy however, is not an all or nothing concept. Autonomy comes in degrees (Levy, 2016) and it is interesting to note that when it comes to people who use heroin society at large and researchers in particular are often willing to blame them for the serious crimes that they commit. We expect them to retain sufficient autonomy to prevent themselves from assaulting others and stealing, but do not afford them enough autonomy to avoid using drugs or to consent to participate in research. Even though addiction has an adverse impact on autonomy, there is no reason to think that many addicts “are not autonomous enough” to give their consent (Levy, 2016, p. 69). Neuroscience research does not indicate that people with addiction issues lack autonomy (Carter & Hall, 2008). While their autonomy can be impaired, they retain some degree of control over their drug use and some degree of autonomy (Carter & Hall, 2008).

Responsible advocacy has been suggested as a way of protecting vulnerable people and ensuring that they are able to participate in research that has the potential to benefit them, their families and communities. Responsible advocacy is about protecting vulnerable individuals from harm, and protecting their welfare by maximizing their capacity for self-determination (Hopkins, Harvey & O’Brien, 2004; Smith, 2007; Ulrich, Wallen & Grady, 2002). Responsible advocacy seeks to marry a researcher’s ethical identity as both advocate and social conscience (Cox, 2006).

There are three principles that underlie responsible advocacy:

1. The research must carefully consider the harms and benefits of possible action.
2. Respect for all persons should be insured.
3. All rewards and difficulties must be equally allocated. (Cox, 2006)

Advocacy is a moral obligation for nurses and it requires them to have a level of understanding about their clients to help them understand the situation they are confronted with and to make good decisions (Smith, 2007). If researchers adopt the position of responsible advocacy, they might be more able to determine if their patients have the capacity to provide informed consent and help them to understand the proposed research (Hewison & Haines, 2006). Responsible advocacy asks practitioners and researchers to not only look at the obvious issues that affect participants but to understand the underlying issues that contribute to social inequality. Research is both objective, using defined, rigorous and replicable methods, and partisan, meaning that it reflects underlying values and assumptions that determine conceptualization, choice and analysis of research problems (Northridge, 1999). It is important to understand how the conduct of the research impacts on participants, and specifically, how our beliefs about informed consent can impact enrolment.

It is possible to involve people who use heroin in research projects, however careful design of the research is needed. Well-designed research can filter out people who lack capacity and recruit those whose capacity to consent is not in doubt (Levy, 2016). Risks need to be minimized and communicated clearly during the consent process so that the participant's decision making is supported (Anderson & McNair, 2018). It is important to understand how coercive factors can affect the voluntarism of participants so that assessments can be developed that detect impairments in self-determination (Geppert & Bogenschutz, 2009b). Informed consent should be seen as an ongoing process that is repeated several times during the interview research process, whether that involves interviews or biomedical interventions (Nordentoft & Kappel, 2011).

It is important to remember that people who use drugs have a right to be involved in research. The Canadian HIV/AIDS Legal Network (2005) has created a manifesto entitled

“Nothing about us without us.” This manifesto outlines the important principles that should be considered when planning research that involves people who use drugs. These principles include having the right to be involved in activities that affect their health and well-being, having the right to make informed decisions about their health, and recognizing that they have unique expertise and experiences that have a vital role to play in defining the health, social, legal and research policies that affect them.

It is important to understand vulnerability as not just a person, but a situation. People are vulnerable as a result of socioeconomic forces that impact on their life. The person needs to be viewed in context. If vulnerability as a context-related and situational concept is combined with existing approaches to informed consent, ethical principles can be balanced and preserved at every step of the research process (Schrems, 2014). Researchers and ethicists often make assumptions about people and their vulnerability and competence based on their lifestyle and socioeconomic status. These assumptions are not always valid. A homeless patient with mental illness may be managing his daily affairs. His diagnosis and membership in a disadvantaged group may suggest impaired research decision making capacity where none exists (Biros, 2018). Potential participants should be treated as moral agents and be given a voice by involving them in the process of determining whether they participate in research or not.

The Tri-council Policy Statement from Health Canada does not preclude vulnerable people from participating in research. The guiding statement is that vulnerable people should be provided with special procedures to protect their interests (Health Canada and the Public Health Agency of Canada’s REB, 2007). There was a plan in this study to protect vulnerable patients by asking the front-line staff to assess the patients before they signed a consent to ensure they were not intoxicated or impaired and therefore not able to provide informed consent.

Conclusion

There is a careful balance between protecting vulnerable participants and making paternalistic decisions that are supposedly in their best interest. It is ironic that the people most in need of attention in order to improve their condition are the people who are most frequently left out of qualitative research (Nordentoft & Kappel, 2011). If there is one theme that is prevalent in the copious literature arguing against inclusion of people who use heroin in research, it is that protectionist concerns about recruitment incentives and consent comprehension may be overstated (Geppert & Bogenschutz, 2009b). Such concerns do not promote the interests of research participants. It is clear that more work needs to be done to establish the rights of people who use heroin to provide voluntary informed consent. Hannah Arendt (1968) talked about the right to have rights and that these rights should be guaranteed by humanity. Qualitative research gives voice to people who are normally silent and marginalized (Nordentoft & Kappel, 2011) and can potentially give them their rights. People who use heroin need to be given their voice and need to be able to tell their story.

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CHAPTER FIVE

Implications for Nursing

A plethora of literature outlines the issues that most nurses have with patients who are addicted to opiates (see for example: McCaffery & Vourakis, 1992; Pauly et al., 2007). There is evidence that nurses are minimally supportive of harm reduction, at best. Most nurses, as with many health care practitioners, have an abstinence based attitude towards substance use (Caplehorn, Lumley, Irwig & Saunders, 1998; Ford, 2010; Goddard, 2003). There is evidence that abstinence oriented approaches limit the effectiveness of methadone maintenance and indeed harm reduction in general (Gerlach & Caplehorn, 1999).

Nurses are ill prepared to deal with the needs of people who use substances. Nurses tend to avoid dealing with patients who use substances by minimizing their contact with them and nurses are reluctant to discuss drug use with their patients (Monks, Topping & Newell, 2012). What this means is that nurses do not discuss harm reduction strategies with their patients or take the opportunity to ensure their patients are using safe injection techniques. The findings from this study can be used to help nurses come to a better understanding of the importance of harm reduction strategies in the care of people with substance use issues. A knowledge translation approach is a strategy that can be used to transform nurses' thinking.

The Principles of Knowledge Translation

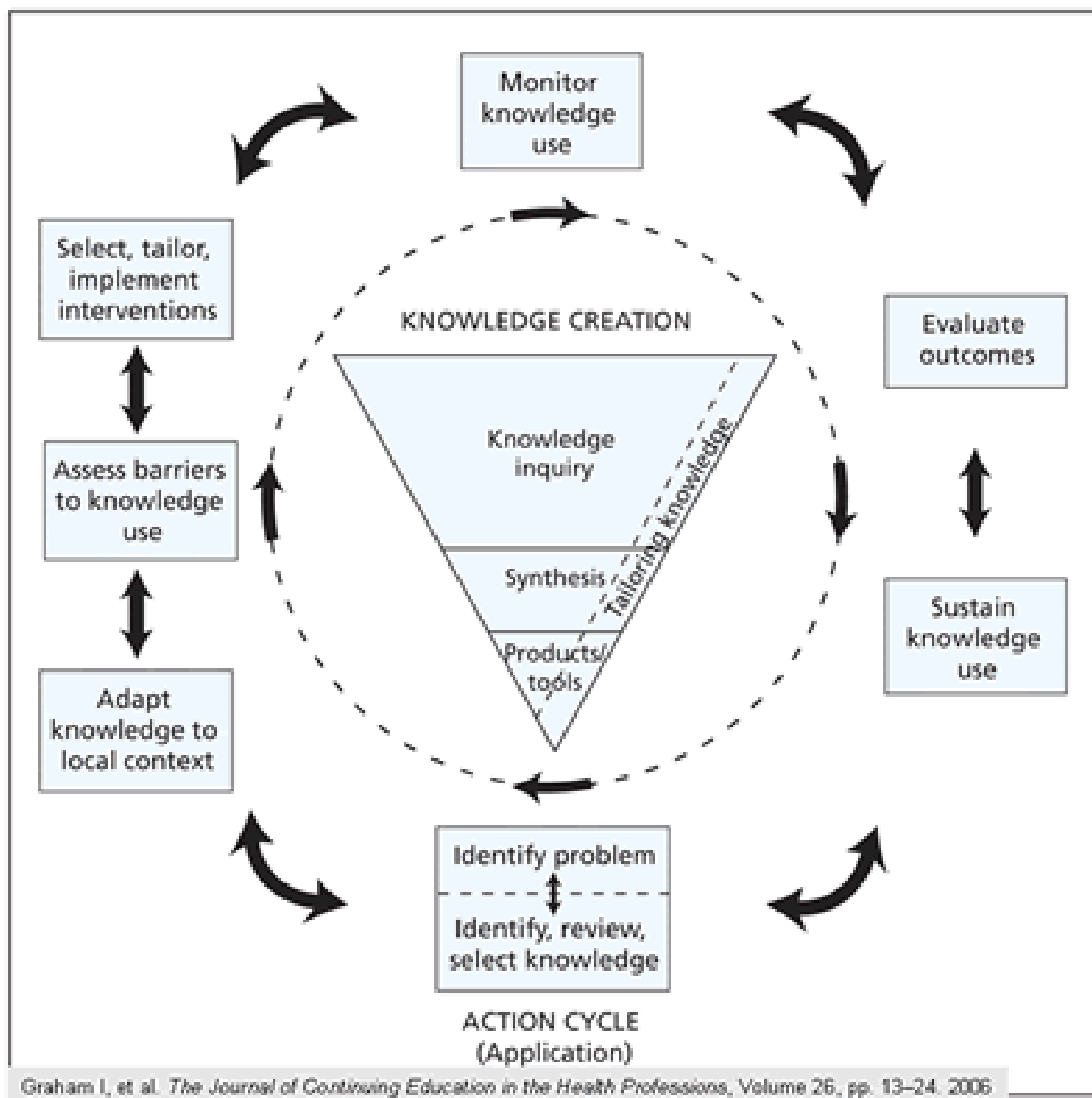
Knowledge translation (KT) is a dynamic iterative process (Canadian Institutes of Health Research, 2015a). KT uses synthesis, dissemination, exchange and ethically sound application of knowledge to ensure evidence based care and treatment, to lead to improved health outcomes, more effective health services and a robust health care system. KT is not just about dissemination of knowledge but about the uptake of knowledge into practice. It is not enough to create, distill,

and disseminate knowledge. Knowledge must be taken up in order to achieve a change in practice. (Straus, Tetroe & Graham, 2009).

There are a number of frameworks that can be used to guide the KT process. One such framework, which has been adopted by the Canadian Institutes of Health Research (2015b), is the knowledge to action cycle (see Figure 1). This cycle consists of seven phases: identifying the problem, which includes identifying, reviewing and selecting knowledge; adapting knowledge to local context; assessing barriers to knowledge use; selecting, tailoring and implementing interventions; monitoring knowledge use; evaluating outcomes; and sustaining knowledge use. These phases can occur concurrently and the action phases can be updated as knowledge changes.

Another approach to KT is the PARiHS framework (Promoting Action on Research Information in Health Services). This framework proposes that evidence encompasses both codified and non-codified sources of knowledge, that implementing evidence is a dialectical process that involves negotiation and a shared understanding, that some contexts are more conducive to the uptake of evidence than others and that there is a need for appropriate facilitation (Kitson et al., 2008). Kitson, Harvey, and McCormack (1998) proposed that equal recognition be given to each of these features so that the actual relations between these four elements can be explored. In this way, when implementation fails, the possible reasons for this can be analyzed relative to the framework.

Figure 1 (see Appendix Four for copyright).



These two frameworks are not actually mutually exclusive. The PARiHS framework can be used in conjunction with the knowledge to action cycle. The PARiHS framework demands attention to negotiation, shared understanding and context, which can be utilized when following the phases of the knowledge to action cycle.

Application to Harm Reduction.

Given the prevailing attitudes of nurses towards patients who use illicit substances, a challenging process of changing practice can be anticipated. Transferring knowledge can be slow and haphazard (Eccles, Grimshaw, Walker, Johnston & Pitts, 2005). It is important to create a methodical, organized process for translating knowledge. It is also important to remember that “the nature of evidence is broader than evidence derived from research” (Rycroft-Malone et al., 2003, p.83). Knowledge not only comes from randomized controlled trials, but is also created as a result of professional craft knowledge. This is why qualitative findings, such as the ones outlined by this study, are an important resource. As the PARIHS framework makes clear, it is also important to consider context and shared understanding. Knowledge translation cannot occur without a clear understanding of organizational cultures.

Understanding organizational cultures means taking a number of steps. The first step is to determine exactly where nurses stand on the topic of harm reduction before the attempt at KT begins. This requires an analysis of the target group, the setting in which the change is planned and the determinants of change (Wensing & Grol, 2005a). Such a process can take a number of forms, from a survey of attitudes to focus groups or interviews with front line nurses to elicit their perspectives (Wensing & Grol, 2005b). Based on the findings from such a process, the appropriate knowledge that needs to be provided can be selected.

The next step in the process is to gain an understanding of the local context. What are the challenges facing the nurses in terms of their daily work life? Are they given opportunities to learn new information? Do their administrators support them? Is there openness to learning new information? As has been noted, context is a crucial piece in ensuring knowledge uptake, dissemination and adoption (Moat, Lavis & Abelson, 2013). Part of context is understanding the

barriers. Dogherty, Harrison, Graham, Vandyk, and Keeping-Burke (2013) identified a number of issues that can be barriers to knowledge uptake, including a lack of engagement and ownership, resource deficits, dissonance and conflict, team functioning and workload, and lack of evaluation and sustainability. If nurses are overwhelmed with their daily work, they will be less likely to be receptive to learning something new. If the initial process of gaining an understanding of nurse's attitudes reveals that the nurses are overwhelmingly negative about substance users and addiction it may be that the process will have to be reworked to focus on nurses understandings about addiction before the concept of harm reduction can be broached.

Step three is selecting, tailoring, and implementing interventions. It is important to ensure that the knowledge that is provided is appropriate and considerate of nurse's time constraints as well as the context of their work environment. It is useful to focus on the need to know as opposed to the nice to know. An important consideration in this step is the use of facilitators. How the knowledge is transmitted is just as important as what is transmitted. It is crucial to consider who will be the purveyor of the knowledge. There are some important characteristics that make a facilitator successful. They need to be a clinical and process expert, not necessarily a content expert. They need to be seen as a resource as opposed to an authority. They need to be able to broker knowledge, relationships and support across all levels from the front line to the administration. They need to be an effective, visionary and passionate communicator. They need to be politically savvy, with excellent interpersonal, relational and marketing skills that they can communicate in an authentic manner (Dogherty et al., 2013). It is also important that the facilitator be seen as someone who is an expert in the field of harm reduction and addiction. Front line staff are more likely to listen if they perceive that the facilitator has knowledge in the field that is the focus of attention.

There is some evidence that knowledge brokers can be key to facilitating the exchange of knowledge. They perform a diverse range of tasks across the domains of knowledge manager, linkage agent and capacity builder (Bournbam, Kornas, Peirson & Rosella, 2015). Knowledge brokers can be useful for bridging the gap between researchers and practitioners. They can liaise between these groups, providing facilitated engagement of practitioners.

An important principle when considering the implementation of knowledge is for the researcher think big and start small. Keep the message simple and easy to understand. Ensure that the information that you are providing is in small, digestible chunks. Utilize different platforms – websites, clinical summaries, posters, apps. Busy health care professionals are more likely to be receptive if the knowledge that they are being asked to absorb is available in a fashion that is easy to take up into practice (Price, 2016).

Monitoring and evaluation is an important consideration to determine current care provision and identify gaps in performance (Braspenning, Campbell & Grol, 2005). In order to know if changes in behaviour have occurred it is necessary to develop quality indicators. A quality indicator is a “...measurable element of performance for which there is evidence or consensus that it can be used to assess the quality, and hence change in the quality of care provided”. (Lawrence & Olesen, 1997, p. 105). Quality indicators can be based on published scientific evidence, by combining evidence and expert opinion or from clinical guidelines (Braspenning et al., 2005). Quality indicators can be assessed using either a qualitative or quantitative process. A chart review, a follow up survey of nurses and/or patients or follow up interviews and focus groups are all appropriate ways of managing this issue.

Sustainment is quite possibly the most challenging aspect of KT. It is relatively easy to provide health care workers with new information. It is not so easy to ensure that the change in

practices as a result of the information is sustained. There are a number of factors to consider in the development of a sustainable action plan. Is the topic relevant? Does it provide benefits to the stakeholder? What are the attitudes of the nurses? Are there networks in place that can facilitate sustainability? Are the leaders engaged? Is the plan articulated and integrated into policy? Is there financial support for the change effort? Can you leverage political stakeholders, such as a minister of health or health authority leadership? (Davies, 2010).

It is important to distribute knowledge of new clinical practices in various organization knowledge reservoirs (e.g. clinical practice guidelines, clinic/hospital policies) in order to institutionalize the practice or to develop organizational memory and ensure its sustainment over time (Verani, Lemieux-Charles, Davis & Berta, 2009). Some of the knowledge reservoirs that should be developed and supported include people, such as nurse champions; routines or standard operating procedures; artifacts such as policies and procedures; relationships such as using patients to cue staff as to appropriate behaviour; organizational space such as using bulletin boards to post reminders of expectations around clinical practice and staff meetings where the issues can be discussed; culture – it is important for staff to share stories and garner support from each other for the practice change and, lastly, structure. The organization must clearly state its expectations around clinical practice issues (Verani et al., 2009). An important strategy is the development of a policy or protocol that directs nurses in the provision of harm reduction services.

There are some specific strategies that can be considered in terms of increasing knowledge and acceptance of harm reduction among nurses. First and most importantly, undergrad nursing programs need to include content about substance use, addiction and harm reduction in their programs. It would be useful if undergrad programs also ensured that their

students had experience working with people who use substances. Health care organizations need to ensure that nurses have access to addiction and harm reduction education when they are initially hired and that ongoing education is available as needed.

Using a Critical Social Theory Perspective for KT

Critical social theory (CST) is a useful framework for KT. It can be potentially liberating when it is used to reconstruct power relations in nursing (Manias & Street, 2000). In this study, as in so many others, it was clear that nurses are constrained by the environment they practice in (Gieryn, 2000; Kilcoyne & Dowling, 2007; Kitchin, 1998). Their stories about the difficulties of working in the physical environment of the clinic and of being stigmatized for their choice of employment made that clear.

A critical social theory approach helps to bridge the gap between theory and practice through a process of reflection (Manias & Street, 2000). By thinking critically, nurses can develop a greater degree of self-consciousness and act to transform existing social norms in order to improve their working conditions and also the lives of their patients. Nurses can use critical reflection to question what is taken for granted, what norms are unchallenged, what works and what does not (Sumner & Danielson, 2007). It allows nurses to identify the systematic suppression in the health care system that impact on their work life and their patients and to identify the power structures that are at work. Knowledge isn't useful if nurses are constrained by the power structures at their place of work. They need to know how to reflect on the issues they confront and how to advocate for change.

Reflections

I came to a greater understanding of what constitutes harm reduction as a result of conducting this study. It is clear that harm reduction needs to embrace relationship building if it

is to be fully realized. The staff in this study talked at length about how they strive to develop positive, therapeutic relationships with their patients and it was evident that the success of this program is dependent on these relationships.

Taking a critical social theory perspective illuminated the struggles that the staff experience with the lack of space. Understanding how CST can help nurses and other health care staff engage in reflection and develop consciousness about their situation will help me as I endeavour to share these findings with them.

Understanding that stigma continues to be an experience that both staff and patients face is also an important result of this study. Stigma is a difficult concept to address. Society at large has entrenched cultural attitudes towards the 'other' that are difficult to change. However, despite the difficulty it is vital that efforts are made to reduce the stigmatization of illicit drug users and their caregivers. It is important for nursing leaders in the field to talk about this issue and to tell positive stories about illicit drug users. The positive stories that came out of this study about the patients are a good place to start.

The lack of preparation that the staff indicated that they had experienced, both in their schooling and in their workplace is another issue that needs attention. It is likely that the issues that health care staff have in dealing with the population of people who use substances can be linked to a lack of educational preparation. It is important that the findings from this study are communicated to policy makers and leaders in education and health care so that this deficiency can be addressed.

Conclusion

The findings from this study provide a road map that can help nurses provide better care to their patients who use illicit opioids. Nurses need to understand the potential for patients to

make better choices when they are stabilized with prescription injectable opioids. They need to appreciate the value of patient centered care for all populations, including people who use illicit opioids. They need to acknowledge the continued stigma that patients face as a result of their substance use as well as the stigma they themselves face. And they need to understand that providing culturally safe, appropriate care to what is perceived as a difficult population can be life changing for themselves as well as their patients. As well, they need to appreciate the importance of hearing their patient's stories and ensuring that those stories help to direct decision-making and policy development. Lastly, when they are confronted with working conditions that make it difficult to practice, they need to consider how power structures impact on their work and on opportunities to advocate for change.

Changing practices is difficult. Knowledge of evidence alone is not enough to gain the support and engagement of front-line staff for the change. It is important to consider all of the factors that go into supporting knowledge uptake. One of the issues that needs to be addressed is to consider the type of knowledge that is being conveyed. If it is a contentious issue such as harm reduction it is important to consider how an audience will be convinced to "buy in" to the expected changes. Harm reduction is an important consideration for a very marginalized population. It is important that nurses are given the knowledge and the support they need to embrace harm reduction practices. In order to achieve this, stakeholders need to ensure that nurses are provided with the knowledge they need in a fashion that ensures its uptake and continued sustainment. The health and well-being of patients who use illicit substances is contingent upon nurses embracing harm reduction strategies and the possibility for nurses to incorporate these into their everyday practices in meaningful and ethical ways.

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Appendix One

A Study is Coming to Crosstown: The Crosstown Clinic: An Enquiry into the Experiences of Staff

The principal investigator for this study is Aggie Black, PhD, RN. Phone: 604-290-5741. Email: ablack@providencehealthcare.bc.ca. This is a UBC study.

A nurse from the University of Alberta, Faculty of Nursing named Jane McCall is planning to conduct this study. She is interested in talking to staff about their experiences with the clinic and its programs.

If you are a staff member, please talk directly to Jane when you see her.

Jane will be at the clinic every Tuesday and Thursday from one to four to talk to whoever wants to participate. She would love to talk to you.

Staff who agree to be interviewed will receive a \$20 Starbucks gift card.

Please consider helping Jane with this important work.

Appendix Two
Interview Guide for Staff

1. First let me tell you a little about myself and why I want to do this study.
2. Can you tell me a little about yourself?
3. What is your biggest challenge in working at the clinic?
4. What is the biggest challenge that the patients provide for you?
5. Tell me how you resolve conflicts between patients and between patients and staff.
6. What is the thing you like most about working at the clinic?
7. Can you tell me specifically about your strategies for providing care to this patient population?
8. How do you think the clinic program makes a difference in patient's lives? Can you give me some examples?
9. Do you think participating in the clinic makes it easier for patients to access the health care they need? Do they seem more comfortable seeking care and interacting with health care providers?
10. Does working here make a difference in your life?
11. Does your education provide you with an adequate background to work at the clinic? What else do you see as necessary?
12. If there was one thing you could change at the clinic what would that be?
13. If others across Canada would like to establish a HAT clinic what advice would you give them?
14. How did the Supreme Court ruling supporting the clinic change your perspective about the work you do?

15. I was initially interested in talking to patients as well as staff but ethics wouldn't let me because they said the patients were impaired from heroin and unable to provide informed consent. Do you think this was a reasonable and informed decision on their part? Do you think they denied the patients their voice?
16. Is there anything you would like to ask me?
17. I am planning to hold a focus group once I have collected all the information to share my findings with the staff. Would you like me to contact you when I have a date and time?

Appendix Three

Informed Consent – Interview

Study title: The Crosstown Clinic – An Inquiry into the Experiences of Staff

Principal investigator: The principal investigator is Aggie Black, PhD, RN. Phone: 604-290-5041. Email: ablack@providencehealthcare.bc.ca.

Who is conducting the study? The study will be conducted by Jane McCall, a student at the University of Alberta, Faculty of Nursing. Phone: 778-230-1690 or email: janemc@telus.net

Why should you take part in this study? You are being invited to participate because you are a staff member at the Crosstown Clinic. I am looking to gain a greater understanding of how staff experience the clinic in the hopes that it will inform how staff deliver care to their patients. I am hoping to interview 25 staff members.

What will happen to you if you agree to participate? You will be asked to participate in a private interview that will take about 30 minutes of your time. This interview will ask you questions about your experiences with the clinic. Some examples of the types of questions you might be asked include: What strategies do you use to provide care to this patient population? and How do you think the clinic program makes a difference in patients' lives? Jane McCall will conduct the interviews. The interviews will take place in a private location at the clinic or a location of your choosing. Interviews will be audiorecorded.

How is the data being collected and stored? The interviews are being recorded on a personal iPhone and the data will be stored on a secured home computer.

What will happen to the study results? The study results will be used towards my PhD dissertation completion. I will be sharing these results with my thesis committee in a way that protects your identity. The files will only be transmitted in a secure fashion. I also plan to hold a focus group with the staff at the clinic to review the findings and determine how they should be used. I will also present the findings at relevant conferences and write an academic paper so that more people will be able to learn from my experiences with you.

Is there any way this study could be bad for you? There is a potential for people to feel badly when talking about the way they provide care. Speaking about such matters can often bring up feelings of guilt or trauma. I recommend that you access the Employee Family Assistance Program at Providence Health if you have any issues. If you are uncomfortable with any of the questions you do not need to answer them.

Are there any benefits to the study? You will not directly benefit from participation in this study. However, you may gain some comfort and relief from sharing your experiences. I hope that being asked to participate in a focus group to determine the value of the findings and what to do with them will be beneficial in some way to you as a participant.

How will your identity be protected? Because the interview will be face to face confidentiality is not possible but all data that is received will be protected with a pseudonym (nickname). No real names will be used on any documents. Data records will be kept on a password protected computer. All paper records including the transcripts of the interviews and focus groups will be kept in a locked file cabinet. Audiofiles will be deleted as soon as the transcript has been prepared. The records of the study will be kept for five years and then destroyed. Your confidentiality will be respected. Information that discloses your identity will not be released without your consent unless required by law. All documents will be identified only by code number and kept in a locked filing cabinet. Participants will not be identified by name in any reports of the completed study.

Will you be paid for your time in this study? Participants will receive a \$20 gift card.

Who can you contact if you have questions about the study? If you have any questions or concerns about what we are asking of you, please contact the study leader. The name, telephone number and email is listed at the top of the first page of this form.

Who can you contact if you have complaints about the study? If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance email RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

Participant Consent and Signature

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your status as a staff member.

- Your signature below indicates that you have receive a copy of this consent form for your records
- Your signature indicates your consent to participate in this study

Participant signature _____

Date _____

Printed name of the participant signing above

Appendix Four

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